



«Fight or Flight? »

Norwegian Young Adult Cancer
Survivors' Experiences of Coping with
Cancer

By

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Preface

In the several years of clinical and institutional work with old, dement, mentally disabled and psychologically disordered persons, I repeatedly got to witness how well some of these people cope with their condition. I met persons, who, despite of having experienced loss, chronic disease or disability, had a strong personality and a heart-warming and positive attitude towards life – maybe even more than their healthy peers. Some of them even regarded their vulnerability as resource to take better care of themselves. The other way around, I also met a range of people who felt locked to their diseases, and whose lives were cantered on loss, unfairness and a notion of powerless exposure to fate. From all these people I learned, that neither “health” nor “well-being” necessarily is dependent of the absence of a disease. That brought about a fascination for the phenomenon, from which the wish to understand the processes that take place when people manage to cope positively with a devastating life event. I always wanted to do something meaningful in these two years of my studies. And I feel that I might have, even though the wheel has not been invented new. But I personally learned much about my own resources, both the internal, and the external.

A year of working with this thesis has ended now, and I look back at it with thankfulness. I experienced so much valuable support from people who strengthened my own SOC during this year. Those people I would like to thank:

First of all, thank you to my supervisors Torill Larsen and May Hauken, who always were there, when I had questions or did not know how to move on. I felt in very good hands the whole year. Special thanks to Torill, who was so supportive in helping me limit the extent of this thesis. Further I want to thank my friends, who had so much understanding for me during that time. Particularly ‘thank you’ to Kyra and Kristine! You supported me emotionally in all possible ways all the time. Thanks to my parents, who are always there for me. Last, but not least, I want to thank all the brave young adult cancer patients, who I never got to meet, but who taught me so much about coping.

While the *research* aims to explore YACPs experience to cope with the disease, the *researcher* hopes to make a contribution to enhance the quality of life of disadvantaged persons and give something back to those people who are in a particular need of gathering supportive coping skills.

Bergen, 16. mai 2013

Nataskja-Elena Kersting Lie

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Abstract:

Background: Young adult cancer patients (YACPs) face unique challenges in coping with the disease, as they are in a life stage that encompasses several developmental challenges. While most research covers the lived experience of childhood, adolescent and adult cancer patients, little is known about the experience of receiving a cancer diagnosis during the already demanding life stage of young adults.

Objective: This study aims to explore the lived experience of coping with the cancer diagnosis and undergoing treatment from the perspective of YACPs in Norway.

Study design: The study embraces in analyses of semi-structured in-depth interviews of 16 participants aged 18-35, who have undergone cancer treatment.

Methods: A phenomenological approach is used to analyse the interviews, applying thematic analysis (TA) as method for analysis.

Results: The findings suggest that coping with cancer in young adulthood is a multifaceted task that constituted a complex web of interrelated issues. Five central themes emerged as important topics to cope with for YACPs in Norway: 1.) getting the diagnosis, 2.) living with cancer 3.) meeting the health care system 4.) the impact of the treatment and 5.) the role of social support. Coping tasks varied throughout the disease. The overarching issue was 'dealing with uncertainty'. Each coping task turned out to be related to and enhanced by the life span young adulthood.

Conclusion: Most of the patients experienced dealing with the disease as an overburdening task and expressed need for professional guiding and support. The findings implicate that the themes emerging from analysis stand in a sensitive relation to each other and can both facilitate and hinder adaptive coping in young adult cancer patients. The results of this study provide a better understanding of the unique perspective of the life-world of the young adult with cancer. The implication of the study is that further research on the topic and a health promoting approach to YACPs' treatment are needed. Practical interventions should be directed towards reducing external strains from the health care system and to facilitating and promoting well-adaptive coping in YACPs.

Keywords: Coping, young adult cancer patients, uncertainty, health promotion, sense of coherence

INTRODUCTION

Getting a cancer diagnosis is a devastating life event. To the current day, cancer poses a major threat to public health all over the world. The overall trend shows an incline in both cancer incidences and survival rates over the past decades, which are predicted to continue rising (World Health Organisation (WHO), 2013). For many years, cancer research and treatment has mainly been directed towards cancer biology, e.g. through attempts to develop methods to destroy cancer cells or preventive measures (Barr, 2011). While these attempts succeeded in improving the survival rates, the rising numbers of survivors and cancer patients also pose new challenges to patients and health care providers: the need for support to cope with physical and psychosocial strains during and after treatment (Albritton et al., 2006). Correspondently, voices are raised in the field of oncology, demanding a renewed perspective in cancer research at international and national levels, which takes into account the cancer patients' quality of life and patient support in coping, habilitation and rehabilitation. There is a general consensus in the field that psychosocial care and support must become an integral part in the future provision of cancer treatment (Helse- og omsorgsdepartementet, 2008).

Moreover, it has become evident from research that appropriate psychosocial support must address age-specific challenges and needs cancer patients have in coping with the cancer at different stages of life. This is especially the case for patients in the age group 18-35, subsequently referred to as "young adults" (Coccia et al., 2012) .

Young adult cancer patients (YACPs) are considered to be a particularly vulnerable population. Young adult cancer has unique features and brings along medical, economical, physical, and psychosocial challenges to these patients, which differ from those of other age groups in the population (Albritton et al., 2006; Bleyer, 2002). Additionally, the age span of "young adulthood" is considered to be a challenging transitional period in life, bringing along considerable changes to adapt to, both for cancer patients as well as for their healthy peers (Zebrack, Mills, & Weitzman, 2007). Young adults experience a great extent of uncertainty in life, regarding the establishment of an autonomous identity, both in terms of internal attitudes and personal values, as well as the external establishment into the society (Bleyer, 2002) . Critical elements include becoming emotionally and financially independent from the parents, building strong peer relationships including sexual and romantic relationships-, starting a family, and establishment in the labour market (Coccia et al., 2012; D'Agostino, Penney, &

Zebrack, 2011). Moreover, the YA population features a limited awareness of one's own mortality, which makes the diagnosis even more shattering. This life event abruptly disrupts the developmental processes illustrated above (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Having to cope with the life-threatening diagnosis, the physiological and psychological constraints from treatment *in addition to* those developmental challenges poses a tremendous burden on individuals at this life stage (Albritton et al., 2006). The double-burden of uncertainty and the unique situation may lead to a social separation from healthy peers and the society (Zebrack et al., 2007), which may in turn impact coping with the situation and even influence the treatment progress negatively (Antoni & Lutgendorf, 2007). Therefore, it is crucial that young adult cancer research and care take into account not only the age of the patients but rather age-specific challenges in order to support young adults in coping with their disease and their struggle to build a sense of identity in this process. Nevertheless, the nature of YA cancer patients' special needs for support is currently poorly understood and not sufficiently covered by existing research (Bleyer, 2002). There is a particular necessity to put psychosocial problem statements of YACPs in the spotlight of international research and to gain more evidence-based knowledge about the key tasks YA cancer patients face during the treatment (D'Agostino et al., 2011; Hølge-Hazelton, 2011). Finally, developing a better understanding of the patients' experiences with the disease will help to promote good psychosocial care and facilitate adaptive coping processes in the YA cancer population (Zebrack et al., 2007).

1.1. Problem Statement and Purpose of the Study

The facts presented above highlight that the discrepancy between advances in medical cancer research and the sparse evidence base of psychosocial needs of YACPs is hampering the achievement of substantial progress in the field (Zebrack, Mathews-Bradshaw, & Siegel, 2010). Consequently, sustainable approaches to cancer treatment will have to envisage a renewed account of health and disease, which incorporates a more holistic view of the patients in accordance with their psychosocial context (Bleyer & Barr, 2007). This research aims at contributing to bridge the gap and to further explore "coping" with cancer from the perspective of YACPs in the Norwegian population.

The problem statement is: *“How do YACPs experience coping with cancer?”*.

In order to explore the phenomenon the study seeks to investigate the life world of the YACP population by analysing YA cancer survivors’ narrated reflections on coping experiences during treatment. The overall research topic will be explored using two evolving sub-questions that further specify the problem statement at hand. The sub-questions are:

- 1.) *“Which challenges do YACPs face during treatment?”*
- 2.) *“How do YACPs cope with the challenges they meet during the treatment?”*

Through the application of the particular research questions the researcher seeks to centre the focus of the study on the illumination of problems at hand. Moreover, the spotlight is directed at meaningful elements that contributed to the coping process in YACPs.

The aim of the research is to explore what challenges YACPs meet and how coping is enacted in the given age group.

2. BACKGROUND : Cancer in the young adult population

This study seeks to investigate the problem statement as it appears to the specific age-population of “young adults” in Norway, which is a subgroup of an overarching cancer population. Accordingly, the following section will at first provide a brief outline of the phenomenon in the overall population in order to facilitate a full understanding of the nature of the problem as it appears in that particular group. The background for doing so is that any attempt to understand the nature of the subpopulation postulates the comprehension of the broader context into which it is embedded. Or, to use the illustration of Keeley (1997), that information needs to be gathered from both the ‘big picture’ and the ‘detail’ perspectives, to fully understand the puzzle.

For that purpose, the following sections will provide an overview of the current state of the public health problem ‘cancer’, moving the focus from “global to national”, and from “all ages to YACPs”. The first section will start out with presenting an introduction to the scope of the problem ‘cancer’ as a public health threat to the total population, as well as specific concern of the young adult population. The section will provide an overarching international perspective of the issue, as well as referring to the national state of being. The subsequent section will sketch the broader context of YA cancer research and action, which is steered by processes and developments in national politics. Thereby, a comprehension of opportunities and limitations of YA cancer research in the current political context shall be provided. The latest development in global and national health policies adds a health promotion perspective to public health agenda. This gives rise to issue of how a health promotion perspective can particularly be applied in cancer research and cancer care. This will be discussed in the last section of the chapter, which comprises YACPs, psychosocial factors and the role of coping.

2.1. The scope of the problem: cancer as a global threat to public health and the situation in Norway

Cancer is the leading cause of death worldwide, which is reflected by 7.6 million deaths in the latest global statistics (Ferlay et al., 2010; WHO, 2013). In Norway the total burden of cancer - expressed as the number of new cases - has been increasing over the last

decade. In 2010, more than 207.000 persons were alive and diagnosed with cancer in Norway, from which 28.271 new cases of cancer were recorded, predicting a continuous increase in future cancer rates (Norwegian Cancer Registry, 2012). The distribution of cancer within the total population varies according to age, gender and cancer type. While cancer is most likely to be found in adult or elderly patients, cancer is considered to be rare amongst young individuals (Norwegian Cancer Registry, 2010, 2012; WHO, 2013). Still, with one million new cases annually in adolescents and young adults (YA) aged 15-39 worldwide, YA cancer has become an important public health issue. The disease is the most common cause of death in YA, after suicides, homicides and unintentional injuries (Barr, 2011; Bleyer, 2007; Bleyer & Barr, 2009). In the age group 20- 39 years, the number of cancer-related deaths is higher than deaths caused by any other disease; except depression-induced suicide. (Bleyer & Barr, 2009). The incidence of cancer is predicted to continue rising in all age groups. This observation is related to both real increases in the risk of several common cancers, but it also reflects the increased supply and use of screening programs and the improving ability to diagnose the disease within the last years (Ferlay et al., 2010; WHO, 2013). This progress in cancer research is reflected in a notable increase in general survival rates as well (Ferlay et al., 2010; Norwegian Cancer Registry, 2012). Nonetheless, the advancement in knowledge of cancer and respectively, improvement in cancer treatment is not equally progressive within the population. (Archie Bleyer, 2007; Ferlay et al., 2010; Norwegian Cancer Registry, 2010, 2012; World Health Organisation (WHO), 2013). In YA, increase of incidence rates is notably faster and there is little improvement in survival in comparison to other age groups (Harlan et al., 2011). Variations in cancer incidences, survival rates and the provision of treatment, can, to a great extent, be explained by a 'research gap' between different subgroups of the population. From the early 1950's onwards, childhood cancer was brought into the spotlight of national and international scientific attention and an additional focus has been directed towards cancer in adults and elderly from the 1970's on (Bleyer, 2007; Bleyer, 2002; Sosial- og helsedirektoratet, 2004). As a result, the age group in between – young adults – has been given substantially less attention, and depict/represent to the current day a notably under-researched population in the field of oncology. This circumstance is reinforced by the fact that YACPs' participation in the comparably little existing research is rather low (Harlan et al., 2011).

2.2. Public health approaches to the problem: Research, health care and the impact of policies

As stated briefly in the introduction, YACPs are an internationally underrepresented and under-researched population, which is earmarked by special needs, distinguishing this age group from older or younger concerned individuals (Albritton et al., 2006). In general, there is a positive trend in cancer research and treatment advances, which becomes apparent in decelerating increases in overall cancer incidences and rising survival rates (WHO, 2013). The specific young adult cancer rates, in turn, show a comparably low improvement, suggesting that conventional or comprehensive advances in cancer do not operate to the same effect in this age group as compared to others. Moreover, it implicates that the progress of cancer treatment and research directed to this particular age group is rather sparse. This has meanwhile become subject to international awareness, advocating an amplified focus on research and age-appropriate quality care and quality of life (QoL) in this underrepresented age group (Barr, 2011).

The problem of underrepresentation, though, is not merely a matter of a lack of knowledge. An evidence gap is rather to be regarded as part of a bigger picture, in which political influences play a significant role. Both scientific investigations and quality health care are always a matter of decision making of different stake holders, ranging from health professionals, practitioners, research investigators, and ultimately politicians. Policies target issues and allocate resources in approaching these, thereby shaping which problem will be approached how and when (Oliver & Peersman, 2001). A public health problem invisible in policies will struggle to get public attention and be targeted as such by health promotion actions (Gray, 1997).

The researcher's attempt to provide an overview over the current state of cancer research and cancer care therefore requires an understanding of its embedding within the political framework. A brief overview will be given in the following.

2.3. Where are we now? The position of young adult cancer as a public health issue on the political agenda in Norway

As depicted above, calls are globally made to incorporate health promoting perspectives in cancer research. In Norway this movement is reflected by the changes in national rules and regulations over time. For instance, in 1997 the need for a holistic approach to treating cancer patients was initially laid down in the first Norwegian Cancer Plan ("NOU 1997:20 ", 1997). The document acknowledged, amongst other aspects, the need for research on the patient's experience of cancer, rather than research interest in purely biological matters of the disease. This orientation was further strengthened by the Norwegian law on special health services ("LOV 1999-07-02), which made *research* an integral part of the hospitals' responsibility field. At the same time, the note "Responsibility and Coping [translated by the author]" was released by the Norwegian Parliament. The document supported the holistic approach to treatment and rehabilitation, also highlighting the need to facilitate coping in concerned patients ("St. meld. nr. 21," 1998-1999). These new focal areas were kept up in subsequent national strategies: the national cancer strategy for 2006-2009 (Helse- og omsorgsdepartementet, 2006) and the national strategy for rehabilitation and habilitation for 2008-2011 (Helse- og omsorgsdepartementet, 2008) emphasised the role of research and advocacy of patients' non-medical needs in cancer treatment, as well as on coping. While these documents promote scientific investigation to understand cancer patients' experiences and needs in general, less attention is given to the YA population. The first named law does indeed give special priorities to childhood cancer, while the second named document takes elderly with cancer into consideration. Even though St.meld.nr. 21 (1998 – 1999) as well as the upgraded "Cancer strategy of 2004" (Sosial- og helsedirektoratet, 2004) include both of these age groups, none of the documents take *young adult* cancer patients into account as an outstanding focus group in official Norwegian rules or regulations.

Nevertheless, the current proposal for the national cancer strategy for 2013 to 2017 puts focus on young adults for the first time, and supports calls for individually adapted treatment programmes for cancer patients- in accordance with international guidelines and through multinational collaboration (Helsedirektoratet, 2012).

2.4. Exploring the evidence base: Research on cancer, YACPs and the role of coping

The foregoing sections have provided an introduction to the current state of cancer as a threat to public health and the well-being of the young adult cancer population, and how and to what extent it is targeted in policies. The focus will now be directed towards the current state in *coping* with the situation. The following sections will outline the given evidence base of

- a) how coping impacts on health outcomes,
- b) how coping impacts on cancer patients' health state, and vice versa
- c) the psychosocial needs cancer patients have in the cancer-coping context.

These topics will be illustrated both in general terms as well as with a particular focus on cancer patients. The final section will highlight the evidence base of coping in relation to YACP. In that line, the present global evidence will be examined, followed by the assessment of scientific evidence on YACPs in Norway.

2.4.1. The relation of psychosocial factors, coping and health outcomes

As outlined in earlier sections, there is a common emphasis amongst various advocates of health sciences to acknowledge the interplay of environmental, psychological and social factors, and their impact on public health problems does play a significant role in this context, and is mediated by those factors (Lazarus, 1993a; Lazarus & Folkman, 1984; Park & McCabe, 1982). There is a wide evidence base that highlights the importance of coping skills in relation to physical and psychological reactions to threatening events or stress: research on coping and managing stress by Ursin and Eriksen (2004), for instance, has shown that coping has direct and indirect influences on the individual's health state. The outcome expectancy was named as one major contributor to the outcome of the situation. Moreover, they found that skills for coping with stress can be trained by altering one's outcome expectations and a positive assessment of one's resources for coping with a given situation (Ursin & Eriksen, 2001).

2.4.2. The relation of psychosocial factors, coping and health outcomes in cancer patients

The relation between psychosocial factors, coping and health outcomes has been found to be true for the particular cancer population as well. Several studies on cancer patients, psychosocial factors and treatment outcomes reveal that the patients' psychosocial context and disease progression are mutually influential: Antoni and Lutgendorf (2007), for instance, found that psychosocial factors may regulate immune responses in cancer, DNA-repair processes, activity of cancer-causing viruses, and affect the expression in tumour cells of genes, which might affect tumour growth and metastasis. These findings are supported by several other studies on the impact of psychosocial factors, stress and social support on cancer (Antoni & Lutgendorf, 2007; Antoni et al., 2006; Lutgendorf et al., 2003; Sephton & Spiegel, 2003; Thaker et al., 2006).

The other way around, there is a growing body of evidence suggesting that long-term medical illness, such as cancer, is associated with an increase in psychiatric and psychological disturbances (Akechi et al., 2001; Craig & Abeloff, 1974; Derogatis et al., 1983; Jackson & Jackson, 2007; Plumb & Holland, 1981; Singer, Das-Munshi, & Brähler, 2009). Jackson and Jackson (2007), for instance, found that depression was a common, though under-recognised co-morbid mental disorder of cancer patients. A meta-analysis of studies on cancer patients and mental health conditions by Singer et al. (2009), revealed that 32% of the total study population (N= 1448) suffered from a mental disorder. Both investigations concluded that psychosocial care and support in coping for cancer patients is essential to provide need appropriate treatment to the population.

The importance of psychosocial factors for the treatment progress is underpinned by recent statistics on cancer, especially when putting the numbers in relation to the heterogeneous scientific evidence base of the needs of the different subpopulations. Here, it can be seen that there is an [indicated](#) progress in both survival rates and knowledge on psychosocial conditions in adults and children. On the other hand, statistics show less progress in young adult cancer population and a comparably scarce research landscape in regards to the needs of the population. This gives some valuable indications to what extent the understanding of the psychosocial impacts of cancer and the associated support takes

influence on facilitating progress in current cancer treatment (Albritton et al., 2006; Siegel, Naishadham, & Jemal, 2013; Zebrack et al., 2007).

2.4.3. Coping and the psychosocial needs of the young adult cancer population

Meanwhile, there exists accordingly a range of scientific investigations in *coping needs in cancer patients* (Goldzweig et al., 2009; Heppner et al., 2009; Lauver, Connolly-Nelson, & Vang, 2007) . In line with this, several psycho-social interventions have been conducted to assist cancer patients in coping with the situation (Hill, Kelleher, & Shumaker, 1992; Rehse & Pukrop, 2003; Roberts, Piper, Denny, & Cuddeback, 1997). Still, scientific literature reveals that the majority of cancer patients remains with unmet psychosocial needs and lack support to develop appropriate coping strategies (Hall et al., 2010; Keegan et al., 2012; Lam, Cohen, & Rote, 2013; Remmers, Holtgrawe, & Pinkert, 2010). This is partly due to a knowledge gap of coping and the cancer experience, which has not been sufficiently bridged yet by scientific investigations in the cancer patient's life world - especially in that of YACPs (Albritton et al., 2006; D'Agostino et al., 2011; B. J. Zebrack et al., 2007).

While a sizable body of international literature on young adult *survivors* of childhood cancer exists, comparably little is known about the unique situations of YACP and the impact of undergoing cancer treatment in young adulthood (B. J. Zebrack et al., 2007).

In 2006, the National Cancer Institute (NCI) in the US in collaboration with the Lance Armstrong Foundation (LAF) US published a first comprehensive report from the US Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) which addresses the importance of research on the unique needs of adolescents and young adults with cancer.(Albritton et al., 2006).

Several empirical studies address particular features of YAC, for instance physical concerns and treatment outcome (Anne E Mitchell et al., 2004; Bleyer, 2002; Feldman & Welch, 1998; Kokkonen, Vainionpää, Winqvist, & Lanning, 1997), concerns of fertility and sexuality (Arai, Kawakita, Okada, & Yoshida, 1997; Janson, 2000; Roberts & Oktay, 2005), and health care services (Taylor, 1999; Zebrack et al., 2006; Zebrack et al., 2010). Most of the

existing literature primarily explores single aspects of cancer patients' experience of their life-world and often lack a particular focus on *coping*.

Further, of the given scientific evidence it in fact targeting coping with cancer a large number of studies make use of a narrowed definition of the term: Many studies limit the investigation of cancer patients' coping experiences to particular psychosocial aspects, like the role of the family (Edwards & Clarke, 2004; Wright & Dyck, 1984), peer support, or psychosocial interventions (Hill et al., 1992; Rehse & Pukrop, 2003; Yaskowich & Stam, 2003), rather than exploring coping with cancer in its entire context. Moreover, a great deal of literature addresses cancer patients' coping experiences from a specific perspective, for instance in terms of gender issues (Arena et al., 2007; Goldzweig et al., 2009; Heppner et al., 2009; Lauver et al., 2007) or in relation to marital status (Goldzweig et al., 2009). Furthermore, these studies explore the coping experience in adult cancer patients (Arena et al., 2007; Ganz et al., 2004; Hill et al., 1992; Rehse & Pukrop, 2003; Yaskowich & Stam, 2003) or adult survivorship (Boehmer, Luszczynska, & Schwarzer, 2007; Goldzweig et al., 2009; Heppner et al., 2009; Lauver et al., 2007). Similarly, there are several other studies which account for an evidence base on coping experiences in children and adolescents (Dongen-Melman & Sanders-Woudstra, 1986; Whyte & Smith, 1997).

Consequently, scientific evidence of coping experiences of *young adult* cancer patients is scarce. Similar to the studies on coping in the adult cancer population, the few existing studies on coping in YACPs are most often limited to single aspects related to coping, like uncertainty (Corbeil, Laizner, Hunter, & Hutchison, 2009; Decker, Haase, & Bell, 2007) or gender (Manuel et al., 2007) or relate to selected psychosocial aspects as the family (Grinyer & Thomas, 2001; Lynam, 1995) or peer support (Elad, Yagil, Cohen, & Meller, 2003; Roberts et al., 1997).

Notably, the existing evidence base on psychosocial needs of YACPs is mainly oriented towards YA cancer survivors and the psychosocial long-term impact of the disease (Felder-Puig et al., 1998; Fobair et al., 1986; Hall et al., 2010; Hauken, Larsen, & Holsen, 2013; Kent et al., 2012; Kornblith et al., 1992; Sammarco, 2001). Only few investigations are directed towards psychosocial aspects and coping processes in YACP *during* treatment

(Daiter, Larson, Weddington, & Ulmann, 1988; Dunn & Steginga, 2000; Hølge-Hazelton, 2011; Kyngäs et al., 2001; Lam et al., 2013).

2.4.4. Coping and the psychosocial needs of the young adult cancer population in Norway

The international development and the changing priority needs in oncology research delineated in the previous sections are reflected nationally by an amplified focus of Norwegian research investigations on coping with cancer. Still, the scientific evidence derived from Norwegian investigations on *young* adult cancer and coping is scarce: Most of the existing studies on the Norwegian young adult cancer population target risk of cancer death or physiological aspects of the disease (e.g. Ghaderi et al., 2012). Studies, which, in turn, do investigate psychosocial factors and coping in Norwegian cancer patients involve mostly adult cancer patients or investigate in particular features, for instance a gender or family perspective on the given matter (e.g. Drageset, Lindstrom, Giske, & Underlid, 2012; Drageset & Lindstrøm, 2003; Isaksen, Thuen, & Hanestad, 2003; Rustøen & Wiklund, 2000).

Even though national research on YACPs and coping still is limited there is a trend towards a stronger scientific focus on this population. This development is reflected in the proposal for a new national cancer strategy for 2013-2017, which, amongst others, aims at giving stronger national attention to cancer in young individuals (Helsedirektoratet, 2012). In line with that has the national cancer union "Kreftforeningen" initiated a study which aimed at investigating young adult cancer survivors' experiences and needs during and after the treatment. From that project first scientific evidence on Norwegian YACPs and coping post to the treatment could be derived (Hauken et al., 2013). The given research is part of the overarching project and investigates the YACPs coping experiences *during* the treatment progress.

3. THEORETICAL BACKGROUND

In the following chapter the theoretical basis of the given study will be presented. The theory base is the starting point for research investigation in any scientific field and serves as a guide to collect, analyse, evaluate and validate empirical evidence on the issue at hand (Dean, 1996). In the field of *health promotion*, from which the given study emanates, a solid theory base plays an especially important role: within this discipline research most often serves as a foundation for public health action to combat causes of ill health or to promote elements supporting good health (Orosz, 1994). Valid knowledge on protecting factors or threats to health is thus a prerequisite to generating effective and responsible health promotion action (Kickbusch & Dean, 1992). A sound and logical theory can be used to assess results from empirical research with regard to contradictions or inconsistencies and is thereby an essential tool to validate findings from research investigations (Dean, 1996).

For that purpose the basic theoretical concepts of the present study will be defined and presented in the following: at baseline, the positioning of the chosen conceptualisation of “health” within the wide range of existing definitions will be clarified. Subsequently, the field of science from which the present study emanates - Health Promotion and Health Psychology - will be introduced and its core principles will be presented. This outline will also include a brief reflection of the role of health promotion and health promotion research in Norway. Finally, an account will be provided in regards to how both of the fields are approached within the study at hand. The following section will provide a short outline of theoretical conceptualisations of coping dominating the field of health sciences. The subsequent sections will account for which coping theories are applied in the given study/study at hand. The Transactional Model of Stress and Coping, in the following referred to as TMSC, by Richard S. Lazarus and Folkman (1984) will be presented, which has been chosen as it depicts the most predominant and widely used conceptualisation of coping mechanisms in health science literature (Morrison & Bennett, 2009). In the final section of the theory chapter the salutogenic model and the concept of “Sense of Coherence (SOC)” by Aaron Antonovsky (1987) will be introduced. This theory conceptualises coping in a broader sense and can be regarded as a life-course perspective on coping, aligning the phenomenological orientation of the study to explore a given matter in its life-world context. Moreover, the concept has been factored into the theoretical basis of the study, as it similarly

issues the topic of “coping”, and takes a health promoting perspective to approach health problems- fitting both the tenets of the scientific field of the study and the topic of investigation.

3.1. ‘Health’ in the 21st century: the need of an expanded health concept to meet the needs of YACPs

Public health concerns can be regarded as a result of the interplay between the historical context and the respective prevailing state of knowledge, values and policies. Accordingly, topics on the public health agenda as well their conceptualisation are subjected to constant changes over time, bringing along conflicts between stakeholders of different views on what constitutes ‘health’ (Elvbakken & Solvang, 2002). Traditionally, the health care system has encountered public health problems through approaches grounded in a traditional-medical view on health and disease. It can be traced back to the early 19th century and is characterised by a pathogenic approach to health, which regards health and disease as two dichotomous entities. Health is as such regarded as a state of absence of disease, which, in turn, is defined malfunctioning of inner and outer parts of the human corpus or through deviance from statistical normality (Boorse, 1977). However, developments over the past decades have brought to light that the application of a mere traditional approach to health has outlived its utility (Cassell, 1979). Several cases, drawn from medicine and health care, have meanwhile demonstrated how medical treatment might be effective in treating the disease, but fail at treating the patient – that is the human in his psycho-social context. Over time, calls have been made - both in the professional health work field as well as in the general public – to extend this narrow view and to acknowledge the interplay of social, psychological and environmental factors. (Franke, 1997; Leder, 1992; Råheim, 1997, 2006; Thornquist, 1993).

Correspondently, in its pre-amble, the World Health Organization (WHO) (1948) has provided a definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” which, in accordance with the United Nations, recognises “the enjoyment of the highest attainable standard” of health as fundamental human right (World Health Organisation (WHO), 1986). Nevertheless, also this definition has been subject to criticism for various reasons. One of it is the wording

“complete”, which paints a picture of health hardly achievable for human beings (Saracci, 1997; Üstün & Jakob, 2005). This is especially true in regard to those who have disabilities and chronic diseases. One of several health definitions aiming at counteracting the claim to absolute health is provided by Aaron Antonovsky (1979). He defines health as part of a continuum, on which disease is located at one end and health at the other while the human being moves along between the two ends during the life course. This definition gave rise to alternative *approaches* to health, but did not become a substitution for the general conception of health as provided by the WHO. Nonetheless, critical voices claim that the WHO’s definition of health lacks the statement of whether health is regarded within – or is dependent on – a wider context. From the original formulation the impression could arise that health is a strictly individual matter independent from external factors. These voices emphasise to acknowledge and to treat the patient as human being in a social context, whose health is impacted by several external conditions. It follows that such external influences contribute to the overall health of the individual and depict an essential part of the individual’s health prerequisites and needs (Mittelmark, Wold, & Samdal, 2012; Wold, 2012).

The necessity to meet the patient’s needs- not merely in a medical manner – in order to improve treatment outcomes, is reflected in research: several studies indicate that psychosocial factors play a significant role to both positive and negative health outcomes and treatment progress (Antoni & Lutgendorf, 2007; Antonovsky, 1979, 1987; E.J. Cassell, 1978; Eric J. Cassell, 1979; Siegrist, 1996; Warren, 2010). While there have been many attempts to propose new conceptualisations of health from various viewpoints (Üstün & Jakob, 2005), the American Psychiatrist Engel (1977) suggests a comprehensive conceptualisation of health and illness through a ‘biopsychosocial model’. It presents illness and health, respectively, as an interaction of both biological (e.g. physical), psychological, social (e.g. cultural) factors. This theory could be regarded as attempt to build a bridge between the traditional concept, the WHO definition and the need for an extended health concept, and builds the basis for the researcher’s viewpoint of health in the present study.

3.2. Health Promotion and Health Psychology

The present research has been undertaken in the context of a master's thesis of the study programme "Health Promotion and Health Psychology". The study at hand addresses the problem statement from the perspective of both fields, which will be introduced briefly in the subsequent sections.

3.2.1. Health Psychology

Health psychology addresses questions concerned with why and how people behave in a healthy manner or not. Its main goal is to develop better comprehension of biopsychosocial factors that are involved in 1.) the promotion of health and its maintenance, 2.) the causes of illness, 3.) the prevention and treatment of illness, and 4.) improving health care systems and health policy (Matarazzo, 1982). Health psychology is an inter- and multidisciplinary field and is thus involved with other health and social sciences, such as health economics, politics, medical sociology and behavioural medicine, as well as with general medicine and related therapeutic disciplines in the field (Morrison & Bennett, 2009). Critics of health psychology claim that health psychology is too concerned with individual aspects of health behaviour and health outcomes and tends to overlook the social context, such as gender, culture, life-span, environment and socio-economic variables impacting health and health behaviour of the human beings (Eiser, 1996; Morrison & Bennett, 2009; Radley, 1996). Moreover, the problem-orientation of health psychology has been challenged as it puts the general focus on illness rather than on health (Marks, 2000).

3.2.2. Health promotion

Health promotion in turn, is concerned with the individual in its wider social context, on the one hand, and seeks to explore factors that contribute to positive health, on the other (Green & Raeburn, 1988; Kickbusch, 2003). Thus, the two approaches can be regarded as complementary disciplines, which in allocation enable a holistic approach to public health problems today. The health promotion approach to public health issues officially came into being at the end of the 1980s. Still today, advocates of the concept struggle to establish health promotion as a distinct discipline in health sciences. Frequently,

health promotion is confused with disease prevention, which is grounded in the traditional medical approach to health and targets individual behaviour to reduce disease. Until the current day, there is a lack of understanding in the general public and other fields of science of what health promotion effectively is and how it works (Oliver & Peersman, 2001). This section seeks to elucidate the equivocality of the debate around the concept by providing a brief overview of its essential characteristics. The concept of health promotion originated from the discussion and critique of the traditional health concept, as illustrated in the previous sections. Thus, it can be regarded as an attempt to provide an alternative and more comprehensive approach to health (Green & Raeburn, 1988). The conceptualisation of health promotion has been laid down in the working document ‘Ottawa Charter for health promotion’ which resulted from the WHO’s first health promotion conference. Within the charter, health promotion is defined as

“the process of enabling people to increase control over their health and its determinants, and thereby improve their health. It is a core function of public health and contributes to the work of tackling communicable and non-communicable diseases and other threats to health” (World Health Organisation (WHO), 1986).

From its release until the current day the Ottawa charter has exerted substantial impact on health conceptualisations, research and public health initiatives. It applies the definition of health by the World Health Organization (WHO) (1948), which extends the scope of responsibility for its attainment from the medical arena to further external realms.

Health promotion provides an inclusive concept regarding health as determinant for quality of life and well-being. It acknowledges the impact of physical, economic, psychological and social factors on each individual’s health outcome and seeks to take these into account when approaching health (Dean, 1996; World Health Organization (WHO), 1984). To that effect, the Ottawa Charter defines five main areas considered relevant for health promotion action: 1.) building healthy public policy, 2.) creating supportive environments, 3.) strengthening community action 4.) developing personal skills, 5.) re-orienting health care services towards prevention of illness and promotion of health (World Health Organisation (WHO), 1986). Extending the tasks of health promotion work to new areas of duty has initiated a repositioning of institutions, actors and perspectives on health

(Kickbusch, 2003). Likewise, it initiated a shifting focus from people at risk for certain diseases towards approaching the population in the wider social context and environment of everyday life. With its emphasis to explore and facilitate determinants of *health*, rather than searching for factors for disease, the health promotion orientation has introduced a new way of regarding 'health': as a positive concept that emphasises personal and social resources (World Health Organisation (WHO), 2009; World Health Organization (WHO), 1984). This orientation gave henceforward rise to several re-definitions of health, such as the "salutogenic approach" proposed by Aaron Antonovsky (Antonovsky, 1979; Kickbusch, 2003) (see chapter 2.3).

In the context of defining health promotion action areas of priorities '*coping*' has become a significant issue. It is, for instance, explicitly mentioned in a central document in the field of health promotion; the report "Achieving health for all: a framework for health promotion" released by Jake Epp (1986), Canadian Minister of National Health and Welfare at the time. The health promotion action framework identifies three main "mechanisms" of health promotion: "healthy environments", "self-care", and "mutual aid, or the actions people take to help each other *cope* [emphasis added]" (Epp, 1986, p. 423). This is, amongst others, endorsed within a research publication by the Research Unit of Health and Behaviour Change (RUHBC) (1995), pointing out that public health actions to improve health have institutionalised a concept of health already pertaining to the impact of environmental factors and clearly moving towards an additional acknowledgement of and focus on social and psychological factors, such as lifestyle, social support, and coping (RUHBC, 1995). These developments show that the concept of health promotion, as laid down in the Ottawa Charter in 1986, has brought a movement into being suiting the tenets of the time. From its resolution to the current day the document has been further amended and adapted in accordance with the progressing knowledge base and changing public health needs over time (WHO, 2009). Within this progress, the concept of health promotion according to the Ottawa Charter is still effective today.

3.3. Theoretical conceptions of health, stress and coping

Health promotion accounts for an understanding of health and disease embedded in a wider context, which, inter alia, includes a person's environment, potentially contributing to or diminishing positive health (WHO, 1986).

In this course, psychosocial needs of patients have been given rising notice within scientific investigation, leading to a solid evidence base on the impact of environmental and psychosocial factors on individual health and well-being. This has implied two essential tasks of health promotion: aiming to promote and facilitate conditions leading to positive health outcomes, and to strengthen individuals or population groups in handling those factors having a potentially negative impact on their health and well-being (Zebrack et al., 2007).

Consequently, *coping* has become an issue which has been attracting particular attention in scientific investigations on health and disease relations. It has been subject to a wide range of scientific explorations of mechanisms which apply in the process of coping. Results of such investigations have provided evidence for psychosocial needs and the process of "coping" being central elements when having to deal with distressing/straining situations, both for healthy individuals in daily life as well as for cancer patients during treatment (Park & McCabe, 1982; Schroevers, Kraaij, & Garnefski, 2008; Tighe, Molassiotis, Morris, & Richardson, 2011). Nevertheless, in most of the scientific literature on coping the term is closely connected to the phenomenon of "stress". Notably, scientific literature offers differing definitions for both stress and coping (Morrison & Bennett, 2009). As a detailed outline of the various conceptualisations of the terms would exceed the scope of this work, the presentation of stress and coping theories will be limited to introducing concepts applied in the context of the present research.

3.3.1. The conceptualisation of "Stress"

"Stress" – as used in this paper- does not merely refer to its common use of people referring to the term to describe time pressure or small 'hassles' in daily life (Kanner, Coyne, Schaefer, & Lazarus, 1981). Applied in health sciences, the term encompasses one or more of three main traits: it is explored 1.) as an external stimulus (stressor), 2.) as a physiological response to a demanding event (stress reaction), and 3.) as a transaction process between a stressor and the exposed individuals' physical and emotional reactions (Morrison & Bennett,

2009). Regardless of how stress is conceptualised there is a common understanding in the research field, acknowledging that stress can have adverse effects on the individual's health, e.g. through various immune processes and physiological responses to a stressful situation (Reme, Eriksen, & Ursin, 2008; Siegrist, 1996; Ursin & Eriksen, 2001). Moreover, the three different views share the basic assumption that stress – to some extent - can be regulated through coping mechanisms in the individual (Ursin & Eriksen, 2004). In the context at hand, stress is understood as a comprehensive phenomenon, which embraces all of the three dimensions mentioned above. This allows for the consideration of physical, mental, and psychosocial challenges that YACPs have to cope with. It has been chosen with regard to the phenomenological-explorative research approach of the study, which aims to grasp the big picture of cancer-coping rather than exploring *one* pre-defined aspect of it.

3.3.2. “Coping” defined

Cognitive, physical, emotional and behavioural *responses* to stressors are conscious or unconscious efforts known as *coping* (Lowe, Norman, & Bennett, 2000). The responses to a stressful event take place in line with how an individual *appraises* the situation. Differences in personality, emotions and cognitions influence the individual's perception or appraisal of a given situation and thereby a person's cognitive, physical, emotional and behavioural responses to a given life-event (Ursin & Eriksen, 2001). Thus, one and the same event can be perceived as stressful for one individual, while another remains unaffected (Antonovsky, 1979). It follows that personal factors and cognitions both directly influence an individual's ways of appraising stress, as well as having an indirect effect on health outcomes resulting from strains and stresses (Reme et al., 2008). This raises the question of how cancer patients' cognitions and appraisals of the disease influence their way of processing the diagnosis and which factors serve to affect their given mind set. Research suggests that, in addition to personal characteristics, external resources such as social support and/or aspects of social relationships have direct and indirect influences on stress appraisal and stress outcomes (Karasek & Theorell, 1990; Roberts et al., 1997; Wold, 2012).

Meanwhile, over 30 theories and definitions of coping exist, and numerous investigations of the stress-coping process have been undertaken (Morrison & Bennett, 2009).

For the current study, the theoretical definition of coping as “the thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful” (Folkman & Moskowitz, 2004, p. 745) is applied to investigate cancer-coping mechanisms. The definition emanates from work of the psychologist Richard Lazarus, who is one of the pioneer researchers in the field of psychological stress, cognitive appraisal and coping responses (Lazarus, 2000). This conceptualisation of coping is illustrated by the cognitive TMS, proposed by Lazarus and Folkman (1984). From the late 1960s until today, this approach has been applied widely to coping research in various fields (e.g. Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Kanner et al., 1981; Lazarus, 2000; Lazarus & Folkman, 1984), as well as specifically to research on coping and cancer (e.g. Boehmer et al., 2007; M. Cohen & Pollack, 2005; Glanz, Steffen, & Tagliabue, 2007; Hulbert-Williams, Morrison, Wilkinson, & Neal, 2013; Johansson, Ryden, & Finizia, 2011). It has been chosen as theoretical basis as this theory has been shown to having had a substantial impact on the conceptualisation of coping processes in the scientific literature (Morrison & Bennett, 2009).

3.3.3. Coping in the light of the Transactional Model of Stress and Coping by Lazarus and Folkman

According to Lazarus and Folkman (1984), coping with a stressful event can be regarded as a complex and on-going process. The process starts with an individual’s encounter with and assessment of a certain event. If the event is appraised as irrelevant or benign, it will be ignored. If, in turn, the event is appraised as important and impacting, the individual is likely to engage in a process of coping, which will be elaborated on in the following.

An individual’s encounter with a stressor is caused by an interaction of the individual’s personality traits, the way events are appraised, the individual’s internal and external resources and the demands the external or internal stressful event poses to the individual. Briefly stated, could stress could be described as being caused by a bad person-environment fit, which is the case when an individual is exposed to a situation in which he or she perceives a mismatch between demands and available capacity to meet those (Folkman, Lazarus, Dunkel-Schetter, et al., 1986). Such a conceptualisation is highly compatible with the situation of YACP: by receiving a cancer diagnosis they are burdened with a stressful

event. Suddenly, they find themselves exposed to a new situation, in which they struggle to assess whether they are able to meet the challenges imposed on them through the disease. According to Lazarus and Folkman (1984), coping attempts aim at re-establishing a balance between the demands and the resources.. This can be enacted by targeting either the stressor or the individual’s appraisal of it (Lazarus, 1993a). Within this theory, coping is not a fixed cause-effect reaction but rather to be regarded as a dynamic process and subject to amendments and change. The crucial elements and the dynamics of the coping processes are captured within their “Transactional Model of Stress and Coping” (Lazarus & Folkman, 1984), which is presented in Figure 1 and will be further described in the following section.

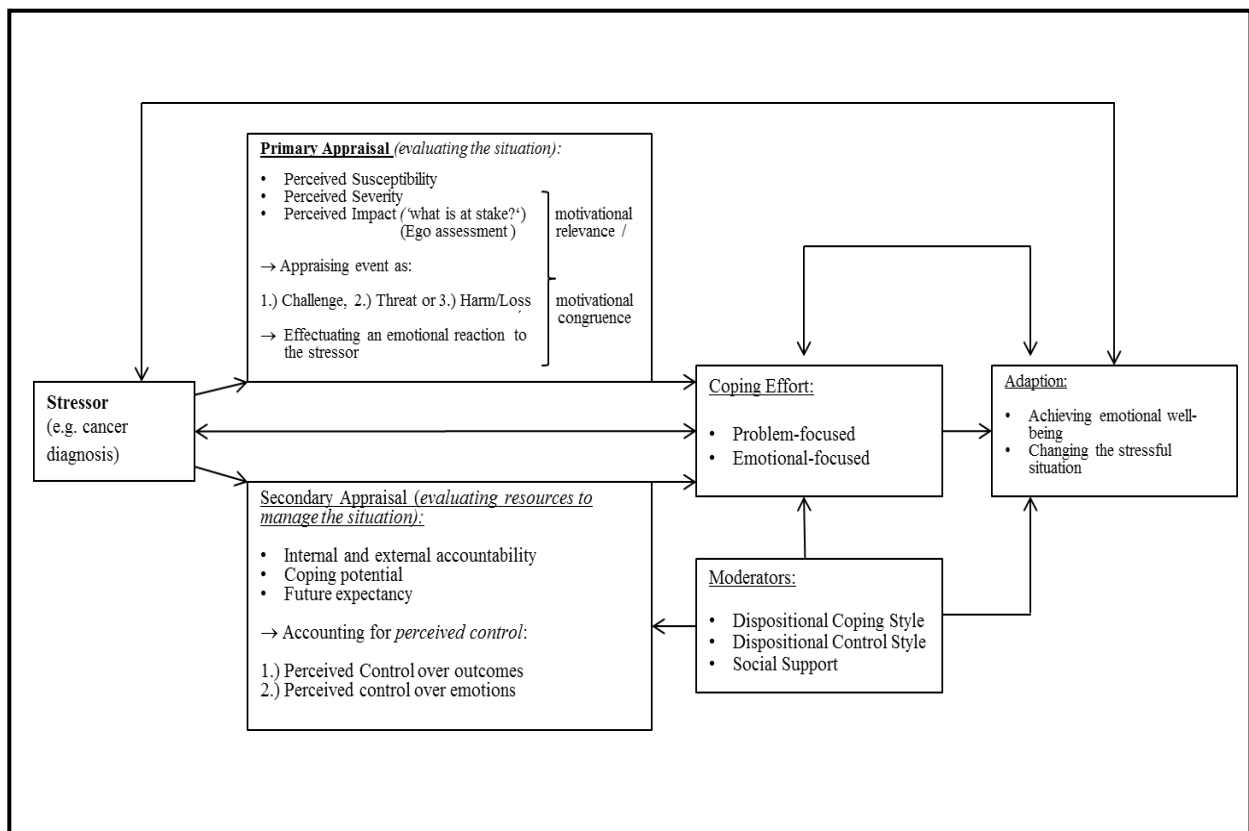


Figure 1: The Transactional Model of Stress and Coping, adapted from Lazarus&Folkmann (1984)

As the model shows, cognitive and motivational variables (which account for the overall appraisal of the situation) play a central role in the coping process. A noteworthy element of Lazarus' theory is that the appraisal of a situation is a mechanism, which is regarded to have two dimensions, categorised as primary and secondary appraisal. The coping process starts with an individual's encounter with and appraisal of a prevalent stressor, for instance being diagnosed with cancer. In the first encounter with a new, demanding situation the individual engages in evaluating the given demanding situation and appraising it according to three main categories as either a 1.) challenge 2.) threat or 3.) harm (Lazarus & Folkman, 1984). 'Challenges' refer to demands from which the individual expects opportunities for personal growth from successfully dealing with it. Situations that are appraised as threat, in turn, are situations from which the individual expects future harm. The third appraisal opportunity takes place when a certain damage already has been done, e.g. in terms of loss or personal failure as a result of the stressful event (Lazarus, 1966). Moreover, the primary appraisal accounts for an evaluation of what is at stake in the given situation. That could, for instance, involve considerations of possible harms to own or others' health and well-being; or of values, commitments, goals, or the self-esteem -, which is considered an appraisal of the ego-involvement (Folkman, Lazarus, Dunkel-Schetter, et al., 1986) .

In later work, Lazarus and colleagues include an *emotion* component in their description of the primary appraisal, identifying a set of feelings that accompany the different types of appraisal (Lazarus, 1993a, 1993b; Smith & Lazarus, 1993). Accordingly, stressors, which are perceived as challenges, have been related to emotional reactions such as worry, hope and confidence. Perceived threats have, amongst others, been related to feelings of anxiety, anger or jealousy. Stressors bringing along potential harm or loss have been related to sadness, hopelessness, despair and depression (Lazarus, 1999; Smith & Lazarus, 1993).

The primary appraisal of the situation is accompanied by the secondary appraisal: the individual's assessment of its manageability. The secondary appraisal includes four main components: accountability, problem-focused coping potential, emotion-focused potential, and future expectancy. *Internal and external accountability* relates to attributing the responsibility for the event to either the individual itself (self-blame, guilt) or to other persons (blame, anger).

Coping potential is the perceived ability to alter the situation through *problem-focused coping mechanisms* (practical coping, instrumental coping); or *emotional- focussed coping potential*, - the perceived capacity to deal with the demands of the situation emotionally (Smith & Lazarus, 1993). This stage involves considerations of what - if anything - can be done to counteract, prevent or overcome potential harm. Accordingly, an assessment of *internal and external resources* to cope with the given demands takes place. Internal factors adding to a given stock of resources comprise, for instance, strength and self-determination, while external factors, amongst others, refer to available money or social support needed to handle a challenge (Lazarus & Folkman, 1984). *Future expectancy* is the estimation of chances that the situation is changeable and adds finally to an individual's overall appraisal of own coping options (Smith & Lazarus, 1993). Together, these evaluations account for the extent to which the individual perceives *control* over the outcome of the encounter and/or the capacity to emotionally cope with it (Lazarus & Folkman, 1984). The primary and secondary appraisals coalesce to determine the *coping effort* an individual makes. That embraces, whether and to what extent the individual engages in regulating the stressful emotions (emotional coping) and/or seeks to alter the imbalances in the person-environment fit, that is, the stressor (instrumental coping) (Folkman, Lazarus, Dunkel-Schetter, et al., 1986). Problem-focused coping may, for instance, include rational, deliberate efforts to problem-solving, as well as interpersonal compassionate or aggressive efforts to alter the situation. Emotion-focussed coping can, in turn, include ways of coping such as accepting responsibility, escape-avoidance, seeking social support, distancing, self-control or positive re-appraisal (Folkman, Lazarus, Gruen, et al., 1986).

The significant element in the amendment of the framework is that emotions and cognitive appraisals are inter-linked. Thereby they impact each other in terms of an on-going, dynamic process of transaction. Furthermore, it implies that events and their emotional and factual consequences are stored in the individual's memory and shapes the appraisal of future situations (Morrison & Bennett, 2009). Thereby, they impact each other in terms of an on-going, dynamic process of transaction. This way, are cognitive appraisals effectuating emotions, and vice versa, do emotions impact on the cognitions a person has about a stressor (Folkman, Lazarus, Gruen, et al., 1986).

3.4. Salutogenesis – a resource-oriented approach to health by Aaron Antonovsky

As outlined in the previous sections, health promotion makes use of an approach aiming at putting factors that contribute to positive health into the centre of attention. There are different ways of approaching or conceptualising such factors - the foregoing sections presented Lazarus and Folkman's attempt to understand the mechanisms of coping in a rather technical way. Still, alternative proposals exist to explain coping in the context of health and disease. 'Salutogenesis' is a theory of health and illness, which nowadays is widely used in Health Promotion and Health Care Sciences (Bergstein, Weizman, & Solomon, 2008; England & Artinian, 1996; Golembiewski, 2012; Skärsäter et al., 2009). The concept was firstly introduced by the Israeli American sociologist Aaron Antonovsky (1923 – 1994) in his 1979 book "Health, Stress and Coping", in which Antonovsky investigated the phenomenon "how people manage stress and stay well". The concept was further developed over the next years and the amended theory was presented within his subsequent work "Unravelling the Mystery of Health" in 1987 (Antonovsky, 1979, 1987). Investigating the relationship of the three factors of health, stress and coping, Antonovsky developed the "salutogenic model" describing a –even until today – somewhat revolutionary approach towards the relationship of health and disease (Henkin & Sperber, 1996). 'Salutogenesis' is derived from the Latin term 'salus' (health) and the Greek word 'genesis' (origin). The term contradicts the traditional pathogenic view on health, whose label is derived from the Greek terms 'pathos' (disease) and 'genesis' (origin), and depicts an orientation towards the cause of a disease (Harper, 2012). The traditional view on health follows a thought which separates health and illness, presuming that the prevalence of a disease diminishes the opportunity to be healthy, while the absence of disease is thought to equal a state of complete health in human beings (Boorse, 1977; Cassell, 1979). Salutogenesis, in turn, is grounded in the thought that health and disease are inseparably connected and stand in a continuous relationship to each other. Antonovsky describes this relation as a continuous variable, which he terms the "health-ease" vs. "disease"-continuum. The idea is based on the assumptions that stressors are a) omnipresent in life and b) that individuals thereby constantly exposed to potential triggers to pathogenic outcomes. In the life course an individual naturally moves along the continuum; sometimes closer towards the "disease end", and sometimes closer to the "health end" (Antonovsky,

1979, 1987). In these terms the traditional medical aim and notion of an achievable “complete” health status is disregarded. Similarly, the salutogenic model challenges the agents of a traditional medical view on health, which claim absoluteness for their cause-effect explanation for diseases (Boorse, 1977).

The task of the salutogenic school is to explore why some individuals are affected by some stressors and why others are not. Rather than exploring causes for diseases, the salutogenic model aims at exploring which factors cause *health*. Nevertheless, Antonovsky acknowledges the merit and the importance of traditional medicine for the public. He highlights that the salutogenic and the pathogenic view on health should not be regarded as mutually exclusive but rather as two complementary schools of thoughts (Franke, 1997).

3.4.1. Coping and health in the Salutogenic Model: resilience, general resistance resources (GRRs) and the Sense of Coherence (SOC)

Extending the pathogenic exploration of cause and effect of diseases, Antonovsky raised the question of why some individuals had negative health outcome in response to stressors while others remained unaffected (Sullivan, 1989). In the same course, the scientist also noted that some people stay or become healthy despite being exposed to possibly straining/challenging stress factors. This emanated from a study of female concentration camp survivors’ mental health and well-being, which showed that 29 % of the women remained emotionally unimpaired in the aftermath of the experience (Antonovsky, 1979; Franke, 1997). Antonovsky developed the theory that there are particular personal conditions, which render some individuals more resilient to stressors than others. In this tenet, *coping* with stressors or stressful life events is the key to the individual’s health outcome from exposure to a straining situation. These personal conditions - which contribute to managing stress and staying healthy- are called ‘generalised resistance resources’ (GRRs) (Antonovsky, 1979). A GRR is any *resource* that contributes *to coping* with stressors in an effective way. Such resources for resilience are, for instance, material resources, knowledge and intelligence, ego strength, commitment and affiliation to a strong social network, cultural stability, rational and far-sighted coping strategies, a stable system of values and beliefs, a preventive health orientation; and genetic or constitutional strengths (Sullivan, 1989). The prevalence of GRRs

and the individual's capacity to make use of them enable the individual not only to manage a stressful life event but also to *make sense* of it. Moreover, Antonovsky argues that repeated positive experiences from the successful application of various GRRs promote the development of an attitude within individuals, which in itself plays a major role for coping, thereby moving to the positive side of the health continuum: 'Sense of Coherence' (SOC) (Antonovsky, 1987). SOC is the central concept of the Salutogenic Model. The term embraces a global orientation that expresses the extent to which an individual has

“a pervasive, enduring though dynamic confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; (3) these demands are challenges, worthy of investment and engagement” (Antonovsky, 1987, p. 19).

Antonovsky (1987) allocates those three main conditions to a strong SOC to a broader term, being (1) comprehensibility, (2) manageability; and (3) meaningfulness. The GRRs are elements that may contribute to the strengthening of each component of the SOC. It follows that an individual's SOC is subject to continuous development and adaptation - in accordance with the life events throughout the person's life course. Moreover, while the SOC is shaped by an individual being's experiences, it does in turn influence the behaviour and attitudes of a single person and therefore the way a person experiences future events. This mechanism can take place in both positive and negative ways. Thus, according to Antonovsky (1987), a person with good GRRS and a strong SOC will be likely to perceive challenges as understandable, manageable, or meaningful. Vice versa, can a weak SOC account for that a person evaluates upcoming challenges or life events as unpredictable, overwhelming and arbitrary; and contribute to new experiences of meaninglessness or helplessness in an individual's life. These new experiences, in turn, may add to the originating viewpoint and reinforce the initially low level of the SOC. As the expectancy of a person is a key element of the SOC, it follows that a strong SOC is somewhat independent of achievements or needs satisfaction. Accordingly, it is rather a result of an individual's faith in lawfulness, sense of predictability, or capacity to make sense of the event. According to Antonovsky (1987), this

mechanism serves as an explanation as to why some individuals may experience failure, loss, suffering or illness without significant weakening of their SOC, in contrast to others appraising the same event in a different way and in accordance with their earlier experiences. The converse argument which can be drawn from the Salutogenic Model is that unpredictability, arbitrariness or inexplicable events are factors weakening an individual's SOC. This mind-set encouraged researchers of that time and today to add a new perspective in scientific investigations in health-disease relations: instead of a mere assessment of causes for illness, the exploration of determinants for health became relevant as well. Meanwhile, several research investigations in the SOC have proven a relationship between the SOC and health, quality of life, and coping (Eriksson & Lindström, 2006, 2007; Fok, Chair, & Lopez, 2005; McCubbin, Thompson, Thompson, & Fromer, 1998; Sanden-Eriksson, 2000). Similar results were found in study's on the role of the SOC and cancer patient distress, quality of life and well-being: Mullen, Smith, and Hill (1994), for instance, have shown that the SOC was a significant predictor of psychological stress in cancer patients. Further research investigations in the field showed that the SOC was related to alleviated follow-up distress in cancer patients (Gustavsson-Lilius, Julkunen, Keskivaara, & Hietanen, 2007), accounted significantly for psychological well-being (Gibson & Parker, 2003) and enhanced postoperative quality of life of breast cancer patients (Gerasimčik-Pulko, Pileckaitė-Markovienė, Bulotienė, & Ostapenko, 2009).

Several studies indicated that the SOC is able to predict health and may serve as a contributor for the development and maintenance of people's health and quality of life (Eriksson & Lindström, 2007, 2008). Further investigations have outlined a significant correlation between the SOC and the ability to cope (Fok et al., 2005). Even though research on the SOC and particular cancer-coping is scarce, there exists some evidence for that the SOC is suitable to explain how cancer patients cope with the disease (Strang & Strang, 2001).

4. METHODS

The preceding chapters have outlined the background of the topic and the theoretical foundation from which the study emanates. Such a conceptual framework is necessary to outline the specific research aim of the study and the topic from which the researcher aims to derive new scientific evidence, respectively. The successive conceptualisation of research methods is the researcher's guideline to gather the desired knowledge. The methodological procedure is not merely limited to choice, description or application of the tools the researcher makes use of to retrieve scientific evidence but must also provide an account of the researcher's opinion about 'what science is' (M. Z. Cohen & Omery, 1994).

Science has been defined in innumerable different ways, depending on the field of research or interest the definition emanates from (Malterud, 2011). The etymologic meaning of science is derived from the Latin word "scientia", is 'knowledge' (Harper, 2012), which has given rise to debates on the verification of 'true knowledge'. Accordingly, research can be explained as the formal work undertaken to explore and systematically increase the stock of knowledge in a given field (OECD, 2002). In this course different methodologies have been developed to derive scientific evidence from research investigation. From the different approaches two main scientific traditions have come to dominate the research field today: the quantitative and the qualitative approach (Cutcliffe & McKenna, 2002). Mixed methods approaches came into being as third main "independent" methodology. The mixed methods approach can be located between the two other main research approaches as it makes use of both qualitative and quantitative elements (R. B. Johnson, Onwuegbuzie, & Turner, 2007).

Qualitative research is often regarded as contrasting research method to quantitative sciences, which is concerned with numbers and 'hard facts'. Qualitative methods are, in contrast, addressing broader questions or themes, as observed from or described by participants of a study investigation (Malterud, 2011). Thus, for a long time, the qualitative paradigm has been struggling to establish itself as a method in science (Cutcliffe & McKenna, 2002; Mays & Pope, 1995). Meanwhile, it is acknowledged that qualitative and quantitative methods are two distinct disciplines to be regarded as complementary rather than exclusive, and each serve different research aims (R. B. Johnson et al., 2007; Malterud, 2001). Nowadays there exists a common sense amongst all research fields that, in order for results of

a study to “qualify” as scientific evidence, some methodological criteria must be met within the research process. The status of all research investigations therefore depends on the quality of the methods that have been applied (Mays & Pope, 2000). The subsequent sections seek to provide a structured account of both the application of methods in this study as well as an outline of their suitability to this investigation.

4.1. Qualitative methods

For the purpose of the present study the researcher has chosen a *qualitative approach* to investigate the problem statement. The choice has, amongst others, been grounded in the study’s problem statement, which approaches a relatively unknown phenomenon (coping with cancer) in an under-researched population (YACP). As the phenomenon has not yet been examined sufficiently in relation to the specific YACP population, it can therefore best be examined in all its facets by using qualitative methods suitable for gathering new scientific evidence within the field (Dowling, 2007). Qualitative research is concerned with describing the nature (“how”) and the meaning (“why”/”how”) of a phenomenon (Malterud, 2011). In this study, its application can support the researcher to understand *how* coping is experienced and which *meaning* it has for YACPs during the treatment. The researcher aims to gather new knowledge and understand as many features of the phenomenon as possible. This is a feature that qualitative methodology embraces as it seeks to gain a holistic comprehension and view the phenomenon with most possible facets (Creswell, 2009). Within a qualitative investigation the lived experience of the phenomenon is understood *as described by the participants* (Moustakas, 1994).

4.2. Preliminary considerations to the present research design: Philosophy of Science

As mentioned in the preceding section, research approaches to a given problem statement vary amongst the different academic disciplines. The choice of research methods is impacted by the academic field the study is embedded in, the nature of the research question and the *researcher’s world view* (Cutcliffe & McKenna, 2002).

The world view of a researcher can be defined as “a basic set of beliefs that guide

action” (Guba, 1990, p. 17). World views describe a general orientation the researcher holds about the world. In the scientific context they are also referred to as *paradigm* (ideas about a proven structure/models of a phenomenon), epistemologies (ideas about (pre)conditions of knowledge) or *ontologies* (ideas about the nature of being) (Crotty, 1998; Lincoln & Guba, 2000). These world views are shaped by the researcher’s academic discipline, their personal interest for and earlier encounter with the phenomenon, or past research experiences. It may also be impacted by belief systems in their environment, e.g. the cultural and historical context or political consideration (Creswell, 2009). Altogether, the term ‘world view’ refers to the *philosophical assumptions* a researcher holds about the world. These result in the *research strategies* the researcher applies to generate the truth/knowledge in terms of their conceptualisation of it (Malterud, 2011). Research strategies in the qualitative tradition are ethnography, grounded theory, case studies, narrative research and phenomenological research (Creswell, 2009). The different world views bring into effect that a certain phenomenon can be approached from different angles and that differing investigations on one and the same issue can bring various results or aspects of ‘the truth’ into being (Malterud, 2001). A deliberate account of the researcher’s world view through which the investigation has been shaped should therefore accompany any description of a study. Thereby the researcher enables the audience to locate and understand the study in a greater context. Moreover, the definition of the researcher’s perspective provides an account of the realm of the study: it determines what the investigation does and does not explore – the latter describing matters outside the given scope (Malterud, 2011).

Consequently, the following sections will provide an overview of the researcher’s world view – in terms of the researcher’s personal context and background as well as the researcher’s philosophical assumptions guiding the investigation of the topic.

4.2.1. The role of the researcher

One of the main characteristics of the qualitative study is the role of the researcher. Qualitative data are mostly collected in the field where the participants experience the phenomenon of investigation or retrieved in direct communication between the researcher and the participants, e.g. in the form of an interview (Creswell, 2009). That makes the researcher themselves a key instrument of the research. They engage in the process through data

collection, examination of documents or through observations. The researcher reviews the data and seeks to organise it into emerging categories or themes and the interpretations are results of the researcher's view on the issue. This, in turn, is influenced by the researcher's view on the world and personal experiences which constitute their personal background from which they approach the problem.

The researcher of the present study adheres to a phenomenological-hermeneutic understanding of 'exploring the truth' in examining the research question. The initial motivation to investigate YACPs's coping experiences was impacted by both the educational background as well as of personal experiences of the researcher. Being a student of the Master's/MSc programme "Health promotion and Health Psychology" at the University of Bergen, the researcher's interest was to investigate an issue which adds value to the existing knowledge base in the field of Health Promotion. Thus, the researcher's focus in exploring the life world of YACP was oriented towards health promoting factors in the cancer patients' life world and respectively, towards possible problem statements needing to be highlighted in further research and health promoting activities in order to facilitate positive health in the YACP population. The interest in coping originates from the researcher's personal background. Having both experienced and observed how drastically disease can impact the life of a human being, the researcher's attention has been drawn to 'the story' of a person for a long time. Once having begun to focus on the issue, the researcher observed – both in the closer environment as well as on a general basis- how some people develop unforeseen strength and the power to deal with a disease or incapacity. These experiences were the driving factor to start working in institutional and clinical settings, wishing to learn from and support patients who had to deal with difficult conditions.

4.2.2. Phenomenology and Hermeneutics

The present study investigates the problem statement: "how do YACPs experience coping with the disease". Thereby the research seeks to develop insight in the patients' life-world. For the purpose of this study the researcher has chosen a phenomenological-hermeneutic approach to the investigations, which is influenced by the philosophical schools

of Edmund Husserl (1970), Martin Heidegger (1962) and Hans- Georg Gadamer (1989). *Phenomenology* has become a dominant agent in the pursuit of knowledge in health sciences as it features “credible displays of living knowledge” (Jones & Borbasi, 2004, p. 99). Phenomenology is an inquiry that is used to identify the essence of the individual’s experiences with a given phenomenon (Dowling, 2007). The investigation in the lived experience depicts the special feature of phenomenology: It embraces two distinct realms as it is a research method just as much as a philosophy (Moustakas, 1994). Moreover, there exist various schools of phenomenological philosophy, posing a notable challenge in the application of a solid phenomenological basis to a study. The reason for this is that the term “phenomenology” is used frequently in qualitative academia, but is applied by numerous distinct schools of phenomenology. Therefore, the term “phenomenology” can - if not further specified- give rise to confusion regarding its actual nature as applied within given research (Dowling, 2007; Malterud, 2001). Its various features bring along a somewhat blurry application of phenomenology, also regarded as “a crisis of representation” (Dowling, 2007, p. 139), in which some researchers fail to state clearly which philosophical and theoretical viewpoint their piece of work originates from.

In order to prevent this, any outline of the interpretative inquiry to the research question must therefore address which philosophical and theoretical framework the researcher adheres to in order to generate the data (Koch, 1999). As “good science emanates from a solid philosophical base” (Packard & Polifoni, 2002, p. 163), the subsequent section will delineate how phenomenology is applied as a philosophical foundation of this? investigation. Thereafter, a separate section will provide an account of the application of phenomenology as a methodological approach to the research question at hand.

4.2.2.1. The phenomenological school of thought

As a philosophy, phenomenology has, *inter alia*, been brought forward by writings of Husserl, Heidegger, Gadamer, Arendt, Sartre and Merleau-Ponty (Moran, 2000). Due to the scope of this research the following presentation is limited to philosophical mind sets constituting the main features of the phenomenological framework for this investigation and does not take into account a reflection on *all* aforementioned schools of phenomenology.

Phenomenology was first developed in Germany before the First World War and has played a significant role in modern philosophy ever since (Dowling, 2007; Moustakas, 1994). The term ‘*phenomenology*’ descends from the Greek word *phainomenon* – describing something that appears or is seen - and the word end “*logy*”, which means a discourse, doctrine, theory or science (Harper, 2012). The philosopher and mathematician Edmund Husserl is deemed to be the founder of the 20th century school of phenomenology. He held a strongly epistemological position, regarding human experience as the substantial source of knowledge (Racher & Robinson, 2003). Thus, the core and aim of his phenomenological approach was to obtain an unbiased understanding of human experience through the study of things as they appear. For this purpose, Husserl drew up the concept of phenomenological reduction. The key strategy is to defer from own subjective views and fundamental ideas about a phenomenon in order to allow for *the essence* of a phenomenon to emerge in an unsophisticated manner (Moran, 2000; Racher & Robinson, 2003). According to Husserl (1970), the understanding of the “life-world” (*Lebenswelt*) of individuals is what is experienced pre-reflectively, free from theoretical reflections or interpretations. The ‘*essence*’ is what constitutes a thing, and without which it would not be what it is (Dowling, 2007; van Manen, 1990). The strategy is to refrain from judgment, respectively, stepping away from one’s familiar conceptualisation of a phenomenon. This is labelled “bracketing” or ‘*epoché*’ – the demand for a fresh way of looking at a phenomenon (Dowling, 2007; Moustakas, 1994). In addition, the phenomenological exploration of an individual’s life-world claims ‘*phenomenological reduction*’ of the issue under study. This means to regard the study subject as independent and to metaphorically put brackets around it to exclude the wider context or its environment that might influence the researcher’s perception of a phenomenon (Valle, King, & Halling, 1989). Phenomenology, in terms of Husserl, aims to *describe rather than understand* a given phenomenon.

4.2.2.2. *Hermeneutics*

The importance of *description* of phenomenon is widely acknowledged amongst various phenomenological streams. Nevertheless, other philosophical schools, e.g. the one of the philosopher Martin Heidegger (1962), disagree with Husserl's view that knowledge about things is based on description rather than *understanding*. The school of Heidegger holds the rather ontological view that the primary matter of phenomenology is to ask for the *meaning of being*, hence to ask for the nature or meaning of the phenomenon in question (van Manen, 1990). Moreover, the school of phenomenology according to Heidegger (1962) addresses the *problem of bracketing*, claiming that individuals can never completely refrain from own prejudices or overlook the overarching context of a phenomenon. Hence, Heidegger suggests the utilisation of '*hermeneutics*' to investigate phenomena, seeing lived experience as an interpretative course (Koch, 1999). The term '*hermeneutics*' originates from the Greek word '*hermeneuō*', meaning 'to translate' or 'to interpret' (Klein, 2000). Heidegger proposed the '*hermeneutic circle*' to illustrate the view that the understanding of lived experience constitutes a reciprocal process between pre-understanding and understanding (Koch, 1996). (Koch, 1996). The same term is also applied by objectivist hermeneutics, who hold the view that a phenomenon always appears as one part of the whole and cannot be regarded independent of its contextualisation (Dowling, 2007). Racher and Robinson (2003, p. 473) suggest, that the hermeneutic circle could be perceived as "revisioning" of phenomenological reduction. The philosopher Hans-Georg Gadamer (1989) took the concept of the hermeneutic circle one step further, emphasising that a full detachment from all prejudices is not possible but that the attempt to do so is facilitating an *understanding of one's own presupposing*. This, in turn, supports the researcher in being cautious about those types of own prejudices, which might obstruct or colour the researcher's understanding of a new phenomenon (Koch, 1999). It follows that the detachment from judgments is a *part of the process of understanding* and moreover *contributes* to comprehending the phenomenon. That makes the researchers themselves an active part of the phenomenon as understanding is "derived from personal involvement by the researcher in a reciprocal context of interpretation" (Dowling, 2007, p. 134). Thus, the hermeneutic research process can be seen as a dialogical method in which the researcher interprets and re-interprets every action in the process, being aware of gender,

social, cultural or other implications that might influence their way of viewing the phenomenon (Dowling, 2007; Koch, 1999).

4.3. Choice of study design

The choice of methods and research tools constitute what is called the research design. Research designs are “the procedures for research that span the decisions from the broad assumptions to detailed methods of data collection and analyses” (Creswell, 2009, p. 3). Each investigation requires a research method which is suitable to the field of interest and the characteristics of the research question, the purpose of the study and the world view the researcher holds (Creswell, 2009; Mays & Pope, 2000). The application of a *qualitative* research design renders possible to choose from a wide range of *tools* to investigate the field. Researchers can make use of multiple data sources; interviews, review of documents, field investigations or observations, amongst others. A well-considered choice of research methods and the tools to perform it is of particular importance to the investigation (Creswell, 2009). The application of appropriate methods accounts for the successful execution of the investigation and the validity of the results, respectively (Eric J. Cassell, 1979). The basic strategy to ensure quality is thus the insurance of a “systematic, self-conscious research design, data collection, interpretation, and communication” (Creswell, 2009; Mays & Pope, 2000, p. 52). Equally important as a well-considered and informed choice of method is the researcher’s *outline* of the applied procedures within a given study (Cutcliffe & McKenna, 2002). Thus, it is crucial to proceed in a way that is both structured and suitable to the question as well as to communicate the procedure to the audience in an understandable and transparent (Malterud, 2011). Correspondingly, the methods of the study and the foundation of the choices will be presented in the following section. The section will start out with a brief summary of the procedure in order to provide an initial overview over the methods to the reader. It will then move on to a more detailed outline of the single elements, in line with a brief presentation of the rationale of the motives for applying the given approaches.

4.3.1. Overview over the study design

To investigate young adult cancer patients' coping experiences, a qualitative, phenomenological inquiry was undertaken and included in-depth interviews with 16 young adult survivors (aged 24 - 35 years) with different cancer diagnoses. The participants were recruited for the research project: "KanNo?" - a rehabilitation programme for young adult cancer survivors. Phd candidate May Aasebø Hauken together with associate professor Torill Larsen and Ingrid Holsen, has designed the evaluation study, and May Hauken has executed the interviews. The semi-structured interviews were conducted a posteriori to the finished cancer treatment. Thus, the informants' narrations are retrospective reflections of their coping experiences during this period. For the purpose of the present research the interviews transcripts were made accessible to the researcher. The theoretical background of the study was influenced by phenomenological and hermeneutic schools. The interviews were analysed qualitatively using Systematic Text Condensation method.

4.3.1.1. Semi-structured in- depth interviews

The study investigates the problem statement by using 16 individual semi-structured in depth interviews, as the research seeks to develop insight in the patients' life-world. Through its philosophical underpinning the present study has been designed to both explore (phenomenology) and interpret (hermeneutics) the YACPs' life-world. In line with the phenomenological viewpoint of Husserl (1970), the researcher seeks to obtain the informant's description of their life-world. This requires the researcher to obtain the study subject's narrations on the experience in question. Interviews are a suitable method to obtain descriptive information and thereby the interviewee's account of 'reality' (Silverman, 2010). Semi-structured interviewing is a method which allows for keeping the flexibility of open-ended interviews while at the same time ensuring that important topics are covered during the conversation (Kvale & Brinkmann, 2009). The semi-structured interview is organised into units of interest, which were laid out as questions in an interview-guide prior to the investigation. These key questions define the areas that have to be explored, while at the same time allowing for diverging from an idea in order to explore it in greater detail (Britten, 1999).

4.3.2. Recruitment of the study sample

The study participants were recruited from different sources: through information by healthcare personnel in primary healthcare facilities and hospitals and through launching information on different websites. Those who were interested were referred to the research project by their general practitioner or oncologist. Criteria for eligibility were a) being in the age group 18-35 years, b) having finished cancer treatment within a maximum of 5 years and c) having received any cancer diagnosis. Of 31 referrals, 11 cancer survivors did not match the selection criteria and were excluded from the study. The final sample included 20 participants, who all met the inclusion criteria. Due to limitations of time, resources and the scope of this research paper, the researcher decided, in accordance with her supervisors, to limit the sample-size to 16 participants. The reduced sample size appeared feasible to both attain data saturation and to ensure that the researcher had the time and the opportunity to analyse the interviews in depth and to keep the quality of analysis at the highest attainable level. The four suspended interviews were randomly excluded to avoid selection bias through purpose sampling, which would not fit the phenomenological basis of the investigation.

4.3.3. Data collection methods

Data were collected through in-depth interviews, which had been conducted using a semi-structured interview-guide, as outlined in Table 1.

Main Questions	Period	Follow-up Topics if Necessary
Can you please tell me about your experiences being young, getting a cancer diagnoses, and going through treatment?	Diagnose and treatment	Symptoms before Diagnose process and reactions and coping Treatment and coping Support from healthcare providers and network Learning outcome, worst and best experiences

Table 1: Semi-structured Interview Guide, designed and applied by Hauken et al. (2013)

The interview guide had been designed prior to data collection and was applied equally to each of the informants. The interview guide covered an introductory question: “Can

you please tell me about your experiences being young, getting a cancer diagnoses, and going through treatment?”. The aim of such a broad, open introductory question is to encourage the informant to speak freely about the topic rather than speaking about what they think is expected to be said (Silverman, 2010). The introductory question is accompanied by 10 follow up-topics: symptoms before, diagnostic process, reactions and coping, treatment and coping, support from health care providers, support from the network, learning outcome, and worst/ best experiences. This “hierarchy” of question types is in line with widely used guidelines in the field advocating to start with a broader, “easier” issue before turning to potentially sensitive or more detailed issues (Britten, 1999). This is, in addition, a good method to enable both researcher and participant to familiarise themselves with the context and to support the informant to feel at ease with the situation (Gill, Stewart, Treasure, & Chadwick, 2008). The *types* of questions in the given manual adhere to generally acknowledged quality criteria, which prerequisite that good quality questions shall be understandable, open-ended (not answerable by yes/no) and sensitive (Britten, 1999). These aim at facilitating informants to build up confidence and open up to the researcher so that rich data might be generated which, subsequently, can further develop the interview (Gill et al., 2008). A further recommendation to generate good-quality interview guidelines is to pilot the questions on test- respondents prior to data collection. The goal is to examine the usefulness and comprehensibility of the questions (Pontin, 2000). Such a pilot test was carried out for the present interview guide and confirmed that the questions were understandable, coherent and matched the criteria mentioned above.

4.3.4. Interview Procedure

The informants were interviewed separately. The interviews were conducted once and face-to- face in an office at the rehabilitation centre. This assured that the interview could be conducted in accordance with the basic condition of an area that is free from external distraction (Gill et al., 2008).

Prior to the interview each informant had been informed about the design and the purpose of the study, through public information on advertising media, through their general practitioner, and verbally by the interviewer. This is in line with general recommendations on

good practices in qualitative research (Britten, 1999). Also, in line with generally acknowledged standards for good quality procedures, the informants had been assured about the ethical principles behind the study - such as confidentiality and anonymity - which are essential aspects of the principle of informed consent. This increases the notion of honesty and trustworthiness between both parties and supports the participants in comprehending what to expect from the interview situation (Britten, 1999; Gill et al., 2008). During the interviews the interviewer adhered in the best possible way to the requirement of sensitivity towards the participants and delicate issues (Kvale & Brinkmann, 2009).

The interviews lasted between 45-70 minutes, which corresponds to the general duration of in-depth interviews in health sciences (Gill et al., 2008). They were digitally recorded to ensure their authenticity and facilitate detailed analysis afterwards. During the interviews field notes were taken on the interviewer's observation during the interview process. All interviews and field notes were transcribed verbatim by the interviewer, including remarks of the interviewer and relevant non-verbal communication/activity. This procedure contributes to protect against biases in reflecting retrospectively on what was said and not said (May, 1991; Pontin, 2000). The transcribed interviews had an average length of 16 pages, using font size 11 and 1,5 line spacing. The transcripts were made accessible to the author for the purpose of her investigation.

4.3.5. Ethical considerations

Qualitative interviewing is a method through which the researcher can gain access to sensitive information on personal, value-laden features of the informant's life and – especially in health research- on topics related to health, illness and death (Malterud, 2011). This is the case in the study at hand, in which informants were interviewed in relation to their personal health status and disclosed confidential medical information, such as parts of their disease history and the accompanying treatment they had undergone. Except for this, some informants shared personal information about their job situation, equally demanding confidential processing. Moreover, the informants elaborated on a very personal situation in their life and /disclosed? intimate feelings. In such a sensitive context it is inevitable for both informants

and researchers involved to safeguard that private information is handled strictly confidentially and the privacy of the informants is by no means invaded (Richards & Schwartz, 2002). This requires strict adherences to ethical guidelines and the patients' informed consent to study participation. For the field of health sciences there exist clearly defined global guidelines on ethical principles for research on human beings. These have been laid out by the *World Medical Association's Helsinki Declaration* in 1964 and were last amended in 2008 (World Medical Association, 2008). In Norway, the *Regional Ethical Committee for medical and health research ethics* (REK) holds the responsibility for assessment and approval of research projects in the field. In addition to the application of the ethical guidelines of the Helsinki Declaration, the REK is, amongst others, committed to ethical principles defined in the national law on research ethics (*Forskningsetikkloven*), the national law on health research (*helseforskningsloven*) and the law on personal information (*personopplysningsloven*) (REK, 2013). The present study was conducted within the framework of the research-project "KaNo? A rehabilitation programme for young adult cancer survivors" which had been assessed by the REK and approved by the NSD. The study protocol was approved by the rehabilitation centre and the University of Bergen. The research was carried out corresponding to the ethical standards of the Helsinki Declaration and the NSD. All researchers involved were familiar with the ethical guidelines and regulations and committed to carry out the research in accordance with those.

The participation in the study was free of charge and based on the principles of the informed consent of the participants prior to the execution of the study (World Medical Association, 2008). Informed consent involves that participants are familiar with the investigation in question- to an extent that enables them to take a position towards whether they seek to participate in the study or not. A basic inherent element is that informants are not merely informed but, equally importantly, that informants understand the setup of the research (Malterud, 2011). Informants should therefore be educated on all essential elements about the study execution, including methods for and context of data collection, subsequent data administration, as well as processing and frame conditions to the protection of their privacy. Additionally, informants need to be educated about their *rights*, including the withdrawal from the study and the possibility to withdrawal and having the provided data deleted (Malterud, 2011; Oeye, Bjelland, & Skorpen, 2007). The availability of information in *writing*

is an essential condition to the provision of informed consent (World Medical Association, 2008). Correspondingly, participants of this study were given both written and verbal information about the research project and the conditions of participation in the study, as outlined in earlier sections. The study participants were informed about the anonymity and confidentiality of data handling. In addition to the intention of following the relevant ethical procedure, this information contributes to support the informant's confidence to provide sensitive information without risking to be identifiable in the context of the data (Malterud, 2011). All participants gave written consent. The *Norwegian Social Science Data Services* approved the study and collection and storage of data was undertaken in accordance with its guidelines. The researcher of the present study was granted access to the data by Red Cross Haugland Rehabilitation Centre and the Hemil Centre at the University at Bergen. The researcher did not have access to any confidential data pertaining to the informants' names, age, places of living and other confidential information, and assigned to a coding number.

4.3.6. Cooperating Partners

This master's thesis is affiliated with the University of Bergen, with first amanuensis Torill Bosgness Larsen as first/primary supervisor. Data derived for the research were provided by the PhD degree project "KaNo? Evaluating a rehabilitation programme for young adult cancer survivors." and were collected by the responsible Cand.pol.May Aasebø Hauken, who is the second supervisor of this master's thesis.

4.3.7. Financial considerations:

The overarching project: "KaNo? Evaluating a rehabilitation programme for young adult cancer survivors" is fully financed by Red Cross Haugland Rehabilitation Centre, Eckbo's Legacyb through Haugland International Research and Development Centre (HIFUS) and The Norwegian Cancer Society. There were no additional expenses related to the accomplishment of the present study.

4.4. Method for analysis: Thematic Analysis

As a methodological approach phenomenology was applied through thematic analysis (TA). TA is a widely used qualitative research method (Boyatzis, 1998; Roulston, 2001) within and beyond psychology and health sciences (Braun & Clarke, 2006; Holloway, 2005). Braun and Clarke (2006), who reviewed different methodological attempts to qualitative research, suggest, that thematic analysis be regarded as a “foundational method for qualitative analyses”. (Braun & Clarke, 2006, p. 78). TA aims at capturing the essence of the phenomenon under study and was therefore a suitable approach to examine the nature of the informants’ experiences of coping with cancer as a young adult patient. Moreover, the thematic analysis approach is an especially recommendable technique to analyse multiple interview transcripts as it is suitable to bring a consensus into the variety of constructions that exist around a phenomenon and to reveal its essential quality (Holloway, 2005; van Manen, 1990). Braun and Clarke (2006) provide guidelines to thematic analysis, which were used to conduct this research. The procedure embraces six core steps: 1.) familiarizing with the data, 2.) generating initial codes, 3.) searching for themes, 4.) reviewing and refining themes, 5.) defining and naming themes, and 6.) producing the report (Braun & Clarke, 2006, p. 87). It must be noted that conducting a qualitative analysis often is a recursive process rather than a linear one, demanding a flexible application of the guidelines – while still following the basic principles- to fit the research questions and the data (Braun & Clarke, 2006; Patton, 1990).

The given data were analysed in accordance with the TA guidelines presented above. The researcher proceeded as follows: all interviews were printed out and read once, to become familiar e with the data and the narrated issues.

Throughout the research progress the researcher tried to be aware of personal, pre-defined viewpoints and to refrain from these as much as possible. Acknowledging that a full detachment of prejudices is hardly realisable, the researcher sought to engage in a process of continuous self-reflection and self-assessment on how and to what extent own conceptualisations and experiences might affect the research progress.

In a second stage, the interviews were re-read while relevant data extracts were highlighted and notes and initial codes were generated manually during the process. *Codes* were understood as labels identifying features of the data that – in relation to the phenomenon of investigation- appeared relevant or interesting to the analyst (Braun & Clarke, 2006).

The highlights and codes made in the print version of the interviews were thereafter transferred to the digital interview-transcripts and saved as an initial working draft. The aim was to facilitate optimal flexibility for subsequent working with the extracts and codes (e.g. through copying essences which fit better than one theme). Moreover, the researcher wished to keep track of changes made, in case it would be necessary to go back to earlier stages in the course of the research process. An example of such a document is presented in Appendix 1. Thereafter, all codes and their appertaining data extracts were excerpted and collected in a separate working draft for each interview, as illustrated in Appendix 2. Each excerpt included pro- or succeeding phrases in order to ensure the content was understood in the context from which it originated. Each of the generated codes and themes were tracked in a logbook, in which the researcher recorded the date of coding, questions, arising topics and other thoughts relevant to analysis. Within this logbook, first assumptions and free associations about interrelationships of codes and collations to possible themes were generated and recorded. The logbook was maintained throughout the analysis and served as record of changes in the coding process. An excerpt of the logbook is shown in Appendix 3.

In a next step, all codes were written out from the second document and collected (separated from the text passages) in order to get an overview over emerging overarching topics in the corresponding interview. For that purpose, the researcher grouped the codes to overarching themes. The researcher applied a conceptualisation of *themes* as defined by Braun and Clarke (2006, p. 82): “A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set”. In the course of grouping and organising codes the researcher aimed to assess relations and possible contradiction between emerging themes. The procedure was conducted for each interview until the themes captured the essences of the coded data in a most suitable/valid way. The second working draft (see Appendix 2) was used to assess the fit of amended codes and generate themes with the corresponding data extracts. In the following, codes and themes from all analyses were collated in order to generate a thematic map of the entire dataset. A mind map software was used to design a card in which possible relationships could be drafted and amended flexibly (see Appendix 4)

During this stage, as well as in every other phase of the process, the researcher

acknowledged that analysis is a recursive instead of a linear course. The researcher aimed to remain flexible and open to change during the analysis, moving back and forth between stages when needed, in order to attain a broad overview and facilitate a rich description of the themes emerging from the data set (Ely, Vinz, Downing, & Anzul, 1997). This process involved repeated viewing and re-viewing of the allocation of the codes and, where necessary, re-naming of the groups/themes, until a coherent overall picture crystallised from the procedure. Once the thematic map adequately reflected the entities of meaning from the data set a whole, the researcher went on to refine the captured codes and themes. In this course, the researcher wrote out themes which had emerged from the mind map and registered them in a new working draft. The listed themes were systematically reviewed and collated to different levels (themes and sub-themes). Codes fitting multiple themes were highlighted correspondingly. Themes and sub-themes were assessed in accordance with the criteria for judging categories given by Patton (1990) in order to ensure internal homogeneity (the meaningful coherence of data within a theme) and external heterogeneity (the relevance of and distinctiveness between the themes). Overlapping themes were consolidated to one theme, internally inconsistent themes were broken down to two or more separate themes have themes, while some themes were discarded from analysis as they did not adequately capture the essence of the coded data. The themes were altered and codes were re-organised or re-named several times until the final draft of the data sheet was generated. An extract of the working draft containing codes and themes is depicted in Appendix 5.

Next, final codes and themes were validated in relation to the data set. That required a re-reading of the captured data and, in some cases, the coding of additional data which had been missed out in earlier stages of the analysis. All codes resulting from the completed procedure were registered in a chart and the interview numbers they had been applied to were recorded. This way, the researcher could assess to what extent codes and themes were supported by data material and consider the discarding of claims not supported by a sufficient amount of data. Within the chart the codes were arrayed in accordance with their overarching themes. An excerpt of the data record is shown in Appendix 6. The final results of the analysis will be presented in the subsequent chapter.

5. FINDINGS

The key objective of the research was to explore YACPs' experiences of coping with

cancer. For that purpose three research questions had been determined a priori in order to guide the investigation and to generate a more nuanced account of the phenomenon. The research questions were:

- 1.) *“What challenges do YACPs face during treatment?”*
- 2.) *“How do YACPs cope with the challenges they meet during the treatment?”*

These two research questions target facets of the phenomenon, which are interrelated. Therefore, the findings of all three questions will be presented *grouped* rather than separated and in chronological order of the research questions. This particular structure has been chosen in favour of the phenomenological nature of the study, which seeks to generate ‘the big picture’ of the phenomenon as it appears to the informants.

The analysis reflected five central themes and several sub-themes of cancer-coping in YACPs. The five main themes were: 1) coping with the diagnosis, 2) living with cancer, 3) meeting the health care system, 4) coping with the impact of the treatment, and 5) the role of social support.

In the following, each theme and its according sub-themes will be presented in separate section; providing an outline of the particular challenge of YAC-coping (research question one), followed by a delineation of how the informants experienced coping with the given feature (research question two).

5.1. Theme 1: Coping with the diagnosis

Facing a potentially fatal diagnosis might be one of the hardest challenges a person could face in life. While the individual stories differed, the reflections covered one shared experience. All informants stated that they were experiencing a massive overburdening in dealing with uncertainty at any stage of the treatment process; prior to and during the diagnosis, in the treatment course and with regard to future prospects. The strategies chosen to deal with the extreme situation, though, varied widely. Some informants denied the mere possibility of having cancer, as one depicts as follows: *“I thought: ‘Well, they sure just misunderstood and just fooled around, (...) So I just took a seat on a sofa and waited for someone to come and tell me that there was nothing at all”* (13). Other patients went into denial, too, although in a different way: they experienced an uneasy sense of that they would get a negative message, and refused the confrontation with the final diagnosis:

“I just went on holidays for two months and delayed the examinations for two months and just didn’t want to hear it. (...) I knew that there was something [wrong] (...) and I just did not WANT to understand it. (...) Then I got the call from the doctor at the hospital and just ignored it a little bit. Then I received a new letter (...) and then they called from the hospital. And then I just totally collapsed” (Informant 11).

In contrast to escaping from uncertainty through denial, some informants eluded from suspense by ending the period themselves. They decided to take a negative outcome for granted and to prepare for the feared situation rather than exposing themselves to repetitive questions and grinding thoughts about the possible examination outcome.

“So then another week passed...But then it wasn’t as tough anymore. Because by then I had – in a way- prepared myself.(...) Even though I didn’t have any affirmative answer yet, I told myself: ‘xxx, you have cancer. Everything points in that direction. In a way – what are the odds for it not being that? Apparently, this is what I have, so I just have to take it as it comes.’ This has been presented to me, and that’s just how it is” (20).

5.1.1. Coping with lethality

This confrontation with death appeared to be an especially sensitive issue regarding the relatively young age group of the informants. All of them had just started or were about to start a new period of their lives, either in terms of finishing studies, starting a family or getting established in the labour market. At a life stage, which they had earlier connected to starting their grown-up life, they suddenly saw themselves confronted with its possible ending:

“Of course this is frightening! (...)What emerged there in front of me, was just...I am just 30, right? (...) I didn't get to live the family- piece then, getting children and family, kind of ...raising them, right? I thought: 'Damn, am I not allowed to experience this?'” (20).

While the extent to which the informants consciously dealt with that matter varied, all informants reported consistently that an underlying thinking about death accompanied them throughout the treatment period: *“When I tried to do some shopping, and would have liked to buy a dress or something, then I thought that, no...the thought was striking me that it is...it is too sad for my parents to clear out my wardrobe”*(13). Another informant remembered: *“And at night, it was all about: 'Is this my life, am I just going to die?’”*(18). It became clear that informants dealt with the fear of dying and the uncertainty of the situation in diverging ways: *releasing their emotions* was something some of them first and foremost needed to do:

“My mother stopped the car and sat with me in the back and held me all the way to Oslo, while I was just crying and crying and crying...I cried so much that I fell asleep in the end, because I was so drained out. But when I arrived to the city, I felt I had cried it away...”(1).

As depicted in this narration, crying and seeking social support was perceived as a releasing factor to process emotions. Nevertheless, the majority of informants approached their situation rather instrumentally. Here, gathering information played an important role to reduce the uncertainty of the situation: *“Well... prognosis...disease course...for all intents and purposes, it was the odds to survive I searched for at first. Because it is a fatal disease”*(14). As reflected in the quote, the informants reported that information about the life expectancy constituted a dominant factor to cope with the situation. Still, even though the existence of the

prognosis was important, its actual implication appeared to have only a minor significance for coping, as the narrations of two informants, who were confronted with different odds, illustrate: *“The doctor said immediately: ‘You are going to get well’ ...but it knocked me off anyway”*(6). In contrast, one informant reacted more positively to a more negative message: *“At my advanced case back then, they anticipated a 50-80% chance. (...) I bore that with dignity. (...) I figured: ‘I can’t think about this, it doesn’t help. I just put it aside and try to get through the treatment’”*(14.)

It appeared that, on a general basis, informants handled a tough diagnosis in a similar way as those informants who received a reassuring message from their doctor. Most informants reported that they, especially after some time of being in suspense, would rather want to deal with devastating facts than with uncertainty. They verbalised a need for a set value to serve as an orientation point from which they could move on and to which they could adapt in the new situation.

5.2. Theme two: Living with cancer

Irrespective of differences in the informants’ cognitive and emotional evaluation of the situation, their narration shared a common feature *all* of the informants experienced: the informants described that they entered a whole new world through the diagnosis. *“So then it was to start the treatment, (...) Unknown world. (...) There is nothing you could relate to, everything is new”* (20). Many informants felt that the confrontation with the situation enforced a re-evaluation of their entire life- with regard to their future, their present and their past: *“Well, you feel in a way the world is falling apart. And that...well ...things you had planned...You’re having plans about things you need to get done and we had just moved...”*(8). Yet, the concerns of the informants exceeded considerations of the present and the future, and were in almost all cases related to the past as well. The informants reported nearly consistently how their thoughts circled around their life history over and over again, in order to find an explanation for why they had been afflicted by the disease. Most of them could not make sense of it, as the following statement illustrated: *“I went on the internet and (...) began to read about it, and there were almost only older aged males who got it. And I was neither overweight, nor did I have an unhealthy lifestyle...”* (9) As presented in the quote of the young women, most informants described being exposed to own and social conceptions

of ‘cancer’, which they could not identify with. The widespread disease entity of cancer created a picture of cancer patients both in their own heads as well as in the imagination of their network. Informant 8, for instance, delineated. *“One has certainly heard loads of horror stories...and you picture yourself laying somewhere, throwing up for a week. (...) Somehow or other, one does have one’s prejudices”*(8). The informants experienced consistently a mismatch of the common disease conception and personal disease perception, which challenged the informants in front of other people. *“The cancer diagnosis (...) is a social stigma, indeed. You lose your hair and that is very tough. People perceive you in a whole other way”*(17). It became apparent that irrespective of personal and socially widespread notion of having cancer, the majority of informants reported that they had struggled with being physically sick in the first place. Informants described that their mental conception of illness was related to a notion of being weak, exposed and devaluated: *“Whew. I feel one is losing so much of one’s merit. Yes. I have always been so incredibly independent”* (13).

Many informants aimed to cope with the feeling of humiliation through counteraction. They described different ways in doing so: some informants wanted to prove that they still were ‘diligent’ and could keep up their normal life despite the disease. They engaged in all kinds of activities, cautious about these not relating to disease-specific issues. *“I had to do things all the time, so that I wouldn’t have to think about it. I washed all clothes in the basement...and felt...or forced myself to be on the ball”*(16). Similarly, another informant recounts: *“So it ended up with me lying in the hospital and calling in references and interviews. (...) And then the doctor entered the room, and I just said: ‘Hush, hush!’ (laughs)”* (2). Many informants reported to be overly occupied with organisation of practical things post-treatment. Female informants, for instance, engaged to a great extent in matters of fertility preservation. Many informants perceived worries about the disease’s impact on their future which most of them experienced as greatly ambivalent to their fears about death they had at the same time. One informant described such a paradox feeling after her surgery, when she found herself occupied with other issues than whether the cancer had spread or not: *“The first thing I asked (...) was whether I had an artificial anus or not.(...) They told me, they had to remove an ovary and parts of the bowel. But all I was concerned with, was the artificial anus”*(9).

Others reported that they engaged heavily in the treatment and conferred their ambitions to perform outstandingly to their role as a patient. They recounted how they got overly engaged with the treatment, ranging from ‘wanting to get through with it as fast as possible’, ‘availing oneself of every possible option’ and ‘not suffering from side-effects’. All of those informants reflected that looking at the treatment as performance, task, or a job was a way to distract themselves from fear and keep themselves occupied with the new task. Some informants decided for an opposite strategy to be able to deal with it. They proclaimed the cancer treatment period as an “exceptional condition” in which they allowed themselves to take a break from the daily tasks and their urge to perform. They regarded the exceptional condition as time-out in which they merely had to focus on themselves and getting through the disease. In order to do so, a great deal of informants felt the need to withdraw from the participation in the day-to-day life and social activities. They described how they created their own world often referred to as ‘cancer bubble’ or ‘time out’ in which they and the convalescence were in the centre of focus: *“The doctor told me: ‘The next year is going to be a null-year (...) you will just have to have focus on yourself and or convalescing. The year after, you can return [to life]’”* (2.)

Other patients, in turn, had a great need for not putting the main focus on the disease. They tried to stick to normality as much as possible: *“I didn’t want to talk about these things all the time. I wanted to do normal things and talk about normal things”*(8).

This depicts a strategy, that was experienced as helpful in coping by many throughout the disease course: ‘putting brackets around it’. This places a focus on handling the situation in that moment, and nothing else. It rendered possible to avoid frightening thoughts about future implications of the challenging event and altered the perception of it in a way that made it seem less huge and overwhelming: *“So Mum said: ‘You need to take it day-by-day. And I guess, that is what I did...and thought about nothing else (smiles)’”(17)*. Another informant described how he put this strategy into practice:

“At first, I thought. ‘Yes, I will just have to get through that surgery’. And when I was done with that, I thought about the next...(...)I focussed a lot of on what I SHOULD. (...)I KNEW that I’d have to go through a lot the upcoming eight months. But this is nothing you can handle all at once”(8).

Nevertheless, there was a common sense amongst the informants that dealing with mentally stressful issues faded into the background during the most acute phase of the treatment. The majority described having reached a point in the course of treatment at which they had such poor physical health that their main concern was to get through the treatment. These cancer patients reported a shift in focus towards the basic need to survive: "*[Losing my hair] was not nice. But at the same time I thought it's a bagatelle. There and then it felt like a bagatelle, because...I just wanted to survive.*"(8) Almost all informants concluded, that 'surviving the treatment' was the issue of highest priority and considered 'undergoing cancer treatment' at least as time and energy consuming as a full time job.

In the beginning, the worst thing for me was to be torn from my world. And all I could think about was to stay in touch with my working place, and that I just wanted to return.(...) That I wanted to return to everybody else and to normality. I didn't want to be the sick person...But now, retrospectively, that hasn't been absolutely essential. There has been...there are so many things that have changed (...) through the cancer disease..."(13).

5.3. Theme three: Meeting the health care system

In entering the new world, as described above, the health care system – respectively the hospital- played a crucial role for the informants, building the base and reference point. Yet, regardless of what kind of service the informants anticipated prior to the treatment, they universally stated that their personal expectations were not fulfilled. The informants point to a lack of information, lacking empathy by the doctors, and missing a holistic system for treatment of cancer patients, as major concerns. This is illustrated by the statement of informant 7:

"I don't think this is the way it should be. (...) For them this is the daily routine, so (...) people might get insufficient information in relation to their needs. I would've expected that it should be (snuffles)...a little more..holistic. (...) There is a missing system around cancer patients. Definitely I think it is strange that

you get more follow up if you crack your femoral neck than if you have cancer...
(7)

From the analysis it became clear that all informants shared similar experiences and perceived some additional strains in meeting the health care system. Still, the way they felt negatively impacted by the given matters and coped with it, varied broadly amongst the informants. Some informants reasoned that the issues of concern demanded for taking action in a certain way. These informants reported collectively the impression that they – as laypersons- were in charge of taking the responsibility to monitor and steer their own treatment process: *"I had to keep an eye on everything. There was nothing that worked.(...) I had the responsibility to call and to reach a doctor to get the test results from the surgery. I found that that was a strain..."* (14). In contrast, other informants describe, that they perceived to have no say in the given matter. They were overwhelmed and felt that they were helplessly exposed to the situation. Thus, some of them remained doing nothing, waiting for the situation to pass, and hoping for being saved by others, respectively: *"[The doctor] talked to me about (...) that one has to steer the process and that one has to WANT to do it. But it isn't easy. Somehow, I did not want to manage it all by myself"* (11). Some informants perceived, in a similar way, that they could not influence the problems they faced with the health care system. But rather than engaging in helpless frustration and anxiety they described how they had decided not to invest energy in things they could not change and managed to come to terms with the difficult situation and focus on positive aspects:

"Irrespective of whether the health care system works or not, (...) I take my hat off, because (...) they who worked there were so proficient. Okay, even though I didn't like to go there, I was at least in safe hands (...) which is why I am satisfied"(20).

5.4. Theme four: Coping with the impact of the treatment

A further compromising challenge the informants had to deal with was the side effects of the treatment. From the analysis it appeared that these had two major implications to cope with. One was related to the actual strains through the treatment that impacted on the physical health of the informants. The second implication of the side effects was related to visible bodily changes and psychological changes, such as mood variations. Together, these accounted for an eminent coping task the informants had to deal with: a perceived change of identity. These challenges and the informants' attempts to cope with them will be further outlined and discussed in the subsequent sub-sections.

5.4.1. Coping with the physical impact of the treatment

Many patients went through incisive bodily changes, of which 'fatigue'¹ was perceived to be the toughest challenge for the major part of the informants. Apart from struggling with the symptoms of fatigue, most of them experienced a tremendous psychological burden from it. That was to a great extent reported to be a result from a 'lack of preparation to side effects' due to the lack of information during the treatment, as previously described. Thus, most informants were not aware of the implications of fatigue and tended to relate the symptoms to personal weakness. They inferred that they 'failed' in convalescing from the treatment and suffered from the tiredness and changes in mood which they could not explain: *"It's tough, physically and mentally. (...) I have never been through something like that. It sapped all my energy. It's weird. (...) And I didn't get it. I didn't understand why I was so exhausted"* (I3[C2]).

The informants described further, how the side effects of their treatment gradually drained the strength of the informants, reducing their physiological and mental capacity to a minimum.

¹ Fatigue (also called exhaustion, tiredness, lethargy) is a common side effect of most forms of radiation therapy, chemotherapy and biotherapy. Generally, cancer-related fatigue is found to be "more severe, more distressing, and less likely to be relieved by rest" than fatigue in healthy people (National Cancer Institute, 2012).

“I have a postbox at the corner of the house. I couldn’t go there.(...)It’s a frightening experience, because (...)you’ve heard about it (...) but it’s completely different to experience yourself, how much it affects your body (...) that it gets that bad!”(14)

Another informant put it into these words: *“I stopped eating, and I stopped walking and then I just was...a vegetable in a bed”(13)*. The analysis showed that few informants found satisfying ways of coping with these circumstances. Many informants explained that they had tried to keep up their familiar daily life tasks despite physical impediment: *“I exhausted myself every time I was doing something!”(11)* They depicted how they failed to live up to these expectations and how their daily life was characterised by stressful situations and frustrating events: *“The zest for life was vanishing (...)it was empty. I have to say, that was tough”(7)*. Informants who found themselves to cope well outlined that *creating a new sense of ‘normality’ and adapting daily life to the current state of health* played a primary role in the process: *“[Before the chemo] I bought a lot of goodies, fruit and what I knew I needed. Yes, in a way, I was preparing to get ill” (8)*. They specified further that acknowledging their reduced capacity to perform in daily life and setting achievable goals strengthened their self-confidence in the situation: *“I focussed on what I COULD do (...) I thought: ‘Okay, this is just the way it is now. I can’t do anything about it anyway, (...) I’ll make the best out of it. And that worked out well.” (14)*

5.4.2. Coping with psychological impacts of the treatment

The above described compromised physical efficiency was accompanied by both cognitive and psychological changes. All informants described a lowered mental capacity, e.g. in logical thinking and focusing on a subject over time. Moreover, all informants described changes in mood and enhanced propensity to negative thinking. They recounted: *“I was mad at everyone and everybody”(13)*. Similarly, informant 9 narrates: *“Well...yes...you didn’t feel any happiness. Because I knew that: ‘Yes, the next days are going to be horrible’”(9)*. The informants reported that the way they dealt with the changes was strongly impacted by the extent to which they could understand why these changes appeared. Some informants had knowledge on body-mind mechanisms and knew that reduced physical health commonly

affects alterations in moods. They reported that the knowledge of the impact of physical changes on the psychological state helped them to cope with the situation as it, at least, facilitated an *understanding and tolerance of the physical and psychological impediments*: “*The body is changing, and the mind, too...I got the feedback that I was irritated and short-tempered. (...) I didn't want to be like this, but if the body is like it is, it just became like that!*” (20). In contrast, informants who lacked knowledge on the interrelation of physical and psychological changes and their common occurrence as side effects reported to cope badly with their state of being. To them, changes appeared as unforeseeable and as inexplicable. They stated that the actual changes were less burdensome to them, as the fact that they did not understand them. Due to the lack of preparation to side effects, most informants felt steered from unknown forces and experienced a frightening loss of control. One informant, for instance, pictured the side effects of chemotherapy as being seized with a ‘*poison-beast*’ (7). These informants stated that they lost trust in their physical and psychological processes and experienced a tremendous fear about ‘what would happen to them’ further. One informant recounts: “*I have always said that I fear the fear. And that is what I said during the whole period, that I... I'm walking around being afraid about getting afraid. I couldn't handle to go back to this stage again*” (2). Most of them perceived the alteration as an identity change and felt alienated from themselves: “*In many ways, I was not me.(...) It felt very...almost brain-washed, like a zombie to be in this...radium hospital. And then being discharged and just....no. Really, this wasn't me at all. Nothing was me*” (13).

The struggle with physical impediments and the informants’ self-perception was particularly substantiated in changes in the physical appearance of the informants. Most informants lost their hair as a result of chemotherapy or went through changes in body weight and shape. Some female informants had their breast removed in addition. These bodily alterations were crucial to the informants in different ways: firstly, changes in the informants’ aesthetic appeal added to the above mentioned notion of identity change and self-alienation: “*When I saw myself in the mirror (...) ...no, that wasn't me*” (7). This resulted often in a decreased self-esteem and struggles with self-acceptance: “*It was tough to see yourself in the mirror. Kind of pink pig-face with thin hair on the head. That was tough*” (16). Secondly, the changes in their looks mirrored to them that they were undergoing the transition from the

“healthy person” to the “cancer patients”, with which none of them could identify initially. The resulting identity conflict was reinforced by the fact that they now were unavoidably exposed to the social stigma, as described in the earlier section: *“It was not only, that I lost my hair, but my eyebrows and eyelashes were ragged, too. Yes, so I felt that ‘cancer patient’ was written on my forehead... That you are sick. That was the worst thing.”*(12). The informants described different reactions to these changes. It turned out that these varied in accordance to the meaning they attached to them. Most informants were less concerned about the hair as such but rather perceived losing the hair as symbol for the transition they went through. Those informants described that the strains and uncertainties of going through the transition as worse than the actual end result. To cope with the change and the transition they went through, most of the informants took a radical decision and shaved their heads immediately. They pictured a notion of relief through steering the process themselves. A few, in turn, were less concerned with the uncertainty of the process of change, than with the fear of the result. To them there was meaning attached to their hair, which depicted a significant part of their identity. They equated the loss of hair with losing a part of themselves and feared to be separated from their old world even more through that.

“If you are young women, your hair is part of your identity.(...) It is something about how you feel as a woman. And it might be the period, in which you find a partner, and this something you just have to withdraw from (cries)”(17).

Thus, these informants faced the matter with avoidance and to prevent the loss of hair as long as possible. Still, informants who did not accept their changes describe that they were “stuck” in transition, which hindered them in moving on in the long run: *“I don’t know, I just held on to what was left. I looked like a loaf...you know, with one hair here, and one hair there (laughs). That was like neither fish nor fowl”*(18).

Informants who experienced the mildest strains from the apparent physical changes and perceived themselves as coping well with the situation were those, who succeeded in detaching themselves from meanings physical changes and the bodily appearance could bring along. They described that they tried to face the facts as given, and nothing else. Thus, they described a rather relaxed attitude towards, for example, the loss of hair: *“No problem! I*

received lots of dinky dressy hats.(...) If I have cancer, then I have cancer. If I lose my hair, then I lose my hair“(20).

5.5. Theme five: The role of social support

The foregoing sections illustrated that being diagnosed with cancer, inter alia, brought along the challenge of embodying disease entities. Apart from difficulties with personal acceptance of the patient role, some informants equally reported to struggle with being dependent on the help of others: *“You know, it is just difficult, because I have been the one who liked to support people, so I have never managed to be the one who just...the one who needs help or...Very difficult!” (11).* The informants’ experience of dependency on the help of other people appeared to play a significant role during the course of disease. Many informants feared an identity change and losing their social role within their network. The common experience was that the informants’ network had great difficulties in dealing with the situation, which partly resulted in either insufficient support for the informants or in the network requiring support themselves. The experienced reactions from the network ranged from trivialising the disease to developing psychological problems: *“My father’s two sisters had to go to the doctor to get sleeping pills”(10)* or somatic diseases as a reaction to the diagnosis: *“My husband developed ulcerative colitis after that, because he worried so much”(9).* Other informants even experienced how parts of the network broke ties with them as a reaction to the diagnosis: *“I said, that I had cancer. And he asks me: ‘Why are you telling me this?’”(18).* As a result, to knowingly put strain on their loved ones made it extremely difficult for the informants to share both information and feelings they needed to talk about:

“I had a big need for talking, but I had to spare my friends a little. And that was what I perceived as hard at times. (...) I could figure that it got too much for them in total. So at times, we had less contact, because it has been too hard for them. To hear: ‘ Yes, I am doing as badly as usual’”(17).

Thus, many informants described *ambivalent feelings* towards their social network and the social support they received. *“Maybe this is why I got afraid, because there was this huge gap between what I WANTED to be...and how I felt” (2).* Moreover, even when opening up to

close persons most of the informants made the experience that they were left alone with their emotional emergency as the network did not know how to support them in dealing with it. The informants perceived that the network's helpless attempts to support most often resulted in belittlement, pitying and 'positive talk'. *"Everybody pitied me, because I was ill and my daughter was just one and a half years old, right? (...) Always: 'poor little you.' I am so sick of it"*(2). At the same time as being pitied, informants made the ambivalent experience of not being 'allowed' to feel bad because of the disease. They perceived that their feelings were not accepted and that a positive attitude was expected.

"They should have met me where I was and listened to how miserable it is, instead of coming with counterarguments like: 'Yes, but you can get a breast prosthesis', 'It can be a good thing', 'it can be this, it can be that'. I want to be listened to and I want acknowledgement for my feelings in this situation"(16).

Several informants described a double burden through this situation. Many informants stated that, instead of "just" being afflicted with a physically and psychologically challenging disease and thus in need of being taken care of and guided, they would in reality find themselves to be "the expert" in addition, having to act as mentors and guides for their network. *"It is difficult...they want to support you, but they don't know what they have to do. And I don't know what I want them to do either,(...) so...what are you actually doing then? (laughs)"*(8). Most informants found it helpful to *engage into an open dialogue* with their close network, in which they explained their feelings and needs to get a better understanding: *"I have some close and dear friends who KNOW how it really IS. Because we have a really good dialogue about it"*(12). Also, some informants found the use of humour spirit-lightening and securing when involving the network into sensitive issues: *"Yes, the thing with the breast removal and the hair, we talked about it... [My children] find it funny with the breast prosthesis, because they stick it to the middle of my stomach. It's admirable!"* (16). In turn, most of the informants who used humour to cope with the situation reported to having made excessive use of humour to ignore the severity of the situation. They also stated that this inevitably brought along a major emotional throwback at a later point of time: *"I barely talked about it, but I joked around a lot and used a lot of humour. And this is what I struggle with now. Now I get sad very often..."*(2). Informants who experienced helpful support and

getting along with their network were those who were incorporating the disease into life and aimed at creating a new normality together. Informant 2, for instance, exemplifies how arrangements and the involvement of both her husband and her friend helped her to get through the treatment: *“My husband put the TV in the bedroom (...) I could stay in there one week, without showering or doing anything. That was in a way okay. But I had a limit (...) I thought, I cannot exceed that”*(2). She narrates further, how she, if necessary, involved friends to help her stick to the arrangements all parties involved had made together:

”I had an arrangement with a very good friend...because I was so afraid to give up. (...) When I realised I couldn't bother to get up, I wrote her a text-message. (...) On a Monday, for instance, I wrote to her: ‘I'll call you on Wednesday. If not, you have to come here’. So she knew, what was going on, and I had the opportunity to give myself a little time” (2).

Informants who were engaged in a relationship described how their partners' acceptance of the changes supported them in finding their peace with it, too. They often experienced social support from the partner as a facilitating factor to cope with the matter. Informant 8, for instance, describes, that she felt surprisingly little affected by the breast removal she had gone through.

“I think it would have been worse if I'd been single. But I am in a solid relationship and felt confident. (...) I thought kind of. 'Yeah, yeah, it is just a period and then I'll get a new one. (...) There are other things that matter more”(8).

This quote exemplifies further a major strategy that the informants perceived as helpful: 'putting things into a greater perspective' was a strategy that many informants described as helpful to adaptive coping in various situations. They perceived that the enormity of the situation could be modified by picturing its significance in the long run or in comparison to other (worse) things.

“It helped me to think, that it could have been worse. It could have been worse if it was one of my children who would have become ill. THAT was the ONLY solace I had to get back to. (...)even if it was cruel that I had it” (16).

5.6. Summary of the findings

All informants described that in the moment of the first encounter with the disease a whole new world with a multitude of unforeseen facets of cancer unfolded in front of them. The analysis of the informants’ description brought into light that the perceived coping tasks were embedded in a complex web, which embraced various entities of coping. The informants’ experience of engaging in the complex web of coping tasks is depicted in Figure 2. The figure illustrates that coping tasks the informants experienced were interrelated and had several subtopics. The main topic identified were: 1) coping with the diagnosis, 2) living with cancer 3) meeting the health care system 4) coping with the impact of the treatment and 5) the role of social support. It illustrates, that despite different experiences and diverging tasks, all informants reported a common trait of the remits: coping with on-going or upcoming changes in their lives. These changes could be attributed to two domains: on the one hand, they sensed changes to their future plans, outlook or perspectives. On the other hand, they experienced changes in their self-perception and sense of their identity. This could, amongst others, include mood variations, reduced physical or mental capacity as well as changes in their physical appearance, needs, and attitudes. In addition, changes in their social relations, such as being treated differently or rejected by the network, accounted for an altered self-perception, which some informants described as alienating. Despite the encounter with cancer entailing a diversification of coping tasks, all informants depicted, how – like a rhombus- the broad range of tasks finally narrowed down to *dealing with uncertainty*.

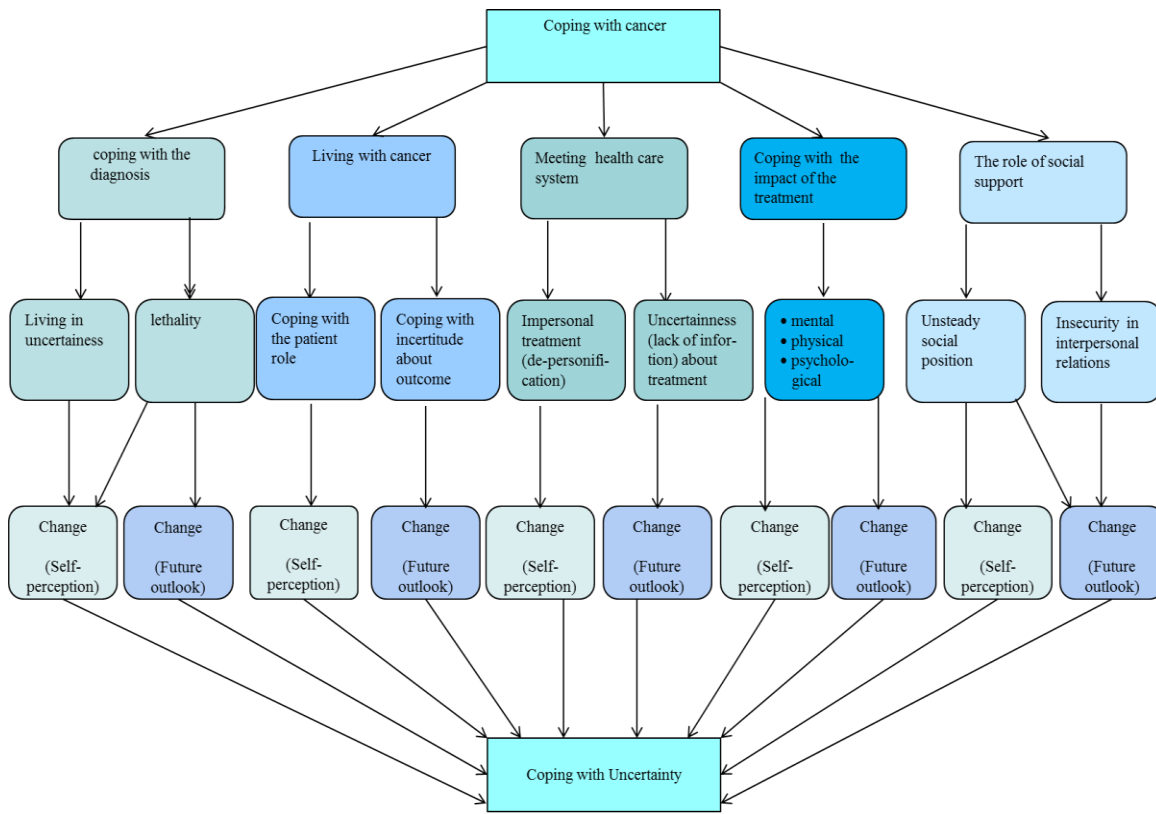


Figure 2: Web of coping tasks in the encounter with cancer. Relations are indicated through uniform colours.

The findings showed further that even though there appeared common themes that accounted for overarching challenges of young adult cancer coping, *the ways* these were perceived and *the extent* to which YACPs felt impacted varied broadly. Similarly, the foregoing finding have presented that coping with cancer could take place in various ways. Rather than illuminating coping ways and coping strategies which applied to all informants or which might have been consistently perceived as especially helpful to one particular challenge, the findings at hand make clear that coping is an individual matter to each of the informants and differs from individual to individual.

6. Discussion:

The rationale of the present study was to explore YACPs cancer-coping experiences. Within the last chapter, the overall picture has been presented as it emerged from the informants' narrations. In the present chapter the results will be assessed and their indications will be discussed, followed by a discussion of the methodological procedure applied to explore the research questions and the validity of the findings.

In summary, the analysis of the informants' narrations on coping with cancer illustrates that coping with cancer is a phenomenon encompassing various multiple facets. The tasks imposed on the informants through cancer exceeded coping with 'merely' the disease or the impact of treatment and affected the individual also in its wider social context. The main findings were that experience of the kinds of coping challenges differed amongst the individuals. Still, the findings showed a common feature: dealing with uncertainty.

These main findings will be discussed in the following under consideration of the theoretical background of the study; the TMS by Richard S. Lazarus and Folkman (1984) and the concepts of Salutogenesis and the SOC by Antonovsky (1987).

6.1. Challenges in cancer coping: being a young adult- a reinforcing factor?

The preceding sections have illustrated that the informants of the study perceived specific challenges as particularly demanding tasks to cope with in relation to the diagnosis, living with cancer, the health care system, the impact of the treatment and the role of social support. The findings from the analysis indicate that informants most often regarded these challenges in direct or indirect relation to their age and life situation. This was particularly reflected in the informant's narrations on the meaning of receiving a diagnosis at this early life stage, its impact on their relation to the social network, which to a great extent consisted of peers, and the informants' fear of the disease's implications on their future plans. All in all, this gives rise to the assumption that being a young adult might be regarded as a multiplier to challenges that cancer patients of all age groups meet. The exploration of the evidence base on YACPs coping challenges supports the findings and their indications in various ways.

The multi-faceted picture that the analysis brought to light is reinforced by research investigations in the field: to the current day there exists a homogenous evidence base,

indicating that young adult cancer challenges embrace multitudes of themes. Studies point out that challenges comprise concerns related to diagnosis and treatment, financial concerns and the health care system, health and somatic complaints, isolation from peers and impacts on social relations (Corbeil et al., 2009; Ettinger & Heiney, 1993; Cleora S. Roberts et al., 1997; Zeltzer, 1993).

The relevance of the given themes identified within the present study is supported by similar findings by further studies in which cancer-coping experiences were addressed. Investigations by Drageset and colleagues, for instance, emphasise “coping with the diagnosis” as a distinct challenge of the cancer-coping process (Drageset et al., 2012; Drageset & Lindstrøm, 2003; Drageset, Lindstrøm, & Underlid, 2010). Further investigations highlight the unique role of coping in newly diagnosed cancer patients, indicating its predictive function to coping in later stages of the treatment process (Degner, 2003; Jadouille, 2006; Schou, 2005). While these findings were predominantly found in cancer patients who were older than informants of this study, earlier research strengthening the relevance of the last four themes also highlighted the additional impact of “being a young adult cancer patient” on the identified challenges.

The discerning theme “living with cancer” is discussed by several studies on the psychosocial implications of cancer treatment and side effects in young adults. (Bleyer & Barr, 2009; Coccia et al., 2012; Felder-Puig et al., 1998; Hall et al., 2010; Kent et al., 2012; Cleora S. Roberts et al., 1997; Zebrack et al., 2010). Studies by Kent et al. (2012) and Brad Zebrack et al. (2010), for instance, brought into light that specific coping tasks of “living with cancer” could be assigned to age-specific psychosocial concerns, such as financial burdens and the matters of identity, growth and development of young adults at this stage in life.

Furthermore, the findings of the present study- indicating that “meeting the health care system” is an important challenge - have been identified as issues of concern in some research investigations on young adult cancer care (Albritton et al., 2006; Bleyer, 2007; Coccia et al., 2012; Keegan et al., 2012; Zebrack et al., 2006; Zebrack et al., 2007). A wide reaching observational cohort study, aimed to investigate the health care needs of 530 Adolescent and YACPs, illustrated that participants had to deal with unmet information needs, missing financial advice and a lack of professional emotional support with regard to

the healthcare system (Albritton et al., 2006). Here, too, the specific age and life-stage of YACPs was shown to be a reinforcing factor to the challenges in comparison to other patient age groups. It was found that neither health care provision for childhood cancer, nor for adult cancer would cover the needs of YACP sufficiently (Coccia et al., 2012)

The present study broached “impact of the treatment” as another significant challenge to cope with for YACPs. Similar findings have emerged in previous studies, emphasising both the burden that side effects of the treatment impose on YACPs as well as their need for assistance in managing disease and treatment effects (Albritton et al., 2006; Coccia et al., 2012; B. Zebrack et al., 2006; Brad Zebrack et al., 2010; B. J. Zebrack et al., 2007). These investigations accentuate that undergoing treatment is specifically challenging for YACPs as they are exposed to harder treatment procedures due to higher physical resilience than younger and older patients. Moreover, possible negative implications of the treatment, such as impeded reproductive capacity, imposing more impacting strains on them as compared to other age groups (Coccia et al., 2012).

Eventually, findings of the present study shed light on the particular “role of social support”, demonstrating that the social network could both support coping as well as impose additional strains on the YACPs. Still, regardless of whether the social network was perceived as supportive or straining, the analysis revealed that social support was an issue of great significance to YACPs. The topic of social support as a coping challenge is confirmed by other studies assessing the psychosocial needs within this age group. Here, disruption of the transitional period young adults usually go through placed an additional burden on the patients. Separation from peers, insecurity with regard to the own social identity and position in the network, as well as lacking understanding from peers of the same age were issues of importance (Archie Bleyer, 2007; D'Agostino et al., 2011; Elad et al., 2003; Hall et al., 2010; Kyngäs et al., 2001; C. S. Roberts et al., 1997).

6.1.1. Coping with uncertainty: a Socratic paradox

The findings of the given study depicted the patients' experience that each arena of their life seemed to be affected by the cancer diagnosis and treatment and became issue to change. That was a given fact for their physical, psychological, social and financial state of

being. Applied to the young adult cancer patients [C3], the famous saying by Socrates “I know one thing- that I know nothing” seemed to express their situation in a nutshell. The informants described further that nothing stayed the way it was before the disease. They narrated how their disease brought along change in each of their life domains and exposed them to a great deal of insecurity. This supports the claim that – as illustrated in the earlier presented Figure 2 - the coping challenges named in the foregoing sections eventually come down to one predominant matter: dealing with uncertainty.

Dealing with uncertainty was a challenge accompanying the cancer patients throughout the treatment. Most of them verbalised having to change their life plans because of this life-turning event. Strikingly, the majority of the informants were confident about their general capability to adapt to a new situation in case of an unforeseeable life event – given that they knew what to expect from the new situation. The informants pointed out that this feature was not given in the encounter with the disease, which posed the actual problem to most of them, much more so than the fact that changes appeared at all. The constant though unforeseeable change turned out to be a matter raised as important to YACPs in other studies as well (Corbeil et al., 2009; Kyngäs et al., 2001).

Corbeil et al. (2009) further support the finding of the given study that uncertainty is related to different life arenas, and challenging topics, respectively. They assessed types of uncertainty, which they allocated to treatment aspects, future life plans and personal matters. This is further supported by several studies identifying different psychosocial challenges in the cancer patient’s life. The corresponding investigations point out that several particular issues to cope with could be allocated to broader groups, and that “uncertainty” is an overarching matter to cope with (Decker et al., 2007; Elad et al., 2003; Manuel et al., 2007; Novakovic et al., 1996; B. Zebrack et al., 2006; B. J. Zebrack et al., 2007).

These implications of the findings can be substantiated through the application of the framework of the present study: within the TMSC by Richard S. Lazarus and Folkman (1984), stressful events are regarded as a situation, in which a mismatch between demands of an event and the perceived ability to cope with it prevails. Unpredictability and incomprehensibility of a given life event is a potential source for stress in individuals (Padilla, Mishel, & Grant, 1992). In the case of YAC, this circumstance is present throughout the

disease: As the informants do not know what the situation demands from them, they struggle accordingly with evaluating what resources are needed to cope and whether or not they could mobilise these. A literature review by Mast (1995) of scientific data on uncertainty in life-threatening illnesses and treatment corroborates this claim: it illustrated that uncertainty was a constantly stressful concomitant of illness and treatment, which had significant influences on the patients' coping responses. The findings of the present study align with the results of Mast (1995) despite the shared experience of YAC-related uncertainty, the analysis of the interviews also revealed that the YACPs met and coped with the aforementioned challenges in divergent ways.

6.2. How do YACPs cope?

As depicted in earlier sections, the informants' perception uncertainty and coping tasks differed to a great extent. Moreover, it became apparent that even if informants mentioned the same issue, some seemed to be more affected by a certain coping task than others - for instance by the severity of the side effects of the treatment, or problems with social support or the health care system. The way how YACPs cope will in the following be discussed with regard to the overarching challenge of uncertainty.

6.2.1. The role of appraisal in coping with young adult cancer

In the case of uncertainty, an explanation for the given differences in the informants' reaction to it can be drawn from the theoretical framework of the study: the analysis revealed that the encounter with the disease encompassed a broad range of reactions throughout the informants: The informants described fear, denial, distancing, pragmatism, acceptance or optimism, amongst other aspects, as a response to the diagnosis. Similar findings have been obtained within other studies on coping with cancer (Carver et al., 1993; Sigrunn Drageset et al., 2010; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992, p. 80; Li & Lambert, 2007; Stanton & Snider, 1993). From the perspective on coping as a transactional process, these variations can be explained with regard to the primary appraisal of the situation. The primary appraisal includes an individual's reflection of: "what is at stake?". The conclusions from these reflections are mostly subjective and vary from person to person in accordance with features that they personally perceive as meaningful. For most informants the apprehension of

the disease went beyond perceiving it as life or health threat but included the consideration of its impact to other meaningful factors in life. For instance, informants who had children immediately regarded the disease as a threat to their family and to some extent set aside worries about consequences to their own life and health. Similar results have been found by Gotay (1984), who found that fear of the future of the family was a dominating issue in cancer-coping, which in some cancer patients could override the fear of being ill or the confrontation with death. The study demonstrated that differences in disease appraisal or/and?fears, respectively, accounted for diverging perceived coping tasks that were more or less achievable. For instance, fear of death was found to be a task which could be coped with less effectively than, for instance, coping with preparing the family to be independent. Importantly, the majority of informants in the present study did not have an own family to take care of yet. They, in turn, were likely to appraise the disease in terms of its impact on their on their fertility, thereby their ability to start a family, job situations or studies, as well as on several types of future plans. Earlier research supports these findings, outlining that YACPs' appraise cancer as a threat to career development, education and employment and family planning. These elements were identified as high priority areas in YACPs' health care needs, indicating that health care providers need to target these specific issues of concern during YACP treatment (B. Zebrack et al., 2006). These findings show that the same stressor - in this case the cancer disease- does not appear the same way to different individuals. This gives some valuable indications to the primary appraisal of the situation, and how diverging focal points influence perceived coping tasks, as displayed in the TMSC of Lazarus and Folkman (1984).

In the present study, some informants reflected on their own appraisal – both primary and secondary- of the disease. Those who did were likely to report having actively sought to alter the focus in order to make the coping tasks more comprehensible and less overwhelming. They described appraising the positive things in life, comparing it to worse, putting the things into a bigger perspective, and putting brackets around it as helpful strategies to cope and to re-appraise the situation. The latter strategy comprised taking the situation out of its context and focus on tasks on a day to day basis- for instance the procedure of chemotherapy- rather than regarding the complete situation and focussing on and fearing future implications. This

strategy contrasts the former strategy of putting things into a bigger perspective, which was seen as helpful as the perceived impact of coping tasks of the moment could be moderated with regard to their actual meaning in the long run. Despite some contradictions, some informants reported having applied several of these strategies to cope as their overarching function affected similar outcomes: a) dealing with the present fear or b) re-appraising the threat of cancer. These strategies have been defined in existing studies although they might have been termed differently. Gotay (1984, p. 609), for instance, points out taking positive effect coping from ‘finding something favourable about the situation[K4]’. Drageset et al. (2010, p. 152) define ‘step by step’ as helpful coping strategy, while studies by Sears, Stanton, and Danoff-Burg (2003) and Manuel et al. (2007) point to positive effects from benefit finding and positive re-appraisal coping. In this project, some informants reported having undertaken own re-thinking the situation on both fear and coping, which they perceived as having a positive effect. These findings are implying that certain ways of appraisal might be ‘taught’ to the patients to support them with coping during the treatment. This assumption is supported by the theoretical pillars of the SOC, in which coping is conceptualised as a learning process during the life course (Franke, 1997). Equally, Carlick and Biley (2004) underpin this indication within their studies, highlighting the importance of re-appraisal and urging nurses to incorporate supportive approaches into their practice. The TMSC provides a solid account to explain and understand the differences to which the informants appraised the situations or coping task they encountered during the disease. The individual’s consideration of the question “What is at stake?” has shown to play a particularly important role on cancer patients’ coping (Dunkel-Schetter et al., 1992).

Anyhow, parts of the findings of the given study contradict the TMSC to some extent: The TMSC theory prerequisites, that the individual’s appraisal of the situation and own coping resources, that account for coping, cohere with the reality. That assumption does not consider the possibility to misevaluate the situation or own resources. Still, that was a problem identified for YACP-coping in the study at hand: For instance, did some informants report, that they assessed their own resources as sufficient to deal emotionally with the situation. In the course of the treatment, it turned out, that they were not capable of doing so e.g. because of fatigue. Most informants, anyhow, were not informed about fatigue, and did therefore not re-evaluate or adapt their attempts to cope. They stuck to the evaluation,

despite the mismatch of own resources and needs or the self-perception and reality. This misconception of the circumstances and the resources hampered them in achieving positive coping outcomes, but did not, in contradiction to the TMSC, effectuate a re-appraisal.

This gives indications to, that coping attempts and coping outcomes are not merely issue to personal appraisal, as sketched in the TMSC. It rather points out, that additional considerations must be made when reflecting upon coping processes in YACPs. That implicate, that YACPs have a need for support in appraising the situation realistically -for instance through the provision of treatment-specific information - care is indicated, in order to facilitate instrumental and emotional coping for the informants.

6.2.2. YACPs and the sense of coherence

Further, the analysis also brought to light that informants who narrated similar ways of appraising the situation, for instance from a student perspective or those who had their families in mind, still reacted in a different manner. This is exemplified in the different ways patients reacted to their prognosis. Here, the analysis showed clearly, that informants who reported having received similar statistical survival odds (= what is at stake?) reacted with great differences, and vice versa. Those findings have also been brought out in earlier research: Dunkel-Schetter et al. (1992, p. 80) highlight the importance of the primary appraisal, stressing that “the cancer patient’s perception of the degree of current stress should influence how he or she is coping at least as much as medical condition”.

Still, there remains the question of why the reactions to similar appraisals differ to the extent found in the present research. The application of the TMSC to YACPs situation would offer the explanation that differences in the informants’ secondary appraisal account for these diverging reactions. Still, analysis has shown that YACPs’ evaluation on own resources corresponded to each other to a great extent. This has been shown in earlier studies as well: due to their unique life stage YACPs shared a common sense of uncertainty and a lack of judgement on what particular resources would be needed and whether or not they would be capable of enacting these (Kynge et al., 2001). Thus, there seem to be further factors to consider when attempting to understand motivations to different appraisal and coping

methods. The theoretical pillars of the SOC proposed by Aaron Antonovsky (1987) can serve to supply the TMSC, which provides explanations for differences in the separate primary and secondary appraisals. The SOC, in turn, may provide an account for why the overall appraisal of YACPs differ, even if some informants' primary and secondary appraisals on issues and resources at stake were similar for some informants. Within this conceptualisation, the SOC of a person accounts for the degree to which an individual perceives an event as structured, predictable and explicable and could thereby be regarded as 'moderator of stress' (Antonovsky, 1987, 1993). In terms of this study this would mean that a strong SOC can provide the informants with the 'skills' to make sense of the cancer disease and the related uncertainty, along with the confidence of getting through this phase. As a consequence, cancer, cancer-related uncertainty and similar cancer-related specific challenges can be perceived as less dreadful from informants with a strong SOC than from informants with a rather weak SOC.

This conclusion gives rise to additional implications to understanding the specific vulnerable situation of YACPs: firstly, the conceptualisation implies that a strong SOC builds upon earlier coping and life experience of individuals. Generally, the SOC is known to increase with age (Eriksson & Lindström, 2005) Considering the relatively young age of the informants it can be reasoned that most of them have yet not been able to build a strong SOC throughout the life course, as might be the case in older cancer patients. Thus, age-specific conditions account for a particular need for coping support in YACP (Kyngäs et al., 2001). Vice versa, the concept of SOC raises the issue of long-term implications of the cancer disease to the informants: assuming that positive and negative life and coping experiences add to each other and account for the strength or weakness of the SOC, it could be concluded that such a shattering event as a cancer disease contributes to an eminent weakening of the informants' SOC. Thus, negative long-term consequences for future appraisal and coping with stressful events would be implicated. Current literature on young adult cancer survivors provide ambiguous accounts of this: on the one hand, studies on young adult cancer survivors' psychosocial challenges and health care needs bring to light that young adult cancer survivors experience higher levels of stress and psychosocial problems, lower quality of life, more anxiety and lower levels of social functioning than healthy peers or in comparison to older cancer survivors (Archie Bleyer, 2007; D'Agostino et al., 2011; Hall et

al., 2010; Kent et al., 2012; B. J. Zebrack et al., 2007). On the other hand, studies indicate that having overcome difficult experiences, such as a cancer disease, would raise awareness of positive aspects of cancer, strengthen attitudes such as hope or the engagement in positive cognitive restructuring and increase the desire to fight for live, the quality of life and coping in cancer patients (Kyngäs et al., 2001; Manuel et al., 2007; Novakovic et al., 1996; Rittenberg, 1995; Rustøen, 1995). Thus, the actual implications of SOC and uncertainty for future stress appraisal in cancer patients have not yet been clearly answered. Still, the findings of the present study reinforce the given implications for the particular need of coping support of YACPs during the treatment, even though both coping skills and needs for support vary (Kyngäs et al., 2001).

6.2.3. Facets of coping

After having outlined in the previous section what the informants perceived as coping challenges in young adult cancer and how appraisal accounted for their experience, the focus of the discussion in the following section will be placed on how the cancer patients cope with disease-related challenges. The assessment of the informants' accounts on coping brought about the suggestion to differentiate/clarify the application of the term 'coping' in YACPs. Analysis revealed that the informants engaged in coping in different ways and by using different tools. Firstly, the analysis indicates three different manners in which informants engaged in coping: non-coping, instrumental coping and emotional coping. These manners are referred to as coping styles in the following. Secondly, coping can be regarded in terms of the specific moves [K5] the informants used to perform a certain coping style. These measures will be referred to as coping strategies. The suggestion drawn from the analysis - to distinguish coping in terms of three coping styles and various coping strategies - can be substantiated by the theoretical framework of the given study. The TMSC by Lazarus and Folkman (1984) incorporates both the component of emotional and instrumental coping, which is labelled as 'coping efforts' and corresponds to what is termed 'coping styles' in the present study. Furthermore, the researchers describe different "forms of coping" (Folkman, Lazarus, Gruen, & DeLongis, 1986, p. 572)- i.e. efforts to alter the situation, which is consistent with the application of the term 'coping strategies' in the present research

investigation. Such a differentiation is applied in several other investigations on coping, although the exact termination or concrete definitions might vary slightly (e.g. Carver, Scheier, & Weintraub, 1989; Ettinger & Heiney, 1993; Folkman et al., 1987; Gibson & Parker, 2003; Pallant & Lae, 2002)

The findings of the present study showed, that *non coping* was a strategy, many informants engaged in, particularly at the beginning of the disease course. For some informants did the fact that they faced a problem which they could not solve, lead the to completely discard the problem as an issue to deal with. For instance, one informant went on holiday in order not to face the facts, while other informants - although acknowledging the diagnosis - ignored the impact of the disease, and, for instance, continued working even from their hospital beds. Several informants highlighted that they - although adhering to the treatment - refused any confrontation with the disease apart from that. They applied strategies like strict avoidance of information, refusal to talk about it and, for that purpose, a meticulous refusal to encounter healthy peers and fellow patients. Informants who acted in this manner described that they were incapable of getting in touch with any feelings or fears about the disease, as this would have been too overwhelming a matter. They reasoned that ignoring the confrontation with the facts was the best way for them to control their feelings in the situation. Shielding themselves in various ways was an important feature to serve this aim. These and similar strategies were identified in other research as well (Kreitler, 1999; Rabinowitz & Peirson, 2006; Vos et al., 2007). At first sight these kinds of strategies could depict informants as not coping with the situation at all. However, rather than marking such attitudes as 'not coping', the results of the analysis denote an inclusion of this behaviour as a particular 'non-coping' strategy. The TMSC by Richard S. Lazarus and Folkman (1984) underpins that proposition. Within it, coping has two major functions: dealing with the problem, causing the stress on the one hand, and regulating the emotion that is generated through the problem. Informants who described attitudes such as ignorance, avoidance or escape similarly delineated that they had put much effort in holding up the behaviour. Furthermore, they reflected retrospectively that they felt incapable of dealing with the facts and related emotions to the given point of time. Thus, both the invested effort in as well as the function of the behaviour - protecting the informant from overwhelming feelings - define the

informants' descriptions of not-coping as actual coping under the given circumstances. This reasoning is further supported by Carver et al. (1989), who, in the context of three main studies, developed and assessed a multidimensional coping inventory of individuals' ways to respond to stress. They point out, that restraint is a coping strategy which is often overlooked or regarded as maladaptive. They conclude their investigation, amongst others, with the claim that 'not acting' can be an active and functional response to stress, and be used as a coping strategy through which an individual's behaviour is focused on dealing in the most effective way with a given stressor. This has particularly been discussed in the light of cancer coping (Rabinowitz & Peirson, 2006). Accordingly, Richard S. Lazarus (1993a) reasons that cancer patients' coping strategies depend on the context in which the disease occurs, the patient's state of mind and the adaptional significance. Hence, in some situations, ruminating thoughts about a situation which exceeds the patient's influence, might be avoided in favour of well-adaptive coping.

Another facet of coping, that was shown within the analysis was *instrumental coping*. Informants who coped instrumentally, reported that taking an active position in the process as helpful. That was applied to those informants who engaged in instrumental coping. Those informants expressed that their way to get through this phase in life was to focus on practical tasks. In contrast to non-coping informants, these activities were mostly related to the treatment in a certain way. Thus, rather than 'non-coping' informants, who first and foremost attempted to control the fear by ignoring the facts, instrumentally coping informants were concerned with controlling the situation. They described that involving themselves in everyday activities and steering the situation helped to control the fear in an indirect way. This included, amongst others, organising delegation of job tasks in working life, participation in setting up their treatment agenda and organising matters related to the post-treatment period and future perspectives. For all informants concerned this involved great organisational and administrative missions, which involved recruiting specialists, making appointments and traveling to relevant examinations. This way they managed to deal with the reality while not being overwhelmed by feelings. These findings are echoed by findings in research by Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, and Till (1989), who emphasise what in the presents study is termed 'taking an active position' in terms of active

patient participation during treatment. The specific role of gathering information has been emphasised in several studies on cancer coping: earlier research points out missing information from the health care system as a negative factor during the treatment, on the one hand (Hall et al., 2010; Keegan et al., 2012; B. Zebrack et al., 2006; B. J. Zebrack et al., 2007). Conversely, gathering information has been identified as a specific coping strategy which relieves anxiety, supports adaptive coping and the feeling of autonomy and control (Luker et al., 1995; Sutherland et al., 1989; Teasdale, 1993). The incorporation of instrumental coping into clinical practice through active patient participation and information is a possible method to support cancer patients in well-adaptive coping. (Sutherland et al., 1989).

In the present study, a variation was shown in the way the informants admitted to instrumental coping: some informants reduced their instrumental coping activity to the possible minimum, taking an emotionally neutral position. They reported to be goal-oriented - they gathered and related to information about their treatment and kept their focus on taking the prevailing step of the treatment plan. If necessary they also engaged in organising the treatment and eliminating hindering factors emerging during the treatment process. Other informants who coped instrumentally, in turn, stretched their active participation in the process to the possible maximum. In contrast to the rather neutral patients/peers, they engaged emotionally with the instrumental coping activity. They worked towards a goal which had meaning to them, for instance to organise that the family is being taken care of or safeguard future perspectives. According to these informants, reaching a goal gave them the feeling of mastery. Many of them who involved themselves emotionally to their instrumental tasks perceived the engagement most often as a 'fight' against an external opponent, for instance the health care system. This phenomenon has been termed "fighting spirit" in earlier research (Classen, Koopman, Angell, & Spiegel, 1996; Moorey, Greer, Bliss, & Law, 1998). Explanations can be contemplated under considerations of the SOC, which points to the need for meaningfulness for coping (Antonovsky, 1987). Similarly, Carlick and Biley (2004) found that establishing meaning was regarded as helpful in coping with cancer. Still, a considerable number of informants who involved themselves with instrumental coping avoided dealing with their feelings in the situation. Notably, all informants stated that 'non-coping or 'instrumental coping' had a negative impact on their well-being in the long run. Each of them

underlined the importance of emotional processing of the fears in the retrospective, which is highlighted in earlier research as well (Carver et al., 1993; Carver et al., 1989; Novakovic et al., 1996). Findings of Novakovic et al. (1996) illustrated that the most frequent advice from young cancer patients of their study cohort to newly diagnosed patients would be to deal with emotional aspects of the disease.

Analysis revealed, that *emotional coping* was scarce amongst the informants. Only few informants evaluated their emotional adaption as satisfying or as having contributed to processing the treatment and the related challenges and emotional strains. They reported a need for psychological support and that the health care system lacked the corresponding supply of professional tutoring during treatment or a responsible entity to approach. Thus, most informants had to rely on own skills to cope emotionally and, if given, on social support from the network.

Social support by the network, in turn, emerged from analysis, that 'turned out to be a mixed blessing in coping with the disease. Many informants described a surprising twist in perception of earlier appraised support. Especially those informants who pictured coming from a tight and supportive network prior to the disease, perceived less hold and greater difficulties in communication, than those informants that described themselves as being alone. Analyses revealed further, that the reason for that was associated with the change in both lifestyle and personality which informants underwent during the disease course. The informants described that the alteration of personal needs, as well as mental and physical limitations due to side-effects of the treatment made it impossible for them to proceed as normally and keep up the social role they had taken prior to the disease. For some informants, the disruption of the habitual way of interaction with the network entailed severe instability in their social relations, and brought along challenges due to a mutual mismatch of expectations and reality. These informants underlined that the insecurity attached to the cancer diagnosis brought along a two-edged challenge: dealing with the incalculability of the disease as such on the one hand, as well as perceiving insecurity and a disarray of the social order. Further, the informants reported that the challenges of re-organising the social construction of the network amplified their overall quest for identity. This was found to be fortified through stigmatisation as a cancer patient and a mismatch of expectations from and to the network and

the reality. Several informants described having experienced both problems in the course of the disease. Earlier research has shown, that the assignment of avoidance behaviour and stigma towards cancer patients is a recurring topic within the social network- cancer patient relation (Peters-Golden, 1982). In relation to the perceived stigmatisation, the informant of the present study narrated feeling alienated from their social network. They experienced a lack of communication and social withdrawal from acquaintances or relatives, who seemed to be overstrained with the situation. Social withdrawal has been found to be a challenge to cancer patients within further research from Wortman and Dunkel-Schetter (1979) who outlined that a lack of communication tends to bring forward attitudes and behaviours in the social network, that cancer patient's perceive as inappropriate or not helpful. The findings of the given study have further shown that the cancer diagnosis posed a coping challenge to the closer environment, just as much as to the informants themselves. This can be further substantiated when incorporating the theory of SOC. In earlier sections, a possible relation between being a YACP and the SOC has been discussed. The inference can be drawn, that cancer affects the networks SOC as well. Indeed, Antonovsky and Sourani (1988) raise this issue with regard to the family of a person. They suggest, a family SOC- that is, how a family as a system define a problem or make sense of a stressor. The authors argue, that a weak family SOC, respectively, that variances of the family SOC and a persons' personal SOC, may account for an additional dissensus. This would serve as a possible explanation for the informants' perceptions of mismatches of expectations and the reality. Similar mechanisms have been described in earlier research on social support for cancer patients: 'forced cheerfulness' of the network has been identified as a particular problem, as it can reinforce the cancer patients sense of being "unnatural" or bring about a notion of not being allowed to talk about their true feelings (Peters-Golden, 1982). Antonovsky and Sourani (1988) claim further that a strong family SOC supports individual adaption to a stressful situation. That hypothesis aligns with the findings of the given study, which have brought forward, that a good and caring network contributes both through practical help, but first and foremost through emotional support to the patients' adaption and well-adaptive management of the situation. This is fortified by findings by Peters-Golden (1982) who points to the importance of social support to cancer patients' adjustment to the disease.

Analyses revealed, that some relations could be drawn between coping styles social ties of the informants. Non-coping informants turned out to be unmated. That was relevant in this context, as the informants mentioned that they, on the one hand, did not have a specific person who could have taken care of them, respectively, their fears. The informants found it therefor to be a too huge task to manage alone. On the other hand, they mentioned that not having to be considerate of anyone, made it possible for the informants to turn a blind eye to the situation. These findings are substantiated through earlier research investigations, in which an association between 'living alone' and 'behavioural escape-avoidance' in cancer patients was demonstrated (Dunkel-Schetter et al., 1992).

Instrumental coping styles seemed to be applied irrespective from whether the informants were lived secluded from a greater social network or had strong ties to a partner network or family. Even though the social network posed additional strains to many informants, did the analysis show, that then etwork could likewise have a great supportive function: All informants who dealt with emotions related to the disease did either live together with their partner or children, or were part of a close and caring network. Their narrations eluded, that they were discharged from all day to day business, being practically and emotionally backed-up by their network. Thus, these informants reported to having had the *opportunity* to occupy with their feelings in the situation. These findings are supported by research by Goldzweig et al. (2009), who found, that married patients coped better with cancer, than unmarried patients; as well as a positive correlation of friends' support and coping.

Nonetheless, the informants of the present study also pointed to that occupying with feelings, in line with having no responsibilities, led to a high sense of dependency of others and led to a low feeling of mastery of the situation. Earlier research on coping in cancer patients issues possible pitfalls of emotional coping as well. Sigrunn Drageset et al. (2010) found, that cancer patient's expression of emotions could entail self-pity and feelings of weakness. Findings by Goldzweig et al. (2009) indicate subjective constraints of emotional support on the patients' autonomy.

The outline given in the preceding section, shows, that emotional coping needs are not easily to meet. It appears, that great variations among the patients make it difficult to assess either *specific needs* or *specific support*. This is additionally underlined through findings in the given study that point to *ambivalent* needs of the informants. They expressed, that they often did not know what they expected from the social network and carers. Friedman, Florian, and Zernitsky-Shurka (1989) broach the issue of ambivalent emotions and needs in young adult cancer patients. They point to the relating feeling of loneliness the patients perceive as a result, indicating the need for psychosocial interventions to support the patients.

Such a need has been expressed by informants within the present study as well. However, they also conceded, that the need for or appropriateness of social support was not indicated at all stages of their disease course. Even those informants, who underlined that they had engaged in emotional coping as much as possible, stated that they didn't or wouldn't have accepted support at an early stage of the treatment. That gives the implication to a hierarchy of needs in the process of well-adaptive coping with cancer in young adults, in which a time dimension seemed to play an important role in addition. These implications will be further outlined in the consecutive section:

6.2.4. *Coping and the hierarchy of needs*

Lazarus (1993) reasons that – as a general principle- the coping efforts and strategies vary in line with the requirements of the threats and the significance of positive adaption. In the present study, this is supported by the informant's reflections on coping with cancer at an early stage of the disease: Here, variations in coping styles could be traced back to differences in the informants' appraisal of the situation (what is at stake?) and the according conclusions about a) the significance to cope well (e.g. need to be healthy for the children, need to get back to the job, need to keep up normal life), b) what coping well indicates (behaving in a normal manner/ becoming healthy/being strong and so on). Still, the narrations of the informants in the given study sketch a somewhat controversial picture, when it comes to narrations about coping at later stages of the disease: All informants describe a *change* in coping processes during the disease course, despite continuously maintaining their evaluation of significance of adaption (such as wanting to get back to the old life, wanting to watch the children growing up). For instance, many informants dealt with uncertainty through denial at

an early stage of the disease course. Still, only few informants stuck to this behaviour during the treatment as well. Similar applied for instrumental coping and emotional avoidance: The informants who rejected dealing with the situation emotionally expressed that they had no urge to talk about their feelings, and, even more, avoided it as much as possible. They narrated that they turned down attempts of others to support them emotionally in any way. Later on, though, they stated to having had a great need to talk, and expressed their disappointment that the support, which had been turned down, did not repeat the offer at a later point of time.

Furthermore, another change in coping appeared from the analysis: All informants experienced a *decrease* in coping efforts, even if some external strains (e.g. through the health care system or the social network) were imposed on them *in addition*. These findings imply, that - in contradiction to the proposition made by Lazarus (1993) - coping efforts not necessarily are tied to the significance of adaption (which stayed the same the informants, while the efforts decreased) or the requirements of the threat (which partly increased, while the efforts decreased). Rather, the analysis of the results gave rise to deliberations about *hierarchy of needs* in coping: The informants' narrations pictured a hierarchy in dealing with the disease: at baseline, the fight to survive, and to get through the treatment. Building upon that, the next most important thing was the need to safeguard good hospital care parallel to financial matters and administrative issues. Building upon it, the maintenance of the social network played a major role, respectively –if given- taking care of the own family. Many informants experienced additionally, how issues that at an earlier stage had been the main subject to coping would become redundant, if any of the more basic conditions was not fulfilled. Thus, it seemed that first when the underlying basic matters 'surviving', 'getting through the treatment', 'dealing with social network' were dealt with, the informants were likely to giving themselves the opportunity to deal with emotional reactions to it. Thus, it seemed that first when the underlying basic matters 'surviving', 'getting through the treatment', 'dealing with social network' were dealt with, the informants were likely to giving themselves the opportunity to deal with emotional reactions to it. Further studies issue the changing needs of patients (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Gotay, 1984, 1985; Harrison, Young, Price, Butow, & Solomon, 2009). Studies by Gotay (1984, 1985) for

instance, highlight that coping needs and attempts vary during the disease course of cancer patients. Specifically information needs and the need for support seem to be altering during the disease; although the exact mechanisms remain unclear. This gives implications to that patient support must target the patients individually, in order to meet their needs (Butow et al., 1997; Harrison et al., 2009).

6.3. Making^[TMBL6] Sense of the disease

It emanated from the analysis that the cancer diagnosis had great implications for the informants' entire life, which concerned not only the present and the future but also effected a re-evaluation of the past amongst the informants. Many of them tried to *make sense of their situation*. They searched for explanations that related to their life-style or genetics or asked their doctors to explain the cause-effect relations in the particular case. The common opinion was, that an understanding of why they were hit by cancer would facilitate to better deal with the situation, even though this would not *change* their present situation. This general notion can be explained through the application of the Salutogenetic Model of Aaron Antonovsky (1979), which emphasizes that the ability to cope is comprised of the individuals' SOC. The strength or weakness of a SOC is, in turn, determined by the comprehensibility, manageability and *understandability* in the coping process. The latter is especially important in making sense and situating the event in a way that it coheres with the individuals' understanding of life. The importance of the role of causal explanations to cancer patients' mental and emotional appraisal of the disease has been confirmed within several research investigations on cancer patients' processing of the situation (Baider & Sarell, 1983; Berckman & Austin, 1993; Gotay, 1985; Linn, Linn, & Stein, 1982; E. J. Taylor, 1992, 1995). These studies point out, that causal explanations account for the meaning the cancer patients attribute to the disease. Further, E. J. Taylor (1995) underlines, that causal explanations can to varying extent- effectuate the feeling of control in cancer patients.

These circumstances, which are prerequisite to a generally strong SOC, are hardly given in YACPs. The informants of the present study were not able to understand why they had gotten cancer, as their conceptualisation of reasons for the onset of the disease often was related to old age or to lifestyle factors such as smoking, overweight or nutrition, or related to

overweight or genetic predisposition. The majority of the informants, though, described themselves as young and healthy, and only few had cancer in their family. Though, they failed to understand and explain what they experienced, which made it specifically hard to them to cope. Similarly do Bloom and Kessler (1994) outline that stigmatisation around cancer has been an important issue over the last years, demanding for special support of people concerned. Finding *meaning*, in turn, has shown to constitute a major factor to the quality of life of the people concerned with cancer (Stam, Grootenhuis, Caron, & Last, 2006). Both the present study, as well as earlier research point to, that coping is a an individual process, and coping tasks and strategies vary (Baider & Sarell, 1983; Boehmer et al., 2007; Carlick & Biley, 2004; Carver et al., 1993). Still, the findings of the present study point to one overarching matter, that constitutes of the divergent coping strategies. It has been shown, that the patients, and their network, attempted to *make sense of the disease*.

As this is especially difficult to YACPs, as mentioned above, and it is hardly possible to *understand* the disease – they tried to make sense for it otherwise. Antonovsky and Sourani (1988) point out, that not all stimuli in life must be coherent, I order to build a strong SOC. Thus, a stimuli, that is not coherent, may be buffered by other meaningful stimuli in life.

That seemed- unconsciously- to have been the aim of some strategies applied by informants of the given study. They tried, for instance to accept the situation, and to find a new balance, for instance through living in accordance with their own need. These factors were also identified as helpful in earlier research on cancer-coping (Carver et al., 1993; Kyngäs et al., 2001; Stanton & Snider, 1993). The acceptance and adaption to changing needs incorporated also, to create a new normality. Mostly, that was related to smaller day-to-day occurrences in which the participants wished to participate; either actively, or, if being too weak, through the narrations of others. The maintenance of normality or participation in daily life of others granted the informants the feeling of still being tied to the ‘old world’ and is known to promote a sense of affiliation to their social network (Kyngäs et al., 2001). Defining such individual parameters for ‘normality’ was also regarded as helpful for facilitating an alternative way to interact with the network (Hilton, 1996). Furthermore, many informants narrated, that a helpful tool to lighten the atmosphere within was to face such sensitive situations with humour, which is known to be a valuable coping strategy to creating the sense

of normality and security (P. Johnson, 2002; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). The overall notion of these kinds of activities seemed to be to integrating the situation into the life, and give *a room to the disease*. A room for the disease seemed important and helpful irrespective of coping style, needs or strategies. The room could be created together with others, bringing along a sense of affiliation, or as “alone time”, in which the patients dealt with it on their own. It embraced both a platform for the informants, as well as it gave limitations to the space the cancer would occupy in their life. The strategy opposes that of those informants, who narrated having been overwhelmed and thus, having coped badly with the disease and described their focus on loss. They quarrelled with the situation, with thoughts circling around deprivation, unfairness, lack of desired treatment or support; or disappointment of the social network. It is shown, that cancer patients who targeted their thoughts towards conditions that wouldn't change, while exhausting themselves with feelings of anger, grief or guilt (Derogatis Lr, 1979). Cancer patients, in turn, who turned their focus to meaningful parts in life, and focussed on their resources, experienced gratitude, normalcy, and *meaning* inspite of the disease.

6.4. Methodological Considerations:

To ensure rigour in the present research, the consecutive sections will provide a discussion of the strengths and weaknesses of the study, alongside with an assessment of the validity of the results.

6.4.1. Study design: the phenomenological-hermeneutical approach

The study at hand is based on a combined phenomenological-hermeneutic foundation. From the perspective of followers of a strictly transcendental phenomenology it could be argued that phenomenological research is limited to pure description and that hermeneutic expands the scope of phenomenology (van Manen, 1990). However, there are researchers holding the view that these schools- rather than being mutually exclusive- complement one

another. They argue that “phenomenology without hermeneutics can become shallow”(Todres & Wheeler, 2001, p. 6). Regarding the phenomenon “coping as a young cancer patient”, a purely descriptive definition of the term would miss its essence, i.e. the experience or meaning of the phenomenon. Hence, applying hermeneutic considerations along with phenomenological assumptions might add significance to the explorations as it allows an in-depth investigation of a health science phenomenon.

6.4.2. Reliability and validity

Reliability and validity are two particularly important criteria in assessing the quality in qualitative research investigations. *Reliability* is a method to assess the consistency and trustworthiness of the results from the data analyses (Kvale & Brinkmann, 2010). This study sought to ensure *reliability of methods* through the thorough application of the methodological procedures. Likewise, the research methods aimed at enhancing the *trustworthiness of the informants' statements* in the best possible way. The semi-structured interviews limited leading questions to a possible minimum and the interview guide did not raise questions which imposed any form of response expectations or demands on the informants (Richards & Schwartz, 2002). These conditions contributed to the reliability of the results: informants who feel comfortable in the interview situation are likely to talk more freely and provide a rich description of the phenomenon in question (Kvale & Brinkmann, 2010). The trustworthiness of the interviewer's processing of the verbal data was given through a so-called *member check* or respondent validation of the interview transcripts (Mays & Pope, 2000). An additional possibility to ensure validity of data and prevent misinterpretation is to ensure the researcher's collaboration with co-workers. This is especially true for novices in the field. The present researcher conducted the study under supervision of two experienced qualitative researchers, to ensure the validity of the results of the analysis (Richards & Schwartz, 2002).

6.4.3. Translation to the English language

In translating the informants statements from Norwegian into English language, the researcher aimed to be as true to the content/ meaning of the statements as possible. This

included the main principle to translate the statements literally. Where figures of speech or colloquial language had been used the researcher refrained from verbatim translation and applied equivalent English phrases or expressions which grasped the meaning of the Norwegian expressions. Overly frequent use of “yes”, “no”, “you know” “ehm” and other filler words were not translated in the report. The accuracy of the translation was verified by an experienced researcher.

6.4.4. Transparency and Reflexivity

All qualitative research has an element of subjectivity. These can be dealt with through the study’s transparency for and verifiability to others, and thereby establish trustworthiness of the research. However, do the terms additionally raise the questions if, and in how far, knowledge derived from interviews can be considered to be *objective*. Objectivity can be characterised by through a) absenteeism of one-sidedness, b) reflexivity, and c) giving the study ‘object’ the opportunity to protest against the researcher’s account (Kvale & Brinkmann, 2010). The present study seeks to account for each of the three criteria. Bracketing was applied as strategy in phenomenology to prevent an overload of abstraction and thereby to refrain from one-sidedness. Anyhow, complete phenomenological reduction is hardly fully practicable, as the researcher’s own experiences and context colours the interpretation (Dowling, 2007). Through using hermeneutics, the researcher’s awareness on own prejudices and pre-judgements was raised, and demands for continuously reflection on how these have influenced the process of analysis.

6.4.5. The role of the researcher

The researcher is a novice in the field. Lack of experience brings along a higher risk of misjudgement of suitable frameworks, epistemological commitments or misrepresentation of the data. These risks lie within the nature of being a novice in a field but can be reduced through certain preventive measures (Richards & Schwartz, 2002). In order to avoid research biases in the best possible way in this study, the researcher placed importance on a thorough and systematic procedure and the accurate outline of the line of action and through supervision of the supervisors. Further, the researcher has not the interviewer in the data collection process. During the analysis, this brought along some particular demands to the

researcher. There were a few challenges with regard to understanding the meaning of single statements. Still, the researcher was most often able to grasp the meaning of the from the given context. Moreover, the present researcher was in contact with the interviewer during the analysis and could, if needed, discuss emerging questions or inconsistencies. On the other hand, was the researcher able to read the interviews detached from their contexts (i.e. the interview situation) and the researcher did not attach any memories and prejudgments to them, which aided the use of bracketing and phenomenological reduction (Richards & Schwartz, 2002).

6.1.4. Limitations of the study:

The nature of the present study incorporates some limitations to the research. Some of these were inherent in the framework of the thesis: limitations of time and space that demanded some curtailing of the extent of both the analysis and the outline of the results. Thus, all factors emerging from the analysis which were not directly related to coping would have exceeded the scope of the thesis and could not be evaluated in-depth. This involves, for instance, the patients' narrations on the health care system, problems with sick leave or loopholes in legislations on sickness allowances or in depth assessment of gender perspectives, physical complaints, and personality dispositions of the informants. The data were rich and allowed for a wide range of interpretation and further discussion. The researcher acknowledges that there are various alternative ways in which coping can be approached and highlights that – just as in every qualitative research investigation- the study at hand constitutes *one* way of looking at the phenomenon.

Conclusion

Cancer in young adult cancer patients turned out to be a tremendous and complex topic to deal with for the young adult patients. Their worries and challenges exceeded the scope of what they could have imagined before and imposed far-reaching coping tasks to them. They were exposed to uncertainties in various life arenas. Upon the devastating fear of dying, there added uncertainties about the frightening treatment process and insecure future outlooks. During treatment, many informants faced fear of losing persons close to them; either through the own death or through rejection or abandonment from persons that could not bear the confrontation with the disease. They experienced difficulties with their social network, who could not seem to understand them anymore. Often, informants were not able, to communicate needs, as they went through physical, cognitive and psychological changes, that they could not understand. Related to this, the informants had to deal with impacting side-effects of the treatment, which reduced their physical functioning to a minimum and caused additional fear. The informants were in great need for information, which they often were not provided from the health care system. The main and overarching challenges were change and related uncertainty. Coping with the broad range of issues often posed a tremendous overburdening to the young informants. That was reinforced by the fact, that they were in a transition face in their life before and during the disease anyways, which brought along the insecurities of establishing an own life. This situation and missing life-experience made the informants especially vulnerable to the various impacts that were burdened upon them. It seemed, that the SOC of each individual is an important factor to coping. A salutogenic attitude, that focusses on the resources turned out to be helpful. The ways informants chose to cope varied from non-coping through avoidance; instrumental coping, through problem-solving and emotional coping, like seeking social support. Both needs and strategies, that were applied, varied broadly amongst individuals. Further, it became clear, that these needs *changed* for the individuals in the treatment course, even though there exist no clear explanations for it yet. Thus, it turned out, that there were no overarching means of coping that fit all informants. Rather, the findings implied that coping is a matter of individual appraisal of the situation and the resources as stake. The implication of the study is that coping needs of this special target group need to be better understand. Psychosocial interventions

should be provided by the health care system, targeting to strengthen the individuals' SOC. The study brings to light, that – even though first health promotion approaches have been implemented in policies and health promoting practices in Norway, the need for further development, especially in the provision of treatment for young adult cancer patients, is given. That could be facilitated through further research, but also through individually targeted, patient-centered and age-specific provision of support during all phases of treatment. A special focus should be directed to the insecurity the informants perceive and support to develop the needed skills to appraise, reappraise and act upon the situation in a helpful way. A holistic approach to YACPs – embracing their psychological and physiological needs, their overall life situation and the social network, in line with the spirit of a health promoting approach to the public health problems today.

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APPENDICES

Appendix 1: Example of an initial working document (working document 1) in the analysis process.

The image shows a PDF viewer interface displaying a grid of 24 pages of a document. The document is titled "Arbeitsdokument 1" and contains extensive text with numerous annotations. The annotations include red boxes highlighting specific sections, yellow boxes highlighting other sections, and red dashed lines connecting related parts of the text. The text is in German and appears to be a technical or scientific document. The PDF viewer interface includes a top toolbar with navigation icons, a status bar at the bottom showing "Seite: 20 von 20 Wörter: 11.953", and a language setting of "Englisch (Großbritannien)".

Appendix 2: Example of a 2nd working document oncollected and coded text passages (extracted from working document 1).

The image shows a screenshot of a PDF viewer displaying a document with a grid of text passages. The grid consists of 10 rows and 2 columns of text. Each cell in the grid contains a short paragraph of text. Red dashed boxes are drawn around specific words or phrases within each text passage, indicating they have been coded or highlighted. The PDF viewer interface is visible, including a toolbar at the top with navigation icons and a zoom level of 19%. At the bottom of the viewer, there is a status bar showing 'Seite: 9 von 9', 'Wörter: 2 878', and 'Englisch (Großbritannien)'. A vertical toolbar on the right side of the page contains various icons for document navigation and editing.

Appendix 3: Excerpt of the logbook kept during analysis

2 1 1 2 1 4 1 6 1 8 1 10 1 12 1 14 1 16 1 18 1 20 1 22 1 24 1 26 1 28 1 30 1 32 1 34 1 36 1 38 1 40 1 42 1 44 1 46 1 48 1 50 1 52 1 54 1 56 1 58 1 60 1 62 1 64 1 66 1 68 1 70 1 72 1 74 1 76 1 78 1 80 1 82 1 84 1 86 1 88 1 90 1 92 1 94 1 96 1 98 1 100

Notes from Interview transcripts

Legend:

- Text in bold letters, underlined: Headlines, interview numbers, notification date, title of a following section/ or a word in a section that is a title in another section
- Text in bold letters: Impacting terms, special focus
- Text marked yellow: Main themes
- Text marked green: Main themes repeatedly mentioned in various interviews
- Text marked red: Themes that bring questions up, need for further investigation
- Text in purple-coloured letters: Text that has been added post scriptum to the tracked date
- List of items that relate to each other

20.09.2012, Interview 010.001: Emergent topics

Misinterpreting symptoms because of other disease

Others take symptoms more serious than oneself

Earlier experience makes attentive to symptoms

Making fun of it, downplaying

- Burdens: To talk about disease
- Borders: No borders/no limited room/get too close

[Edited 19.11.2012]

What does being headed imply?

21.09.2012

Disease = feeding incomplete

- Mixing something coming with a failure, not working (like a product with production-mistake)

Copying = the ability/need to deal with a external imposed difficult situation, challenge, in order of to make a decision or make the space of myself out

What contributes to coping:

- accepting special situation
- recognizing special needs
- facilitating preconditions for special needs and special situation
- engaging social support in special needs and special situation
- communicating special needs and explaining life world to others
- the experience that life-world adapts to special needs, and that one does not have to not keep up to the familiar daily life with the special needs

22.09.2012, Connection:

Discipline/Rules/limits to prevent getting lost

- Taking responsibility/leadership for own live
- Passing on responsibility to others

Restructuring Themes: Deleted Themes: "Change"

With codes: Disease = Life disrupting/life turning event

Dissonance of identity and illness conception

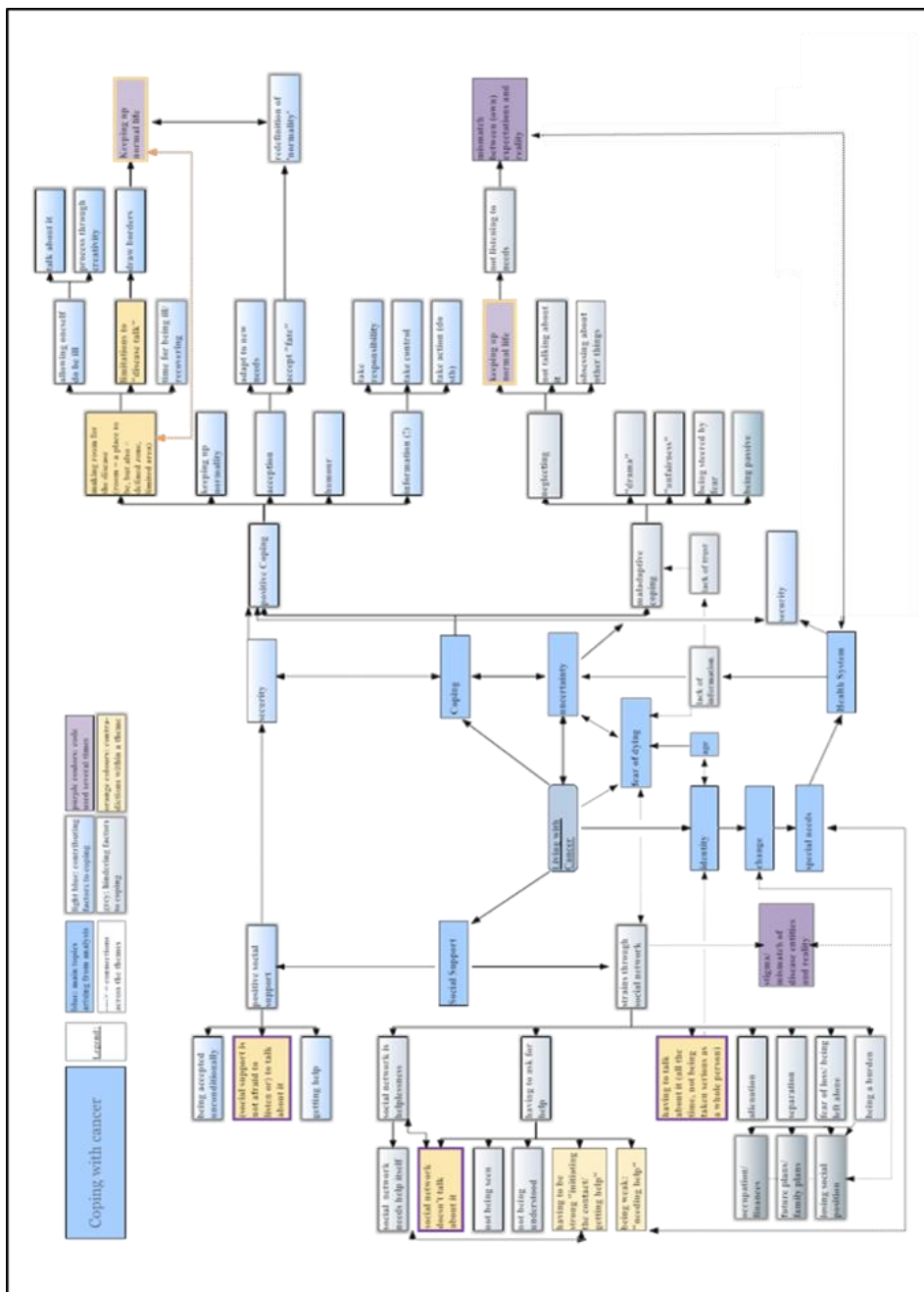
23.09.2012

Set parameters for how/2be treated/needs/normality

- Integrating social support to keep up ones plan
- Allowing to be ineligible

Seite: 1 von 71 Wörter: 11 881

Appendix 5: Thematic mind-map on cancer-coping



Coping with cancer

Lazarus:

What's main topics... (light blue box)

How do you cope? (yellow box)

Solid line: How do you cope? (thick line)

Dashed line: What's main topics... (dashed line)

people embrace, make good survival times

High level: controlling factors in coping

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

How do you cope? (yellow box)

Appendix 5: Extract from the working document on coding and generating themes (blue font has been applied for codes that were allocated to multiple themes)

Appendix 6: Excerpt of the registry on codes and interviews in which they were applied

A1	POSITIVE COPING (emotional coping)	
A	B	
1	POSITIVE COPING (emotional coping)	Coded in interview: (roman numbers in parantheses indicate how often)
2		
3		
4		
5	HELPFUL ATTITUDES	
6		
7	to be mentally prepared (to something negative) rather than being exposed helpless (=taking control) (toughen up' for chemotherapy)	1, 6, 7, 8 (III), 9, 12, 20 (II)
8		
9	expectation/ attitudes are deciding factors for coping (one can choose which attitudes one adopts)	1, 6 (III), 8 (III), 9, 11, 12 (II), 13, 14 (II), 16, 20 (IV)
10		
11	being realistic, rather than being disappointed	9, 12, 14
12		
13	having an acknowledging/ appreciating attitude towards life (seeing blessings in disguise) (looking at other parts in life, which are good)	1, 6, 8, 13 (III), 20 (V)
14		
15	humor (joking around with the wig)	1, 2, 9, 13 (II), 14, 16, 20
16		
17	making use of earlier coping strategies (you don't change...)/ using ones resources/skills to cope	1, 2, 6, 8 (III), 9, 10, 11, 12, 13, 16, 17, 20 (II)
18		
19	helpful to having undergone tough periods at an earlier life stage/ or directly prior to the disease ('I was doing bad anyways.../I was used to it because of my sister') (I learned it in the time when I have been to the psychologist)	10, 11, 12, 17 (II), 20 (II)
20		
21	being satisfied with one's own coping/ find peace with ones state of being)	1, 2, 7, 8 (II), 12, 16 (II)
22		
23	generous attitude towards mistakes of health personnel (everyone can make mistakes/ in the end, it has been good treatment after all)	6, 13, 14 (II), 20
24		
25	communicating needs to the network/ working out practical solutions (too tired to welcome visitors, need to go to sleep instead)	2, 6, 11, 12, 14 (II), 16, 20 (III)
26		
27	understanding for social circle/ their challenges (gathering information brochures about dependants of cancer patients); acceptance of network; acknowledging that everybody is the way he/ she is	6, 13, 16, 20 (II)
28		
29		
30		
31	FOCUS (aim: what do they want? E.g. being normal, healthy, get saved, being taken care of) (focus equals perception: cancer as fight, hell on earth, task, challenge, life destroying event, limited period...)	
32		
33	stick to normality (hair)	7, 11, 13, 18
34		
35	sette pris på det som er/ det man har, fokus på det gode	1, 10, 11, 13 (II), 16 (III)
36		
37	ha et håp/ prøve å holde motet oppe	3, 8, 9 (II), 13, 14 (II), 16, 20
38		
39	fighting spirit (it is no alternative to die) / being positive ('this is going to be fine') / positive outcome expectation	2, 6, 9, 10, 13, 14, 17, 20 (II)
40		
41	putting oneself in the first row (having a 'mull year')	2, 13
42		
43		
44		
45	HANDLING REALITY (the invisible disease)	
46		
47	accepting the reality and dealing with the situation (rational) (making room for it) (being honest to the situation) (keeping one's head) (being open: 'it is a little	2, 6, 8 (III), 10, 11, 12 (II), 13 (II), 14 (III), 16 (II), 17 (II), 18, 20 (III)
48		
49	accepting disease as a given fact, not pondering over reason for it/ unfairness/ or being frustrated, give up control/ accept loss of control, focus on what is effective/ helping (one doesn't get anywhere by meditating on questions)	8, 10, 13, 14 (III), 18, 20 (V)
50		
51	salutogenic attitude (focus on resources/ 'this is what I have')	1 (II), 11, 14 (II), 17 (II), 20 (II)
52		
53	being conscious	13, 20
54		
55	establishing a new habit (safety), defining a new way of 'normality' (with the help of other patients (?)), adapt to the situation/ make room for being ill ('everything can become a habit' (making the best out of it/ something that is joyful) (a habit gives room to focus on other things again, small things, joy in life) (habit= learning to handle the situation; 'I'm healthy my way') ('align goals to resources available to reach them')	2, 8 (III), 12, 13, 14 (III), 16 (IV), 17 (III), 20 (IV)
56		
57	giving oneself room to be sick/ ill/ mad (e.g. talk about it) ('meeting the situation with honesty' (e.g. mad about it))	2 (II), 12, 13 (II), 16, 18, 20
58		
59	putting things into perspective (time perspective, or other patients who were worse off) ('what you loose is a bagatell in comparison to what you already have been through/ what you may keep') ('happy that children are healthy')	1, 8 (III), 12, 13 (II), 14, 16 (II), 20
60		
61		
62		
63	ACCEPTANCE/ SELF-ACCEPTANCE	
64		
65	allowing oneself to get help (I, in turn, gave much earlier) ('it is my right as employer to take sick-leave')	13, 18, 20
66		
67	finding peace with one's condition, accepting it, allowing oneself that it is how it is, not living up to own expectations	16, 17, 20 (IV)
68		
69	taking care of oneself/ rest/ learn to have cancer/ (exploring/ listen to oneself/ one's needs/ limits (to social support needed), balance, not living up to other's expectations, taking enough time for something (also recovering), being patient)	1, 3, 6, 7, 8 (III), 9, 10, 11 (III), 12, 13, 16, 20 (III)
70		
71	the whole picture is important - not only the physical shape/ recovery, but also the mind and everything else, to make it work (it= processing/ coping)	14, 16, 17, 20
72		
73	allowing oneself feelings	20
74		
75	accept cancer as a part of oneself	13, 20