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**MEANINGFUL LIFE WITH(OUT) CANCER**  
COPING NARRATIVES OF EMERGING FINNISH ADULTS

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ACADEMIC DISSERTATION

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# ABSTRACT

For young people, the occurrence of cancer disrupts the coherence of life and disturbs hopes and dreams for the future. Even though cancer is relatively rare among young people, and the cure rates are quite high, cancer is the most common reason for disease-related death in young people. Moreover, the age-specific needs of care are often unmet and survivors enter into survivorship unprepared.

As most of the existing studies take a quantitative approach, and the issues of religion and worldview are hardly noted in the process, the aim of this research was to discover, with a narrative approach, how religion and worldview impacted the process of coping with cancer. The data consists of life tree drawings, autobiographical interviews, blogs, and a letter which were all subjected to narrative analysis. The textual data were analyzed utilizing both a narrative holistic analysis and a thematic perspective. Additionally, the drawings were analyzed by elaborating a visual-narrative analysis.

The introductory article represents a meta-analysis of four independent articles. These articles encompass the appearance of religiosity in the coping process; spheres of religion, spirituality, and the secular as manifested in the meaning-making process; and the appearance of hope and despair in the participants' future narratives. Since the drawings provided a novel approach to the visual-narrative analysis, one article scrutinizes the analytical process in more detail.

Building on the results of the articles, the introductory article seeks to find answers to the following questions: 1.) How does the surrounding context of an individual, and their close relationships, affect the coping process and the experience of meaning? 2.) What are the conditions for the process of coping with cancer to become a meaningful part of the self and life? What is the relation between discovering meaning in cancer and experiencing meaning in life? These questions are scoped with a theoretical discussion about meaning in life within a narrative understanding.

It was found that the meaning-making process occurs particularly within the spheres of self/others. For many of the participants, cancer caused a loss of meaning in multiple areas of life. Through the process of meaning-making, an individual can appraise cancer as a meaningful part of life and self. As the changes in the self were situated in the personal context of life, loved ones had a significant role in the coping and meaning-making. Often, personal relationships intensified. Sometimes new and highly significant relationships formed.

Further, emerging adults discovered inner strength within themselves, and this strength buffered personal identity. The experience of strengthened identity led individuals to follow their personal goals and dreams in life. The changes in the self were also described as religious and spiritual activation.

Often, lived religion served as a source of meaning and comfort during the crisis, but religion was rarely described as an explicit source of meaning for cancer. Rather, the buffered self and important relationships were perceived as a source of meaning in cancer.

However, sometimes life events can be so difficult that meaning cannot be composed. Furthermore, not all individuals have the need to find meanings in cancer. Therefore, meanings made from the crisis cannot be dealt with as a parallel concept to meaning in life.

Even though a meaningful life is constructed from multiple sources of meaning, hope and despair are likely to follow the emerging adults for years to come. Therefore, it is extremely important to implement “dignity in care” also in the survivorship care of young people. With a detailed support plan, young people with cancer are encountered as holistic human beings with individual needs and they can be guided through the emotional effusion that cancer arouses during treatment and in the long term.

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*Emerging adulthood is a distinctively vital time for the formation of the kind of critically aware faith that undergirds the trust, agency, sense of belonging, respect, compassion, intelligence, and confidence required for citizenship and leadership in today's societies.*

*Sharon Daloz Parks (2011), Big Questions, Worthy Dreams*

Within the emerging adult was planted a seed to grow my academic aspiration to become a doctor of theology. Within my journey towards this goal, I have come to across people who have made both my academic work and life much richer.

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# LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications:

- I Saarelainen, S.-M. (2015). Life Tree Drawings as a Methodological Approach in Young Adults' Life Stories during Cancer Remission. *Narrative Works*, 5(1), 68-91.  
[An open access publication]
- II Saarelainen, S.-M. (2016). Coping-Related Themes in Cancer Stories of Young Finnish Adults. *International Journal of Practical Theology*, 20(1), 69-96.  
[Reprinted with the kind permission of De Gruyter]
- III Saarelainen, S.-M. (2016). Emerging Finnish Adults Coping with Cancer: Religious, Spiritual, and Secular Meanings for the Experience. *Pastoral Psychology*,  
online first DOI 10.1007/s11089-016-0735-z  
[Reprinted with the kind permission of Springer]
- IV Saarelainen, S.-M. Landscapes of Hope and Despair: Stories of the Future and the Life Tree Drawings of Emerging Adults with Cancer. The original version of the paper will appear in *The Journal of Empirical Theology*.  
[Reprinted with the kind permission of Brill]

The publications are referred to in the text by their roman numerals.

# 1 INTRODUCTION

## 1.1 FINLAND AS A COPING CONTEXT FOR EMERGING ADULTS WITH CANCER

Emerging adulthood is a time for many hopes and dreams: human development focuses on maturing cognitive functions, which assist in gaining independence from parents and fitting in with peers. As a life period, it includes elements of searching for personal identity, many kinds of instabilities, and a focus on oneself (Arnette, 2004; Parks, 2011; Docherty et al., 2015). Arnette (2004) defines emerging adulthood as a stage between adolescent and young adulthood (between ages of 18 and 25); the phase describes the changes and delays in the maturing process that have occurred in Western, well developed, countries. In contrast Parks (2011) concludes that emerging adults could be identified as “twentysomethings” and that this stage is followed by tested adulthood, while mature adulthood is a long process that is only achieved around the age of forty. When cancer occurs during emerging adulthood, it intrudes on the vision of life, and arouses age-specific needs for care and support (e.g., Zebrack et al., 2014a, 2014b).

Since cancer and its treatment can impede cognitive maturation (Docherty et al., 2015), I use the term “emerging adult” to refer to the interviewees of this study, whose age varied between 18 and 35 (the age parameter for young adult cancer patients in Finland, see Sonninen, 2012). I decided to utilize the concept of “emerging adults” during the study, when realizing that participants were facing turbulent identity questions. Moreover, (faith) development theories suggest that “there is a minimum age under which it would be unusual to find a person at a particular stage” (Fowler, 1987: 67); yet, these developmental stages may occur later in life or never (Fowler, 1987; Parks, 2011).

Previous research has shown that the process of coping is always situated in the particular life context of an individual (Pargament, 1997; Ganzevoort, 1998a, 1998b; Stringer, 2011), and is impacted by the surrounding cultural metanarrative (see Ganzevoort, 2013). Finland as a healthcare context is known for good access to and affordability of care (Murray, 2015). Further, Finnish people have low barriers to accessing care (Paal, 2011).

In terms of religious coping, Finland is characterized by a strongly post-Lutheran context. Membership of the Lutheran Church was taken for granted in the 1950s, when 95.1 percent of people were members (Heino, 2002: 22-23). The number has decreased since then, to 71.9 percent of the population at the beginning of 2017 (Tietoa kirkosta, 2017). Yet there are strong regional differences: in Northern and in Swedish-speaking areas, the rate of membership is around 80 percent, contrasted with under 60 percent in the metropolitan area (Tilastollinen vuosikirja, 2016). During the years in which

the participants of this study were born, the proportion of newborn babies baptized slightly decreased, from 90.9 to 86 percent. During the years in which the generation turned 15 years old, around 90 percent of them attended confirmation school (Tilastollinen vuosikirja, 2005). These rituals are still fairly popular, but religious attitudes and beliefs have changed.

Ketola (2007) has proposed that the “subjective turn”, which reduces traditional Christianity and promotes the new forms of spirituality (Heelas et al., 2005), is not fully transferable to the Finnish context. Since at the beginning of this millennium, many Finns have found their religious commitment in small demographic movements within the church, and in addition, the Pentecostal movement has had the strongest impact in the 21<sup>st</sup> century. Yet Finns are more likely to practice religion and spirituality privately than to attend public events. The number of people praying daily has significantly dropped from 66 to 21 percent, whereas 5 percent reportedly did yoga and tai chi on a weekly basis, and 9 percent reported meditating several times per month. Most Finns identify themselves as “Lutheran” and “Christian”. Further, more and more young people are becoming more interested in atheism, and 22 percent of young Finns define themselves as atheist. Conversely, only 15 percent of young Finns subscribe to belief in the Christian God (Palmu et al., 2012). There are emergent indicators that, the current new generation of young people no longer feel the need to be members of a church (Niemelä, 2015).

I have briefly outlined the coping context for the emerging adults of the present study. Based on oncology and health sciences research, I will next introduce the special features of cancer among young people. This is followed by a review of the literature on religious coping in the Nordic countries; moreover, I will evaluate earlier studies that focus on the appearance of religiosity and spirituality among young patients coping with cancer.

## **1.2 DIAGNOSIS, COPING, AND LIFE WITH CANCER**

### **The Occurrence of Cancer and Special Case of Young People as Patients**

Within oncological studies, the term “AYA” is utilized to describe cancer patients spanning from adolescence to young adulthood. Cancer among AYAs is relatively rare, but 70 000 young people in the U.S, and 20 000 in Europe, including six hundred emerging Finnish adults, are diagnosed with cancer annually. These figures indicate that cancer in young people is a global health issue. Even though the overall cure rate is 80 percent, cancer is the most common cause of disease-related death for young people (Vassal et al., 2014; Nass et al., 2015; Doherty et al., 2015; Sylva, 2017). When AYAs do have symptoms of cancer, these can be misdiagnosed, because harmless indicators such as a long-term cough or vague pain can be early signs of

cancer. Furthermore, for various reasons, the actual cancer diagnosis for AYAs is often delayed (Grinyer, 2009; Docherty et al., 2015).

There is a growing body of research dealing with the age-specific issues faced by young people with cancer. Earlier studies usually hold a quantitative perspective (Kent et al., 2012); as a result, Grinyer (2007, 2009) notes that the lived experience of young patients is easily neglected. Moreover, both the positive and negative sides of cancer are rarely dealt with in a single body of research, and phenomena such as the impact of cancer on young people's body image is approached only seldom (see Belizzi et al., 2012).

It is well known that diagnosis during the AYA years impacts dreams in many ways: career goals, finding a life partner, and raising a family become jeopardized. Moreover, survivors are likely to face late effects of cancer. Cancer and its treatment can lead to life-threatening chronic medical conditions, such as a second primary cancer, heart problems, circulatory and respiratory diseases, which increase the risk of mortality. Despite this, it seems that AYAs' needs remain unmet, and the issues of care remain highly complex (Nass et al., 2015; Patterson et al., 2015).

Psychological late effects appear as post-traumatic stress in both female and male patients, whereas females are more likely to suffer from depression, anxiety (Patterson et al., 2015), and greater distress (Sansom-Daly & Wakefield, 2013). For young people, the type of disease is not measurably related to facing post-traumatic stress symptoms (PTSS) or post-traumatic stress disorder (PTSD). Moreover, it has repeatedly been shown that the severity of the cancer or survival rates do not predict psychological outcomes. However, the severity of the cancer can impact future plans and the ways in which the sufferer perceives vocational goals (Docherty et al., 2015). Earlier studies draw varying conclusions about how treatment (type, duration, intensity) impacts as a potential modifier of later psychosocial outcomes (Kwak et al., 2013; Sansom-Daly & Wakefield, 2013).

The greatest distress occurs at the points of diagnosis and transition to survivorship (Kwak et al., 2013). After treatment, young survivors reported lower scores in their Quality of Life (QoL) assessment, social and emotional challenges (Echo, 2016). Moreover, cancer has a negative effect on the experience of being in control of one's life (Warner et al., 2016). Often, cancer survivors encounter emotional and practical barriers to social well-being: the challenges of returning to school, education, and work (Patterson et al., 2015). Additionally, financial burden and feelings of being "left behind" are experienced. Overall, the issues of self-esteem, body image and physical legacy, emotions, family dynamics, fertility issues, future plans and difficulties trusting one's health provoke distress (Grinyer, 2007, 2009; Park et al., 2014; Nass et al., 2015; Echo, 2016; Warner et al., 2016).

Cancer challenges social networks, yet social relations are integral to the well-being of the patient. For instance, AYAs report overprotectiveness by their parents or spouse and abandonment by friends. Challenges in intimate and sexual relations are also reported and, in addition, the divorce rate is

higher among AYA survivors than in the general population (Kent et al., 2012; Docherty et al., 2015; Warner et al., 2016). Young cancer patients become socially isolated easily, and this can lead to behavioral problems such as smoking, misuse of alcohol, and risky sexual behavior (Patterson et al., 2015).

However, other studies show that relationships with family, friends, church, God, and peer patients all provided inspiration to survive (Zebrack et al., 2014a). Where the support of the family was intensive and meaningful throughout the cancer experience, young people felt that they were never alone. Also, the hospital and its staff provided a positive environment for treatment (Jones et al., 2010). AYA survivors discovered gratitude for people who helped them, and they grew to have strong empathy toward younger children with cancer (Grinyer, 2009).

From the perspective of identity, collective sources of identity – family, different networks, religious communities (Kumar & Schapira, 2013), and peer survivor communities – are important in recovery and redefining life after cancer. Yet after cancer, young patients seek new identity labels for themselves, and the most cherished identity is “someone who has had cancer” (Cho & Park, 2015: 14). Discovering an identity built on survivorship is linked with better adjustment (Cho & Park, 2015), and can provide ground for personal growth (Grinyer, 2009). AYAs are interested in support groups, and connections with peer survivors were much more highly ranked by the young people themselves than by healthcare providers (Zebrack et al., 2006; Echo, 2016; Walker & Lewis, 2016; Warner et al., 2016).

The long-term legacy of cancer can also contribute to positive outcomes. Both males and females find the same level of benefit in survivorship (Sansom-Daly & Wakefield, 2013). Findings in the literature are mixed regarding the relationship between sociodemographic variables (age, gender, ethnicity, socioeconomics) and post-traumatic growth (PTG). The large majority of AYAs have reported experiences of positive changes in life after cancer (85 percent in Barakat et al., 2006; 88.5 percent in Yi et al., 2015). Especially sharing and being heard (Zebrack et al., 2014a; Zebrack et al., 2014c; Yi et al., 2015), as well as planning for the future seem to promote PTG (Kyngäs et al., 2000; Belizzi et al., 2012).

As is shown here, many previous studies discussed challenges and the importance of social and psychological well-being. A few researchers mentioned religion and worldview as part of young peoples’ well-being. To build up a comprehensive picture of the phenomena of religious coping in the Nordic countries, I will next introduce studies of religious coping with cancer without specific age parameters.

### **A Nordic Perspective on Religious, Spiritual, and Existential Coping with Cancer**

In 2010, la Cour & Hvidt (2010) pointed out that most studies of health-related religious coping were quantitative. To establish whether there were

changes in the proportions of quantitative and qualitative studies, I conducted a keyword search from various databases using the words “religious coping” and “cancer”. The search was limited to peer-reviewed articles published between January 2000 and October 2015. I discovered more than 1 000 articles, of which only a handful were conducted with a qualitative approach. Furthermore, none of these studies focused on young people coping with cancer.

In the fall of 2016, I reran a similar search, using more focused keywords, within journals of psychology of religion and pastoral/empirical theology (the terms “meaning,” “meaning-making,” “young adults,” and “emerging adults” were added), but the same dominance still existed. Moreover, I scrutinized qualitative doctoral dissertations conducted within the Nordic countries. The following discussion is limited to Nordic qualitative studies conducted in the 21<sup>st</sup> century that are related to cancer and appearance of religion, spirituality, and existentiality in the process of coping with cancer.

When an individual faces a cancer diagnosis, this person confronts an existential awareness of their own death. The energy of this individual becomes targeted towards the will to live and fight against negative thoughts (Landmark et al., 2001). However, on a societal level, cancer patients are expected to take on the role of the patient and act as a dying person (Paal, 2011). Personal capability to hope can still be fragile, since an individual can experience himself or herself as being weak and strong simultaneously (Seibaek et al., 2013). Therefore, hope is constructed from having mental distance from the disease, the soundness of one’s body, treatment, a positive attitude, comparing downward, and having a positive model. It has been argued that cancer patients who have not entered into the role of a victim of their situation are able to sustain hope (Salander, 2014).

Cancer threatens the individual’s views of the future and, therefore, it is important to maintain positive thoughts of recovery (Landmark et al., 2001; Salander, 2014). The future is anticipated in terms of life and death, but the individual tries to fight against the fear of death. With positive thinking and searching for a sense of normality, relief is experienced (Landmark et al., 2001; Seibaek et al., 2012). For many, the concept of time changes and living in the moment intensifies (Paal, 2011; Seibaek et al., 2012; Nielsen & Sørensen, 2013).

Psychosocial support, given by healthcare providers, promoted a sense of well-being (Seibaek et al., 2012). In an empathetic atmosphere where an individual is listened to and able to share their feelings and emotions, emotional support can be achieved (Nielsen, 2005; Hvidt, 2013b). Moreover, hospital caregivers can assist patients in finding hope and offer them courage to face the new reality of life (Seibaek et al., 2013; Haugh, 2016b). Especially nurses, who follow patients’ medical journeys, must be aware of the existential issues that cancer arouses (Landmark et al., 2001). Nevertheless, there are problems in physician-patient relationships, and patients describe a lack of spiritual support (Paal, 2011).

From the perspective of religious coping, both negative and positive reappraisals of God were found. For instance, a negative image of God is a burden and interactions with God can be an obstacle to understanding “why” questions: in some cases, after the diagnosis patients wondered whether God was punishing them or why God would allow this to happen to them (Nielsen, 2005; Torbjørnsen, 2011; Johannessen-Henry, 2012; Nielsen & Sørensen, 2013). Positive appraisals were described in terms of God’s presence in the changed life situation; faith was experienced as the power that kept things together during the crisis (Landmark et al., 2001), and some felt that God acted concretely through their healthcare providers (Lundmark, 2016b). Others specified that a vision of Jesus (Lundmark, 2010; Paal, 2011; Haug, 2016a) or a strong bond with Jesus (Johannessen-Henry, 2013; Synnes, 2016) was empowering during the cancer process.

Overall, it seems that the use of religious practices intensifies during the cancer process, and especially prayer provides security when suffering from cancer (Nielsen, 2005; Ahmadi, 2006; Lundmark, 2010; Torbjørnsen, 2011; Ausker, 2012; Saarelainen, 2012; Hvidt, 2013a; Johannessen-Henry, 2012, 2013). Moreover, for some, church attendance and pastoral conversations are also highly valuable (Lankinen, 2001; Nielsen, 2005; Torbjørnsen, 2011; Saarelainen, 2012). Nature and meditation was found to be important sources of spiritual and religious experiences (Johannessen-Henry, 2013; Ahmadi, 2015; Butters, 2016, for aesthetic nature experience). Music and song lyrics were significant channels for religious and spiritual expressions (Ahmadi, 2011, 2013; Butters, 2016). Moreover, Ausker (2012) points out that non-religious beliefs were as helpful to non-religious people as religious beliefs were for believers.

Earlier studies indicates that meaning in life and searching for a meaning in cancer are linked to each other. If cancer raises existential questions, this can add a sense of meaning to the cancer experience. For some people, this existential process was part of the process of becoming whole as a person (Seibaek et al., 2013). Existential, religious, and/or spiritual meaning-making are momentarily activated by the cancer diagnosis (Hvidt, 2013a), and patients reframe the situation according to their personal worldview (Nielsen, 2005; Butters, 2016; Lundmark, 2016a; Haug, 2016a).

For people who were dying for cancer, meaning-making was found in terms of having meaning in life; when dying of cancer, the disease itself was often experienced as meaningless (Nielsen, 2005; Johannessen-Henry, 2010). Butters (2016) found that within the aesthetic meaning-making process, rituals and experiences such as music and art can provide the dying patient with a “rhythm for an otherwise chaotic situation” (p. 108). Especially for older, dying cancer patients, the meaning-making process was related to resilience – the experience of having meaning in life provided stamina to overcome difficulties (Haug, 2016a, 2016b).

So far, I have shown that cancer is a deep existential process that impacts holistically on the individual experience of life and meaning. The following

discussion will focus on the significance of religion and spirituality for young cancer patients in particular.

### **Young People and Religious Coping**

At the turn of the millennium, Kyngäs and others (2000, 2001) outlined that belief in God provided hope and comfort for young Finns undergoing cancer treatment. However, this is the only investigation into these phenomena found in Finland. More broadly, I found that AYAs' views on religious coping with cancer were extremely scarce, as I will now show. It must be noted that most of the following studies were conducted with a quantitative approach in the United States.

God and faith became an important part of coping with cancer for AYAs, and many of them returned to their earlier belief system (Jones et al., 2010). Young people reported that their faith alleviated their loneliness and fear, and that their faith was strengthened (Ragsdale et al., 2014). Moreover, religiosity and spirituality impacts positively on the health-related behavior of young patients (Park et al., 2009a). Furthermore, Ragsdale and others (2014) concluded that the significance of religious and spiritual coping were found to be surprisingly high, even in the context of the United States, where more than 90 percent of young people believe in God. Yi and Zebrack (2010) found that often survivorship was praised as God's miracle and religion was important in terms of coping. These authors also discovered that young patients and their families evaluated religion as part of their culture.

Moreover, AYA survivors perceived that cancer happened for a reason: it made their life better in terms of attitudes, behavior, relationships, and reduced risky behavior (Jones et al., 2010). Some believed that God had chosen to give the cancer to them (Ragsdale et al., 2014). In addition, appraising cancer with a sense of meaning was related to lower levels of distress (Thomsen & Jensen, 2007). For some AYAs, cancer affirmed the purpose of life (Grinyer, 2009; Ragsdale et al., 2014).

Spiritual struggles promote problems in the adjustment process (Park & Cho, 2016) and misuse of alcohol (Park et al., 2009a). However, Ragsdale and others (2014) found that young people who had experienced spiritual struggles addressed their problems by praying or utilizing other religious rituals. Still, AYAs framed problems in terms of unmet needs for religious and spiritual counseling (Zebrack et al., 2014b).

Overall, spirituality is an individual matter, and it is not meaningful for all the young people. Still, it must be noted that for those to whom it matters, spiritual well-being correlates positively with some aspects of psychological adjustment (Park & Cho, 2016; see Yanez, 2009, on spirituality, peace, and meaning as contributors to cancer-related growth). These earlier studies provide a standing point to enter into a research gap and focus on the human experience – experiences of emerging adults with cancer and the significance of religion in the coping and meaning-making processes – as the participants portray it themselves.



## **2 RESEARCH TASK AND FRAMEWORK OF THE STUDY**

### **2.1 A CALL FOR AN EXPERIENCE-ORIENTED APPROACH**

The aim of this research was to deepen knowledge about emerging adults' experiences with cancer. A review of earlier studies showed that the vast majority of both health-related studies of religious coping and AYA cancer studies were quantitative. There is a significant shortage of qualitative research pertaining to cancer experiences of young people, and even less work on the impact of worldview, religious coping and meaning-making among emerging adults with cancer. The case of religious coping by young people is important for understanding the meaning patterns in a post-secular society.

Therefore, the articles of the study encompass the appearance of religiosity in the emerging adults' coping processes (II); and in addition, how the spheres of religion, spirituality, and the secular are described in the meaning-making process (III). Moreover, the future stories of emerging adults were scrutinized within the continuum of hope and despair (IV). A further article provided detailed information on how these experience-oriented narratives and drawings of cancer were analyzed (I).

To support the analysis, the task of the introductory article is to focus on the coping processes of emerging adults with cancer from the perspective of the pastoral theological dichotomy of self/others (see Capps et al., 2013). This task is approached with the following questions:

- 1.) How do the surrounding context of an individual, and their close relationships, affect the coping process and the experience of meaning?
- 2.) What are the conditions for a process of coping with cancer becoming a meaningful part of the self and life? What is the relation between finding meaning in cancer and experiencing meaning in life?

With the first set of questions, the perspective of others is approached in terms of personal context and the people involved. The specific focus is to determine to what extent the support of the context and important people influences the coping process. The second question group is about the experience of self within the cancer process. I will approach coping from the perspective of identity-related questions, such as changes in the self and embodied experience of the disease. By seeking an answer to these questions, the experience of meaning in life after cancer is grasped.

As Anton T. Boisen (2005/1936) defines it, “the living human document” is one of the key resources for pastoral theology. In this study, the human experience and understanding the individual is central, as it focuses on spoken, written, and drawn experiences of cancer and life in emerging adulthood. Next, I will define my understanding from these narrative premises and other aspects of the theoretical framework used here.

## **2.2 THE GUIDING THEORIES AND THEIR ROLE WITHIN THE RESEARCH**

### **Narrative Framework**

The first underlying assumption in this research was that narratives and narrating personal life story have the ability to provide a sense of coherence and meaning in life (e.g., Ricouer, 1984; Bruner, 1990). However, some life events are so devastating that the unity between the temporal dimensions of the past, present, and future cannot be fully revitalized (e.g., Andrews, 2010). Therefore, some questions arise from the meaning-focused life story perspective. For example, if a “narrative” is strictly defined as stories that have a beginning, middle, and an end, important identity issues are neglected and the stories which stem from meaning are excluded (see Sartwell, 2000; Bülow & Hýden, 2003).

To be able to overcome the possible underestimation of traumatic experiences or incoherent stories, I needed a definition of “narrative” which would grasp the experiences of cancer and life stories of emerging adults in a comprehensive way. Therefore, I supplemented a coherent life story perspective to include a small story approach (see Bamberg & Georgakopoulou, 2008; Bamberg 2011a; Bamberg 2011b; I). These small stories include fragmentations of stories and hypothetical stories. Later, I realized that the idea of including coherent stories, fragments of thoughts, and images of the future as self-narratives was not that new (see Hermans, 2014a). I consider that this broad definition of “narrative” freed me from excluding data from the analysis; a rich territory of narratives was discovered through the combination of coherent stories and the small story perspective (Patterson, 2008; Freeman, 2010, 2011). Within my research, the term “narrative” is utilized to refer to the act of telling, drawing and sharing a personal life story including the time dimensions of the past, present, and future; the research material consists of visual, textual, and oral narratives.

From the autobiographical perspective, the viewpoint of the future was crucially important. Future stories become especially important during crisis situations. Hence, realistic future stories imply personal capacity to imagine and wish: positive attitude, fighting spirit and sense of purpose are related to composing a future story, whereas, when people lose their capacity to look forward, this implies an experience of despair (Lester, 1995; Herbert, 2014; IV). Furthermore, it has been noted that pastoral theologians easily neglect

the perspective of the future in both research and counseling (Lester, 1995; Van den Berg & Ganzevoort, 2014; Moschella, 2016).

Most of all, narrative framework used here is actualized through an understanding of human nature, the study design and selected analytical tools. However, the selection of strong theoretical discussions on coping processes, and the thematic form of the results, made this research different to what I originally expected. I did not understand the scale of the theoretical discussion I was entering, or how fascinating I would find trying to discover a balance between the data and theories. The forthcoming section describes the processes of discovering analytical tools to grasp the religious aspects within the data.

### **Theories of Religious Coping**

When planning the data collection and the theoretical framework, I kept thinking that it is possible that there is no role for religion in these coping stories. When I discovered Pargament's (1988, 1997, 1998) work and the Many Methods of Religious Coping (RCOPE), I decided to adopt it as the guiding theory to my analysis. I found out that RCOPE was tested in several countries and offered clear tools to analyze religious coping: religion could provide meaning, assist in grasping control of the altered situation, contribute to life transformation, bring comfort and closeness to God, and bring individuals closer to each other (see Pargament, 1997). In addition, definition of religion as an umbrella concept, including spirituality, seemed a good starting point. However, there was a lack of references in Finnish to religious coping.

When conducting the analysis, I kept discovering that the way emerging adults described religion was more nuanced than RCOPE's classification. Therefore, I needed more analytical tools to comprehend what makes "religion" religion and "spirituality" spirituality in the European context (see Stifoss-Hanssen, 1999). I realized that there was a marked continental difference between my data and the American model: RCOPE included community-based coping, which was almost absent from my data. Moreover, in my data there were several points that implied religion, religious activation, or religious rituals, but could not be grasped in terms of RCOPE (II). I began to share Ahmadi's (2006) notions that it is questionable how Pargament's defines "religion" as an umbrella concept for "spirituality". Moreover, I came to the conclusion that the RCOPE lacks does not adequately describe lived experiences of religion (II; see also Nielsen, 2005) and overemphasizes the Judeo-Christian tradition (Xu, 2015).

My problems with RCOPE correlated with the criticism of Van Uden and others (2004): Pargament assumes that people have an active relationship with a personal God and that individuals are directly focused in their ways of handling problems (see also Alma et al., 2003; Kwilecki, 2004). In addition, RCOPE is based on quantitative data (see Ganzevoort, 1998a) and Pargament (1997) seems to overlook the value of qualitative research by equating such

studies with “self-reports”. It could also be added that RCOPE fails to grasp the developmental stages and biographical changes which individuals experience.

It is argued by Fowler (1987) that both identity and faith are developed through different phases. For instance, usually in young adulthood, an individual enters into the individuating-reflective phase. Within this phase, a person begins to process personal belief, values, and commitments; people undergo difficulties and angst when trying to define a personal worldview. In emerging adulthood, according to Parks (2011), fragile inner-dependence begins to build up. Emerging adults commit to their faith and values by probing; mentoring communities are needed to provide surroundings for an individual to construct a personal meaning system and identity.

It became clear that to be able to grasp the questions of worldview and religious coping of emerging adults, a more hermeneutical stance was needed to supplement the RCOPE. At this point, I found Ganzevoort’s (1998a, 1998b) approach on narrative religious coping insightful. Ganzevoort (1998a) formulates that religion could appear as the religiosity of the author or in the form of a divine audience for a story, as a religious story, or discovering a religious purpose for a story. With these guidelines, I was able to discover theoretical notions of the appearance of religiosity which embraced more than explicit religious acts. Ganzevoort (1998a) defines the narrative approach to religious coping processes, in order to overcome the pitfalls of Pargament’s theory: notions of the cultural context of an individual, inadequately addressed identity issues, and the ability to diversify the empirical data to include qualitative data (see also Bjorck et al., 1997; Xu, 2015). This approach to religious coping can also be used to understand an individual’s religious experiences at different life phases and developmental stages.

Ganzevoort’s theory of narrative religious coping was a highly valuable, and especially the narrative criteria opened up new perspectives on the analysis. Ganzevoort (1998a) maps four dimensions – religion, coping, context, and individual – that are “constantly evolving and fully interrelated” (p. 266). However, appearances of religion in the coping processes of emerging adults seemed to differ slightly from the theory. According to my understanding, Ganzevoort (1998a) sees that the dimensions are independent, in the sense that it is possible to distinguish them as mutually evolving. Nevertheless, the religiosity of emerging adults was not narrated as an independent concept; rather, religiosity appeared *only within* the dimensions of identity, context, and practices (see II). Still, these findings seem to confirm Ganzevoort’s (1998a) views that religion and religious coping are formed from experience, interpretation, and behavior as matters that relate to God. Thus, I began to formulate my views on how to distinguish religion and spirituality from one another, as I explain in the following section.

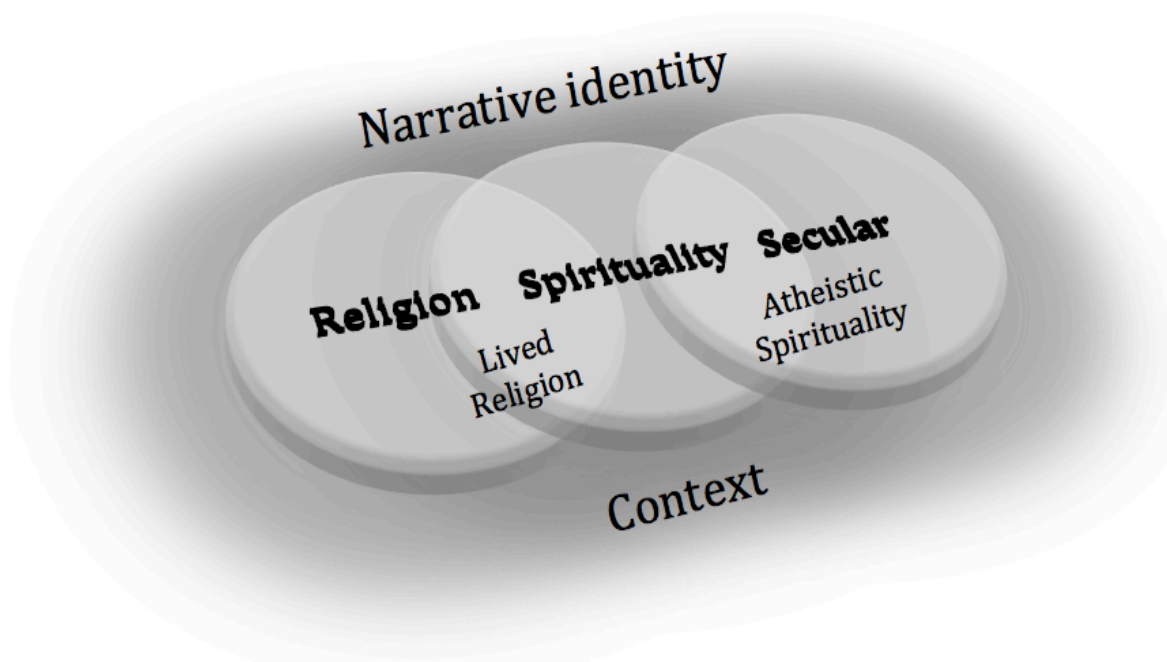
## **Defining Religion and Spirituality**

Earlier studies show that religion and spirituality can serve as a way of coping and as a source for meaning in life (see Chapter 1 for details). Yet my aim was to discover definitions that would grasp the worldview and experiences of my participants; therefore, I understand that religion is related to God, a higher power or an ultimate being. At the level of practices, religion can include both explicit and implicit religious practices, as well as practices of lived religion.

Lived everyday religion is constructed from a bricolage of practices and assists in making sense of daily life. As a theoretical frame, lived religion points out that within individual experiences and everyday living, religion is more than institutional. Lived religion includes individually formed bodily rituals as part of spirituality (McGuire, 2008; Stringer, 2011; Ganzevoort & Roeland, 2014). However, Ammerman (2013: 276) criticizes McGuire's (2008) suggestion that lived religion includes spirituality. In addition, Ganzevoort and Roeland (2014) opted out of defining spirituality, suggesting that they are likely to see spirituality as part of lived religion.

As I agree that religion and spirituality are closely linked and interwoven, I was challenged by my data at this point. I discovered spiritual elements that could be categorized as explicit religion and/or lived religion. However, there were strong elements which seemed spiritual, but were unrelated to God in any sense. At this stage, a referee of Article II brought to my attention the European Association of Palliative Care (EAPC) definition of spirituality as comprising the areas of existential questions, value-based considerations and attitudes and, additionally, religious considerations and foundations (Nolan et al., 2011). With the data findings and the knowledge of people defining themselves as "spiritual" rather than "religious" (Ammerman, 2013) it seemed quite logical to deal with spirituality as a broad concept. I concluded Article II thinking that it would be artificial to separate the elements of the religious, the spiritual, and the mundane from each other. However, the prospect of making a full turn, and defining spirituality as an umbrella term, kept occupying my thoughts.

I continued grappling with the theoretical notions in Article III within the meaning-making framework, and found my theoretical position inadequate. I learned that in the process of discovering a meaning for cancer, the dimensions of religious, spiritual, and secular orientations all intersect and that the concepts were not superior to one another, but rather, co-existent (see la Cour & Hvidt, 2010; Hermans, 2014b). Only at this point was I able to consider the role of secular and mundane matters within the same spheres. Therefore, I also needed to reposition the role of spirituality in the process. Figure 1 summarizes my theoretical understanding of the concepts of religion, spirituality, and secular.



**Figure 1** Parallel Spheres of Religion, Existential Spirituality, and Secular Orientation.

As the figure shows, I understand that the context of each individual provides space for elements of religion, existential spirituality, and the secular. Moreover, these spheres and their significance are negotiated through the individual's narrative identity and social relations. Figure 1 is similar to what I described in Article III as spheres of meaning-making, but expresses deeper relations to both context and narrative identity.

As a concept, spirituality is diverse, and includes a sense of ultimate meaning (III). Issues of identity, personal relationships, nature, aesthetics, existential issues, values and ethics are all included in the spiritual. Spirituality fulfills the notion of the most important and the element of the contingent (in the sense of being necessary); indeed, existentiality is likely to be the core of spirituality (Stifoss-Hansen, 1999).

Existential questions are also relevant to atheist individuals. Atheistic spirituality can be defined as spirituality without a God, in the sense of a beginning or an end, the transcendent or the eternal (Schnell, 2009, 2012; Schnell & Keenan, 2013). More broadly, I have utilized the terms mundane (II) and secular (III), to refer to things that are not religious or spiritual. These include ordinary matters, normal everyday experiences or practices (Hermans, 2014b)

My understanding has grown: the practices of lived religion seek to provide meaning. Thus, lived religion is likely to include the existential relevancy of spirituality; new rituals are sought after, since traditional religious practices are losing their essence (see Ganzevoort, 1998a). However, spirituality as an umbrella concept is inadequate, at least for two reasons. 1) It has been suggested that not all aspects of religion include the element of being relevant, in a sense grasping the existential relevancy (Hermans,

2014b); 2) the “sacred” as a core of spirituality is too narrow and religiously oriented to grasp the experiences of atheists, who are likely to experience spiritual processes (Stifoss-Hanssen, 1999). Based on these premises, the concepts of religion, spirituality, and the secular should be seen as parallel to each other.

### **2.3 THE IMPACT OF CRISIS ON NARRATIVE IDENTITY AND MEANING**

So far I have combined the key areas of the theoretical discussion utilized in the original articles to address my research questions, and slightly supplemented this to meet the needs of the present introductory piece. Next I will introduce the theoretical discussion on narrative identity and meaning in life, guiding the findings of the study.

People are storytellers by nature: narrating stories is a two-way process, in which an individual tells his or her personal stories, and simultaneously utilizes stories from culturally shared narratives. Within this process of sharing and selecting stories, the personal stories are organized in relation to the cultural stories. Narrative identity is constructed by telling stories of the self within the frames of temporality and social relations. Within the crossroads of the world and the individual, narratives are shared, compared, and restored. The surrounding culture is the context for composing our meaningful personal stories from life events (Ricoeur, 1984; McAdams, 1988, 2009; Bruner, 1990; Hänninen, 2002).

The experience of meaning in life is bound into social relations, the surrounding context, and temporality. For instance, purpose in life is goal oriented and one strives to actualize these goals in the future. Value in life can be characterized as discovering justification for the individual’s actions in the past and present. These justifications are searched for within a cultural context. Efficacy, as an experience of having control over personal life, is oriented within the dimensions of the present and the future. Self-worth comprises past and present events: individuals compare themselves to others and can discover a sense of belonging through social relations (see Baumeister, 1991; Martela & Steger, 2016). Meaningfulness is appraised in terms of coherency, significance, direction, and belonging (Schnell, 2009).

Crises are likely to shake up the experience of meaning in life (Baumeister, 1991; Schnell, 2009; Park, 2013). Life-threatening situations, such as cancer, occur within cultural frames, and this type of crisis impacts the stability of an individual’s lifeline (Ganzevoort, 1998b). When an individual loses the sense of meaning in life, the renewed search for meaning begins: new meanings are sought after and remaining sources of meaning become more important. The process of meaning-making follows the distress that occurs from the violation of global meanings (Baumeister, 1991; Schnell, 2009; Park, 2013). The crisis triggers an evaluation process, in which an

individual assesses the seriousness of the threat and personal resources to formulate a response (e.g., Lazarus, 1999).

Both hope and despair are linked to temporality. During the “universal loss of meanings”, despair, an error in the hoping process, occurs (Lester, 1995: 73). The inability to combine temporal perspectives of the past, present, and future into a coherent story, as well as the loss or negation of a future story, contributes to despair. Yet hope thrives by acting upon the dimension of the future; hope is related to having a purpose in life and achieving the desired result. Hope relates to coping, in that sense that the people who can discover hope in the midst of stress are able to cope (Herbert, 2014). At a crossroads in life, stories are shared and narrated in the hope of gaining acceptance (Ganzevoort, 1998b). The stability of one’s lifeline requires the coherent unity of life events, that is, a balance between the experiences of the past, the present, and the future (Lester, 1995). If a coping process is successful, with time, the lifeline of an individual stabilizes (Ganzevoort, 1998b), and new meaning can be made (Park, 2013).

This chapter has outlined the construction of my theoretical framework. The following chapter explains the design and conduct of the study in detail, after which I will present the key findings of the articles and results.



## 3 DESIGN OF THE RESEARCH

### 3.1 RESEARCH PROCEDURE

#### **Recruiting the Participants**

The participants were recruited on a voluntary basis: I posted an advertisement regarding the research in a large number of Internet chat rooms that had to do with cancer and its treatment. Although I knew that it was likely that, within these open and public chat rooms, people would be more likely to discuss their fears, “what *if* I have cancer,” I wanted to try recruiting participants as transparently as I could. When I did not receive any contacts from these chat rooms, I reached out to the Finnish Cancer Society and the administrator of the young patients’ chat room, in order to obtain permission to submit my advertisement to their chat rooms. Very soon after the advertisement was published in these targeted chat rooms, young people began contacting me.

I announced that I was interested in hearing the life stories of young people who had had cancer during the previous five years. In the beginning, I defined emerging adults as people under 25 years old. However, while the data was being collected, the Finnish Cancer Society published a guidance booklet for young patients, defining this age group as 18 to 35 years old. This definition encouraged me to broaden my own understanding of emerging adults, which also helped me to find enough participants.

Even with the more expansive age parameters, I had around ten interviewees, and male candidates were outnumbered. I contacted Sylva ry (a support organization for children, youth, and their families) to find more interviewees. My advertisement was now sent to a mailing list of young patients that were involved with Sylva. In order to find male participants, I re-posted my chat-room notification and targeted it toward males. In addition, one of my interviewees pointed me towards a male blogger, whom I contacted myself.

I was able to utilize the stories of 16 emerging adults. First, I interviewed 13 females and four males. One female candidate had a serious health condition that was different from the others’. However, as she volunteered, I thought that it was important to hear her story. That said, in the interview she explained that she did not have cancer, although she was dealing with a life-threatening condition. The interview was significantly shorter and she avoided many questions. Based on these facts, I thought it would be ethical and reasonable considering the research task to omit this interview from the data. Aside from actual interviews, I had some email contacts that did not lead to a meeting. I usually sent one email reminder about the research, but remained sensitive to the fact that people had their privacy with such delicate issues. The following table (Table 1) introduces the participants of the study.

**Table 1** Participants.

<b>Name</b>	<b>Cancer</b>	<b>Time from the treatment</b>
Anna (I10)	Hodgkin lymphoma, first diagnosis as stage 2A was changed to stage 3 after six months of chemotherapy; because of the changes in spreading the treatment was continued for two months.	5 years
Ava (I5)	Non-Hodgkin lymphoma, more local but made breathing difficult and caused other symptoms as well.	2 years
Beth (I6)	Hodgkin lymphoma, stage 4A. Remission time in between the treatment: a couple of years.	2 year
Cain (I14)	Testicular cancer, spread to lymph nodes.	5 years
Chloe (I12)	Hodgkin lymphoma, stage 4B, relapsed during treatment.	3 years
Emily (I11)	Non-Hodgkin lymphoma, no descriptions of spreading. Six months of treatment and no external signs that could refer to more local cancer.	5 years
Emma (I4)	Hodgkin lymphoma, stage 4B.	1 year
Gina (I7)	Lymphoma, large spreading and multiple tumors likely to mean stage 4B.	3 years
John (I15)	Hodgkin lymphoma, stage 4B. Relapse after seven years in remission.	Right after the treatment
Macy (I9)	Lymphoma, diagnosis changed during the treatment to spreading stage 4.	7 months
Mark (I13)	Hodgkin lymphoma, no descriptions of spreading. Six months of treatment could refer to more local cancer.	7 months
Olivia (I16)	Hodgkin lymphoma, stage 2A.	During the treatment and 4 months after
Sarah (I1)	Hodgkin lymphoma, no notification of exact spreading. Symptoms: tumor near the collar bone and tiredness.	5 years
Sophia (I8)	Osteosarcoma (knee). More local cancer since an amputation was not needed.	5 years
Thea (I2)	Sarcoma (back), stage 4B.	4 years
Tom (I3)	Osteosarcoma (knee), chemo and amputation. Refers to spreading on some extant.	2 years

Within the Table 1, the first column (name) indicates the imaginary names of the participants that were utilized in Articles I, III, IV and codes that assisted in Article II. The second column (cancer) provides information about the type and spread of the disease (stage 4 stands for the greatest spreading; letter A means that there are no other physical symptoms and B indicates the appearance of other physical symptoms such as night sweating, lumps, or a persistent cough). Regarding the types of cancer, lymphomas are cancers of the lymphatic system, part of the immune system. Bone sarcomas are malignant tumours in bones, as the participants describe. Moreover, diagnosis of the Hodgkins disease in young people peaks between the ages of 15 and 34 (Lymphoma, 2017; Sarcoma, 2017; Lindholm & Kivioja, 2010; Turpeenniemi-Hujanen, 2010).

The third column shows the duration of time from the treatment at the moment of interviewing. Most of the participants were in the remission stage of their disease: their active treatment had ended, but they were still attending regular check-ups. The temporal distance from the treatment varied from some weeks to five years. In practice, this meant that most of the participants were 18 to 35 when being diagnosed, while a few were adolescent during the diagnosis. A few of them had a relapse that was treated in later years.

As Table 1 shows, one of the interviewees was interviewed twice. She contacted me right after the diagnosis. As her diagnosis was so recent, we agreed to wait a few months, to give her time to reflect upon her situation. For the first interview, I decided to start with loose themes and give her the freedom to speak as she wished. However, as a setting, it turned out to be very similar to other interviews. To be consistent with the data gathering, I asked if she would be willing to participate in a second interview after treatment. The second interview was recorded a few months after the end of the treatment.

### **Selection and Evaluation of Multilayered Data**

My original thought was to take McAdams' (2009) approach to conducting a life-story interview: the participants are asked imagine their life as book with chapters and describe the important persons and ups and downs of life. On top of this, I planned for the participants to draw a lifeline. However, when I brought these ideas to my narrative study group, I was asked to consider the possibility that stories are not coherent, and therefore, "books" are impossible to compose. What if the end of the lifeline is associated with the end of ones' life? From these premises, I started to build up a different approach to the study guide and to consider using different visual elements. The following paragraphs explain how I ended up constructing the research and how ethical considerations were taken into account.

Selecting a life tree as a visual element of the narrative data collection was a sum of several coincidences. In my previous study, I had utilized the lifeline as a method of plot analysis (Saarelainen, 2009), so I thought it could also be

used for visualizing life with cancer. Previous studies also reported the advantages of using lifelines with delicate research topics (e.g., Guennette & Marshall, 2009; Sheridan et al., 2011). But when my colleagues had raised the question about paralleling the end of life and end of line, I wanted to take a more neutral approach.

I considered a variety of different elements. When I presented my thoughts at a conference, someone from the audience shared his positive experiences of utilizing the shape of a tree when discussing identity-related issues. I then researched different tree methods and possible applications. I found that earlier tree methods included a lot of guidance: they utilized the shape of the tree in rich way but left little room for individual interpretation of it. Therefore, I decided that I would only ask the participants to use the shape of a tree and give them a free hand for drawing (see I).

From these premises, each of the interviews started with the phrase: “I ask you to think about your life, thus far, as a tree. What does your tree look like?” No further instructions were given about how to draw or what colors to use. They were given an A4 sheet of a paper and selection of colored markers. The interviewees had different ways of drawing: some explained their tree and the vision while they worked, and others drew in silence. Some referred to the drawing throughout the interview and others set it aside after finishing. I gave them the opportunity to choose whether or not they wanted to use their drawing as the framework for their interview. At this point, I was not sure how to deal with the drawings later on, and I thought it was best to follow the participants’ personal preferences regarding how to continue the interview. Still, they were asked to describe what they had drawn.

In accordance with the idea that stories may be fragmented, I decided to create an open thematic interview guide. The main themes would serve as the minimum information that I would ask each participant to provide. Otherwise, I would continue with probing questions stimulated by each of the situations. The guide included themes of childhood and family, adolescence as a life stage, life at present, and future outlook. Also, each individual’s cancer story and the role of religion and worldview in it were addressed (see Appendix 1). The basic idea was to start the meetings with a visual assignment, and the interview guide would be used when needed.

Beforehand, I was aware of the importance of starting with “easy” questions, in order to build some trust, before entering into more difficult topics such as cancer. I learned in the process, that the drawing task was quite an efficient way of breaking the ice for the interviewee. Furthermore, I soon came to notice that the participants were there to share their cancer story, and whenever I started the interview (after the drawing task) with the question: “Where would you like to start?” they chose to start from their first suspicions that they might have cancer or their current life situation.

I was not prepared for their great willingness to share their cancer stories instead of sharing their life stories. The tree was selected to portray life stories with cancer, but I turned to have cancer stories that are mastered by

the remission experience, addressing what it meant to live at this point of life, after the cancer treatment. Even though only a few participants were at the post-remission stage, the narratives focused on life during the treatment and the remission period. Article I gets its name from these premises: Life tree drawings as a tool for examining the remission narratives.

However, the tree is not as neutral a symbol as I had initially expected. As a symbol of life, the tree (and plants) is likely to call to mind seasons of life and death: an autumnal tree is likely to arouse thoughts of life coming to its end (Lakoff & Turner, 1989). Moreover, the tree is a biblical metaphor. For instance, God plants the tree of life in Paradise (Genesis 2). The tree of life provides happiness (Proverbs 3:18) and people who follow the commandments “may have right to the tree of life” (Revelation 22:14). Yet, the branches that do not bear fruit are cut off (John 15:1). Nevertheless, participants did not, themselves, bring these issues up in our meetings. Rather, the seasons of tree provided them with an opportunity to organize their cancer experience (I; see also Keats, 2009; Hinthorne, 2012; Pain, 2012).

I consider the drawings and interviews as primary data, since all the participants had the same opportunity to produce their story. However, I learned that three of the interviewees were writing a blog about their cancer journey. The participants gave me their permission to utilize the blogs for research purposes. The blogs are different in that sense that they give a detailed picture of cancer treatment, side effects, and daily life. Since some of the authors are still continuing the writing process, I decided to analyze the period from the beginning of the blog until the end of the year 2012. The data collection focuses on the years 2011 and 2012. I also included one older piece of data in this research, since it supplements the experiences of one participant. In my earlier research, I gathered letters and interviews from cancer patients, considering their mental and spiritual needs (Saarelainen, 2009). The letter used here was posted to me in 2007, and the participant re-volunteered to be an interviewee for the present study. The letter is utilized as part of her story to demonstrate some changes in experiences which occurred with time.

As Keats (2009) defines, written, spoken, and visual data sets can comprise narrative inquiry. However, multidimensional analysis is needed to grasp the various layers of narratives. The next section introduces how I handled the analysis of this multilayered data.

### **Ensemble of Visual, Thematic, and Holistic Perspective of Narrative Analysis**

The data consists of life tree drawings, autobiographical interviews, blogs, and a letter which were all analyzed from a narrative perspective. The interviews contained approximately 90 minutes of discussion on the actual research topic. All in all, the average length of the interviews was around 105 minutes, when ethical discussion and thoughts about participating in the

interview are accounted for. Besides the textual material, each of the interviewees had drawn a life tree. Next, I will describe the process of analyzing this multilayered data.

When watching the first interviewee draw her tree, I was fascinated by the way she reflected her emotions with her selection of colors and the growth of the tree. At that moment, I was convinced that the drawings would be equally as important forms of data as the interviews themselves. I was determined to discover a method for visual-narrative analysis, since Tamboukou (2010) noted that visual data is often underestimated.

To create a basis for the visual analysis, I decided to analyze the textual material first but laid the drawings on the table so I could see them at the same time. Taking a case-centered approach within narrative studies, I initially analyzed cases one by one, focussing on the coping process. The unit of analysis – the focus of analysis – can be summarized as meaning-making with and within the cancer process. According to Riessman (2008), this is the main difference between the narrative approach and basic content analysis; each interview is analyzed as an independent case before making connections on an intratextual level – considering all the data as a whole. My decision not to apply software-based analytical methods was also grounded in narrative principles; instead of breaking the stories into hundreds or thousands of codes, it was highly important to me to “keep the ‘story’ intact” (Riessman, 2008: 53). The analytical tools that I utilized can be seen as combining a thematic narrative analysis and holistic content perspective (Lieblich, 1998: 62-87; Riessman, 2008: 53-76).

First, I transcribed all the interviews, a total of 414 pages of raw transcription, supplemented by the seven-page letter and 200 pages of textual material from the blogs after they were converted into .doc format. Once all the data was in the same format, I read the transcriptions without any specific goal. After a few rounds of reading, I started dividing the text into “meaning units” (Riessman, 2008: 35). As Riessman (2008: 35-37; see also Mishler, 1986: 47) states, this process is helpful in achieving accurate transcription. The meaning units were simply formed with extra line spaces between changes in storyline. The authors usually had automatically divided their blog texts into a fairly coherent form, thus there were not so many changes. These units were helpful during the next stage of discovering the themes.

When reading the stories of each individual one at a time, I was able to identify central themes within each case. These were marked in the text with colored pens and/or short open codes. For example, the factors which hinted toward religious issues were usually underlined with one color, and to be more specific, codes such as “RC” as positive religious coping or “NRC” negative religious coping were recorded in the transcriptions. Moreover, codes such as, “Family” or “Loneliness” were connected to adjectives (“Supportive” or “Painful”) which helped to determine different tones within

the themes. Overall, the codes provided me with the tools to handle the data based on themes and tones, rather than dividing the text into small pieces.

The holistic theme lists were created next. I continued to read each case theme-by-theme, following characters and changes thematically. Now it was possible to note where each theme started and ended. In each theme list, the main themes were bolded and subthemes were grouped under them, and ordered to follow the structure of each individual's story. These lists made it possible to simultaneously maintain a holistic and structured view of each story. The main themes and subthemes were organized so that it was possible to follow which themes were linked to each other, how they connected and where they overlapped (Lieblich, 1998; Riessman, 2008; I for literature on narrative analysis).

After the textual analysis, I returned to the drawings and recorded my general notions onto the drawings; I called this phase thematizing the drawings. At this point, I had quite a clear vision of what the participants were narrating in their interviews. However, in order to scrutinize the tree-related descriptions, I separated the tree narrations from the transcriptions and worked in detail with both materials. I referred to the drawing as I continued to read the narration. I recorded details such as selection of colors, use of symbols and recording of different life events. When I had thematized the drawing, I compared it to the holistic theme list and noted the differences between the themes. Some themes were highlighted in the drawing and others were completely left out of it. In the process of reading the tree narrations, thematizing the trees, and comparing the themes, a new layer of the experience of cancer emerged: the life tree drawings incorporated metaphorical expressions of cancer.

Within this study, metaphors are more than a figure of speech (Billing, 2004; Cornelissen, 2008, for figurative speech), since the drawings offered their composers an opportunity to select a symbol system that is freed from the constraints of language itself (Coufal & Coufal, 2007). Yet my understanding of metaphor is based on language; metaphors are culturally-bound tools which grasp the reality of life, death, and time in an incomparable way (Lakoff & Turner, 1989). Besides the linguistic metaphors, I found that metaphorical thoughts were portrayed in visual narratives as a unique form of cancer experience. In this study, the term "metaphor" refers to the conscious (and sometimes unconscious) expressions of the thoughts embedded in oral and drawn narratives (I, IV). I am aware that this definition of metaphor is limited and the term is easily related to semiotics. However, this study focused merely on metaphors as *visual narratives* and as descriptive layers of a cancer experience.

Summing up, reading, rereading and comparing the data sets were the key elements in the process of analysis. As Gadamer (2004) notes, the hermeneutic process includes the element of infinite dialogue, in which mutual understanding is constructed. However, the researcher aims to understand and interpret in order to take the next step and to be able to

grasp the experience (Smith & Osborn, 2008; I). Therefore, I will next evaluate the validity, reliability and nature of this research.

## **3.2 THE NATURE, VALIDITY, AND ETHICS OF THE RESEARCH**

### **Validity, Reliability, and Ethical Considerations of the Study**

The research facilities, interview process and analysis are evaluated here in terms of validity, reliability, and ethics. First, before starting to conduct the research, both of my supervisors and the board of the doctoral school of theology at the University of Helsinki accepted the original research plan. The pastoral theology seminar and other seminars provided me with regular feedback. So although the articles were written independently, groups of colleagues provided me with regular feedback.

When conducting the interviews, I followed the same procedure of explaining participants' rights and my commitments as a researcher. The consent forms were printed in duplicate, one copy each for the participant and the researcher. At the beginning of the interviews we discussed the procedures of writing the academic articles and the summarizing book. Participants were assured that they could withdraw from the research without any explanation, and leave uncomfortable questions unanswered. Usually, after the interview, we revisited the consent forms and discussed what the participants were willing to share from their story for research purposes. In cases in which participants wanted to sign the forms at the beginning of the interview, I double-checked in the end whether they still consented. They were also provided the opportunity to select which parts of the data (interviews and/or drawings) they were willing to give to research and teaching purposes.

In the interviews, I was aware of the possibility of opening wounds. Therefore, they were always concluded with the questions: "How do you feel at the moment?" "How did it feel to share your story with a stranger?" or "With what feelings you are leaving the interview setting?" I was prepared to advise them with opportunities for support in discussion groups or even acute support, but this was not needed. However, retrospectively, it would have been wise to contact the participants a week or two later, ask how they were doing, and offer to help them find proper channels to share their feelings, if they so required.

During the analytical process, I discovered that there were significant differences between the online blog stories and the interviews. The blogs provided public stories of being treated for cancer and the interviews expanded upon personal experiences of suffering and dealing with cancer. Moreover, the blogs were brimming with medical language, whereas the interviews were more emotional narratives. The ethical difficulty lies



between the spheres of the public and the private. The blogs are still available on the Internet, and are full of photos and identifying factors. Nevertheless, the authors volunteered as interviewees with the promise of anonymity. Because of the significant risk of violating the participants' privacy, I did not connect the blogs to the specific code or name of an individual. In Article II, I made mention of the blogs as an entity. In Articles III and IV, I do not distinguish items derived from the blogs. Moreover, none of the quotations are drawn from the blog texts. I understand that the blogs had a broader scope than the material I engaged with. That said, I chose to follow our mutual understanding regarding the anonymity of participants, rather than taking any risks of violating their privacy.

After the analysis, I started second-guessing whether I should have considered more participatory research. I planned to meet the participants only once, because I wanted to minimize the possible emotional diffusion aroused by recalling the cancer journey. Still, I considered that if any of the participants asked for their transcriptions, it would have been possible to handout the transcriptions for them to read and comment. Moreover, if they wished to comment on my analysis, I would have considered it. None of the participants asked about these possibilities, although some were aware of different research practices. At least some confirmation of my ultimate decision was provided in one of the research blogs. The blogger wrote down some individual thoughts about having a pleasant interview, but being exhausted for days after the discussion. After reading this, I believe that I made the right decision.

Since participants volunteered themselves through an online chat group, it is likely that they already had experiences of sharing and learning about the cancer experiences of others online. Still, one possible bias in the research arises from the self-selection of the interviewees. Moreover, some participants were discovered through the support organization (Sylva), which can have an impact on the way in which positive experiences from peer groups are highlighted. From these premises, it is likely that my advertisement was more efficient in reaching those emerging adults who were already active in group discussions, or sought comfort by sharing their personal experiences.

Moreover, I discovered that some of my interviewees knew each other and had told each other that they were participating in the research. One of the participants told me this, with a positive chuckle. In addition, the participants were eager to help me find interviewees, and a few of them told me that they would ask their peers to contact me. Therefore, I was especially concerned about how to anonymize details, so it would not be obvious to the interviewees "who said what". For this reason, I have not published specific ages, social relations or occupational fields in any of my work. All the names are imaginary and based on a random selection of international names. I have tried to select direct quotations in such a way that none of the

participants would be overly presented. Even Article III, which is more focused on three interviewees' experiences, is related to the data as a whole.

### **Limitations of the Study**

Within the years of conducting this research many things have changed, both in the Finnish religious climate, and in terms of research methods. When I gathered the data, there was no discussion about open data policy or reusing the data. Therefore it was not possible to make the data accessible for others to use or analyze. Still, I was aware of the uniqueness of the data and was granted permissions to utilize it for both research and teaching purposes (see Appendix 2).

Furthermore, the gathering, analyzing and presenting this heterogenous data was a process of several negotiations. One of the first was the role of the blogs, as explained above: unlike these public narratives, the interviews included darker tones and more intimate stories. Secondly, one of the participants was interviewed twice. Thirdly, one of the participants wanted her earlier letter to be included as part of her story. My leading thought through this process was to respect the participant – by whatever means and in whatever form the material was given to me, I wanted to take it seriously and include it in the research. In all cases, narrative truths are always temporal truths that are bound to the actual situation and context of composing them (e.g., Polkinghorne, 1995; Riessman, 2008; I). In a different time or place, with a different researcher, the participants could have narrated or drawn something different. Within this study, narrative inquiry is an ensemble of narratives in different forms but all sharing the experience of having cancer as in adolescence or in emerging adulthood.

Also the process of writing an article-based dissertation raises some issues. To be honest, the publication processes were much more demanding than I had predicted. Especially, discovering suitable publication channels was time consuming. As I was enthused by interdisciplinary approaches, I found it immensely important to publish in the journals that are central and relevant to pastoral theology, or methodology. Still, the pressure to publish within certain timeframes provided problems of coherence for the research. As I demonstrated in the theoretical discussion, my understanding regarding the relationship between religion, spirituality and the secular developed between the articles. Yet, this is living proof of the plurality within the field of definitions. The process of discovering my personal theoretical definitions was a years' long debate between data, literature, and myself. I postulate that it is not a weakness, but rather a natural part of becoming an independent researcher. The following section discusses my position as a young researcher researching young people in more detail.

### **My Position as a Researcher**

During the doctoral research project, I found that my position varied from that of semi-insider to semi-outsider (see Corbin Dwyer & Buckle, 2009). I

have some knowledge of daily life with cancer, since I have followed several cancer stories closely over the years. Some of my closest family members, co-workers, and a supervisor have been diagnosed with and treated for cancer. Some of them survived, others have passed away. Nevertheless, I did not have a family member with an acute cancer situation during the research, nor have I been diagnosed to have cancer myself. Still, when acute cancer situations arose in my circle of acquaintances, I deliberately took some distance from my analysis. At these times, I focused my energy on theoretical and methodological issues.

In the beginning of the interview process, I found that participants were eager to know about my personal relation to the research topic. I decided not to share all my personal experiences with them. However, I told those who asked about my previous research and shared a short story about my friend who was diagnosed some years before the research. Surprisingly often, the participants asked if I had children. At that time I did not have children and I interpreted that it was a relief for some of my interviewees: the gestures suggested that they felt free to share their thoughts, fears, and grim issues considering their fertility. The fact that they were sharing their stories to a young female, approximately same age as themselves, seemed to be a good thing. Being the same age, it seemed natural to share experiences of life.

The participants of the study brought some ethical issues to my awareness, by asking about my background as a theologian: Would it matter if they were not believers or members of the Lutheran church? Would I hear their stories instead of my own agenda? When starting the interviews, I made a conscious decision to keep an open mind in hearing the experiences of the emerging adults. However, in the pages of the research diary, I was able to process my own thoughts about emerging adults' expressions of religion and spirituality. I personally found it very important to write and process those thoughts, in order to put my personal thoughts aside, since I cannot divorce my Christianity or priesthood from my personal identity. However, in the interviews, I successfully made a conscious effort not to introduce any of my thoughts or any teachings of the church into the discussion.

The research diary was an important tool for my work also from another angle. For instance, I found out that during the interview process I was tired, but could not really figure out why. All the interviews went well: the emerging adults were eager to share their experiences, some tears were shed, but often laughter played a part. I read the diary when I was transcribing the data and realized that between their smiles, jokes, and laughter, the interviewees were expressing agony. Then, I understood that this type of research takes reflective time: to be able to hear, I need to call a halt and listen even more carefully. I also discovered that I had a tendency to listen to the stories of significant others (including spouses, family members and close friends) in detail. This made me conscious of not over-emphasizing the experiences of significant others in my research.

To sum up, when it comes to cancer, I am an insider from witnessing it and an outsider to having it. From the perspective of Lutheranism, I am an insider. However, I feel that I discovered a place where I can hear and analyze different worldviews, without infusing them with any of my personal convictions. I became an insider, from the perspective that I hope that I learned about and from the stories I heard. I hope that I keep following my interviewees' notions of what makes life meaningful. I hope that I know (at least every now and then) how to stop and enjoy the moments in the present; both significant and small, with compassion, joy, and love.

Next, I will briefly introduce the key findings of the articles and then describe how the emerging adults described their experience of having, losing, and reconstructing a meaning in life during their cancer process.

## 4 SEARCHING FOR MEANING

### 4.1 KEY FINDINGS OF THE FOUR ARTICLES

#### **Article I: Life Tree Drawings as a Methodological Approach in Young Adults' Life Stories during Cancer Remission**

The methodological article introduces the steps in the analytical process that led me to discover the results, especially coming to understand their life tree drawings. It was found that most participants selected the use of colors carefully. Often, green pictured growth and symbolized positive matters, whereas pink and red pictured love and other positive elements in life. Symbols of cancer – dead branches, scars, witches' brooms – were usually colored with a black marker. Analysis of the visual narrative also led me to discover metaphors of time, body, self and support.

The metaphor of support was often described through the roots of the tree; the contribution of significant others became tangible when the roots kept the tree standing. The metaphor of self, and the impact of cancer on the self, was illustrated by the growth or blooming of the tree; these narrations combined both the positive and negative experiences on the personal path of identity. Furthermore, the long-lasting embodied experiences of cancer were visualized through the metaphor of the body. Often, the metaphor of time was represented in a linear way; yet, for some, the future remained under-scoped.

#### **Article II: Coping-Related Themes in Cancer Stories of Young Finnish Adults**

In the paper, I answer to two questions: 1.) How did young adults describe their coping with cancer? 2.) How were religion and spirituality narrated as part of the coping process? I found that identity, context, and practices were described as the core dimensions of coping. The dimension of identity included stories of a personal relationship with God and difficulties understanding how God could have allowed the cancer to happen. Furthermore, the participants highlighted their personal mental strength as a key issue in coping. The context dimension was described from two perspectives: as an impact of Finnish religiosity and as tangible support provided during the cancer process. The dimension of practices included turning to religious rituals, the experience of catharsis discovered from cancer, and elements that helped interviewees to deal with emotions.

Within the core dimensions – identity, context, and practice – religious, spiritual and secular aspects were intertwined. From the theoretical point of view, it was found that Pargament's (1997) RCOPE lacked understanding for lived experiences of religion and implicit aspects of religion in the coping

stories, whereas Ganzevoort's (1998a, 1998b) narrative approach provided a more comprehensive platform for different elements of religiosity.

### **Article III: Emerging Finnish Adults Coping with Cancer: Religious, Spiritual, and Secular Meanings for the Experience**

In the third paper, I seek to understand the meanings constructed from the cancer experience. To gain a deeper understanding of the coping and meaning-making processes, the stories of Beth, Sophia, and Anna are explored in detail and then compared to the experiences of the other participants. Over time, many of the participants were able to find meaning in their cancer experience. An explicit religious meaning was rarely found, but for some, the disease was discovered as a calling from God. However, ascribing a spiritual meaning to cancer was more common; within the stories of buffered identity and important relationships, cancer had a special significance. For some, a secular meaning of cancer was found in the courage to make a career change.

In conclusion, meaning-making is found to be thoroughly existential process that incorporates elements of the religious, spiritual, and secular. The results show the needs for closer co-operation between the disciplines of theology and psychology of religion, since current theories of meaning-making are at risk of forgetting the theological and sociological aspects of lived religion (e.g., McGuire, 2008; Ganzevoort & Roeland, 2014).

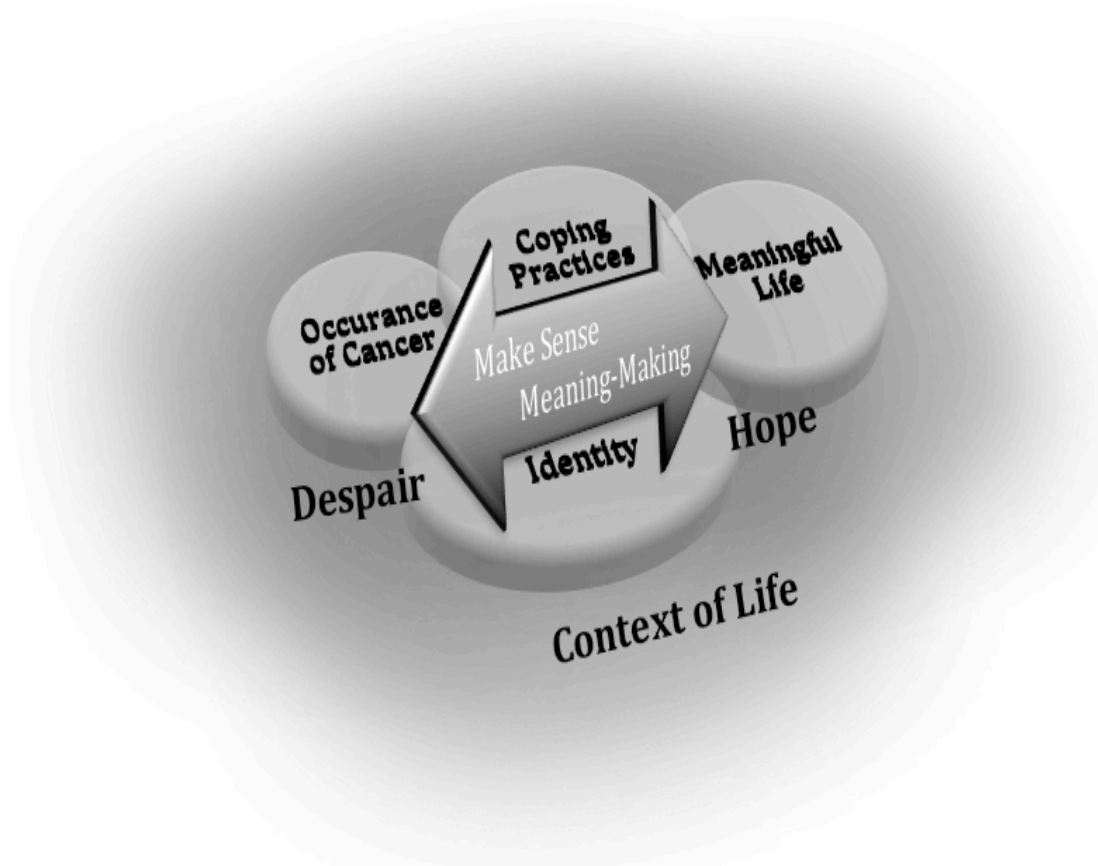
### **Article IV: Landscapes of Hope and Despair: Stories of the Future and the Life Tree Drawings of Emerging Adults with Cancer**

The focus of the paper was to scrutinize how the future stories of the participants were related to experiences of hope and despair. Moltmann's (1965/2002) theology of hope, and Lester's (1995) views on the hope and despair within the future story of an individual were essential to creating the theoretical framework. I found that participants described their future in three different ways: stories of a fragile, dualistic, and positive future were discovered.

Within the fragile future stories, the future was narrated with hesitation and hopes for the future was thin and bounded. Moreover, the fragility was vividly visible in the trees in which the protagonists have trouble framing the impact of cancer to the tree. The dualistic future stories incorporated these similar elements of despair – the fear of relapse was reality; however, the dualistic stories included stronger elements of hope – wishes to live a full life according to personal values. The dualism became visible in the trees that follow narrations of both the elements of growth and the disease. The positive future stories took a step further away from despair; the future was seen as full of hopes and dreams. Cancer was often found to be very meaningful; furthermore, the trees visualized the meaningful life more generally. Still, I discovered that meaning in life and discovering an explicit meaning for cancer cannot be juxtaposed.

### **Individual Papers as a Starting Point for the Introductory Article**

The results of the four individual papers constitute the basis for this introductory article. It can be summarized that the occurrence of cancer triggers an assessment process that is negotiated within social and cultural contexts. Within this process, most individuals considered cancer as a threat, in terms of making sense of what is going on. Some who did not appraise cancer as a threat continued life mostly as it was before the diagnosis. However, the majority of the emerging adults interviewed entered into the meaning-making process. The quest for a meaningful life activated each individual's coping practices. These practices were individually selected in order to make sense of the person's changed life situation. Both the identity of an individual and the surrounding context had an impact on finding helpful practices. Additionally, in most of the stories, the importance of personal context and significant others was highlighted (II, III, IV). The next figure summarizes the coping process and its key elements.



**Figure 2** Cancer Crisis and Meaningful Life.

As Figure 2 pinpoints, the occurrence of cancer aroused a meaning-making process, since most of the participants experienced loss of meaning. It could be characterized as follows: the greater the loss of meaning, the more despair was felt. Additionally, the amount of revitalized sources of meaning was

linked to the appearance of hope. Overall, meaningfulness was linked to the experiences of hope. Even when cancer was appraised as a meaningless experience, the future could be seen as bright. Even when undergoing tribulation, the interviewees had hope: hope for stability, hope of discovering a meaning, hope of having a normal life. Furthermore, for many, the future was full of hopes and dreams to be achieved. Therefore, it cannot be said that people need to compose a meaning for crisis, loss or change in life, in order to live a meaningful life. Yet, many emerging adults described the discovery of an explicit meaning for cancer, and some felt that they were in the middle of the meaning-making process. The following sections will present details, firstly, of how context provided sources of neglect and meaning during the cancer process; secondly, how the cancer coping process was described on the level of the individual self.

## **4.2 CONTEXT AS A SOURCE OF NEGLECT AND MEANING**

### **Unmet and Met Needs within the Healthcare Context**

The baseline stories were narrated with only a few words; yet, the Finnish background contextualized many of the stories in terms of the Finnish healthcare system and religious upbringing. Therefore, I will next focus on the impact of context on the cancer process.

The healthcare context was narrated openly as the official source of support. For instance, some met a psychiatric nurse and found it easier to talk to someone who was not emotionally involved with them. Others specified that it was their personal nurses who were a great support (II, III, IV). Overall, it seemed, as Lankinen (2001: 287-191) describes, that after cancer diagnosis, the authorities are regarded in a more familiar way.

Still a strong counter-narrative for a workable healthcare system appeared when many of the emerging adults described the lack of information at the beginning of their cancer journey. This unmet need was narrated in terms of not receiving enough information regarding the disease itself or the side effects of the treatment. Therefore, emerging adults utilized the Internet to gain more knowledge about their situation. However, the Internet as a tool to gain more information was harmful: often, the web provided stories of worst-case scenarios (II). Even though AYAs of today can be characterized as “diginatives” and the Internet is full of mentoring communities for young people (Parks, 2011), a surprisingly low number of patients actually finds or searches for information or support from online communities of cancer patients (Zebrack et al., 2014b). While truthful information was highlighted by dying patients (Mattila, 2002), it also seemed that young patients should be better informed about their life situation and they would have appreciated



time and more in-depth delicate discussions with the medical staff (e.g., Zebrack et al., 2009).

These experiences of a lack of information were related to the absence of emotional support when information was given. DeRouen and others (2015) noted that two-thirds of young patients reported a lack of information. Additionally, for almost half of these patients, the information lack was related to the experience of not having control over their own life. Both information and control over one's life were negatively associated with health-related quality of life. These findings pinpoint that giving information includes elements of emotional care and support, and healthcare personnel have an important role as a provider of emotional and social support (e.g., Zebrack et al., 2006; Zebrack, 2011).

Emerging adults found that especially the information considering fertility issues was often dismissed and handled poorly in various ways (II). However, when discovering that she or he was able to bear or conceive a child, participants felt a sense of relief (see IV). As a physical outcome, 80 percent of both female and male patients experience reduced fertility (Patterson et al., 2015). Since, after the diagnosis, AYAs are eager to begin treatment, they might have difficulties considering all the consequences that it might cause. Fertility issues should be more thoroughly discussed and negotiated with the patient (Docherty et al., 2015), since only around 25 percent made arrangements that considered their fertility issues before the treatment began (Nass et al., 2015). Later in life, infertility becomes a psychosocial concern and arouses feelings of being different (Patterson et al., 2015).

When emerging adults entered into survivorship, the most important source of emotional and practical support was the individual's family and friends. Nevertheless, during and after treatment, participants often described their willingness to protect their loved ones from their personal misery. The participants felt that the cancer caused such a significant crisis to their loved ones that they did not want to be a burden for them (II, III). A serious health condition is also a burden for family members: loved ones suffer their own crisis and try to support the individual with the condition simultaneously (Morse & Johnson, 1991). Moreover, family carers struggled to fit together their other life obligations (such as work), personal strengths and taking care of their loved one (e.g., Kauppinen, 2015; Kauppinen & Silfver-Kuhlampi, 2015)

As an ensemble, the stories of emerging adults affirm earlier discoveries that the requirement of care and support is long-term. The need for emotional support continued, and even five years after the treatment the yearning for emotional sharing was reported (IV). As the emerging adults described, the transition to survivorship is extremely critical: AYAs consider themselves unprepared for survivorship, which includes elements of being abandoned and feeling unsafe (Patterson et al., 2015; Walker & Lewis, 2016). According to Sansom-Daly and Wakefield (2013), clinical distress was found

to be highest between 1-2 years after treatment and high levels of distress have been reported as much as 20 years afterwards. In addition, long-term negative effects were described even more than 30 years after the treatment (Grinyer, 2009). Therefore Thomas and others (2010) suggest that regular counseling meetings, at least once every six months, should be arranged for the first five years after treatment, and that counseling should continue on yearly basis thereafter.

### **Activated Religious Context and Lack of Religious Support**

Being raised according to “Finnish religiosity,” was the second context-bound description discovered from the narratives. As a theme “Finnish religiosity” was more difficult to tackle, because the interviewees took this for granted. As thinly narrated within the stories, “Finnish religiosity” spans belonging to the church, being taught to pray evening prayers, attending confirmation education, and going to church at Christmas and on some other special occasions (II, IV). Still, it was quite rare that religious support was received or expected from significant others. Only a few described that their parents’ religiosity activated after the cancer diagnosis, which resulted in personal religious activation of the emerging adult. In addition, a few described the comfort provided by intercession (II, III; see also Johannessen-Henry, 2013).

I interpreted that the religious activation was based on the participants’ Lutheran upbringing and confirmation schooling. I summarized that the Lutheran metanarrative plays a role in coping narratives, and that it was actualized as lived religion in the meaning-making process. The diagnosis awoke the participants’ tendency to consider their Lutheran roots, and shaped their religious considerations and rituals to serve their personal needs during the coping process (II, III). Similarities were found in Johannessen-Henry’s (2013) study: she formulated that everyday religion, rooted in Christianity, was an important source of comfort in the Danish context. In contrast Ahmadi (2006), who argued that religious elements are no longer culturally accepted in Sweden, concluded that it cannot be said that cancer made people religious. Rather, because of the diagnosis, people had the tendency to think about religious and spiritual matters.

From the perspective of emotional care, I find it surprising that even after spiritual, religious, and existential questioning, only a few of the emerging adults received pastoral care. Moreover, the usefulness of the pastoral care given remained unclear: one participant felt that she would have needed “much more” pastoral care, and another reported discussions “only about ordinary matters” even though his condition with cancer relapse was extremely serious (II). I wonder if this is a result of the fact that the support was offered right at the beginning of treatment, when an individual had just gained some of the experience of efficacy of the treatment and momentarily alleviation of existential anxiety. This is significant as, for many, the existential process began only after entering to survivorship (IV).

The faith development theories could be interpreted so that there is a crucial need for religious and spiritual care and support for young people in crisis. Since, Fowler (1987) points out that abstract thinking appears between ages of eleven and thirteen, and within this phase of synthetic-conventional faith development, the understanding of self becomes reflective; the personal identity becomes a struggle as it is socially constructed within peer relations. In the individuating-reflective phase of emerging adulthood, personal meaning systems – values and faith – are explored, contested, and probed. Even without a crisis such as cancer, developmental changes may not occur; without support or mentoring communities, the big questions of life, values, and identity remain unsolved (see Parks, 2011).

I have now outlined the met and unmet needs for support within healthcare and religious environments. However, context and other people also served a setting for discovering meaning, as I will next demonstrate.

### **Significant Others as a Source of Meaning**

This section discusses how social relationships, situated in the personal life context of an individual and in Finland as a broader coping context, were described. Besides oral narration, significant others and their contribution to the cancer experience were often drawn onto the trees; these key people constituted the metaphor of support that kept the tree in balance (I, III, IV).

During the cancer process, these close relationships became important in a new way: they provided a strong source of meaning in life when being accepted with and after cancer. Family members became closer and new friends – soul mates and spouses – were found because of cancer. For some, these relationships became so important that it was hard to imagine a scenario where the cancer had not occurred. These close relationships made cancer an important and meaningful part of the individual's life story. These significant social relations provided a value-based spiritual meaning for cancer (III).

Stronger relationships with significant others, and a greater capacity to feel empathy for others, can be seen as positive late and long-term effects of AYA cancer (Grinyer, 2009). Overall, significant others are an important source of meaning (40 percent). Additionally, work (around 15 percent), and interpersonal relations (around 10 percent) also bring a sense of meaning to life (see Delle Fave et al., 2011). Further, the sense of belonging has found to be closely linked to the subjective experience of personal well-being (Pessi, 2017). From these premises, it is not surprising that meaning-making was strongly spiritually laden rather than religiously shaped (III).

There are surprisingly similar elements in the stories of emerging adults who survived cancer and the stories of older people with terminal cancer. Haug (2015, 2016b) discovered that social relations are the key to providing a space for existential meaning-making. For terminal cancer patients, existential meaning-making with behavioral resources assisted in achieving daily goals and adjusting these goals to one's life situation, and these

elements were strongly related to experience of resilience. Hardiness, self-encouragement, pressing negative feelings, and cherishing positive feelings and laughter are key components of resilience (Bonanno, 2004). Further, Haug (2016a) specifies that meaning-making was built from the experience of meaningful time spent together with significant others and participating in meaningful daily activities. Moreover, cancer was reframed using variables that arose from the individual's worldview, culture, and meaning-making.

For the emerging adults, the experience of self-worth was rebuilt in terms of experiencing hope and belonging through and within the social relations. Overall, the strong presence of the metaphor of support highlighted family and loved ones as essential to the coping process: significant others kept the tree standing even in the midst of the crisis (II, III, IV). Ganzevoort (1998a) states that during the coping process, social relations included different levels. At the primary level, there are people who bring a sense of balance and security to the process, just as the interviewees' loved ones were described. In addition, the second level of relations included other people who can introduce alternative interpretations to the situation.

Meetings with fellow patients seemed to bring both balance and new interpretations to the changed life situation. Among peers, it was possible to share thoughts about cancer without explaining all the details, and without feelings of stigma. In addition, friends and hobbies were described as providing a break from cancer, and were a source of second level relations. Friends provided sense of normality during the treatment. Just having a cup of coffee, sharing a laugh or participating in normal activities with friends, served as a reminder of life before cancer and provided hope for the future (II, IV).

The coping context was a source of neglect and support; both experiences of despair and hope grow from and within personal relations (IV). Hope and despair become vivid in their contrasts. However, the true essence of Christian hope comes vivid as "genuine co-humanity and of authentic life in the rough sea of circumstances which the ordinary man can after all do nothing to alter" (Moltmann, 1965/2002: 304). Even though the emerging adults did not see their family and loved ones as Christian community, from the perspective of pastoral theology, it can be concluded that significant others provided support in the search for meaning at moments of despair. Next, I will introduce the process of losing and composing meaning from the perspective of the individual.

## 4.3 LOSS AND DISCOVERY OF MEANING

### Searching for Alleviation

The overarching theme in the stories of the emerging Finnish adults with cancer was changes in self, which were narrated and drawn by most interviewees. This section describes the emotional suffering and loss of meaning identified in the narratives.

Usually the cancer narratives began with the shock following the diagnosis. Then the onset stage included difficult existential questioning: What have I done to deserve this? Why would God allow this to happen? These negative religious appraisals were described in terms of looking to oneself or God for a reason for cancer. Moreover, negative appraisals were described in terms of not being heard by God (II). Similar existential pain was described by Paal (2009, 2011) who discovered that linguistic metaphors such as drowning, a tree trunk or stone falling on the individual, or feelings of being cold, empty, and broken were utilized to express the experience of the cancer diagnosis. Encountering cancer has also been associated with encountering personal death: role expectations are mixed when cancer patients are expected to fight against (Landmark et al., 2001) and to take on the role of the dying patient (Paal, 2011).

The emerging adults described how bewilderment and shock started to alleviate when the treatment began. Often the treatment provided security since it gave an experience of concrete action vis-à-vis the disease. Lived religion and religious behavior were narrated as comforting; especially the importance of prayers was described, as these provided the feeling of having a religious audience for the prayers (II). In addition, the treatment alleviated existential anxiety and, for many, religious interpretations of the situation shifted from negative to positive (see also Torbjørnsen, 2011; Johannesen-Henry, 2012). Even though religion rarely offered an explicit meaning for cancer, it served as a source of meaning and comfort during the crisis and was momentarily a more important part of the global meaning system (III).

With Baumeister's (1991) terms, these religious coping narratives reflect restoring control and efficacy after the diagnosis. The emerging adults turned to a higher power or God for comfort and security (II); horizontal self-transcendence activated and promoted a sense of meaningfulness in life (III; see Schnell, 2009). More than fifteen years ago (Kyngäs et al., 2000, 2001), young Finns found that God provided comfort during cancer treatment. In this research, emerging adults expressed that comfort as more often provided by a higher power or a universal God, rather than (simply) God (II). These discoveries show how important it is to have hermeneutical understanding of human religiosity (Ganzevoort, 1998a); religiosity includes biographical changes, and elements of explicit and implicit religion.

From the perspective of the self, the treatment period was a time to call a halt. On one hand, this created the positive opportunity to do nothing. Yet,

the standstill was expressed within a few of the drawings with the cyclic movement of time that referred to experiences of despair. These discoveries confirmed Lester's (1995) notions that despair is more likely to appear in closed systems where it is difficult to reach the future (IV). Also earlier studies show that for many, the concept of time changes and living in the moment intensifies (Paal, 2011; Seibaek et al., 2012; Nielsen & Sørensen, 2013).

Embodied dimensions of cancer also impacted on the emerging adults' experience of self. Along with the actual treatment, nausea and a risk of infection became a part of daily life. These bodily changes and experiences of being different were linked to stigma. Stories of hair loss, changes in body weight, or not identifying oneself were often described in the treatment stories. These reports are in line with the suggestion that more than half of young patients struggle with issues relating to body image (see Belizzi et al., 2012). Still, the metaphor of the body appeared relatively rarely. It was pictured only in the drawings of those who experienced longer-lasting changes (IV).

Regarding stigmatization, significant others were sometimes described with a negative tone: being dependent of others caused humiliation and feelings of helplessness and neediness in terms of care. The experience of despair deepened with the experience of being different (IV). In these cases, the lack of meaning was related to negative appearance of a self-worth. In comparing oneself to others, it was difficult to feel full belonging. Within the narrations of stigma, despair, hope, and belonging were often intertwined. These findings could be loosely associated with Moltmann's (1965/2002) views on hope; hope was built on social relationships and human dignity. Further, I found that despair was related to disruption of belonging and self-worth (see II, III, IV). Grinyer (2007) points out that the backward shift to dependency can be extremely difficult, especially to adolescents who have just gained the new experience of independence. For young people who have already lived on their own, moving back to their parents' house can add distress and embarrassment.

Overall, the drawings made difficulties in life concretely visible. The visual narratives grappled with the loss of self-worth when cancer was pictured as an external intruder that impacted the growth of the tree, as dead parts of the tree, or as witches' brooms in the foliage of the tree (I, III, IV). These expressions portrayed the sustained impacts of cancer on oneself: the metaphor of the self described how the disease manifested by making one "small" or being "ripped apart" but also as "being alive" even though there was no meaning discovered from the cancer itself (I, IV).

Furthermore, the emerging adults visualized their insecurities about the future by drawing the future as part of the tree; some left the future undrawn on purpose. These visual findings grasp the essence of loss of purpose in life, when the dreams of the future are difficult to reach. At the same time, the standstill in life drove them to ask how they had lived their lives thus far (II,

IV). For cancer patients, the future is anticipated in terms of life and death, but the individual tries to fight against the fear of death. With positive thinking and searching for a sense of normality, relief is experienced (Landmark et al., 2001; Seibaek et al., 2012). Cancer threatens the individual's views of the future and, therefore, it is important to maintain positive thoughts of recovery (Landmark et al., 2001; Salander, 2014).

This research confirmed that, for emerging adults, the thought of a quick recovery to normal life kept their spirits up during the treatment (see Kyngäs et al., 2000). Additionally, often right after the treatment, values and goals in life were clarified. Still, the return to daily life turned out to be something unexpected. Many of the participants described that the deepest crisis followed during this period. When they entered survivorship, they had the courage to reflect upon what had happened or what could have happened. Still, they felt that they were expected to continue life as it had been before cancer (II, IV). In sum, the emerging adults entered survivorship without being prepared (see Thompson, 2009; Kwak et al., 2013; Patterson et al., 2015).

After treatment, the despair was mostly described in terms of being afraid that the negative events would recur, or as experiencing the future as dangerous. This unpredictability was tangible in fragile descriptions and dualistic views of the future. Both these future dimensions emphasized the fear of relapse and death. Moreover, sometimes the loving relationships added agony. Some emerging adults were not afraid for themselves, but rather feared how their loved ones would cope after a relapse or death (IV; see Lester, 1995). Fear of relapse has a negative impact on physical and mental health-related quality of life (Cho & Park, 2015). Intrusive thoughts are related to poorer adjustment. However, continued intrusive thoughts can be a sign of an ongoing endeavor to discover a meaning for the cancer, which some patients do find (Park et al., 2010).

To sum up, cancer strongly encouraged the emerging adults to adopt a reflective stance in their lives. They had to come to a halt, encounter the possibility of dying, and reconsider what makes their life meaningful – in terms of values, habits, faith, and way of living. As a result, the emerging adults entered into mature identity (see II, III). According to Fowler (1987: 68-69), as a life stage young adulthood includes conflict of roles; at this stage, an individual adopts “a third-person perspective” from which one is able to construct personal system of belief by examining thoughts of the self and others. Parks (2011) frames the questions of meaning and faith as the developmental task of emerging adulthood; before committing oneself to mature adulthood, an individual has to explore their personal commitment and values.

### **The Buffered Self as a Source of Meaning**

Within time and with reflective thoughts, many of the emerging adults discovered that their cancer experience had a special meaning. Identity-

related changes were narrated as part of the coping process (II), and as meaningful experiences of changes in self (III). These pleasant changes in the self, actualized as hopes and dreams for the future (IV). Moreover, the strong presence of metaphors of the self highlighted the fact that cancer happened to individuals and also reiterated the fact that it was “me” who was the key to coping (I, II). These spiritual meanings were found to lead to long-lasting changes in the global meaning system and were also depicted in the life trees: the promise of growth and blooming of the tree were drawn as related to the experiences of the self, significant others, and hopes for the future (II, III, IV).

Some of emerging adults stated that cancer meant a sudden shift to mature adulthood. This shift was forced and unpleasant. However, some felt, encountering the possibility of death provided a higher appreciation of life and close relationships. Theoretically, it seems that the actual salience of death is a demanding reflective process which takes time. Especially among young people, the understanding of the salience of death takes at least a year to form (Little & Sayers, 2004). Still, a greater appreciation of life can be found by encountering the possibility of death. Moreover, it was found that some find changes in attitude to life in terms of not being troubled by small things and cherishing new opportunities (Grinyer, 2009).

These identity-related changes became spiritually meaningful, since many emerging adults described their personal inner strength as integral to coping (II). Often, the participants described how they discovered unexpected – even astonishing – powers within themselves that helped them to stand on their own two feet again. With this new buffered identity, the emerging adults narrated changes in their selves as courage to live up to one’s own goals and follow personal dreams. The most frequently described tangible changes were shifts in the field of study or career. For a few, the change of career was significant, but the new job was not existentially relevant but was rather interpreted as an ordinary change of career. For others, the new study field provided a channel to do something good and was seen as a spiritual process (III). Especially in dualistic and positive future stories, the element of following personal dreams, and therefore living a full life, was described (IV). Searching for meaning in life was linked to reconsideration of values in terms of the justification for personal actions (see II, III; Baumeister, 1991). Also Grinyer (2009) described greater self-confidence after cancer.

For some, offering peer support provided an opportunity to find meaning in their suffering: they were able to share their knowledge and help others in the same situation (II, III). These experiences could also be seen as promoting meaningfulness in life by actualizing a vertical self-transcendence and belonging (see Schnell, 2009). Further, it was recently found that the “Protestant work ethic” still retains a highly substantial foothold in Finnish society: 75 percent of Finns find important to be able to work in such way that they can serve others, which is seen as rewarding and valuable, even though the work in itself is not “religious” (Ketola et al., 2016: 85-87). In



Lundmark's (2016a) research, strongly religiously-oriented cancer patients reframed their cancer experience with an aspect of religious meaning by evangelizing, being prepared to meet new people, and discovering new forms of religious service to others.

In general, these emerging adults' experience of the buffered self – discovering a stronger sense of self, mature identity and personal meaning system – can be linked to earlier evidence that the majority of AYAs experience post-traumatic growth (Barakat et al., 2006; Yi et al., 2015). The opportunities for discussion provided by intervention groups, optimism of family and peers, and re-experiencing and cognitive processing of the cancer were found to be extremely important to PTG, as were emphatic listening, validation, acceptance, and empowerment (Zebrack et al., 2014a; Zebrack et al., 2014c; Yi et al., 2015).

To reach PTG, an individual must go through the trauma. However, there is a growing body of research indicating that a notable percentage of people are resilient to severe misfortune in life. These resilient people do not go through crisis processes in the same way as others. Resilient people undergo loss and sorrow, but have a different capability to remain steady. Resilience is a different phenomenon to post-traumatic growth. Since resilient people do not enter into trauma, their storyline can also be shaken but it does not sink, and the degree of change is much lower (Bonanno, 2004). When conducting the interviews, I was not familiar with resilience, and was therefore unable to probe questions to elicit the interviewees' possible perceptions of being resilient. Nevertheless, it seems that also in emerging adults' stories, resilience could clarify the experience of being able to keep hold of clarity, having no sense of an extreme life change, and stable thoughts of a future right after the treatment (see IV), whereas post-traumatic growth was narrated by many participants.

Among emerging adults, changes in self were also narrated as activation of the spheres of religion and spirituality. However, explicit religious meanings were rarely described. It seemed that religious activation and its significance was important during the acute phase of diagnosis and the treatment, but when time passed, practices such as praying decreased (II, III, IV). Religion was drawn only in one of the trees (I, IV), and it seemed that it was not permanently central to the participants' global meaning system (II, III, IV). This is in line with Delle Fave and others (2011) discovery that less than 4 percent of individuals define religion as a source of meaning in life.

During the crisis, lived religion served as a source of a meaning by buffering efficacy: comfort was found in individually important rituals. This sort of religious behavior was important when an individual felt afraid or was preparing for treatment. For instance, the interviewees described tactile coping rituals such as taking protective angel figures or praying cloths to the treatment. A praying cloth is a blessed linen cloth that is believed to provide God's protection, utilized within charismatic Christian movements. As Lundmark (2015) demonstrates, tangible practices, such as holding a praying

cloth, can be a highly valuable source of God's protective powers. Further, the embodied practice of walking in nature also alleviated agony, providing a sense of God's closeness and comfort (II, III). Danbolt and Stifoss-Hanssen (2011) point out that in crisis situations, rituals assist in grasping the reality of life and composing meaning in the midst of chaos. Moreover, the tangible element of a ritual makes it a strong bodily experience, and rituals are likely to have "symbolic and existential significance" (p. 30).

In addition, the narratives of the emerging adults point out the value of implicit forms of religion and lived religion. If religion is only addressed from explicit point of view, it is likely to be neglected. Further, the biographical changes need to be noted; even though cancer rarely had explicit religious meaning, in periods of extreme loss of meaning, religion was an important source of meaning (II, III, IV). These personal, embodied rituals of lived religion and more implicit religiosity highlight the limits of the RCOPE categories. If the religious experiences and rituals are reduced to categories of RCOPE, the diversity of lived religion is neglected. These discoveries confirm Pessi's (2017) notions on religion as a source of meaningfulness. Pessi reminds us about a crucial point; religion can provide meaning or a system of meanings in daily life and in hard times. Furthermore, when personal "religiosity is complex and open," (p. 32) an individual experiences life as more meaningful.

## 5 CONCLUSIONS

### 5.1 SUPPORT AND SHARING LINKED TO POSITIVE VIEWS OF THE FUTURE

This introductory article was based on two sets of questions. First, how the surrounding context of an individual, and their close relationships, affects the coping process and the experience of meaning. Second, the aim was to scrutinize the conditions for a cancer-coping process to become a meaningful part of the self and life. This included figuring out the relation between finding meaning in cancer and experiencing meaning in life. Further, the dimension of the future was found to be crucially important in this process, since discovering meaning in life after cancer was related to discovering meaningful future. Therefore, the concluding remarks of the introductory article outline intertextual findings from the future stories. The following Figure 3 summarizes the results of the original articles and findings of this introductory article from the perspective of the future.

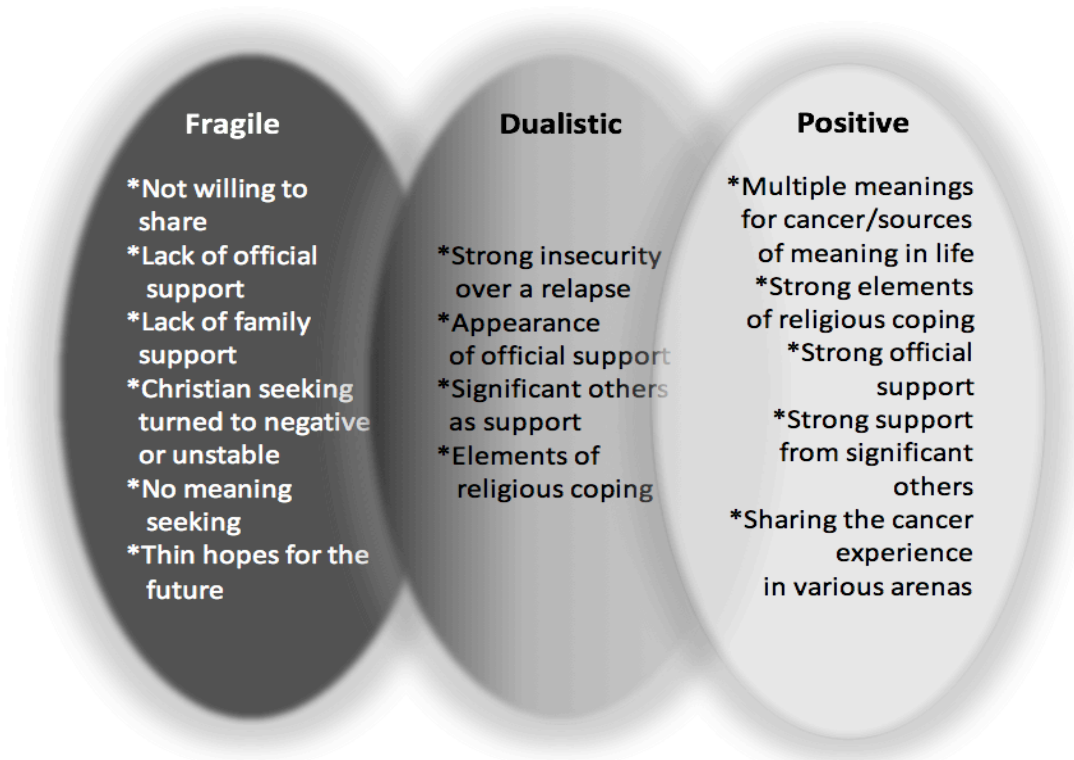


Figure 3 Dimensions of the Future.

First, those who had fragile views of the future reported a lack of support from their family, and in addition, some of them experienced that their needs were not met by official support givers (in term of psychiatric nurses,

psychologists, pastoral care). Some of them highlighted unwillingness to share their thoughts about cancer with others. Moreover, many of them went through a search for faith, and often Christianity was found to be deficient or irrelevant. Visions and hopes for the future were related to mainly to the ability to work. Still, it must be said that often these fragile views of the future were narrated soon after the cancer treatment. Those who described their future as fragile, had not (yet) appraised cancer as meaningful.

In contrast to the fragile stories, the positive views of the future included strong hopes and wishes for the future. Cancer was found to have a strong meaning in the life of these narrators. As a coping method, religious rituals and prayer were found to be important. Moreover, family was narrated as a strong source of support and new kind of meaning in life, also after cancer. Importantly, official support givers usually supported the participants who had positive views of the future.

The dualistic future stories provided an interesting viewpoint between and beyond the two extremes. The dualistic stories seemed to oscillate between the extremes of total despair and fulfillment of hopes and dreams for the future. From the data available, I was unable to determine the roots for dualistic views of the future. The protagonists had a clear individual worldview, many of them found their personal relationship with God or a higher power comforting, and they had support from their families. Interestingly, this group consisted of emerging adults whose treatment had ended between 2 and 5 years before the interviews.

Both the positive and dualistic future stories highlight the essentiality of being heard and supported by both the official caregivers and loved ones. Moreover, telling personal stories helped participants find coherence in difficult life situations and meaning in life – also in the midst of despair. The passage of time did not fully explain the variations between the future dimensions; both fragile and positive views occurred at different stages. Rather, the level of formal and informal support was most strongly linked to future hopes and experiencing meaning in life.

Further, it could be summarized that within the cancer process, an individual and his or her life context is likely to undergo radical changes. The context provided both sources of neglect and care; furthermore, cancer was found to be explicitly meaningful when loved ones were seen as significant in new way. In order to overcome the loss of meaning, support was needed for individuals to find personal inner strength to cope and to rediscover meaning in life. Those participants who felt that they had grown with a stronger identity because of cancer, found cancer carried an explicit meaning in their lives.

Still, it must be noted that these discoveries are bound in time and biographical changes have affected the participants of this research. It is likely that many changes have occurred. Therefore, it is possible that those who had fragile, dualistic, or positive views at the interview could now hold different views, hopes, and expectations of the future.

This study reinforced the earlier findings that some young patients are living more meaningful life after cancer (see Zebrack & Walsh-Burke, 2005); that the ability to find a positive meaning for cancer and peace in life seemed to promote well-being (Park et al., 2010); and contributed favorably to adjustment during cancer survivorship (Park et al., 2009b). Little and Sayers (2004) found that less than one third of the cancer narratives they assessed were a search for meaning. However, in this study the experience of entering into the meaning-making process was usual. A deeper understanding of emerging adults' construction of meaning was found when religious, spiritual, and secular meanings for cancer were taken into account.

## **5.2 IMPLICATIONS OF CARE**

The awareness of being heard and the possibility to share cannot be over-emphasized, since emerging adults framed their experiences of sharing with the experience of emotional support. Moreover, telling personal stories assists in discovering coherence in difficult life situations. Therefore, narrative care should be implemented more carefully as part of the holistic care of an individual (Synnes, 2016). Moreover, earlier studies advocated the importance of sharing and being heard for PTG.

Both post-traumatic growth and the unmet needs of emerging adults highlight the fact that a stronger sense of “dignity in care” is essential. (Tranvåg et al., 2016). Absolute dignity refers to understanding human beings as holistic creatures that have spiritual needs, essential values, and an ethical awareness of dignity of self and others. Moreover, how and what the individual sees as dignity or violation in care are highly personal experiences (Tranvåg & McSherry, 2016). The viewpoint of dignity should be implemented in survivorship treatment plans and age-specific care (Docherty et al., 2015; Patterson et al., 2015).

From the perspective of pastoral care and diaconia, church welfare work, it is extremely important to note that coping with cancer includes wave-like movements of hope and despair. Within the cancer process, existential dimensions are at stake; when encountering mortality, people utilize implicit religiosity and rituals of lived religion in order to make sense of changes. Therefore, it is crucial to comprehend that people with different worldviews and orientations are likely to undergo similar types of questioning. Pastoral caregivers have the knowledge and skills to support the process as a whole: pastoral counseling could and should assist an individual, the carer, and their relationship. Pastoral care can provide hope at all different stages of the health crisis and provide a listener to existential questions that take time to process. Only with realistic hope can an individual be able to re-build personal identity (see Gothóni & Vähäkangas, 2010) – realistic hope provides foundations for the discovery of meaning in life.

### 5.3 IMPLICATIONS FOR FUTURE RESEARCH

Future stories were found to be essential source of information in this research. Therefore, it would be important to map carefully different perspectives on the future, in order to identify the conditions under which different views emerge. Moreover, the three dimensions of the future – fragile, dualistic, positive – need to be further tested within different life settings, crisis contexts and age populations.

Visual inquiry offers endless opportunities for re-evaluating the cancer experience, but this requires much more development. Although the metaphors discovered led me to findings that would have not been explicit otherwise, it seemed that worldview, coping practices, and matters that were momentarily important were difficult to present in the drawing. Further, the coherence and incoherence between oral and drawn narratives needs to be scoped more carefully. In general, life tree drawings are a promising tool for comprehending life stories but the tree method needs to be further tested and analytical procedures confirmed. Moreover, techniques such as photovoicing give young patients and their families the opportunity to discuss and encounter the illness from new perspectives (Yi et al., 2015). This type of participatory and active research would introduce new insights from a qualitative perspective, simultaneously encouraging young patients' self-expression and promoting the experience of being heard when meeting peers.

The present work focused on the Christian tradition and its post-modern impact. Yet, there is a growing body of research focusing on religious coping within different religious traditions (e.g., Boelsbjerg & Baig, 2011; Boelsbjerg, 2013). What do multicultural issues mean for healthcare and chaplaincy? Is there something that visual elements could add to these types of research? It would be interesting to discover how different backgrounds and cultural contexts impact a visual portrayal of the experiences of illness.

Moreover, there is a need for further research from both qualitative and quantitative perspectives, to provide a more comprehensive picture of the phenomena of religious and spiritual coping and meaning-making of young people with health-related issues. Within the age parameters of this study, it seemed that religious and spiritual issues were not age-specific. However, more studies of religious coping are needed to scope the similarities and differences between AYAs and of other age groups. Biographical and developmental changes, implicit forms of religion and lived religion need to be taken into account more carefully in future research on religious coping.

# SOURCES AND REFERENCES

## Data sources

17 interviews and drawings, led by the researcher

3 blogs converted into .doc format for analysis by the researcher

## Bibliography

- Ahmadi, F. (2006). *Culture, religion and spirituality in coping. The example of cancer patients in Sweden*. Studia Sociologica Upsaliensis, Nr 53. Uppsala: Uppsala Universitet.
- Ahmadi, F. (2011). Song lyrics and the alteration of self-image. *Nordic Journal of Music Therapy*, 20(3), 225-241.
- Ahmadi, F. (2013). Music as a method of coping with cancer: A qualitative study among cancer patients in Sweden. *Arts & Health*, 5(2), 152-165.
- Ahmadi, F. (2015). *Coping with cancer in Sweden: a search for meaning*. Uppsala: Acta Universitatis Upsaliensis.
- Alma, H.A., Pieper, J.Z.T. & Uden, M.H.F. van (2003). When I find myself in times of trouble: Pargament's religious coping scales in the Netherlands. *Archive for the Psychology of Religion*, 24, 64-74.
- Ammerman, N.T. (2013). Spiritual but not religious? Beyond binary choices in the study of religion. *Journal for the Scientific Study of Religion*, 52(2), 258-278.
- Andrews, M. (2010). Beyond narrative. The shape of narrative testimony. In M. Hyvärinen, L-C. Hýden, M. Saarenheimo, & M. Tamboukou (Eds.) *Beyond narrative coherence* (pp. 147-166). Philadelphia, PA: John Benjamins.
- Arnette, J.J. (2004). *Emerging adulthood. The winding road from the late teens through the twenties*. New York: Oxford University Press.
- Ausker, N. (2012). *Tid til forandring? Forhandlinger af religiøs kontinuitet, forandring og forbrug hos kræftpatienter i Danmark*. Doctoral dissertation. Faculty of humanities: University of Copenhagen.
- Bamberg, M. (2011a). Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, 21(1), 3-24.
- Bamberg, M. (2011b). Who am I? Big or small—shallow or deep? *Theory & Psychology*, 21(1), 122-129.
- Bamberg, M., & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text and Talk*, 28(3), 377-396.
- Barakat, L.P., Alderfer, M.A., & Kazak, A.E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *J Pediatr Psychol*, 31(4), 413-419.
- Baumeister, R. (1991). *Meanings of life*. New York: Guilford Press.
- Belizzi, K.M., Smith, A., Schmidt, S., Keegan, T.H., Zebrack, B., Lynch C.F., Deapen, D., Shnorhavorian, M., Tompkins, B.J, & Simon, M. (2012). Positive and negative psychological impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, 118(20), 5155-5162.

- Bjorck, J.P., Lee, Y.S., & Cohen, L.H. (1997). Control beliefs and faith as stress moderators for Korean American versus Caucasian American Protestants. *American Journal of Community Psychology*, 25(1), 61-72.
- Boelsbjerg, H.B., & Baig, N. (2011). 'En hver skal smage dø den' Billeder af døden og det evige liv i et muslimsk perspektiv. *Omsorg*, 1/2011, 25-28.
- Boelsbjerg, H.B. (2013). Det hellige rum: Sjælesorgssamtaler på hospitaler. *Tidsskrift for Forskning i Sygdom og Samfund*, 10(18), 67-86.
- Boisen, A.T. (2005/1936). The living human document. In R.C. Dykstra (Ed.) *Images of pastoral care. Classic readings* (pp. 22-30). St. Louis, Missouri: Chalice Press.
- Bonanno, G. (2004). Loss, trauma, and human resilience. Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, 59(1), 20-28.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Butters, M.K. (2016). Aesthetics as metaphysical meaning-making in the face of death. *Approaching Religion*, 6(2), 96-111.
- Bülöw, P.H. & Hýden, L.-C. (2003). In dialogue with time: Identity and illness in narratives about chronic fatigue. *Narrative Inquiry*, 13(1), 71-97.
- Capps, D., Carlin, N., & Dykstra, R.C. (2013). New directions on old connections: Body/soul, flesh/spirit, self/others. *Pastoral Psychology*, 62(5), 545-547.
- Cho, D., & Park, C.L. (2015). Cancer-related identities in people diagnosed during late adolescence and young adulthood. *British Journal of Health Psychology*, 20(3), 594-612.
- Corbin Dwyer, S., & Buckle, J.L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.
- Coufal, K. L., & Coufal, D. C. (2007). Colorful wishes: The fusion of drawing, narratives, and social studies. *Communication Disorders Quarterly*, 23(2), 109-121.
- Danbolt, L.J., & Stifoss-Hanssen, H. (2011). Public disaster ritual in the local community. A study of Norwegian cases. *Journal of Ritual Studies*, 25(2), 25-36.
- Delle Fave, A., Brdar, I., Freire, T., Vella-Brodrick, D., & Wissing, M. (2011). The Eudaimonic and Hedonic Components of Happiness: Qualitative and Quantitative Findings. *Social Indicators Research*, 100(2), 185-207.
- DeRouen, M.C., Smith, A.V., Tao, L., Bellizzi, Lynch, C.F., Parsons, H.M., Kent, E.E., & Keegan, T.H. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psycho-Oncology*, 24(9), 1104-1115.
- Docherty, S.L., Kayle, M., Maslow, G.R., & Santacroce, J. (2015). The adolescent and young adult with cancer: A developmental life course perspective. *Seminars in Oncology Nursing*, 31(3), 186-196.
- Echo, L.W., Kent, E.E., Trevino, K.M., Parsons, H.M., Zebrack, B.J., & Kirchoff A.C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*, 122(7), 1029-1037
- Fowler, J.W. (1987). *Faith development and pastoral care*. D.S. Browning (Ed.), Theology and Pastoral Care Series. Philadelphia: Fortress Press.



- Freeman, M. (2010). "Even amidst": Rethinking narrative coherence. In M. Hyvärinen, L.-C. Hýden, M. Saarenheimo, & M. Tamboukou (Eds.), *Beyond narrative coherence* (pp. 147-166). Philadelphia, PA: John Benjamins.
- Freeman, M. (2011). Stories, big and small: Toward a synthesis. *Theory & Psychology, 21*(1), 114- 121.
- Gadamer, H. G. (2004). *Philosophical hermeneutics* (2nd ed.). D. E. Linge (Ed. & Trans.). Berkeley: University of California Press.
- Ganzevoort, R. (1998a). Religious coping reconsidered part one: An integrated approach. *Journal of Psychology and Theology, 26*(3), 260-275.
- Ganzevoort, R. (1998b). Religious coping reconsidered part two: A narrative formulation. *Journal of Psychology and Theology, 26*(3), 276-286.
- Ganzevoort, R.R. (2013). Introduction: Religious stories we live by. In R. R. Ganzevoort, M. A. C. de Haardt, & M. Scherer-Rath (Eds.), *Religious stories we live by: Narrative approach in theology and religious studies* (pp. 1-17). Leiden: Brill.
- Ganzevoort, R.R., & Roeland, J.H. (2014). Lived religion: The praxis of practical theology. *International Journal of Practical Theology, 18*(1), 91-101.
- German, M. (2013). Developing our cultural strengths: Using the "Tree of Life" strength-based, narrative therapy intervention in schools, to enhance self- esteem, cultural understanding and to challenge racism. *Educational and Child Psychology, 30*(4), 75-99.
- Gothóni, R., & Vähäkangas, A. (2010). Toivon häivähdyksiä hiv-tartunnan saaneiden ja ylivelkaantuneiden arjesta. Diakonian tutkimus. *Journal for the Study of Diaconia, 2010/1*, 27-45.
- Grinyer, A. (2007). *Young people living with cancer: Implications for policy and practice*. Buckingham: Open University Press.
- Grinyer, A. (2009). *Life after cancer in adolescence and young adulthood: The experience of survivorship*. New York: Routledge.
- Guenette, F., & Marshall, A. (2009). Time line drawings: Enhancing participant voice in narrative interviews on sensitive topics. *International Journal of Qualitative Methods, 8*(1), 85-92.
- Haug, S.H.K., Danbolt, L.J., Kvigne, K., & DeMarinis, V. (2015). How older people with incurable cancer experience daily living: A qualitative study from Norway. *Palliative and Supportive Care, 13*(4), 1037-1048.
- Haug, S.H.K., DeMarinis, V., Danbolt, L.J., & Kvigne, K. (2016a). The illness reframing process in an ethnic-majority population of older people with incurable cancer: variations of cultural- and existential meaning-making adjustments. *Mental Health, Religion & Culture, 19*(2), 150-163.
- Haug, S.H.K., Danbolt, L.J., Kvigne, K., & DeMarinis, V. (2016b). Older people with incurable cancer: Existential meaning-making from a life-span perspective. *Palliative and Supportive Care, 14*(1), 20-32.
- Heelas, P., Woodhead, L., Seel, B., Szerszynski, B., & Tusting, K. (2005). *Spiritual revolution: Why religion is giving a way to spirituality*. Malden, MA: Blackwell.
- Heino, H. (2002). *Mihin Suomi tänään uskoo*. Porvoo: WSOY.
- Herbert, R. (2014). *Living hope*. Suffolk, UK: KM Publishing.
- Hermans, C.A.M. (2014a). Narratives of the self in the study of religion. Epistemological reflections based on a pragmatic notion of weak rationality. In R.R. Ganzevoort, M. de Haardt, & M. Scherer-Rath (eds.)

- The religious stories we live by narrative approaches in theology and religious studies* (pp. 55-74). Leiden: Brill.
- Hermans, C.A.M. (2014b). From practical theology to practice-oriented theology. The study of lived spirituality and lived religion in Late Modernity. *International Journal of Practical Theology*, 18(1), 113-126.
- Hinthorne, L.L. (2012). A picture is worth a thousand words: using the visual interpretation narrative exercise to elicit non-elite perceptions of democracy. *Field Methods*, 24(3), 348-364.
- Hvidt, E.A. (2013a). Sources of 'relational homes': A qualitative study of cancer survivors' perceptions of emotional support. *Mental Health, Religion and Culture*, 16(6), 617-632.
- Hvidt, E.A. (2013b). Exploring spiritual orientation among Danish (secular) cancer patients in rehabilitation: Combining empeiria and teoria. In M. Fowler, J. L. Hochheimer, & J. Fernandez-Goldborough (Eds.), *Spirituality: Theory, praxis and pedagogy* (pp. 121-146). Oxford: Inter-Disciplinary Press.
- Hänninen, V. (2002). *Sisäinen tarina, elämä ja muutos*. Doctoral dissertation. The department of sociology and social psychology: University of Tampere.
- Johannessen-Henry, C.T. (2010). Cancer and the quest for meaning: The religious dimension in the context of health sciences. *Studies in Science and Theology* 12, 180-191.
- Johannessen-Henry, C.T. (2012). The call of cancer: God-talk in a speech act perspective. In D. Evers, A. Jackelén, & T.A. Smedes (Eds.), *Yearbook of the European Society for the Study of Science and Theology: Studies in Science and Theology* (pp.201-220), Vol. 12. Tübingen: T&T Clark International.
- Johannessen-Henry, C.T. (2013). *Hverdagskristendommens polydoksi. En empirisk-teologisk undersøgelse af tro i cancerrejsens kontekst*. Doctoral dissertation. The faculty of theology: University of Copenhagen.
- Jones B.L., Volker D.L., Vinajeras Y., Butros L., Fitchpatrick C., & Rossetto K. (2010). The meaning of surviving cancer for latino adolescents and emerging young adults. *Cancer Nursing*, 33(1), 74-81.
- Kauppinen, K. (2015). "Työ on henkireikä" – työssäkäyvän läheisen kuolema, suru ja siitä selviäminen. In K. Kauppinen, & M. Silfver-Kuhlampi (Eds.) *Läheis- ja omaishoiva – työssä jaksamisen ja jatkamisen tukeminen* (pp. 95-132). Sosiaalitieteiden laitoksen julkaisuja 2015/12, [online publication].
- Kauppinen, K & Silfver-Kuhlampi, M. (2015). Johdanto. In K. Kauppinen, & M. Silfver-Kuhlampi (Eds.) *Läheis- ja omaishoiva – työssä jaksamisen ja jatkamisen tukeminen* (pp. 11-20). Sosiaalitieteiden laitoksen julkaisuja 2015/12, [online publication].
- Keats, P.A. (2009). Multiple text analysis in narrative research: Visual, written, and spoken stories of experience. *Qualitative Research*, 9(2), 181-195.
- Kent, E.E., Parry, C., Montoya, M.J., Sender, L.S., Morris, R.A., & Anton-Culver, H. (2012). "You're too young for this": Adolescent and young adults' perspectives on cancer survivorship. *J Psychosoc Oncol.*, 30(2), 260-279.
- Ketola, K. (2007). Spiritual Revolution in Finland? Evidence from Surveys and the Rates of Emergence of New Religious and Spiritual Organisations [SIC]. *Nordic Journal of Religion and Society*, 20(1), 29-40.

- Ketola, K., Hytönen, M., Salminen, V.-M., Sohlberg, J., & Sorsa, L. (2016). *Osallistuva luterilaisuus. Suomen evankelis-luterilainen kirkko vuosina 2012-2015*. Kuopio: Grano Oy.
- Kumar, A.R., & Schapira, L. (2013). The impact of intrapersonal, interpersonal, and community factors on the identity formation of young adults with cancer: a qualitative study. *Psycho-Oncology*, 22(8), 1753-1758.
- Kwak, M., Zebrack, B.J., Meeske, K.A., Embry, L., Aguilar, C., Block, R., Hayes-Lattin, B., Li, Y., Butler, M., & Cole, S. (2013). Trajectories of psychological distress in adolescent and young adult patients with cancer: A 1-year longitudinal study. *J Clin Oncol*, 31(17), 2160-2166.
- Kwilecki, S. (2004). Religion and coping: A contribution from religious studies. *Journal for the Scientific Study of Religion*, 43(4), 477-489.
- Kyngäs, H., Jämsä, T., Mikkonen, R., Nousiainen, E.-M., Ryttilähti, M., Seppänen, P., & Vaittovaara R. (2000). *Terveys ei ole enää itsestään selvyys. Se on elämän suuri lahja. Tutkimus syöpää sairastavien nuoren selviytymisestä sairauden kanssa*. Oulu: Pohjois-Pohjanmaan sairaanhoitopiirin julkaisuja, 1/2000.
- Kyngäs, H., Mikkonen, R., Nousiainen, E.-M., Ryttilähti, M., Seppänen, P., & Vaittovaara R., & Jämsä, T. (2001). Coping with the onset of cancer: coping strategies and resources of young people with cancer. *Eur J Cancer Care*, 10(1), 6-11.
- laCour, P., & Hvidt, N.C. (2010). Research on meaning-making and health in secular society: Secular, spiritual and religious existential orientations. *Social Science & Medicine*, 71(7), 1292-1299.
- Lakoff, G. & Turner, M. (1989). *More than cool reason: A field guide to poetic metaphor*. Chicago, IL: The University of Chicago Press.
- Landmark, B.T., Strandmark, M., & Wahl, A.K. (2001). Living with newly diagnosed breast cancer – The meaning of existential issues. A qualitative study of 10 women with newly diagnosed breast cancer, based on grounded theory. *Cancer Nursing*, 24(3), 220-226.
- Lankinen, J. (2001). *Syöpäpotilaan pastoraaliset odotukset. Doctoral dissertation*. Faculty of theology: University of Helsinki.
- Lazarus, R.S. (1999). *Stress and emotions. A new synthesis*. New York: Springer.
- Lester A.D. (1995). *Hope in pastoral care and counseling*. Louisville, Kentucky: Westminster John Knox Press.
- Lieblich, A. (1998). The holistic-content perspective. In A. Lieblich, R. Tuval-Mashiach, & T. Zilber (Eds.) *Narrative research. Reading, analysis and interpretation*, (pp. 62–87). Thousand Oaks, California: SAGE.
- Lindholm, P., & Kivioja, A. (2010). Luusarkooma. In H. Joensuu, P.J. Roberts, L. Teppo, & M. Tenhunen (Eds.) *Syöpätaudit* (pp. 532-542). Duodecim, WS Bookwell Oy: Porvoo.
- Little, M., & Sayers, E.-J. (2004). While there's life... hope and the experience of cancer. *Social Science & Medicine*, 59(6), 1329-1337.
- Lundmark, M. (2010). When Mrs. B met Jesus during radiotherapy – A single case study of a Christic vision – Psychological prerequisites and functions and considerations on narrative methodology. *Archive for the Psychology of Religion*, 32(1), 27-68.
- Lundmark, M. (2015). Religious objects and the coping process. *Archive for the Psychology of Religion*, 37(1), 54-83.

- Lundmark, M. (2016a). Suffering for others as religious meaning-making: varieties, prerequisites, and functions in the coping process of a sample of practising Christians living with cancer. *Mental Health, Religion & Culture*, 19(6), 522-537.
- Lundmark, M. (2016b). Sanctification of Health Care Interventions as a Coping Method, in A. Village, & R. Hood (Eds.), *Research in the Social Scientific Study of Religion* (pp.1-23), Volume 27. Brill Online Book: 10.1163/9789004322035.
- Lymphoma. (2017). <https://www.kaikkisyovasta.fi/tietoa-syovasta/syopataudit/imukudossyopa-lymfooma/> (28.3.2017).
- Martela, F., & Steger, M.F. (2016). The three meanings of meaning in life: Distinguishing coherence, purpose, and significance. *The Journal of Positive Psychology*, 11(5), 531-545.
- Mattila, K.-P. (2002). *Syöpäpotilaan palliatiivisen hoidon keskeiset eettiset ongelmat*. Doctoral dissertation. Faculty of theology: University of Helsinki.
- McAdams, D.P. (1988). *Power, intimacy and the life story: Personal inquiries into identity*. New York, NY: Guilford Press.
- McAdams, D.P. (2009). *The person: An introduction to the science of personality psychology* (5th ed.). Hoboken, NJ: Wiley.
- McGuire, M.B. (2008). *Lived Religion: Faith and practice in everyday life*. New York: Oxford University Press.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Moltmann, J. (1965/2002). *Theology of hope. On the ground and the implications of a Christian Eschatology*. Translated by James W. Leitch. London: SCM Press.
- Morse, J.M., & Johnson, J.L. (1991). Towards a theory of illness: the illness constellation model. In J. M. Morse and J. L. Johnson (Eds.) *The Illness Experience* (pp. 315-342). London: SAGE.
- Moschella, M.C. (2016). *Caring for joy: Narrative, theology, and practice*. Brill: Leiden/Boston.
- Murray, S. (2015). 2015 Quality of Death Index. *The Economist: Intelligence Unit*.
- Nass, S.J., Beupin, L.K., Demark-Wahnefried, W., Fasciano, K. Ganz, P.A., Hayes-Lattin, B., Hudson, M.M. Nevidjon, B., Oeffinger, K.C., Rechis, R., Richardson, L.C., Seibel N.L., & Smith, A.W. (2015). Identifying and Addressing the Needs of Adolescents and Young Adults With Cancer: Summary of an Institute of Medicine Workshop. *Oncologist*, 20(2), 186-195.
- Nielsen, R. (2005). *Her kan man få lov at være sig selv*. Hellerup: Sankt Lukas Stiftelsen.
- Nielsen, R., & Sørensen, E.E. (2013). Det døende menneske som livets læremester. *Nordisk Sygeplejeforskning*, 2, 117-129.
- Niemelä, K.M. (2015) No longer believing in belonging: A longitudinal study of Finnish generation Y from confirmation experience to church-leaving. *Social Compass*, 62(2),172-186.
- Nolan, S., Saltmarsh, P., & Leget, C. (2011). Spiritual Care in Palliative Care: Working towards an EAPC Task Force, *European Journal of Palliative Care*, 18(2), 86-89.
- Paal, P. (2009). Cancer and emotions – The moment of diagnosis and metaphoric transformation. *Tidsskrift for kulturforskning*, 8(4), 39-51.

- Paal, P. (2011). *Written cancer narratives: An ethnomedical study of cancer patients thoughts, emotions and experiences*. Doctoral Dissertation. Folkloristic: University of Helsinki.
- Pain, H. (2012). A literature review to evaluate the choice and use of visual methods. *International Journal of Qualitative Methods*, 11(4), 303-319.
- Palmu, H., Salomäki, H., Ketola, K., & Niemelä, K. (2012). *Haastettu kirkko. Suomen evankelis-luterilainen kirkko vuosina 2008-2011*. Porvoo: Kirjapaja.
- Pargament, K.I. (1997). *The psychology of religion and coping. Theory, research, practice*. New York: The Guilford Press.
- Pargament, K.I., Kennel, J., Hathaway, W., Grevengoed, N., Newman, J., & Jones, W. (1988). Religion and the problem-solving process: Three styles of coping. *Journal for the Scientific Study of Religion*, 27, 90-104.
- Pargament, K.I., Bruce, S.W., Koenig, H.G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion*, 37(4), 710-724.
- Park, C. (2013). Religion and meaning. In R. Paloutzian, C. Park. (Eds.) *Handbook of the psychology of religion and spirituality* (pp. 357-379), 2<sup>nd</sup> edition. New York: The Guildford Press.
- Park, C.L., Chmielewski, J., & Blank, T.O. (2010). Post-traumatic growth: Finding positive meaning in cancer survivorship moderates the impact of intrusive thoughts on adjustment in younger adults. *Psycho-Oncology*, 19(11), 1139-1147.
- Park, C.L., & Cho, D. (2016). Spiritual well-being and spiritual distress predict adjustment in adolescent and young adult cancer survivors. *Psycho-Oncology* (online first), DOI: 10.1002/pon.4145
- Park, C.L., Edmondson, D., Hale-Smith, A., Blank, T.O. (2009a). Religiousness/spirituality and health behaviors in younger adult cancer survivors: Does faith promote a healthier lifestyle? *J Behav Med*, 32(6), 582-591.
- Park, C.L., Wortmann, J.H., Hale, A.E, Cho, D., & Blank, T.O. (2014). Assessing quality of life in young adult cancer survivors: development of the Survivorship-Related Quality of Life scale. *Quality of Life Research*, 23(8), 2213-2224.
- Park, C.L., Zlateva, I., & Blank, T.O. (2009b). Self-identity after cancer: "survivor", "victim", "patient", and "person with cancer". *J Gen Intern Med*, 24(2), 430-435.
- Parks, S.D. (2011). *Big Questions Worthy Dreams*, 2<sup>nd</sup> edition. San Francisco: Jossey Bass.
- Patterson, W. (2008). Narratives of events: Labovian narrative analysis and its limitations. M. Andrews, C. Squire, & M. Tamboukou (eds.), *Doing narrative research* (pp. 23- 40). London: Sage.
- Patterson, P., McDonald, F.E.J., Zebrack, B., & Medlow, S. (2015). Emerging issues among adolescent and young adult cancer survivors. *Seminars in Oncology Nursing*, 31(1), 53-59.
- Pessi, A.B. (2017). Dazed and amazed by moonlight – Exploring sense of meaning as the mediator of the effects of religion, belonging, and benevolence on well-being. *Nordic Journal of Religion and Society*, 30(1), 24-42.
- Polkinghorne, D. (1995). Narrative configuration in qualitative analysis. J.A. Hatch, & R. Wiesniewski (Eds.) *Life history and narrative* (pp. 5-23). London, England: Falmer.

- Ragsdale, J.R., Hegner, M.A., Mueller, M., & Davies, S. (2014). Identifying religious and/or spiritual perspectives of adolescents and young adults receiving blood and marrow transplants: A prospective qualitative study. *Biol Blood Marrow Transplant*, 20(8), 1242-1247.
- Ricoeur, P. (1984). *Time and narrative*. Volume 1. Chicago: The University Press of Chicago.
- Riessman, C.K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Saarelainen, S.-M. (2009). *Elämää syövän kanssa: Narratiivinen tutkimus henkisen ja hengellisen tuen merkityksestä syöpää sairastavalle*. Unpublished Master's thesis.  
<https://helda.helsinki.fi/handle/10138/21720>
- Saarelainen, S. (2012). Positive adjustment to cancer – Meaning of inner design and external support. *Procedia – Social and Behavioral Sciences*, 45, 54-65.
- Salander, P., Bergknut, M., & Henriksson, R. (2014). The creation of hope in patients with lung cancer. *Acta Oncologica*, 53(9), 1205-1211.
- Sansom-Daly, U.M., & Wakefield, C.E. (2013). Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Transnational Pediatrics*, 2(4), 167-197.
- Sarcoma. (2017). <https://www.kaikkisyovasta.fi/tietoa-syovasta/syopataudit/sarkoomat/> (28.3.2017).
- Sartwell, C. (2000). *End of story. Toward an annihilation of language and history*. Albany, NY: State University of New York Press.
- Schnell, T. (2009). Sources of meaning and meaning in life questionnaire (SoMe): Relations to demographics and well-being. *The Journal of Positive Psychology*, 4(6), 483-499.
- Schnell, T. (2012). Spirituality with and without religion: Differential relationships with personality. *Archive for Psychology of Religion*, 34(1), 33-61.
- Schnell, T., & Keenan, W. J. F. (2013). The construction of atheist spirituality: A survey-based Study. In H. Westerink (Ed.), *Constructs of meaning and religious transformation: Current issues in the psychology of religion* (pp. 101-119). Göttingen: V&R Unipress.
- Seibaek, L., Petersen, L.K., Blaakaer, J., & Hounsgaard, L. (2012). Hoping for the best, preparing for the worst: the lived experiences of women undergoing ovarian cancer surgery. *European Journal of Cancer Care*, 21(3), 360-371.
- Seibaek, L., Hounsgaard, L., & Hvidt, N.C. (2013). Secular, spiritual, and religious existential concerns of women with ovarian cancer during final diagnostics and start of their treatment. *Evidence-Based Complimentary and Alternative Medicine*, 2013/1, 1-11.
- Sheridan, J., Chamberlain, K., & Dupuis, A. (2011). Timelining: Visualizing experience. *Qualitative Research*, 11(5), 552-569.
- Smith, J. A., & Osborn M. (2008). Interpretative phenomenological analysis. In J.A. Smith (Ed.) *Qualitative psychology. A practical guide to research methods* (pp. 53-80), 2nd edition. London: Sage.
- Sonninen, S. (Ed.). (2012). *Nuoren syöpäpotilaan selviytymisopas*. Redfina, Finland: Suomen Syöpäpotilaat ry.
- Stifoss-Hanssen, H. (1999). Religion and spirituality: What a European ear hears. *The International Journal for the Psychology of Religion*, 9(1), 25-33.

- Stringer, M. (2011). *Contemporary Western ethnography and the definition of religion*. London: Continuum.
- Sylva. (2017). <http://sylva.fi/fi/nuoret-ja-nuoret-aikuiset/> (18.3.2017)
- Synnes, O. (2016). Storytelling as a dignity-preserving practice in palliative care. In O. Tranvåg, O. Synnes, & W. McSherry (Eds.) *Stories of dignity within healthcare* (Chapter 5 of the E-book). M&K Publishing: UK.
- Tamboukou, M. (2010). *Nomadic narratives, visual forces Gwen John's letters and paintings*. New York: Peter Lang.
- Thomas, D.M., Albritton, K.H., & Ferrari, A. (2010). Adolescent and young adult oncology: An emerging field. *J Clin Oncol*, 28(32), 4781-4782.
- Thompson, K., Palmer, S., & Dyson, G. (2009). Adolescents & young adults: Issues in transition from active therapy into follow-up care. *European Journal of Oncology Nursing*, 13(3), 207-212.
- Thomsen, D.K., & Jensen, A.B. (2007). Memories and narratives about breast cancer: Exploring associations between turning points, distress and meaning. *Narrative Inquiry*, 17(2), 349-370.
- Tietoa kirkosta. (2017). <http://evl.fi/tietoa-kirkosta/tilastotietoa> (18.3.2017).
- Tilastollinen vuosikirja (2005). *Kirkon tilastollinen vuosikirja 2004*. Hämeenlinna: Karisto.  
[http://sakasti.evl.fi/sakasti.nsf/o/ED10B30F92B933CCC22577AE00428A63/\\$FILE/Kirkon\\_tilast\\_vuosikirja\\_2004.pdf](http://sakasti.evl.fi/sakasti.nsf/o/ED10B30F92B933CCC22577AE00428A63/$FILE/Kirkon_tilast_vuosikirja_2004.pdf)
- Tilastollinen vuosikirja (2016). *Kirkon tilastollinen vuosikirja 2015*. Suomen ev-lut. Kirkon julkaisuja 49. Helsinki: Kirkkohallitus.  
[http://sakasti.evl.fi/sakasti.nsf/o/8A75CE045AD09FE4C22577AE00256611/\\$FILE/TILASTOLLINEN%20VUOSIKIRJA%202015.pdf](http://sakasti.evl.fi/sakasti.nsf/o/8A75CE045AD09FE4C22577AE00256611/$FILE/TILASTOLLINEN%20VUOSIKIRJA%202015.pdf)
- Torbjørnsen, T. (2011). *"Gud hjelpe meg!" Religiøs mestring hos pasienter med Hodgkins sykdom*. Doctoral dissertation. Faculty of theology: University of Oslo.
- Tranvåg, O., & McSherry, W. (2016). Understanding dignity: A complex concept at the heart of healthcare. In O. Tranvåg, O. Synnes, & W. McSherry (Eds.) *Stories of dignity within healthcare* (Chapter 1 of the E-book). M&K Publishing: UK.
- Tranvåg, O., Synnes, O., & McSherry, W. (2016). Preface: The necessity of dignity in healthcare. In O. Tranvåg, O. Synnes, & W. McSherry (Eds.) *Stories of dignity within healthcare* (The Preface of the E-book). M&K Publishing: UK.
- Turpeenniemi-Hujanen, T. (2010) Hodgkinin lymfooma. In H. Joensuu, P.J. Roberts, L. Teppo, & M. Tenhunen (Eds.) *Syöpätaudit* (pp. 639-650). Duodecim, WS Bookwell Oy: Porvoo.
- Van Uden, M., Pieper, J., & Alma, H. (2004). 'Bridge over troubled water'. Further results regarding the receptive coping scale. *Journal of Empirical Theology*, 17(1), 101-114.
- Van den Berg, J.A. & Ganzevoort, R.R. (2014). The art of creating futures – practical theology and a strategic research sensitivity for the future. *Acta Theologica*, 34(2), 166-185.
- Vassal, G., Fitzgerald, E., Schrappe, M., Arnold, F., Kowalczyk, J., Walker, D., Hjorth, L., Riccardi, R., Kienesberger, A., Jones, K.P., Valsecchi, M.G., Janic, D., Hasle, H., Kearns, P., Petrarulo, G., Florindi, F., Essiaf, S., & Ladenstein, R. (2014). Challenges for children and adolescents with cancer in Europe: The SIOP-Europe Agenda. *Pediatr Blood Cancer*, 61(9), 1551-1557.

- Walker, A.J., & Lewis, F.M. (2016). Adolescent and young adult cancer survivorship: A systematic review of end-of-treatment and early post-treatment. *Nursing and Palliative Care*, 1(1), 1-6.
- Warner, E.L, Kent, E.E., Trevino, K.M., Parsons, H.M., Zebrack, B.J., & Kirchoff, A.C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*, 122(7), 1029-1037.
- Xu, J. (2015). Pargament's theory of religious coping: Implications for spiritually sensitive social work practice. *British Journal of Social Work*, 46(5), 1394-1410.
- Yanez, B., Edmondson, D., Stanton, A.L., Park, C.L., Kwan, L. Ganz, P.A, & Blank, T.O. (2009). Facets of spirituality as predictors of adjustment to cancer: Relative contributions of having faith and finding meaning. *J Consult Clin Psychol*, 77(4), 730-741.
- Yi, J., & Zebrack, B. (2010). Self-Portraits of families with young adult cancer survivors: Using photovoice. *Psychosoc Oncol*, 28(3), 219-243.
- Yi, J., Zebrack, B., Kim, M.A., & Cousino M. (2015). Posttraumatic growth outcomes and their correlates among young adult survivors of childhood cancer. *Journal of Pediatric Psychology*, 40(9), 981-911.
- Zebrack, B.J. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer*, 117(10), 2289-2294.
- Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer*, 107(12), 2915-2923.
- Zebrack, B., Block R., Hayes-Lattin B., Embry L., Aguilar C., Meeske K.A., Li Y., Butler M., & Cole S. (2014b). Psychosocial Service Use and Unmet Need Among Recently Diagnosed Adolescent and Young Adult Cancer Patients. *Cancer*, 119(1), 201-214.
- Zebrack, B.J., Chesler, M.A., & Kaplan, S. (2009). To Foster Healing Among Adolescents and Young Adults with Cancer: What helps? What hurts? *Supportive Care in Cancer*, 18(1), 131-135.
- Zebrack, J.B., Kent, E.E., Keegan, T.H.M., Kato, I., & Wilder Smith, A. (2014a). "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. *Journal of Psychosocial Oncology*, 32(1), 1-15.
- Zebrack, B., Kwak, M., Salsman, J., Cousino, M., Meeske, K., Aguilar, C., Embry, Leanne, Block, R., Hayes-Lattin B., & Cole, S. (2014c). The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psycho-Oncology*, 24(2), 162-168.
- Zebrack, B.J., Oeffinger, K.C., Hou, P., & Kaplan, S. (2006). Advocacy skills training for young adult cancer survivors: the Young Adult Survivors Conference at Camp Māk-a-Dream. *Support Care Cancer*, 14(7), 779-782.
- Zebrack, B., & Walsh-Burke, K. (2005). Advocacy Needs of Adolescent and Young Adult Cancer Survivors: Perspectives of Pediatric Oncology Social Workers. *Journal of Psychosocial Oncology*, 22(2), 75-87.



# APPENDIX

## Appendix 1 The interview themes

General discussion about the topic, ethics, and consent forms

Drawing the tree

I ask you to think about your life, thus far, as a tree. What does your tree look like?

Life in the present

Where are you at this moment in your life?

Childhood

What kind of memories do you have from your childhood?

Probing questions on family and significant others

Youth

What kind of a story can you tell about your youth?

Probing questions on important persons

Cancer

How did your cancer story start?

Probing questions on treatment, feelings and emotions, people involved, meaning of the disease

Worldview and religion

How would you describe your worldview?

Probing questions on values: Is religion/spirituality linked to your worldview? Probing questions on the significance of religion during cancer, changes in commitment, meaning from a whole life perspective

Future

How do you see your future?

Careful probing questions on views of the future

Do you recognize a thread or combining theme in your life?

Is there something you would like to add? Was there something that I did not realize to ask?

How do you feel at the moment?

Return to the consent forms and signatures

Appendix 2  
Research consent form

**TUTKIJAN SITOUMUKSET** (Commitments of the researcher)

Kenenkään henkilöllisyys ei paljastu tutkimusprosessin aikana eikä tutkimuksen valmistuttua. (The anonymity of the participants is respected during and after the research)

Tutkija säilyttää tutkimusmateriaalin henkilökohtaisesti. (The research data will be stored personally by the researcher)

Aineistoa käytetään tutkimuskäyttöön (artikkelit, esitelmät, väitöskirja). (The data will be utilized for research purposes, such as articles, presentations, doctoral dissertation)

**TUTKIMUSHENKILÖN OIKEUDET** (Rights of the participant)

Oikeus saada tietoa tutkimuksen edistymisestä ja sen vaiheista. (The right to be informed about the progress of the research)

Oikeus vetäytyä tutkimuksesta missä tahansa prosessin vaiheessa. Tässä tapauksessa haastattelu poistetaan ja tutkimusmateriaali hävitetään. (The right to withdraw from the research at any stage in the process. In such cases, the data will be destroyed)

Tutkimuksen valmistuessa oikeus saada itselleen tutkimus sähköisessä muodossa. (The right to receive the doctoral dissertation in electronic format)

Haastattelussa syntyneitä piirroksia saa käyttää opetus- tai esimerkkimateriaalina   
(The drawings can be utilized as teaching or example material)

Osallistun tutkimukseen ja ymmärrän omat oikeuteni sekä tutkijan sitoumukset tutkimuksen suhteen   
(I will participate in the research and understand my rights and the commitments of the researcher)

Aika ja paikka (date and place)

\_\_\_\_\_

Allekirjoitukset ja nimenselvennykset: (signatures and printed names)

\_\_\_\_\_ Tutkimushenkilö (participant)

\_\_\_\_\_ Tutkija (researcher)  
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