Being a Pediatric Oncologist: A Nationwide Study of Personal Resources and Difficulties When Working with Children with Cancer

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The cover photo, by Miriam Grip, is a picture called “The child on the path” and illustrates the artist’s view of the world of a child with a malignant disease.

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”To each one of you the practice of medicine will be very much as you make it
– to one a worry, a care, a perpetual annoyance;
to another, a daily job and a life of as much happiness and usefulness
as can well fall to the lot of man.”

Sir William Osler (1849-1919)

To all pediatric oncologists

ABSTRACT

Being a pediatric oncologist involves facing medical challenges, life-threatening conditions, psychosocial issues and existential provocation. The first nationwide study of 90 Swedish pediatric oncologists focuses on the psychological aspects for physicians meeting children with cancer, as well as physician-related factors promoting health and well-being. The experiences of the study population cover a period of more than 40 years.

The thesis aims to study the everyday life of pediatric oncologists, i.e. their motivating factors, stress-resilience capacity, life satisfaction and work-related difficulties, in relation to relevant background characteristics, length of experience (more/less than 10 years) and type of medical center (academic/non-academic).

The study design was cross-sectional and used both quantitative and qualitative methods. Paper I presents the development of a study-specific questionnaire. Papers II and III present the background characteristics for 89/90 physicians, working at academic medical centers with 25-90 new cancer patients every year and non-academic centers with 3-20 new patients. The response rate was 88/89% in the target group. The study-specific questionnaire and five psychometric instruments measuring coping resources, sense of coherence, life satisfaction, emotional distress and personality were used. Optimal pediatric oncology included several colleagues and a multi-professional healthcare team and the work was regarded as very stimulating for personal development. Time pressure was a reality for every participant, as were a wide range of coping resources, high sense of coherence, average overall life satisfaction and low levels of emotional distress. More experienced pediatricians reported a higher impact by motivating factors, past overall life satisfaction and a lower degree of somatization. Future overall life satisfaction was higher among physicians who met more pediatric oncology patients. Their personality traits showed low levels of negative affectivity and high levels of positive affectivity (Hedonic Capacity). Male pediatricians were more satisfied with their present lives and physicians working at academic medical centers were more confident about the future. One in ten needed professional help to deal with work-related psychological problems. Personality traits (Hedonic Capacity) and low levels of depression contributed to every aspect of overall life satisfaction. Work-related aspects influenced present and future life satisfaction. Paper IV, a grounded theory analysis of in-depth interviews with 10 experienced physicians, focused on their main concern, the demanding role of breaking bad news. Strategies for handling the challenges were related to seeking knowledge and support, building a close relationship with the patients and families, having reflected on central life issues but avoiding identification. Practical implications and physician-related recommendations are presented.

The overall picture of this study group reveals an optimistic attitude and stable emotional status, pointing to a high level of satisfaction. The impediments are particularly related to time pressure, risk of emotional distress, having less experience and the need for colleagues, plus a multi-professional team. The role of messenger requires strategies to handle the challenges. Knowledge acquired from the present study is expected to be useful in improving the physician-patient relationship, thereby helping to retain experienced physicians and recruit new specialists in pediatric oncology.

Keywords: Physician, pediatric oncology, nationwide study, well-being, stress-resilience, life satisfaction, motivational factors, breaking bad news, emotional distress, instrument development

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CONTENTS

LIST OF PUBLICATIONS

This thesis is based on the following studies which will be referred to by their Roman numerals:

I. Stenmarker M., Palmérus K., Márky, I. An Instrument for Measuring Psychological Aspects of Being a Pediatric Oncologist
Submitted for publication

II. Stenmarker M., Palmérus K., Márky I. Stress-Resilience Capacity of Pediatric Oncologists: A Swedish Nationwide and Population-Based Study of Motivation, Emotional Distress, and Overall Life Satisfaction.
Pediatric Blood &Cancer 2009;52:503-509

III. Stenmarker M., Palmérus K., Márky I. Life Satisfaction of Swedish Pediatric Oncologists: The Role of Personality, Work-Related Aspects, and Emotional Distress.
Pediatric Blood &Cancer 2009; 53:1308-1314

IV. Stenmarker M., Hallberg, U., Palmérus K., Márky I. Being a Messenger of Life-Threatening Conditions: Experiences of Pediatric Oncologists.
Pediatric Blood &Cancer 2010; 55:478-484

ABBREVIATIONS

ALL	Acute Lymphoblastic Leukemia
AML	Acute Myeloblastic Leukemia
NHL	Non-Hodgkin's Lymphoma
CNS	Central Nervous System
SBLG	Swedish Pediatric Leukemia Group
VSTB	Board for Solid Tumors in Childhood
VCTB	Board for CNS-tumors in Childhood
SIOP	International Society of Pediatric Oncology
SALUB	Swedish Working Group for Long-term Follow-up of Children with Cancer
SSP	Swedish Society of Pediatricians: section for hematology and oncology
VPH	Board for Pediatric Hematology
BMT	Bone Marrow Transplantation
NOPHO	Nordic Society of Pediatric Hematology and Oncology
SCCF	Swedish Children's Cancer Foundation
GRR	General Resistance Resources
SOC	Sense of Coherence
CRI	Coping Resources Inventory
POCQ	Pediatric Oncology Coping Questionnaire
HP5i	Health-relevant Personality 5 (Five-Factor Model=FFM) inventory
GT	Grounded Theory
L-o-L	Ladder-of-Life
SPSS	Statistical Package for the Social Sciences
ANOVA	Analysis of variance
SCL	Symptom Check List
GSI	Global Severity Index

PROLOGUE

When searching for my reasons for performing this research, I have asked myself what impact personal experiences could have on the choice of topic. As a teenager, I was diagnosed with a severe malignant disease. For approximately two years, I spent much of my time being a patient struggling to survive. Through the procedure of diagnosing and treating the disease, I had the privilege of meeting several very skilled physicians within different specialties, but there was something special about the pediatric oncologists. My mother has reminded me of the fact that, at a very early stage, I commented on the way these physicians met my needs, fascinated by their compassion, warm eyes and hearts. Fifteen years later, when I returned, as a pediatrician, to the same department to spend some weeks of training in pediatric oncology, I realized that the medical field of pediatric oncology was extremely interesting, but I was once again captivated by the atmosphere, the attitudes and role models of the physicians. The discrepancy between a community which was threatened by childhood cancer and pediatricians who obtained satisfaction from working close to severe conditions was obvious and touched my personal experiences of the importance of the caregivers' approach to young patients suffering from fatal diseases. The slumbering question arose again: What are the motives and the challenges for physicians facing severe illness and death in childhood? While searching in the literature to find an answer to these questions, an internal process started and several years later this process was converted into the present research project.

BACKGROUND

1. A brief history of ethical aspects and eras that have influenced physicians in the western world

During the last century, clinical humanistic (holistic) medicine has experienced a renaissance. The humanistic approach is centered on the patient's different needs not the disease. This view is defined as holistic medicine [1] . The role of holistic medicine has varied throughout medical history and has its roots in the ancient Greece, i.e. 400 to 500 BC. The profession of medicine is known since this era, as is the ethical foundation for physicians. The first ethical code was the Hippocratic Oath which has influenced the profession throughout history [2]. This code prescribed that physicians should practice medicine "to the best of their ability for the good of their patients and try to avoid harming them". Respect for patient confidentiality and professional secrecy was declared at this early stage.

Several centuries later, during the medieval period, medical aid in Europe was influenced by Christianity and terms like "sin" and "punishment" were related to sickness and suffering. The "Cartesian Dualism" (René Descartes (1596-1650)), i.e. a theory regarding the mind that thinks and the body that does not, initiated a breach with the church. A more materialistic way of thinking characterized the 17th and 18th century, as natural science obtained a stronger foothold in medical history. The clinical practice of psychoanalysis, introduced by Sigmund Freud (1856-1939), was a reaction to this rationalism during the 19th century. The term "psycho-somatic diseases" was first introduced by J.C.A. Heinroth (1773-1843) in 1818. During the second part of that century, Sir William Osler (1849-1919), enlarged the psycho-somatic perspective. He was a clinician and a humanitarian who encouraged his students to take time to listen and see their patients and established medical residency. He has been called the "Father of Modern Medicine" [1]. Around the middle of the 19th century, there was once again a change of paradigm focusing on objective quantifying experiments. This paradigm was personified by the cellular pathologist Rudolf Virchow (1821-1902) and the physiologist Claude Bernard (1813-78), and modern medical statistics were introduced in the 1830s. At the same time the concept of positivism, i.e. knowledge should be based on logical experiments and positive verifications excluding metaphysical aspects, was developed by August Comte (1798-1857). Sir Karl Popper (1902-1994), continued the work of Comte and introduced the term "falsification", i.e. every scientific hypothesis should be falsifiable. This pure positivistic orientation of science was broken and a new revival for humanistic medicine was established, when Edmund Husserl (1859-1938) introduced the philosophical movement of phenomenology, believing that experience is the source of all human knowledge. Deeper methodological studies, by Martin Heidegger (1889-1976) and Georg Gadamer (1900-2002), resulted in so-called hermeneutic phenomenology, which also includes an interpretation of the experience. Different qualitative research methods gradually developed, primarily within the social sciences. During the last few decades, these methods have been shown to be essential components of health research as well [3].

Today, clinical holistic medicine is central and medical ethics raise the questions of "values, responsibilities and rights" and reflect on physician-related behavior and decision-making. In its Ethics Manual of 2009, the World Medical Association established that medical ethics in practice and research still means "putting the patient first" [4].

2. The early period of Swedish pediatric oncology and its pioneers

2.1 An international background

Pediatric oncology has come a long way since the early attempts to treat children with malignant diseases. Before World War II, surgery and irradiation were the only available treatment modalities. As a single therapy, they resulted in only a short remedy and the vast majority of children died within a relatively short time period. The first milestone in the chemotherapeutic era was reached in 1948, when Sidney Farber discovered that the folic acid antagonist aminopterin was able to kill leukemia cells and he made use of this agent in the treatment of children suffering from acute lymphoblastic leukemia (ALL). Aminopterin as a single therapy was, however, only able to abolish pain and prolong the life of these children, but it did not cure them. When several different chemotherapeutic drugs were combined during the 1960s, an increasing number of children experienced long remissions, but 60-70% of them still relapsed with central nervous system (CNS) disease [5]. It was not until the late 1960s when prophylactic CNS irradiation was added to the chemotherapy regimen – the so-called "total therapy" – that a cure for ALL became an option [6,7]. From then on, the cure rate continued to improve and today more than 75% of the children diagnosed with ALL are cured [8]. The results for childhood solid tumors soon followed the same trend. In 1966, the two-year survival for children with Wilms' tumor was 58%, while with current treatment 88% of these children are cured [9]. In 1976, Wollner and co-workers from Memorial Sloan Kettering in New York reported that 76% of the children suffering from non-Hodgkin's lymphoma could be cured with intensive chemotherapy [10]. The average survival rate for childhood malignancies as a group is currently at the same numerical level, but some diagnoses have even higher figures [11].

2.2 Developments in Sweden

In Sweden, the first report of any success in the treatment of a childhood malignancy appeared in 1955, when Vahlqvist et al. described the achievement of remission with aminopterin and 6-mercaptopurin in five of 31 children suffering from ALL [12]. In 1967, on the initiative of Vahlqvist, the Swedish Pediatric Leukemia Group (SBLG) was set up and the first task the members undertook was to survey ALL in Swedish children and to unify the diagnostic procedure and treatment of this disease [13]. The formation of this group was the first step towards the current organization of pediatric oncology in Sweden. During the years that followed, diagnosis-specific working groups were established: in 1974 the VSTB (Board for Solid Tumors in Childhood) for solid tumors, in 1993 the VCTB (Board for Brain Tumors in Childhood) for brain tumors, in 2001 the SALUB (Swedish Working Group for Long-term Follow-up of Children with Cancer) for late effects and today there is also a board (working group) for pediatric hematology (VPH) and for bone-marrow transplantations (BMT) [14]. In 1987, the Swedish Society of Pediatricians: section for hematology and oncology (SSP) was set up. Under the leadership of the Swedish Society of Pediatricians, these diagnosis-specific working groups are responsible not only for treatment and follow-up recommendations but also for organizing scientific and educational meetings for pediatricians working in the field of child oncology. The SSP has also promoted the introduction of pediatric oncology as an official sub-specialty (2006).

The pioneering generation of pediatric oncology, who initiated these working groups, realized at an early stage the importance of close collaboration with Nordic and international colleagues. They participated in SIOP (International Society of Pediatric Oncology) meetings from the beginning of the 1970s, were represented in the society's working groups and organized the SIOP annual general meeting in Stockholm in 1975. The first Nordic meeting was held in Sweden in 1980 and the Nordic Society of Pediatric Hematology and Oncology (NOPHO) was established in 1984. The NOPHO has since held annual meetings with educational programs.

The physicians of this pioneer generation also realized that "quality assurance", with the rigorous registration of treatment, complications and outcome, was an inevitable part of current and future treatment success. Detailed registration within all the Nordic countries was initiated. The Swedish Childhood Cancer Registry was established at the beginning of the 1980s and today every Nordic pediatric cancer case is reported to this registry [14].

During this early period of pediatric oncology, the physicians had to fight for the needs of their patients. Colleagues in different specialties opposed offering children with incurable diseases such toxic treatment and, as pediatricians without formal training in oncology were responsible for the care, clinicians on pediatric wards were not always prepared to follow the new protocols. There was no comprehensive organization for caring for children with malignant diseases and they were treated on general pediatric wards without specially trained staff.

Between 1978 and 1982, four special child cancer units were established at the University Hospitals of Stockholm, Gothenburg, Lund and Uppsala, followed later by a unit in both Linkoping and Umeå. This achievement was preceded by lengthy discussions with hospital management teams and politicians. The parents of sick children participated in the struggle to open these specialized wards and the process was facilitated when pediatric cancer societies were established in different parts of the country. In 1982, these societies formed the Swedish Children's Cancer Foundation (SCCF).

While establishing cancer registration and organizing pediatric oncology at local and national level, the pioneers faced diseases causing suffering not only from the disease itself on a daily basis but also from disease- and procedure-related pain and nausea and 70% of their patients died. The child cancer units improved conditions both for the patients and for the physicians taking care of them. The technical developments in the field and the increasingly advanced treatment strategies required a specific knowledge not only of oncology but also of supportive care, i.e. transfusions, the treatment of infections, nutrition, pain management and palliation. During the 1980s, general anesthesia for procedure-related pain, indwelling catheters and pharmacological treatment for nausea and vomiting were introduced. The child cancer units with their specially trained staff meant that it was possible to meet these new requirements. The way the units function, together with the Nordic method of cooperation, the common registers/reports and the increase in the survival rate of childhood cancer, has been regarded as the "gold standard" in Europe [11].

3. The conceptual framework of the thesis

During the first decade of the 21st century, there has been growing interest in "positive psychology" focusing on life satisfaction, well-being, and engagement as the positive antithesis of burnout in occupational stress research [15-17], including the well-being of oncologists[18,19]. In this research field, different conceptual frameworks focusing on how people manage their daily lives in spite of difficult circumstances and life conditions have been introduced. A large number of varying theories have been defined. Within sociology, *salutogenesis* is the predominant concept, while related central concepts in psychology are *resilience* [20,21] and *coping* [22]. Furthermore, the concept of *empowerment* [23], which is influenced by perceived *self-efficacy* [24], the terms *locus of control*, *learned resourcefulness* [25] and *hardiness* [23], are other stress management theories within medicine, psychology, sociology and the social sciences.

The theoretical framework of this thesis on pediatric oncologists is based on the salutogenic approach and the outcome variables are stress resilience, life satisfaction and different strategies used to handle and overcome the difficult role of messenger.

3.1 A salutogenic perspective

The word "salutogenesis" originates from the Greek language, consisting of *salus* (=health) and *genesis* (=origin), i.e. the origin of health. This model was introduced by a medical sociologist, Professor Aaron Antonovsky (1923-1994) [26], and can be regarded as a new paradigm in health research [21]. In terms of health promotion, this way of thinking focuses on resources for health in contrast to the pathogenic approach, which focuses on obstacles and causes of disease. In salutogenesis, health is regarded as a movement toward the pool of health in a continuum between total health (ease) and total ill-health (dis-ease) [27]. The model is based on the concept of general resistance resources (GRRs) and sense of coherence (SOC). GRRs are psychosocial (e.g. social support), biological (e.g. intelligence/knowledge) and material (e.g. money) factors which help people mediate a variety of stressors. SOC, the key concept in salutogenesis, is the ability to use these resources, i.e. having the confidence and capability to see that, whatever happens in life, people can manage to handle the situations [28]. Successful coping with stress includes the main resources of SOC, i.e. *comprehensibility*, *manageability* and *meaningfulness*. The salutogenic model is suggested to examine and treat occupational stress among physicians and studies with this model are needed [25].

3.2 Resilience

Resilience is a complex concept, which is difficult to grasp, and different schools of knowledge have developed the theory [21]. There is no clear common definition, but the core of the concept is "the ability of an individual to positively adjust to adversity" [29]. Resilience can be regarded as the maintenance of equilibrium in spite of circumstances, as different from recovery from different challenges in life [29]. Recently, resilience has been described as "an individual's stability or quick recovery (or even growth) under significant adverse conditions" acting as a conceptual bridge between the "short-term state" of coping and the "longer term changes" of development [20]. Resilience can be either physiological or psychological [29,30]. The physiological aspects are related to the autonomous nervous system and the homeostatic mechanisms, e.g. regulation of heart rate and hemorrhages [29] . Psychological resilience can be defined as "the effective coping and adaptation [when] faced with loss, hardship or adversity" [31]. It has been suggested that the most important key to resilience is established in childhood when the young person is confirmed and respected through the so-called *reflective dialogue* with another person [32]. Resilience is likely to develop over time and circumstances and can also be described as personal characteristics, but there is an ongoing discussion about whether it is innate [29].

In this thesis, we have focused on psychological resilience while studying the daily challenges facing pediatric oncologists.

3.3 Coping

The concept of coping has its roots in the psychoanalytical theory of defense mechanisms, as mediators of stress, to attain inner balance [33]. Coping is defined as a process which entails "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" [22]. The primary appraisal is the individual evaluation of a challenging situation. If that situation is regarded as stressful, the secondary appraisal is the individual handling of the threat. The primary and secondary appraisals are integrated and, as soon as there is a change in the transaction between a person and his/her environment, continuous evaluations or reappraisals are made. Lazarus and Folkman [22] have defined two functions of coping: the problem-focused and the emotion-focused approach. The problem-focused strategy is directed towards the problem to try to change the circumstances, while the emotion-focused strategy deals with the internal regulation of the emotional response. Some researchers emphasize that there is a relative stability in preferred coping strategies, i.e. a personal profile [34]. According to Lazarus, the coping process changes over time, is adjusted to the situational demands and the object is to deal with a situation rather than to master it [22,33]. A difference between coping resources and coping strategies has been proposed [35]. Coping resources have been defined as "any aspect of the organism's functioning which could be viewed as a mediator of stress"[36] or "those resources inherent in individuals that enable them to handle stressors more effectively, to experience fewer symptoms upon exposure to a stressor, or to recover faster from exposure" [37]. Coping strategies/skills are the ways we use these available coping resources and competences when coping in different specific situations. These resources are generally regarded as health promoting and individuals with large resources and a broad coping repertoire are more resilient and less vulnerable to stressful events and this may be measured by the coping resources inventory (CRI) [37].

In 1997, a revised stress and coping model was introduced with a new category, meaning-focused coping, including positive emotions in the stress process [38]. According to Folkman, "these emotions and appraisals influence the stress process by restoring coping resources and providing motivation needed in order to sustain problem-focused coping over the long term" [39]. Initially, this concept included four categories: positive reappraisal, revision of goals, spiritual beliefs and the infusion of ordinary events [38]. The modified and developed model has five categories: benefit finding, benefit minding, adaptive goal processes, reordering priorities and infusing ordinary events with positive meaning [39].

The theory of proactive coping is another way of focusing on positive aspects in the stress process [40]. Proactive coping is oriented towards future actions to protect an individual from stress. This is in contrast to the traditional form which regards coping as an adaptive reaction to diminish stress that has already occurred. Furthermore, proactive coping may act as a mediator between the coping resource of social support and subjective well-being, pointing to the idea that social support and coping work synergistically in the direction of positive outcomes [41].

3.4 Life satisfaction

Quality of life, subjective well-being and life satisfaction are related concepts. Life satisfaction could be described as the individual's subjective perception of quality of life, excluding the multidimensional functional status related to social, emotional, economical and physical well-being and functional ability [42]. Life satisfaction has also been defined as the cognitive component of subjective well-being including a judgmental process in which your goal is to minimize your unpleasant experiences and maximize your pleasant experiences [43]. In this sense, life satisfaction is not a direct measure of emotion, but it may be influenced by affect [43]. Research relating to subjective well-being, i.e. life satisfaction, has introduced two theoretical models labeled top-down and bottom-up theories [43]. The top-down theories [43-45] focus on the foundation of stable individual characteristics predisposing the level of life satisfaction, indicating an association with global personality traits [46,47], in particular Extraversion and Neuroticism [48-51]. In contrast to the top-down approach, the bottom-up theories assume that temporary conditions or current mood influence life satisfaction [52], but it may also depend on general contextual sources in life. According to the bottom-up theory, factors such as working conditions [17,19,53], social support [17,19,53,54], leisure activities including physical training [17,19,55], psychosocial challenges [56,57] and negative life events [17], could influence a physician's life satisfaction. Different studies of this kind have presented various results, ranging between comparably high [55], average [58,59] and low levels [17] of satisfaction.

The top-down and bottom-up theories may even be integrated to describe the perspectives of subjective well-being [47,60]. Research incorporating these two models proposes that objective circumstances have an influence on individuals' satisfaction, but the impact of this influence is filtered by personality traits, i.e. both dimensions have an indirect effect on the interpretation of an individual's life circumstances [60].

The theoretical framework of this thesis is based on the integration of the two models as we consider this approach as the most preferable way of describing the complex aspects of life satisfaction.

4. Protectors and challenges for physicians in their daily work

4.1 Motivation

Motivation could be described as the internal state/condition/ "generator" that drives people to work and act in the direction of a desired goal without the need of external stimulation [61] or it may be defined as a a person's stress-resilience capacity [62]. Motivation differs from satisfaction, which is defined as the external "refueling station for that generator" [63]. On the other hand, work-related motivating factors may be divided into extrinsic (positive or negative) and intrinsic factors. However, measuring work motivation is not an easy task [64], although there are multiple self-reporting instruments to assess a person's motivation [65].

Studies of physicians reveal that intrinsic motivating factors may be intellectual challenges, autonomy and sense of competence in skills. Job security may be regarded as a positive extrinsic factor, while long working hours are often a negative factor. All these factors may interact [63]. In balancing all the daily stress of working with life-threatening illnesses, motivational factors may play a key role as well. We were not able to find any nationwide studies of possible motivational factors for pediatric oncologists. In this study these physicians' internal motivation, coping resources and stress-resilience capacity, are measured by the psychometric instruments; sense of coherence (SOC) and coping resources inventory (CRI). In our study-specific questionnaire, the POCQ (Pediatric Oncology Coping Questionnaire), the variable "Factors of Motivation" includes aspects of internal and external (positive and negative) motivation.

4.2 Personality

An individual's characteristic behavior, cognitive style, and affective tendencies are fairly stable over time, according to trait psychology [66], but certain traits also show patterns of normative change across the life span [67]. There are several multidimensional models describing different traits and several different measures to assess personality [68]. Many of these instruments include several hundred items and they are time consuming and may negatively influence the response rate in a survey using different questionnaires. The framework of the Five-Factor Model (FFM) [69] is widespread and includes five dimensions: Agreeableness, Conscientiousness, Openness, Extraversion and Neuroticism.

The FFM has strong genetic factors [12,13], high stability throughout life [14] and diverse cultures [8,15-17] and is able to predict outcomes such as well-being [8]. Global personality traits [6,7], in particular Extraversion and Neuroticism [8-11], are associated with the top-down theories of life satisfaction [3-5].

In this thesis, the FFM has been studied by using a short questionnaire (n=20), using the HP5i (Health-relevant Personality 5 (Five-Factor Model = FFM) inventory), which is specifically applicable in health and personality research [68]. The five subscales are labeled: Antagonism, Impulsivity, Hedonic Capacity, Negative Affectivity and Alexithymia and intend to measure facets of the five factors. *Antagonism* represents a hostile behavior and cynicism, and may cause interpersonal conflicts and distress. *Impulsivity* is related to risk-taking and unhealthy behaviors and non-planning activities, but it may also express impatience and "an excessive competitive drive" [70]. Impulsivity has been identified as a part of the concept of Type A behavior which is a risk factor of coronary heart disease [71], and Impulsivity has also been associated with burnout in medical students [72]. *Hedonic Capacity* is correlated to positive affectivity, excitement and assertiveness. *Negative Affectivity* is characterized by negative emotions, psychasthenia, anxiety, and nervous tension. *Alexithymia* means literally "no words for feelings" and is associated with difficulties experiencing and expressing emotions, lacking imagination, having feelings of meaninglessness and being socially conforming [73].

A person low in Antagonism/high in Agreeableness is likely to be helpful, kind, forgiving, generous and sympathetic. Low levels of Impulsivity/high levels of Conscientiousness characterize individuals who are reliable, organized and efficient and hard working, with a sense of duty. A high level of Hedonic Capacity/Extraversion describes persons with an optimistic, sociable attitude, full of energy and enthusiasm, prepared to take risks, active and with a tendency to be impulsive. Low levels of Negative Affectivity/Neuroticism are typical of those who have stable self-esteem, are calm and have low levels of anxiety and depression. An individual low in Alexithymia/high in Openness is often curious, high in creativity and imaginative [69].

4.3 Professionalism

"Professionalism" is a term which has its roots in the guild system in Europe during the medieval era [2]. At that time, the guilds were organizations that gave their members the status of master craftsmen. When this form of guilds died out, some professions were organized in a similar way, e.g. the physicians. This background has given the medical profession a high status in different cultures and the profession has been related to a high educational level and high socio-economic status. Physicians have also been recognized as belonging to a group with a high degree of freedom within their professional practice and with an opportunity to come to a decision based on the individual's acquired knowledge. Medical professionalism has been associated with physicians who are skilled and appreciated, who make well-considered ethical decisions and can also be condemned. There has been a change in the professional role, the expectations and the demands during the last few decades [56]. These changes are related to increased expectations in relation to medical efforts and results, combined with expectations relating to reduced costs and new organizational models [74]. According to Karasek's demand-control model, the most stressful challenge is to combine low control of work with high demands [75]. Recent research concerning physician professionalism emphasizes the influence of environmental and personal factors, including well-being [76,77].

4.4 Breaking bad news

The strained role of breaking bad news is known to be the doctor’s agony, as he or she has been trained to cure but is forced to deliver bad news, feeling that he/she has failed to realize the “goal of cure”, while living in a society fearing death [78]. Communicating bad news is therefore a stressful task [79] and may contribute to the oncologist’s anxiety and depression and lack of personal fulfillment [80]. Communication in oncology is also characterized by several challenges [81,82], including cultural aspects [83]. Relapse has been identified as the most stressful message, because it could signal the terminal phase [84]. The fear of being blamed for the message, the fear of facing personal illness and death [85] and a sense of powerlessness at losing words to express one’s feelings may be present [86]. To regain control, the strategy of developing expertise is known to be one way of improving the oncologist’s self-esteem and tackling the tasks as challenges is another way of reformulating the disease and its consequences into soluble problems [87]. This intellectual approach may also reduce the professional risk of developing psychiatric disorders known to be associated with dealing with treatment toxicity/errors and the stress of being overloaded [80]. Patient-doctor communication, building a relationship, is regarded by the parents of terminally ill children as a principal determinant of high-quality physician care and, when appropriate, it also allows for communication directly with the child [88]. This method has mostly been practiced by physicians in western countries [85,89]. A direct approach, talking about the cancer diagnosis and death with the child or the adolescent, presupposes cultural sensitivity [83,90], although studies of parents whose child is undergoing treatment for cancer [88] and parents who have experience of losing a child to cancer [91] emphasize openness and talking. Bedside communication training with role models is a promising way of teaching communication [92], as it is a core clinical skill [93,94].

5. Risks and harmful consequences

5.1 Mental distress among physicians

Historically, the physician’s health and well-being was threatened by external work-related exposure such as chemical agents, X-rays and severe infectious diseases. Today, health-related studies involving physicians have shown that they are somatically as good as, or healthier than, the general population [95-97] and their external environment is mostly under control. However, the internal environment is threatened and several reports indicate psychological problems and mental distress [18,96,97], in particular among young physicians [98,99]. In the general population, there are known gender differences relating to depression, which is more common in women than in men [100]. Suicide rates among physicians in Scandinavia have been studied and have been shown to be higher in this profession, particularly among female physicians [101] compared with other educational groups [101-103]. During the last two decades, some studies indicate declining suicide rates within the profession, together with decreasing gender differences [102,103]. Focusing on medical specialties, some studies have suggested that physicians dealing with critically ill, incurable or dying patients, e.g. oncologists and psychiatrists run a greater risk of developing burnout [104] and the choice of pediatrics are related to high levels of death-related agony [84]

According to a psychodynamic theory of illness, a psychological conflict may be transformed into bodily distress, so-called somatization [105]. This term has also been defined as a pattern of abnormal illness behavior and disturbances in the regulation of physiological systems may play a role [105,106]. Somatization is one of the manifestations of the somatoform disorders [107] and may be regarded as an altered cognitive process, with an augmented perception of sensations from the body, and a key element in this process is alexithymia [108]. Cross-cultural prevalence studies reveal significant cultural variation, partly dependent on these different definitions [105].

5.2 Stress and burnout in oncology

The concept of stress has no uniform definition. In scientific literature, the concept has been separated into two different areas, defined as physiological and transactional stress [109]. The physiological reaction is related to the rapid activation of the sympatho-adrenal system and a slower cortisol response, both of which also have effects on the immunological system. Transactional stress focuses on the cognitive and emotional processes influencing the reaction. Internal and external stressors are factors that activate these different areas and the significance of a stressor is dependent on the individual evaluation (appraisal). The end result of stress, the burnout syndrome, has been known as a concept since the late 1970s and it is defined by three dimensions: emotional exhaustion, depersonalization (cynicism) and low [110] personal accomplishment (inefficacy) [15]. Burnout studies in physicians have been associated with pre-existing individual vulnerability [51,111], while other studies have emphasized the role of personality and work-related factors [112,113]. Among cancer professionals, aspects of occupational, demographic, personal and organizational factors have been studied [57] and the prevalence of burnout is elevated, although there is heterogeneity across the studies [80,114,115]. Young healthcare professionals have the highest levels of stress dealing with oncology patients and workday stress [99]. Studies focusing on medical oncologists suggest that 30 to 50 % experience significant burnout [80,114,116,117] and the difficulties are related to certain aspects of the disease, e.g. their own reactions and the interaction with patients [87]. The specific challenges in pediatric oncology have mainly focused on stressors for nurses revealing aspects of bereavement, ethical dilemmas, complex treatment regimens and general aspects relating to work load and interpersonal conflicts, for example [118]. Pediatric oncologists have expressed stress related to communication [81], parent-physician interaction [88,119], , and decision-making [120,121]. Time constraints is known to be a predictor of the pediatric oncologist's anxiety when meeting dying children and their parents [122] and there is a lack of formal education and evidence-based practice in pediatric palliative care [122,123]. Furthermore, pediatric oncologists may have difficulties mastering their own mental health, having experiences of illnesses or severe medical events during their own growth [84]. According to Mukherjee et al [124], "the evidence on stress and burnout in pediatric oncology staff is extremely limited".

6. Pediatric oncology today

The medical history of pediatric oncology is the history of how a previously uniformly fatal disease became curable within just a few decades (Figure I). In spite of this improvement, 20% of the children still have incurable diseases and only palliative measures and psychosocial support can be offered. In addition to these burdens, physicians working in the field today also have to deal with the risks and severe side-effects of the increasing intensity of the current and successful treatment strategies. In the early years of pediatric oncology, a cure was considered a great achievement. Today, the demands made by both the patients and society to offer curative treatment are increasing and are sometimes even taken for granted when it comes to such highly complicated procedures as a bone marrow transplantation. These increasing demands, together with the even more complicated treatment protocols, are a heavy burden for today's pediatric oncologists. The training to become a pediatric oncologist lasts for approximately 8 years upon graduation. This training includes working at a pediatric oncology center for at least 3 years. Furthermore, training within child and adolescent psychiatry, radiotherapy, and hematology is recommended.

At the present time, about 300 children and adolescents (0-18 years) are diagnosed with cancer every year in Sweden. In all, around 65-70 will die during the course of the disease. The initial work-up and first chemotherapy treatment for every new child is centralized at six child oncology centers. At these academic medical centers, surgery and radiation therapy are also performed, while some parts of the chemotherapy are given at non-academic medical centers. The work of the pioneering generation created a stable foundation and still influences the clinical and scientific work of pediatric oncology. The keyword was, and still is, collaboration at national, Nordic and international level.

My personal experiences have influenced the research questions in this project. However, there are some specific arguments when it comes to studying the psychological aspects of being a pediatric oncologist, i.e. (a) every new patient will die if he or she does not undergo treatment, (b) the surviving patient runs a great risk of having/developing long-term sequelae [125] and the oncologist's decisions may have a decisive impact on the child's future, (c) emotional and existential issues are continuously present in this field and the holistic view is crucial, (d) in a medical world of increasing data on evidence-based medicine, pediatric oncologists still partly rely on "trial and error" when encountering death and suffering [122,123], (e) physicians with demanding patients risk developing disillusion-stress-burnout [126] and (f) previous research in Sweden has pointed out that physicians facing severely ill children rate this task as particularly difficult [127]

There are currently some central questions: what are the needs, the rewards and the difficulties for physicians working with severely ill children?

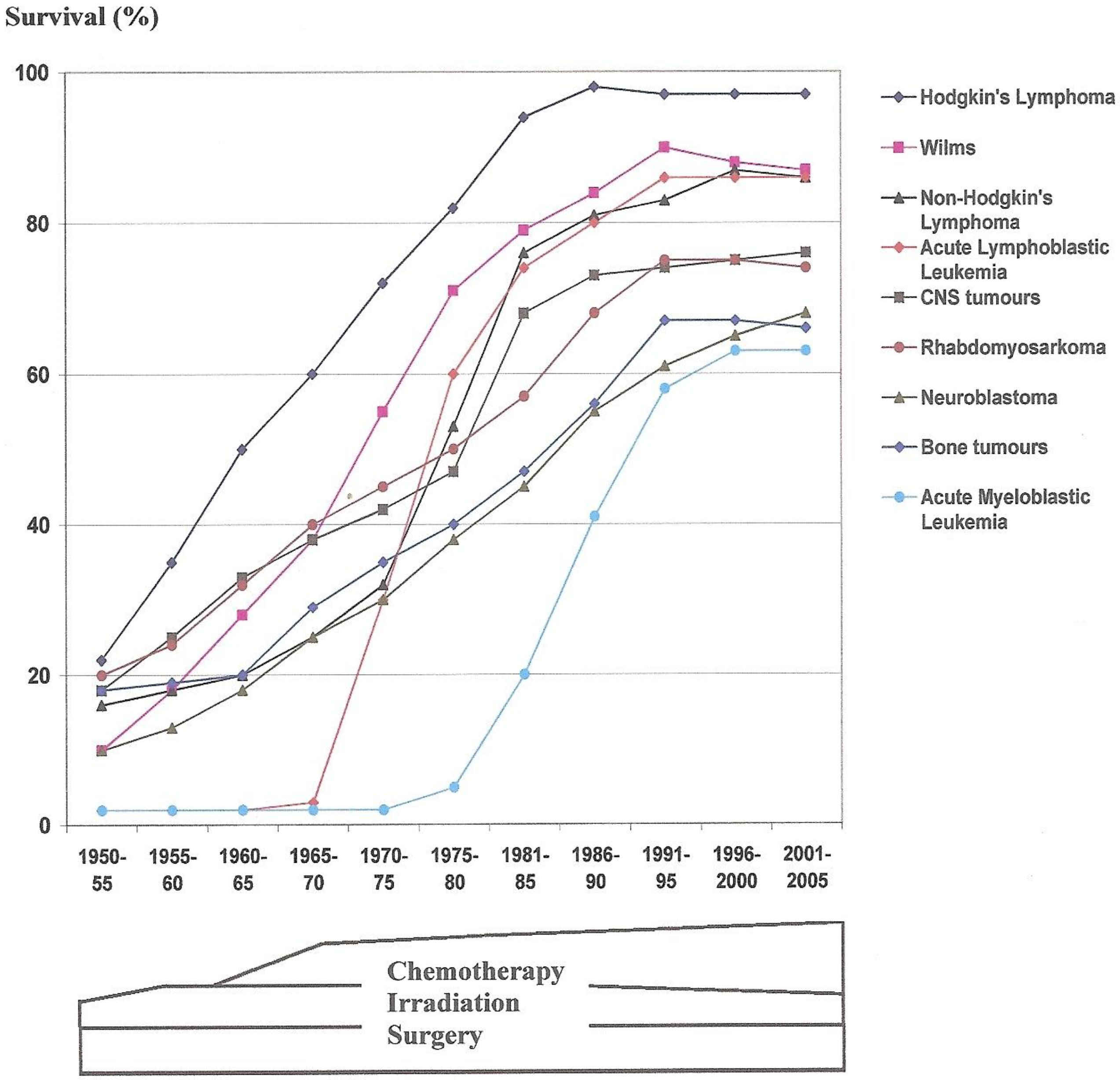


Figure I. The prognosis (5-years survival) over time for selected diagnostic groups. The most pronounced improvements in prognosis occurred during the period 1970-1990, especially for the ALL, NHL, AML and CNS-tumors. The results during the last decade seem to have reached a plateau. (Gustafsson, G. et al. 2007. Report.)

AIMS OF THE THESIS

General aims

The general aim of the present thesis was to study the everyday life of pediatric oncologists, i.e. their motivating factors, stress-resilience capacity, life satisfaction and work-related difficulties. These factors are studied against relevant background characteristics, the length of experience (more/less than 10 years) and type of medical center (academic/non-academic). To realize this general aim, three exploratory studies were conducted: the development of an instrument (Paper I), a nationwide cross-sectional study with questionnaires (Papers II and III) and an interview study (Paper IV).

Specific aims

The specific objectives were formulated as below.

Paper I: To develop a study-specific questionnaire based on a literature review and 4 interviews with professionals with experience of crisis management, plus 9 interviews with physicians who had been pioneers in pediatric oncology

Paper II: To examine the stress-resilience capacity of 89 pediatric oncologists, analyzing the role of motivation, emotional distress and overall life satisfaction

Paper III: To examine the life satisfaction of 90 pediatric oncologists, analyzing the role of personality, work-related factors and emotional distress

Paper IV: To examine experienced physicians’ main concern and the strategies they used to handle these challenges when working with children with cancer.

METHODS

1. Design

The design of this thesis was descriptive and cross-sectional, with an inductive approach [128]. The methodological framework was a mixed research strategy including qualitative (interviews) and quantitative (questionnaires) methods [129]. Qualitative data are useful in an attempt to arrive at an holistic understanding of a context and the quantitative approach makes it possible to have generalizability [129]. Qualitative interviews, together with a literature review, were performed to develop an instrument suitable for a quantitative nationwide study. In order to obtain a deeper understanding of the results of the nationwide study, new qualitative interviews were carried out. An overview of the design, study period, participants, procedure and data analyses is presented in Table I.

Table I. Overview of the studies included in this thesis

Paper	Study Period	Design	Participants	Procedure	Data analyses
I	2004-2005	Development of an instrument	Four professionals (physicians, priest, welfare-officer) and Nine physicians/pioneers in pediatric oncology	Qualitative interviews Literature review	Thematic analysis Reliability
II	2006-2007	Descriptive Quantitative	89 physicians with 4 months to 43 years of experience in pediatric oncology	Questionnaires	Parametric statistics
III	2006-2007	Descriptive Quantitative	90 physicians with 4 months to 43 years of experience in pediatric oncology	Questionnaires	Parametric statistics
IV	2007	Descriptive Qualitative	10 physicians with more than 10 years of experience in pediatric oncology	Qualitative interviews	Grounded Theory

1.1 Quantitative methods

The traditional way of conducting medical science is the quantitative approach. This research culture has its roots in a positivistic philosophy involving confirmation and falsification [129]. In this tradition, the impact of statistics and statistical significance is very important and purists within this culture emphasize that even social observation and qualitative data should be treated in much the same way as mathematical phenomena. Other researchers would argue that analyzing the ordinal quality of data with quantitative methods is problematic. Furthermore, using parametric methods to study non-numerical data is controversial, although it has long traditions in different research fields, especially within the areas of sociology and psychology [130,131]. Quantitative methods are useful for studying a large number of participants and it is possible to generalize research findings. Physicians in general, and this target population in particular, are familiar with these methods. Swedish pediatric oncologists continuously report data relating to their patients to the common Nordic childhood cancer database and, as a result, we expected a high response rate, guaranteeing confidentiality. Furthermore, questionnaires have few geographical limits, can be relatively easily distributed and collected and have financial benefits. The questions are standardized, i.e. they are presented in exactly the same way to every participant, as are the alternative answers. In our study-specific questionnaire, free comments could be added to every item and even questions with free-worded answers were offered.

In spite of these advantages, questionnaires are time consuming, especially when combined with a number of psychometric instruments. Limitations in self-report research also include the risk of socially desirable answers and the stability of the reported data may be weak [132]. Ethical aspects related to sensitive issues must be taken into account and there is no way of knowing for certain how the respondent interprets a question.

1.2 Qualitative methods

The purists in qualitative research culture argue in favor of a strong ontological relativistic approach, emphasizing that every person has his or her own reality and not just his/her own perspective of reality [129]. The advantages of these methods include aspects of the suitability for in-depth studies with few participants. The participant's local circumstances and complex contexts can be described in detail. On the other hand, qualitative data call for rigorous control to ensure "reflexivity" [133], i.e. a critically and transparent attitude towards the context and the analyses. However, some researchers would claim that remarks relating to qualitative research are questionable because it is not possible to generalize the interpretation, i.e. the study is finalized and unique to itself. Furthermore, the interviewer may influence the respondent and his/her answers and no quantitative predictions are possible to perform [129].

2. Reliability and validity

When using empirical measurements, it is crucial to take account of their basic properties, i.e. their reliability and validity[134]

2.1 Quantitative studies

Reliability refers to the reproducibility of a measurement. Reliability can be measured using the internal consistency method (Cronbach's alpha), the test-retest method, the alternative-form method or the split-halves method [134]. Cronbach's alpha, which measures the consistency of the entire scale, is the most widely used [135]. Cronbach's alpha and the split-halves method can be conducted on one occasion. The test-retest method and the alternative form require two administrations. The internal consistency method depends on the number of items on the scale and the average item correlation. In the split-halves method, the scale is divided into two halves and the correlation between the score for the two parts constitutes an estimation of the reliability of the total scale. When the test-retest method is used, the same population answers the same test after a period of time. This contrasts with the alternative form where the same population answers an alternative form of the same test the second time.

Validity refers to the ability of an instrument to capture what it is intended to measure. Three different kinds of validity are suggested to constitute the basis of the concept [60,136]. Construct validity applies to a process "analogous to theory testing", i.e. measuring a theoretical construct [136]. Criterion (or predictive) validity exists when the goal is to match a test with "some other measurement that already exists" [136]. Content validity is used when measuring "a particular application established by the researchers" [136] and focuses on the logical process showing that the items correspond to what the test is intending to test, i.e. not the correlation between two instruments. Face validity is sometimes regarded as content validity [135], but others would argue that it is "merely the informal evaluation of apparent validity by the test users" [136].

2.2 Qualitative studies

In qualitative research, there is no consensus regarding ways of handling the concepts of validity and reliability. If these terms are used, they should not be separated, as they are closely related, reflecting how well the categories correspond to reality, telling "the truth" [137]. In classical GT, validity should be judged by the following criteria: fit, relevance, workability and modifiability [16,19]. Fit is how closely the concepts are grounded in data and relevance is reached if the study reflects the real concern of the participants. Workability means that the categories can explain how the problem is being resolved and modifiability includes openness to future research to develop or alter the theory when new data are introduced.

3. Participants and procedures

3.1 Paper I

This nationwide research project started in 2004 and the first goal was to create a study-specific questionnaire, as no validated instrument was available. The process of developing this instrument was divided into five phases. These phases included interviews with professionals with work-related experience of crisis management (two physicians, a psychiatrist and a general practitioner), a literature review, interviews with pioneers in pediatric oncology (nine physicians), pre-tests and revisions of the created study-specific questionnaire and a validation of the instrument.

Phase I. The open interviews performed in this phase were designed to focus on themes relating to any specific difference expressed by the medical professionals, as compared with the non-medical ones, when it came to their experience of these demanding situations [138,139]. Furthermore, the aim was to identify relevant issues relating to ways of handling crises, in order to develop items included in the study-specific questionnaire [140]. The interviews were tape-recorded, lasted for approximately 60 minutes and were performed by one of the authors (MS) at the participants' workplace. The Interview guide I is presented in Appendix

Phase II. The literature review focused on studying the specific challenges in pediatric oncology, i.e. the vulnerability, reactions and attitudes of physicians treating childhood malignancies. In 2004, few studies had focused on this topic [86,122,123,141,142] and none had been conducted in the Nordic countries, nor did they have a nationwide, population-based approach. In order to obtain a broader field of earlier publications relevant to our aims, articles by medical oncologists were included. Taking account of national and cultural differences, we focused on studies by Swedish physicians facing illness and death in cancer care [87].

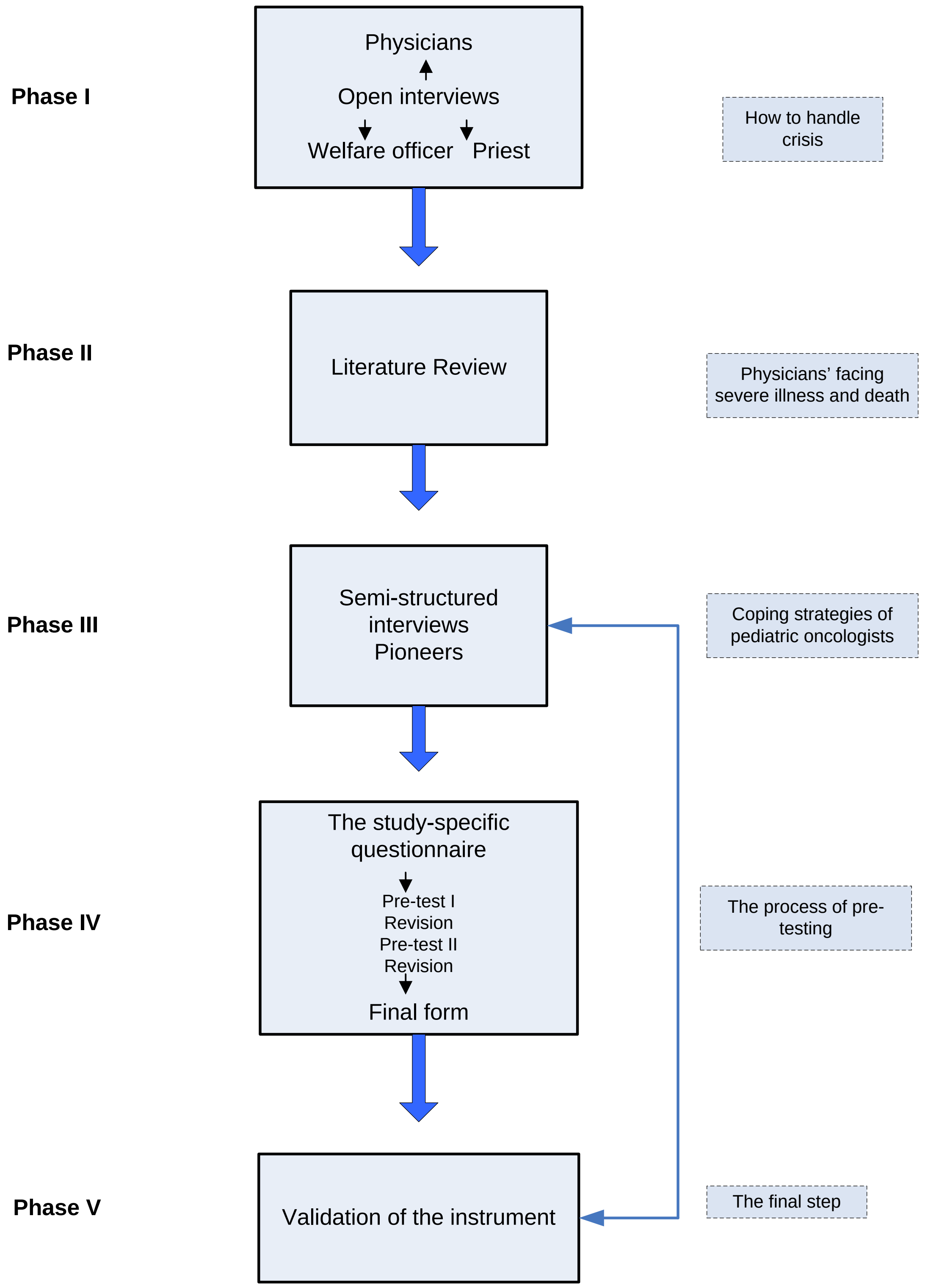
Phase III. A semi-structured interview guide was compiled. In this process, central themes relating to aspects of medical decisions and crisis management for physicians were identified from the interviews in Phase I. The physicians described their role as complex and they also described how they balanced between handling pain management and anxiety related to death, potent pharmacological treatment and patient-related powerlessness and physical/psychological impairments and uncertainty about the future. Themes identified in phase two [87], together with challenges in pediatric oncology, were used to formulate questions suitable for a semi-structured interview guide. The interview guide had two main parts. Part one focused on aspects of crisis management, i.e. conceivable coping strategies for pediatric oncologists. Part two included questions specifically designed to penetrate the experience of physicians who had been pioneers in pediatric oncology and who, during their working life, had witnessed the dramatic change in the prognosis for childhood malignancies from a uniformly fatal disease to a disease that was curable in almost 80% of cases [143]. Interviews using the semi-structured guide were conducted in 2004 and 2005 with nine pioneers (aged 64 to 83 years) in pediatric oncology in Sweden. Details concerning the work of these physicians are presented above, under the heading "The Early History of Swedish Pediatric Oncology". Seven of the nine participants had retired, but five of these retired physicians were still partially working as pediatricians. Every physician had participated in at least one national or Nordic educational session for pediatric oncologists the year before the interviews were conducted. Furthermore, everyone pointed out that they had regular contact, and often discussed clinical issues, with their younger colleagues. All the interviews were performed by one of the authors (MS) at the physicians' home or workplace; they lasted for approximately 90 minutes and were recorded and transcribed word for word.

Phase IV. The semi-structured interviews were analyzed, primarily the questions in the first part of the interview guide, and including aspects of the two authors' (MS and IM) experience of clinical work in pediatric oncology to create a study-specific instrument. The identified variables, e.g. the role of knowledge and needs in optimal pediatric oncology, were operationalized to formulate questions that could be suitable for a postal questionnaire. This study-specific questionnaire was divided into three different parts. The first part comprised demographic variables (n=20), e.g. gender, age, marital status, years of experience of pediatric oncology and type of medical center. Part two consisted of coping-related variables (n=68), initially organized into 13 theoretically based main categories. The answers to the questions were given on a five-point Likert scale anchored with "I disagree" (1) to "I fully agree" (5). Free comments could be presented in addition to each question. In the third and last part of the questionnaire, 12 to 14 questions with free-worded answers were presented. The physicians had an opportunity to express their work-related causes of rejoicing, their difficulties and obstacles, their current situation and their needs in terms of support/supervision. To some extent, the questions differed in relation to years of experience in this field. Physicians with fewer than five years in pediatric oncology were asked to comment on not only their current work-related situation but also their expected future thoughts (14 questions).

This new instrument was distributed to ten pediatricians, the majority with some experience of pediatric oncology. All the physicians were asked to document their comments and to state the time it took to complete the form. One of the authors (MS) conducted a short interview with each pediatrician, giving him/her the opportunity to present an oral report as well. In particular, the written and oral comments discussed indistinct formulations. Suggestions for supplementary questions were made. Face-to-face validation, i.e. ensuring that the questionnaire was relevant to the target population [144], was achieved by sending the revised form to another ten pediatricians. The new comments resulted in a second revision. In addition to our research group, a psychiatrist, a psychologist and a senior professor in the research field of coping participated in the entire process, by reading and reviewing the items and adding expert opinions. After this gradual refining pre-test process, the questionnaire reached its final form and was used in a national study of 90 pediatric oncologists. The questionnaire was called *The Pediatric Oncology Coping Questionnaire (POCQ).* When the national study was completed, the need for a further revision of the categories was obvious in order to focus on central themes and consider aspects of test reliability. This reliability, i.e. the internal consistency, was analyzed by calculating the Cronbach alpha value for each main category [135].

Phase V. The pioneers in pediatric oncology, who had participated in phase three, were included in the nationwide study. Their questionnaires were analyzed separately and their answers were reviewed in detail. In this phase, no specific statistical analyses were performed, but the results of the questionnaires were compared with the results of the interviews using a qualitative analysis. This analysis involved an additional text review of the opinions expressed in the interviews and a parallel review of the answers given on Likert scales, comparing the degree of unanimity, i.e. a form of validation. The whole process is described in Figure 2**.**

Figure 2. Development process of the study-specific questionnaire



3.2 Papers II and III

The study group comprised all the Swedish physicians who worked or had been working in the field of pediatric oncology for at least 3 months, at academic or non-academic medical centers, from the late 1960s to June 2006. Even pioneers, i.e. retired pediatric oncologists, were included. Initially, in an attempt to reach all physicians with any experience of children with cancer, we chose to adopt a broad approach to invite presumptive participants and, in all, 163 physicians (women n=65, men n=98) were identified. A letter of introduction was sent to these physicians between April and June 2006. The self-evident target group within this population comprised physicians who were members of the Swedish Pediatric Oncology and Hematology Organization (SSP), n=101. The two physicians (MS and IM) engaged in this research project, who are actively involved in pediatric oncology, were excluded (n=99). The extended group, i.e. the remaining 64 participants were identified by either personal contact (n=29) with every pediatric oncology center (university hospitals) and every pediatric department at county hospitals or from an unofficial list (n= 35). Telephone calls and e-mail correspondence were performed by MS. The director of the department, the head of the oncology unit or colleagues in pediatric oncology at the hospitals were contacted. They were asked to nominate possible candidates for the study. Every name mentioned was included. The unofficial list was created when the official organization (SSP) had invited physicians to a national educational day. The participants were asked to write down their names in order to have an opportunity to acquire more information regardless of their background; if they were active or previously active in pediatric oncology or just showed some interest in the field.

The letter of introduction was left unanswered by 30 physicians (women n=12, men n=18) and 25/30 belonged to the group identified from the unofficial list. We excluded these 30 physicians from our target group as we assumed that they did not feel they had experience of children with cancer, i.e. did not belong to the group. The remaining 133 physicians were contacted by telephone or e-mail and offered the opportunity to answer further questions. Twenty-eight physicians (15 women and 13 men) declined to participate, 10/28 explaining that they did not belong to the group and they were also excluded (n=123), 10/28 declined because of lack of time/too heavy a work load, 5/28 had not been working in the field for several years and 3/28 did not comment. The formation of the final study group is presented in Table II. Those that agreed to participate, 105/123, were sent a study-specific questionnaire and five self-report questionnaires by mail. All the forms were sent coded and returned in a pre-paid envelope, together with written agreement. Three reminder letters were sent between June and October 2006. In all, 89/105 of the questionnaires were returned in 2006. The last form arrived in 2007 (90/105). The vast majority, 87/89 (Paper II) and 88/90 (Paper III), of the respondents belonged to the official organization, yielding a response rate in the self-evident target group (n=99) of 88% and 89% respectively. More than half the study group (58%) practiced/had practiced at an academic medical center, meeting 25-90 new pediatric cancer patients a year, while 42% worked at a non-academic medical center, with 8-20 new patients every year. In all, 55% (56%) of the physicians spent at least half their time in direct patient care within pediatric oncology. Their age varied between 29 and 83 years, which was equivalent to normal distribution. Their experience of pediatric oncology ranged between 4 months and 43 years (median 15.0 years, mean 15.6 years). One out of ten had experienced illnesses or severe medical events in the lives of their family members during their own growth and half of the population had pediatrics as a specialty goal when they left medical school. According to previous studies physicians with more than 10 years in oncology were defined as experienced [87,99,145] and we used the same limit. The final study group, 90 participants, is presented in Table III.

Table II. Formation of the final study group

Participants	**Number**
Physicians identified as presumptive participants	163
Physicians who could not be reached by telephone nor by mail/e-mail	-30
Physicians who explained that they did not belong to the group	-10
Physicians who declined to participate	- 18
Physicians who received the questionnaire	105
Physicians who did not return the received questionnaire	-15
Participating physicians (the final study group)	90

Table III. Characteristics of the Final Study Group of Responding Pediatric Oncologists (N=90)

Characteristics	Total n (%)	Female n (%)	Male n (%)
Number of Physicians	90	29 (32.2)	61 (67.8)
Active in Pediatric Oncology	69 (76.7)	24 (34.8)	45 (65.2)
Previously active or retired	21 (23.3)	5 (23.8)	16 (76.2)
Place of work:			
Academic medical center	52 (57.8)	15 (28.8)	37 (71.2)
Non-academic medical center	38 (42.2)	14 (36.8)	24 (63.2)
Experiences in Pediatric Oncology:			
≤ 10 years	34 (37.8)	15 (44.1)	19 (55.9)
> 10 years	56 (62.2)	14 (15.5)	42 (46.7)
Marital status:			
Married or has a partner	81 (90.0)	23 (28.4)	58 (71.6)
Single	9 (10.0)	6 (66.7)	3 (33.3)
Number of children:			
One	10 (11.1)	2 (20.0)	8 (80.0)
Two	27 (30.0)	7 (25.9)	20 (74.1)
Three	26 (28.9)	9 (34.6)	17 (65.4)
Four or more	16 (17.8)	5 (31.2)	11 (68.8)
No children	10 (11.1)	6 (60.0)	4 (40.0)
Not stated	1 (1.1)		1 (100.0)
Physicians who have tested another profession in the social service			
Yes	5 (5.6)	4 (80.0)	1 (20.0)
No	83 (93.3)	24 (28.9)	59 (71.1)
Not stated	2 (2.2)	1 (50.0)	1 (50.0)
Physicians with another professional education			
Yes	14 (15.5)	6 (42.9)	8 (57.1)
No	75 (83.4)	22 (29.3)	53 (70.7)
Not stated	1 (1.1)	1 (100.0)	

3.3 Paper IV

Classical Grounded Theory (GT), an inductive general research method, was chosen in this exploratory study [146]. GT was initially called the constant comparative method with roots in medical sociology in the 1960s, when Glaser and Strauss combined aspects of quantitative sociology with symbolic interactionism. GT is suitable and useful for qualitative data, although any kind of data can be analyzed [147]. The goal is to generate new theories where little is yet known and new perspectives and knowledge of phenomena that cannot be studied using quantitative methods, including social processes. Today, GT is the most quoted and widespread method when it comes to qualitative data analysis in the world [148]. The ontological position of the classical GT version [146] resembles positivism, assuming that a researcher can objectively study the existing “real reality” without affecting the result [149]. The unit of analysis is the incident that is reported and not the participating person [146] and, as a result, the number of participants is less interesting. The result is presented in the form of probability statements based on categories which emerge when analyzing the substantive data, reflecting the participants’ main concern/problem, i.e. the core category [147] .Validity should be judged by the four criteria of fit, relevance, workability and modifiability [147,150]. Classical GT appeared to be the most suitable research method in the present study because little is known to date about the challenges and obstacles for physicians working in pediatric oncology.

This study group consisted of 10 oncologists (5 female, 5 male) from our nationwide population-based study with questionnaires in 2006/2007. The following selection criteria were used: more than 10 years’ experience (median 16.3) of pediatric oncology, both genders, nationwide representation, active or previously active in pediatric oncology and employed at academic or non-academic medical centers. The physicians were strategically selected on the basis of their comments expressed in the free-worded answers to the questionnaire to maximize the variations in experience [146]. They received verbal and written information about the aim and procedure of the study and the right to withdraw at any time without having to justify such a decision. A tape-recorded interview based on a semi-structured interview guide, lasting approximately 90 minutes, was conducted by two students (five interviews each) in their tenth semester prior to graduating in clinical psychology, at the University of Gothenburg. Each interview was carried out in a separate room at the physician’s workplace. These qualitative interviews included themes such as the role of intrinsic and extrinsic motivational factors, the workplace, the need for support and help and existential issues. During the interview, the participant had the opportunity to raise questions and, at the end of each interview, add any information he or she regarded as relevant to the management of pediatric oncology patients. Data collection is recommended to continue until saturation is reached, i.e. no additional information is provided in new interviews.

4. Questionnaires

A study-specific instrument and five psychometric instruments have been used in this thesis. They all measure individual variables and all the scales are of the Likert type. The data are presented at group level. The scales reflect emotional distress (Symptom Check List (SCL), life satisfaction (Ladder-of-Life (L-o-L), coping resources (Coping Resources Inventory, (CRI) and sense of coherence (SOC). The stress-resilience capacity presented in Paper II was measured by the CRI and SOC instruments, while life satisfaction (Paper III) was measured by the L-o-L instrument. The demographic data relating to the study population were collected from the study-specific instrument.

4.1 Pediatric Oncology Coping Questionnaire (POCQ)

The development of, and details relating to, this instrument are presented under the heading “Participants and Procedures”, Paper I. In the Appendix, the interview guides (Interview guide I and guide II (part I)) together with the questionnaire itself can be found.

4.2 Sense of Coherence (SOC)

The sense of coherence instrument measures a person’s stress-resilience capacity and the salutogenic factors that influence a person’s location on the ease/disease continuum. The instrument can be divided into three components: comprehensibility, manageability and meaningfulness. These components are intertwined and therefore, according to Antonovsky, the SOC concept should be regarded as unidimensional [26]. The instrument includes 29 items with 7 alternatives for each item [151]. The scores vary between 29 and 203. A high score indicates that health-giving factors are available, i.e. points to the direction of “ease”. However, there is no clear cut-off point between high/low scores, because Antonovsky did not define the level of a normal SOC [26]. Different studies have expressed different levels and used different terms to define the levels, such as high/low, low/moderate/high and weak/strong [152]. Mean values above 150 are usually regarded as “high”. Examples from each of the three domains are presented: a)

Comprehensibility (cognitive); Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them? b) Manageability (instrumental/behavioral); Do you have the feeling that you're treated unfairly? c) Meaningfulness (motivational); Most of the things you do in the future will probably be: Completely fascinating (1) – Deadly boring (7).

4.3 The Coping Resources Inventory (CRI)

The CRI assesses an individual's stress-management capacity [37]. The instrument consists of 60 statements, grouped according to five domains: cognitive, social, emotional, spiritual/philosophical and physical coping resources. Each statement can be answered on a four-grade scale with the alternatives never or rarely (1), sometimes (2), often (3) and always or almost always (4). The total score constitutes the sum of the scores for the different subcategories. A high score indicates greater resources. According to Hammer and Marting [37], the cognitive scale is related to a person's "sense of self-worth, positive outlook toward others, and optimism about life in general", e.g. I feel as worthwhile as anyone else. The social domain reflects the role of the supportive social network, e.g. I am part of a group, other than my family, which cares about me. The emotional domain is "the degree to which individuals are able to accept and express a range of affect", e.g. I can show it when I am sad. The influence of personal philosophy, religion, familial and cultural tradition guiding one's values is measured in the spiritual/philosophical domain, e.g. I accept the mysteries of life and death. Finally, the health-promoting behaviors are measured by the physical scale, e.g. I exercise vigorously 3 to 4 times a week.

4.4 The Ladder of Life (L-o-L)

In this instrument, the respondent rates his/her past, present and expected future overall life satisfaction. The rating presents the most desirable life at the top of the ladder (10) and the least desirable life at the bottom (1) [153,154]. The three questions are formulated as follows: At present, which of the steps would you say you are standing on? One year ago, which of the steps would you say you were standing on? If you think about your future, where will you be standing when one more year has passed? A "Total overall life satisfaction" scale was calculated, suggested by Professor Kjell Hansson, which constitutes the sum of the scores for each of the three domains (Paper III). The Cronbach alpha value was 0.83. This L-of-L instrument was used when Reiss et al. prepared a large "Twin Mom Study" comparing Swedish and American samples [155,156]. The normative values presented in Paper II (Table

IVA) were selected from this preparation stage (personal notes, Professor Kjell Hansson, who participated in that study).

4.5 The Symptom Check List (SCL-90)

This self-report instrument is used to assess psychological and emotional symptoms in adults [157]. It has been used worldwide and contains 90 items, organized in ten subscales. The instrument was standardized to Swedish conditions in 2002 [158]. A Global Severity Index (GSI), i.e. the overall symptoms could be calculated, as well as an index for each subscale. In this study, the subgroups of anxiety, depression and somatization were used, making a total of 35 items. The answers are given on a five-point Likert scale ranging from 0 (not at all) to 4 (very much), covering the last seven days. A low score indicates lack of psychiatric symptoms and a good state of mental health.

4.6 The HP5i (Health-relevant Personality 5 (Five-Factor Model = FFM) inventory) is a short personality inventory (n=20) specifically applicable in health and personality research [68]. This instrument was chosen in order to avoid an overly extensive protocol. It consists of five subscales labeled: Antagonism, Impulsivity, Hedonic Capacity, Negative Affectivity and Alexithymia. Each of these subscales corresponds to each of the main factors in the FFM for personality traits [69] Agreeableness, Conscientiousness, Extraversion, Neuroticism and Openness. A four-point Likert scale anchored with “Does not apply at all” (1) to “Applies completely” (4) is available for each statement.

STATISTICAL ANALYSES

The Statistical Package for the Social Sciences (SPSS) versions 13.0 (Papers I and II) and 15.0 (Paper III) were used to perform the statistical calculations. One participant left more than 25% of the items on some scales unanswered and was excluded from these analyses (Papers II and III). Descriptive statistics, one-way ANOVA and multiple regression equation models, i.e. linear regression analyses (Paper II) and hierarchical regression analyses (Paper III), were used. To analyse the differences between the study group and normative groups, one-sample t-test was used. Analyses were carried out separately for males and females when appropriate. Pearson's product-moment correlation was calculated when studying the bivariate relationships between dependent and independent variables. The internal consistency of the main categories of the study-specific instrument (POCQ) presented in Papers I, II and III and the different psychometric instruments (Papers II and III) were shown by the Cronbach alpha measure. This alpha coefficient reflects the relationship between items within a score. A level of 0.70 is generally recommended, but a coefficient of 0.60 is suggested in exploratory studies [135]. Effect sizes (R^2) between each group in the hierarchical regressions were calculated and were defined as small around 0.02, medium around 0.13 and large around 0.26 [36]. The following statistical symbols were used: *= $p < .05$, **= $p < .01$ and ***= $p < 0.001$. All the presented data are statistically significant, two tailed and a type I error rate of 0.05 was used in each test. The different statistical methods are presented in Table IV.

Table IV. An overview of statistical methods used in Papers I to III

Methods	Paper I	Paper II	Paper III
Descriptive statistics			
Mean		X	X
SD		X	X
Range		X	X
Differences between groups			
One-sample t-test		X	X
One-way ANOVA		X	X
Reliability			
Cronbach's alpha	X	X	X
Association			
Pearson product-moment correlation		X	X
Linear regression analyses		X	
Hierarchical regression analyses			X
Step Effect Size			X

ETHICAL APPROVAL

The Regional Ethical Review Board in Gothenburg approved the study (archive number 175-6). Every participant received written information about the aim and procedure of the study and was offered the opportunity to raise questions and the right to withdraw at any time without having to justify such a decision. To guarantee confidentiality, all the questionnaires were coded and registered separately from the signed informed consents. The registration was performed by a secretary with no connection to pediatric oncology.

The study was supported by the Swedish Organization for Pediatric Hematology and Oncology (SSP). The chairman wrote a letter, which was attached to the written information to emphasize the need for such a study.

ERRATA

Papers II and III

The instrument L-o-L, Table IVA (Paper II) and Table III (Paper III), consists of three one-item scales. The computation of internal consistency does not apply to these scales. In Table IVA (Paper II) the Cronbach alpha values are incorrectly reported at each statement. In Paper III (Table III) the total L-o-L scale is presented. The correct Cronbach alpha value for the total scale is 0.83 (Table V). The alpha values at each statement, regarding the L-o-L, in Table IVA (Paper II) and Table III (Paper III) should be deleted.

RESULTS

Descriptive statistics of the five psychometric instruments are presented in Table V. The results are compared with national and international normative groups. These groups are described in the original data sources [68,155,156,158-160], and represent different professions including hospital staff. The sample sizes are very varying and are presented as total and/or female/male populations.

1. Developing a study-specific questionnaire (Paper I)

In Sweden, and in the Nordic countries, there are no studies of the psychological challenges involved in being a pediatric oncologist. The project of developing a study-specific questionnaire started with interviews with professionals with work-related experience of crisis management (Phase I). The analysis revealed that the ultimate challenge for physicians meeting individuals in a state of crisis was related to the balance between having medical responsibility and giving psychological support to the person with whom he/she was interacting. This multidimensional role was assumed to be a reality for physicians in different specialties, including oncology. The interview analysis focused on statements relating to the physicians' own feelings when facing severe illness and death. A previous research review (Phase II) pointed out that the medical culture has not allowed physicians to express their vulnerability and feelings of fear when facing disaster and stress**.** In such an environment, detachment and denial may be ways of coping with your own feelings of insufficiency, or you may reduce/moderate your levels of stress by a deep involvement and a positive attitude towards taking on challenges [161]. Pediatric oncologists have reported several challenges related to the care of dying children [122] and studies of physicians in cancer care have shown that they use certain coping strategies, in order to handle their daily work [87]. The semi-structured interview guide compiled in Phase III was based on Phases I and II. The guide was divided into two parts. The first part focused on conceivable coping strategies and identified some central areas, e.g. motivation, personal qualities/traits, the physician-patient relationship and work-related factors. Part two revealed the process the pioneers went through during their working life. Data relating to this process, analyzed according to the qualitative method of grounded theory, will be presented elsewhere.

Table V. Study Group of Pediatric Oncologists in comparison with Normative Groups. Mean values, Standard deviations and Cronbach alpha values for the Psychometric Instruments.

	Studygroup				Normative group CRI (Ekecrantz, Norman & Psykologiforlaget AB) 1991			
Variable	Mean value (SD)			Cronbach's alpha	Mean value (SD)			Cronbach's alpha
	Total (N=89)	Female (N=29)	Male (N=60)		Total (N=33)	Female (N=20)	Male (N=13)	
TOTCRI	171.4 (17.8)	175.6 (19.4)	169.3 (16.8)	0.78	168.8			0.91
COCCRI	28.4 (3.6)	28.4 (4.1)	28.3 (3.4)		28.3			
SOCCRI	40.2 (4.6)	41.4 (4.7)	39.5 (4.4)		40.4			
EMOCRI	44.9 (6.8)	46.2 (7.1)	44.2 (6.7)		44.5			
S/PCRI	29.2 (4.6)	30.1 (4.6)	28.7 (4.5)		28.2			
PHYCRI	29.4 (4.7)	28.9 (4.4)	29.6 (4.8)		30.0			
					Normative group SOC (Hansson & Olsson, 2001)			0.89
						Female (N=63)	Male (N=65)	
SOC	152.2 (15.5)	150.2 (15.8)	153.2 (15.4)	0.76		150.8 (24.5)	154.9 (18.4)	
					Normative group L-o-L (Reiss et al, 2001)			
L-o-L						Female (N=650)	Male (N=649)	
L-o-L, present	7.7 (1.4)	7.1 (1.4)	7.9 (1.3)			7.7 (1.5)	7.6 (1.3)	
L-o-L, past	7.7 (1.4)	7.1 (1.7)	8.0 (1.1)			7.1 (1.8)	7.2 (1.5)	
L-o-L, future	8.1 (1.2)	8.0 (1.1)	8.1 (1.3)			8.3 (1.4)	8.2 (1.3)	
					Normative group SCL-90 (Fridell et al, 2002)			0.98
SCL - 90						Female (N=707)	Male (N=309)	
Anxiety	0.1 (0.4)	0.1 (0.4)	0.1 (0.3)	0.73		0.6 (0.5)	0.3 (0.4)	0.82
Depression	0.1 (0.4)	0.1 (0.3)	0.1 (0.4)	0.73		0.7 (0.7)	0.4 (0.5)	0.91
Somatization	0.2 (0.3)	0.2 (0.4)	0.2 (0.5)	0.73		0.5 (0.5)	0.4 (0.4)	0.81
					Normative groups HP5i (Gustavsson et al, 2003)			
5HPi					Total (N=303)			
Antagonism	1.9 (0.5)	1.8 (0.4)	2.0 (0.5)	0.66	2.1 (0.6)			0.65
Impulsivity	2.0 (0.5)	2.2 (0.7)	1.9 (0.4)	0.74	2.1 (0.5)			0.66
Hedonic Capacity	3.1 (0.4)	3.2 (0.4)	3.1 (0.4)	0.57	2.1 (0.4)			0.54
Negative Affectivity	1.8 (0.5)	1.9 (0.5)	1.8 (0.4)	0.64	1.8 (0.6)			0.69
Alexithymia	1.8 (0.5)	1.7 (0.6)	1.9 (0.4)	0.61	2.1 (0.5)			0.70

Abbreviations: SD (standard deviations), CRI (Coping Resources Inventory) - TOT(Total), COG(Cognitive), SOC(Social), EMO (Emotional), S/P(Spiritual/Philosophical), PHY (Physical) and SOC (Sense of Coherence), L-o-L (Ladder-of-Life), SCL (Symptom Check List), 5HPi (Health-Relevant Personality 5 (FFM) inventory

The study-specific questionnaire compiled for and used in the nationwide study in Phase IV was based on the results of the previous phases. When the study was completed, the 13 theoretically based main categories were revised and six themes related to motivation were identified (Cronbach alpha 0.65), the workplace (Cronbach alpha 0.70), the physician-patient relationship (Cronbach alpha 0.73), psychological handling and support (Cronbach alpha 0.86), feelings about making mistakes (Cronbach alpha 0.86) and physician-rated good qualities (Cronbach alpha 0.87). Every main category included items with the full range of options presented on the Likert scales. The main categories, "Factors of Motivation" and "Work-Related Aspects", are presented in Papers II and III and the remaining categories will be published separately. In the last phase (Phase V), when the national study was terminated, the questionnaires of the pioneers were analyzed separately. The qualitative analysis revealed a high level of congruence between the results of the interviews and the questionnaires. The pioneers' ratings were also compared with the answers given by the other participants by studying every answer item by item. The range of options presented on each rating scale did not differ between this sub-group and the other participants. After this validation, the data from the pioneers' questionnaires were included in the statistical analyses of the entire study population, i.e. 89/90 physicians. Only one of 89/90 participants left more than 25% of the items on some scales unanswered.

2. Stress-Resilience Capacity of Pediatric Oncologists (Paper II)

The stress-resilience capacity was measured by the CRI and SOC-29 instruments and the role of motivation, emotional distress and overall life satisfaction was analyzed.

2.1 Factors of Motivation

The vast majority of the participants rated the following motivational factors as very important in handling oncological challenges: the need for advanced professional knowledge, national courses, international updates, security with routines, several colleagues and a multiprofessional healthcare team. The majority were stimulated by solving problems and being given the opportunity to take responsibility for the medical issues in which they were interested. A parallel finding was that not a single physician managed to accomplish his/her tasks within regular hours of work and, when facing this lack of time, even seeking solutions became a burden (37%). Two in five expressed the opinion that pediatric oncology was not a high-priority area at their clinic.

Matters relating to philosophy of life were regarded as a vital aspect for the oncologists and they regarded the meeting with pediatric oncology patients as a way of being aware of the essential issues of life. More than 70% were willing to discuss these questions. Cronbach's alpha for the main category "Factors of Motivation" was 0.65. Descriptive statistics are given in Table VI.

2.2 Importance of experience-based knowledge and the number of new patients

More experienced physicians reported a higher impact from motivational factors and overall life satisfaction related to the past. On the other hand, reported somatization was higher in the less experienced group. Pediatricians meeting 25-90 new cancer patients a year (academic medical centers) were more confident about the future.

2.3 Explained variance in stress-resilience capacity

A multiple linear regression model was used to control for the influence of the background variables (Table III). The independent variables: number of children, contemplated another profession and whether the physician had any other education were able statistically to explain 19% of the variance in the social coping capacity. There were no statistically significant differences related to any other measured background variable.

The SCL-90 and L-o-L instruments are intercorrelated and were handled in different linear regression analyses. The models for each domain within "stress-management capacity" are presented in Table VII (SCL-90) and Table VIII (L-o-L). The motivational factors displayed a tendency ($p = 0.053$) to be a part of the explanation in the equation with SCL-90 even in terms of the cognitive capacity.

3. Life Satisfaction of Pediatric Oncologists (Paper III)

The stress-resilience capacity analyzed in Paper II revealed that the life satisfaction of these physicians was a central theme explaining their stress resilience. In Paper III, we wanted to examine in more detail the life satisfaction of these Swedish pediatric oncologists by studying the role of personality, work-related factors and emotional distress.

Table VI. Main Category “Factors of Motivation” with Mean values, Standard Deviations (SD), Range and High Score Range

Variable	Mean value	SD	Range 1-5	High Score 4-5 (%)
In Pediatric Oncology it is:				
a) Very essential with professional advanced knowledge when meeting the patients	4.7	0.5	3 – 5	87 (97.8)
b) Essential to take part in national continuation courses	4.7	0.6	3 – 5	83 (93.3)
c) Essential to take part in further international training	4.4	0.8	2 - 5	80 (89.9)
In the Daily Work:				
a) It is a *stimulating* challenge to keep on seeking solutions to difficult problems	4.3	0 .8	2 - 5	75 (84.3)
b) Established routines give a sense of security when managing different diagnosis	4.6	0.6	3 - 5	86 (96.6)
c) It is stimulating with improvisations	3.8	0.9	2 - 5	53 (59.6)
d) It is a *stressful* challenge to keep on seeking solutions to difficult problems	3.2	1.2	1 - 5	33 (37.1)
The Place of Work:				
a) My place of work is in a very good order taken as a whole	3.7	0.9	1 – 5	59 (66.3)
b) I manage to accomplish my tasks within regular hours of work	2.0	1.0	1 – 4	12 (13.5)
c) Not managing to accomplish ones’ tasks within regular hours of work is a stressful factor	2.7	1.2	1 – 5	45 (50.6)
My employer:				
a) Supplies my need of further training in pediatric oncology	3.7	1.2	1 – 5	59 (66.3)
b) Regards pediatric oncology as a work with high priority	3.5	1.2	1 – 5	54 (60.7)
c) Gives me wanted responsibilities for areas corresponding to my wishes	4.0	0.8	1 – 5	73 (82.0)
Needs in optimal pediatric oncology:				
a) Several colleagues to share your experiences with	4.7	0.5	3 – 5	87 (97.8)
b) A multi-professional healthcare team around the patient	4.7	0.5	3 – 5	85 (95.5)
Philosophy of life:				
a) Meeting seriously ill and dying children makes me aware of essential issues in life	4.4	0.7	2 - 5	80 (89.9)
b) “Help and ease attitude” is part of my philosophy of life	3.6	1.2	1 – 5	51 (57.3)
c) In my daily work I am prepared to discuss questions about life and death	4.1	0.9	2 – 5	66(74.2)

Table VII. Linear Regression Model for “Stress-Resilience Capacity” concerning Motivational Factors and Emotional Distress

Variable	TOTCRI	COGCRI	SOCCRI	EMOCRI	S/PCRI	PHYCRI	SOC
				Standardized beta coefficients			
Factors of Motivation	.42***	n.s.	.44***	.42***	.33**	n.s	.31***
Depression	-.37***	-.52***	-.30**	-.29**	n.s.	-.54***	-.60***
Adj R^2	.30	.29	.27	.25	.11	.29	.45

CRI (Coping Resources Inventory) – TOT (Total), COG (Cognitive), SOC (Social), EMO (Emotional), S/P (Spiritual/Philosophical), PHY (Physical) and SOC (Sense of Coherence)
*p < 0.05 , **p < 0.01, ***p < 0.001, n.s. = not significant

Table VIII. Linear Regression Model for “Stress-Resilience Capacity” concerning Motivational Factors and Overall Life Satisfaction

Variable	TOTCRI	COGCRI	SOCCRI	EMOCRI	S/PCRI	PHYCRI	SOC
				Standardized beta coefficients			
Factors of Motivation	.41***	n.s.	.43***	.41***	.32**	n.s.	.31**
Overall life satisfaction, future	.34***	.39***	.37***	.36**	n.s.	.33**	.46***
Adj R^2	.28	.17	.32	.30	.08	.10	.30

CRI (Coping Resources Inventory) – TOT (Total), COG (Cognitive), SOC (Social), EMO (Emotional), S/P (Spiritual/Philosophical), PHY (Physical) and SOC (Sense of Coherence)
*p < 0.05, **p < 0.01, ***p < 0.001, n.s. = not significant

3.1 Working conditions

The pediatric oncologists stated that working in this medical field was very stimulating for their personal development and they did not find the work more trying than expected. They rated their work as emotionally and intellectually demanding, but these challenges were possible to handle. Two of three physicians denied being anxious about making incorrect medical judgments or giving incorrect medical ordinations. Female physicians at non-academic medical centers scored highest for the latter as a problem. Distressing factors were informing adolescents about their disease and meeting the parents of children with cancer. Some oncologists (13.4%), needed professional help to deal with work-related psychological problems, and the majority was females at non-academic medical centers. Time pressure was a reality for every physician and was regarded as a stressful factor for half the participants, as were tasks affecting their leisure time (31.1%). Male physicians at academic medical centers had the highest rating for time pressure and the lowest rating for performing their work within regular hours of work. Contributory factors making pediatric oncology emotionally demanding were economic discussions and organizational aspects at the workplace, but few participants (7.8%) found that economy influenced their potential for providing satisfactory care. Cronbach's alpha for the main category "Work-related aspects" was 0.70. Descriptive statistics are given in Table IX.

3.2 The role of personality, gender and type of medical center

The whole group of pediatric oncologists rated their levels of Antagonism, Impulsivity and Hedonic Capacity in line with comparable samples but rated their Negative Affectivity and Alexithymia at lower levels [68]. When focusing on comparisons in the subgroups, those working at academic medical centers reported higher levels of Impulsivity and were more confident about the future. Male physicians were more satisfied with their present life and their levels of Antagonism were higher. Female physicians reported higher levels of Impulsivity. The Hedonic Capacity showed a significant bivariate correlation in relation to all aspects of life satisfaction. There were no statistically significant differences related to experience in pediatric oncology or any other background variable.

3.3 Explained variance in life satisfaction

Hierarchical regression analyses were performed with total, present, past and future life satisfaction as the dependent variables. The independent variables were entered into the models according to a specified hierarchy: background variables (gender, type of medical center), personality trait (Hedonic Capacity), work-related aspects and emotional distress (depression). The four hierarchical models explained between 5 and 43% of the variance, i.e. effect sizes between small/medium and large (Tables X to XIV). Personality trait and emotional distress contributed to every aspect of overall life satisfaction. Being a male physician and employment at an academic medical center influenced total and past satisfaction. Work-related aspects contributed to present and future satisfaction to a minor degree.

Table IX. Main Category “Work Related Aspects” with Mean values, Standard Deviations (SD), Range and High Score Range

Variable	Mean value (x)	SD	Range 1- 5	High Score 4-5 (%)
Working with pediatric oncology is:				
a) Emotionally demanding	4.3	0.7	1- 5	(91.1)
b) Intellectually demanding	3.9	0.9	1 - 5	(70.0)
c) Time consuming	4.6	0.7	1 - 5	(93.3)
The problems I encounter at work are:				
a) Emotionally manageable	4.3	0.7	2 - 5	(90.0)
b) Intellectually manageable	4.3	0.6	3 - 5	(91.2)
c) Time consuming	4.5	0.7	1 - 5	(87.8)
Working with pediatric oncology is *more* emotionally demanding than I had anticipated	2.6	1.1	1- 5	(21.1)
Giving a cancer diagnosis to a teenager is a *particularly* emotionally demanding task	4.3	0.9	1 - 5	(86.6)
Meeting the parents of children with different kinds of cancer is an emotionally demanding task	4.1	0.8	2 – 5	(81.1)
I often worry about making incorrect medical *judgments*	3.0	1.1	1 – 5	(36.7)
I often worry about giving incorrect medical *ordinations*	2.9	1.2	1 – 5	(32.2)
I think that my employer regards pediatric oncology as a top priority	3.5	1.2	1 – 5	(61.1)
Organizational aspects at work are one of the reasons working with pediatric oncology is so demanding	2.9	1.1	1 – 5	(36.6)
Economic considerations at work are one of the reasons working with pediatric oncology is so demanding	2.3	1.1	1 – 5	(15.5)
I think that economic considerations influence my potential for providing satisfactory pediatric oncology care	1.7	1.0	1 – 5	(7.8)
I am able to perform my work within normal working hours	2.0	1.0	1 – 4	(13.3)
Not having the time to do my work within normal working hours is one of the reasons working with pediatric oncology is so demanding	3.3	1.2	1 – 5	(47.8)
I find pediatric oncology work that affects me during my leisure time very stressful	2.7	1.3	1 – 5	(31.1)
I have had to seek professional help for work-related psychological problems	1.6	1.2	1 – 5	(13.4)
Working with pediatric oncology has an extremely stimulating effect on personal development	4.1	0.9	1 – 5	(76.7)

Table X. Hierarchical regression for *the total* overall life satisfaction (n=90)

	Overall Life Satisfaction			
	Standardized beta coefficients			
Independent variables	Step1	Step2	Step3	Step4
Background				
1. Gender	.23*	.28**	.28**	.23**
2. Medical centre	-.29**	-.22*	-.22*	n.s.
Personality				
3. Hedonic Capacity		.36***	.35***	.29**
The Physician's grading:				
4. Work related aspects			n.s.	n.s.
Emotional distress				
5. Depression				-.48***
Adj R2	.13**	**.24*** **	.23***	**.43*** **

*p<0.05, ** p<0.01, *** p<0.001
bold type indicates significant change in variance from previous step

Table XI. Hierarchical regression for *the present* overall life satisfaction (n=90)

	Overall Life Satisfaction			
	Standardized beta coefficients			
Independent variables	Step1	Step2	Step3	Step4
Background				
1. Gender	.26*	30**	.30**	.25**
2. Medical centre	n.s.	n.s.	n.s.	n.s.
Personality				
3. Hedonic Capacity		.31***	.31***	.25**
The Physician's grading:				
4. Work related aspects			n.s.	.19*
Emotional distress				
5. Depression				-.48***
Adj R2	.09**	**.17*** **	.16***	**.35*** **

*p<0.05, ** p<0.01, *** p<0.001
bold type indicates significant change in variance from previous step

Table XII. Hierarchical regression for *the past* overall life satisfaction (n=90)

	Overall Life Satisfaction			
	Standardized beta coefficients			
Independent variables	Step1	Step2	Step3	Step4
Background				
1. Gender	.27**	.30**	.31**	.28**
2. Medical centre	-.32**	-.28*	-.31**	-.23*
Personality				
3. Hedonic Capacity		.20*	.19*	n.s.
The Physician's grading:				
4. Work related aspects			n.s.	n.s.
Emotional distress				
5. Depression				-.35**
Adj R2	.18***	**.21*****	**.22*****	**.31*****

*p<0.05, ** p<0.01, *** p<0.001
bold type indicates significant change in variance from previous step

Table XIII. Hierarchical regression for *the future* overall life satisfaction (n=90)

	Overall Life Satisfaction			
	Standardized beta coefficients			
Independent variables	Step1	Step2	Step3	Step4
Background				
1. Gender	n.s.	n.s.	n.s.	n.s.
2. Medical centre	-.25*	n.s.	n.s.	n.s.
Personality				
3. Hedonic Capacity		.43***	.43***	.37***
The Physician's grading:				
4. Work related aspects			n.s.	.21*
Emotional distress				
5. Depression				-.43***
Adj R2	.05*	**.21*****	.21***	**.36*****

*p<0.05, ** p<0.01, *** p<0.001
bold type indicates significant change in variance from previous step

Table XIV. Hierarchical regression models for the Total, Present, Past and Future Overall Life Satisfaction (Dependent Variables) and the Role of the Independent Variables

	Total	Present	Past	Future
Background: Gender	Male	Male	Male	
Medical Center	Academic		Academic	(Academic)
Personality trait	Hedonic Capacity	Hedonic Capacity	Hedonic Capacity	Hedonic Capacity
The Physician's grading		Work-related		Work-related
Emotional distress	(-)Depression	(-)Depression	(-)Depression	(-)Depression
Effect sizes	13-43%	9-35%	18-31%	5-36%

4. Being a Messenger of Life-Threatening Conditions: Experiences of Pediatric Oncologists (Paper IV)

The main concern of Swedish pediatric oncologists working with seriously ill and dying children was related to their role as messengers breaking bad news. Six conceptual categories were identified in the data analysis. The core category, *being a messenger of life-threatening conditions,* describes their main concern. The other five categories illuminate and explain the strategies used to handle this problem. These categories/strategies are labeled as *obtaining knowledge and information, saving one's strength and resources, building a close relationship, avoiding identification* and *dealing with one's attitude to central life issues*.

These five categories are presented, together with illustrative quotations, in Tables XV to XIX.

4.1 Being a messenger of life-threatening conditions

The physicians emphasized that their ultimate challenge was to make and provide information about difficult decisions. "Being a messenger of life-threatening conditions" was identified as the core category. Working conditions included facing severe suffering and a number of daily decisions which continuously balanced between refraining from treatment because of the child's condition and, at the same time, being aware of the risk of disease progression if treatment was withheld. There was no room for a "wait and see" attitude; the decisions had to be made and information had to be given.

The greatest cause of concern was associated with the situation of informing a patient and his/her family about recurrent disease and/or the transition to palliative care, in particular if the physician was alone in this process. The feeling of sometimes being alone was particularly expressed by physicians working at non-academic medical centers. Every single oncologist wanted to share or have some kind of consensus with colleagues, including international contacts, when it came to these decisions. All of them wanted to be well prepared before meeting the families. Several physicians commented that the situation was extraordinarily difficult when the patient was a teenager, as these young people are in a phase of physical and psychological growth calling for independence. They are also living with many existential issues, they reflect deeply on injustices in life and they work on their process of death, but they may not want to discuss it. The following quotation expresses the challenge:

"You shouldn't be alone with such a decision, you just shouldn't! It's dangerous. You exaggerate your role and the burden is too heavy to carry alone".

4.2 Obtaining knowledge and information

Every participant underlined the significance of seeking knowledge and information as a very central part of their professional role. The process of seeking knowledge was self-evident and easy; the challenge was to evaluate the source reliability and applicability to local circumstances. The physicians developed expertise by reading scientific articles, participating in multicenter studies, attending scientific congresses/meetings/educational sessions and through personal contact with colleagues, mail, e-mail and frequent telephone calls. Common Nordic/European protocols and national guidelines were used to ensure the equivalent treatment of every child. The cooperation between colleagues was described as very open and generous. The child-related information was collected from a direct personal family contact and medical case records. Some physicians emphasized their anxiety about prescribing highly dangerous medications, as well as their frequent agonizing about having made a mistake. Others expressed the opinion that these tasks were inevitable and should be regarded as self-evident parts of being an oncologist. Everyone followed the security system for avoiding making mistakes, e.g. systems with double-checks when giving ordinations. Ending treatment when a cure was out of reach was based on the current knowledge status (Table XV).

Table XV. The category Obtaining knowledge and information

Strategies	**Quotation**
• Seeking knowledge and evaluating the source • Reading scientific literature, protocols and attending congresses/educational sections • Contact with colleagues at national and international level • Talking to the child and his/her parents • Reading the child's medical case records • "Being a clinician" struggling for knowledge • Following the created security system avoiding mistakes	*"It's an ethical exhortation…a part of our professional ethics…never ever to give up before you have exhausted every prospect of knowledge concerning that specific type of cancer… knowing that you have reached the ultimate border of knowledge and nothing more can be done."*

4.3 Saving one's strength and resources

The physicians' high working tempo and high ambitions often interfered with the need for advanced medical decisions when time constraints created an imbalance between free time and work and a lack of time for recovery. Sometimes feeling inadequate and "carrying the patient home" could cause insomnia and tiredness and several physicians emphasized that this professional activity required dedicated time. Some oncologists were available to their workplace even in their free time, while others stressed the importance of clear-cut limits in order to have the energy to stay in pediatric oncology. The physicians' most natural strategy for seeking support was to share difficult events and worries with colleagues. Some of them were offered professional guidance, but the consequences were unclear. In the first place, they wanted clinical tutors and the best clinical prerequisite was support, competence and defined roles in a multiprofessional team. Not all physicians had access to these human resources. Time for reflection was not a matter of course, but it was requested. One invaluable source of help was a private life including social support from families and close friends, different physical activities and hobbies.

Clinical work with close, direct patient contact was much appreciated, preferably combined with research, teaching and administration. The oncologists' internal driving force to regard their tasks as challenges or "positive stress factors" which were parts of "creative solutions" was a further source of strength. The greatest reward was seeing the children cured and grow up (Table XVI).

Table XVI. The category Saving one's strength and resources

Strategies	**Quotation**
• Having a competent multi-professional team with defined roles • Balancing free time and work and your availability • Sharing difficult experiences with pediatric oncologists • Having clinical tutors with "emotional life experience", "mature opinions" and genuine interest in the field • Having a private life including a wealth of opportunities • Combining clinical work with a variety of tasks • Looking upon one's tasks as soluble challenges	*"This work is deeply satisfying, and never give me problems with my internal motivation, but the challenge is to have the energy to go on working, to create expertise, while taking on more and more tasks, without letting the work take all my time and all my soul…not letting the work kill me."*

4.4 Building a close relationship

Building a close relationship with the patients and their parents was the most common strategy in this study group. This building process was thought to take place on a multidimensional level with different interactions between the physician and the small child/the teenager/the whole family. The physicians adopted the attitude of "being the child's solicitor". The goal of the physician-family partnership was to create feelings of security, ensure treatment compliance and support the family to grow in their handling of their situation. Crises of confidence were regarded as very serious problems, while possible aggressiveness from the patient was considered as a natural, comprehensible part of the individual crisis. Experience of working with patients and families was developed primarily by following physicians skilled in the field of psychosocial pediatric oncology at the bedside and learning empathy in clinical practice from them. The term "empathy" in this setting included openness, being honest, not telling lies, being prepared to listen, keeping one's word and supplying comfort, consolation and confidence and, above all, radiating hope – never abandoning the family. The atmosphere at the pediatric oncology departments was described as warm and positive, in spite of the severe situations. In an established relationship, built-up confidence, humor and a peal of laughter could be parts of the conversation (Table XVII).

Table XVII. The category Building a close relationship

Strategies	**Quotation**
• A multi-dimensional interactive process with the child and his/her family • Creating feelings of security and support • Handling crisis of confidence and individual crisis • Developing experience and teaching empathy by role models • Radiating hope always being able to do something • Humor and a peal of laughter as parts of the established relationship	*"All the energy and all the time you spend trying to build a close relationship between yourself and the patient you'll also receive over and over and over again in return. This is a reality, especially in those cases when the treatment doesn't work."*

4.5 Avoiding identification

The pediatric oncologists described their colleagues as people who were dedicated and devoted to their profession, taking great responsibility for their decisions and having difficulty saying “no”. The work-related emotional satisfaction was obvious, but it raised the question of the individual reasons for the commitment. The contact with the families was described as authentic, honest and special but with a need to take account of the risk of becoming indispensable. It was important for the participants to clarify the role of the profession in showing empathy and sometimes identifying themselves in the sense of being a parent, but never in the sense of being a parent of a child suffering from a malignant disease. Empathy was a way of radiating your experience of having been close to families in similar situations. Identification would mean crossing a border using words such as “I understand exactly how you feel”. The risk in identification was losing the ability to make objective decisions and judgments, increasing the risk of professional burn-out and having patients and parents carrying the doctor’s anxiety. The term “empathetic distance” was used to emphasize the importance of coming close but not too close. Another way of creating this “distance” was to work in a system where the medical expertise at the department was shared between several colleagues, enabling them sometimes to withdraw. This strategy reduced the patient-related continuity but increased the physician-related recovery time (Table XVIII).

Table XVIII. The category Avoiding identification

Strategies	**Quotation**
• Being dedicated taking great responsibility but not tying people to closely to you • Having an authentic and honest relationship avoiding letting the work satisfaction be your major source of emotional nutrition • Showing professional empathy trying to imagine the situation of the suffering family • Being aware of the risk of an unprofessional identification • Trying to represent an “empathetic distance” • Sharing the medical expertise leading to the possibility to sometimes withdraw	*“You shouldn’t be incorporated in the process, in the drama…you must look at yourself and analyze your work just a little from the outside and you must realize that you are just a part of the drama, the engine in this process in the reactions of the family and all that – that is the disease itself and not you yourself…You are important but you are finite…This approach reduces your guilt too.”*

4.6 Dealing with one's attitude to central life issues

The majority of physicians defined these questions as very important and complex and therefore necessary to reflect upon and work with. The most common definition of central life issues was to have "a carefully prepared view". The physicians stated that, primarily for reasons of their own individual vulnerability, this strategy was essential. The lack of such a "view" could increase the risk of transmitting your own fear of death to the patient. Every oncologist emphasized that families in crisis should not be subjected to pressure relating to central life issues. Some physicians were prepared to discuss these issues, emphasizing that this approach could facilitate the relationship, presupposing that the questions were raised by the families. Physicians who were not prepared to discuss central life issues said that this topic could be regarded as provocative, crossing a line, with a risk of losing their neutral position.

"Meaningfulness" was another essential term which included the opportunity to acquire an insight into central life issues and to protect the dignity of the sick child. Ethical aspects relating to "meaningfulness" raised questions such as "What is a worthwhile life? Cure at any price?". For pediatricians in palliative care, death is a part of life, but every child's death is a very tragic event and an existential provocation (Table XIX).

Table XIX. The category Dealing with one's attitude to central life issues

Strategies	**Quotation**
• Regarding the area as complex assuming different standpoints • Emphasizing the need of having "a carefully prepared view" of life and death • "A carefully prepared view" could be a philosophy of life and/or include religious aspects • Being prepared to discuss central life issues or referring the issues to "the private world" • Personal traumatic events could be valuable or increase your own vulnerability • "Meaningfulness" was an essential term describing their work-related feelings	*"You need to have reflected on your own view, to have thought about the existential vulnerability of the human being, to have thought about the meaning of empathy and your view of the fairness or the unfairness of the fact that we all are going to die one day and that you have reflected on your own role in this drama within your profession."*

DISCUSSION

1. Methodological considerations

1. 1 Study design

Mixed methods research is a form of method triangulation, i.e. a way of validating the results from different perspectives [3]. According to Patton [162], triangulation can also be regarded as an attempt to protect the whole research process from bias related to research (preconceptions or prejudices of the researcher), information (a systematic exclusion or an imbalance of data) and selection (imbalance in materials or subjects). The choice of mixed research was also based on the fact that this is a small population and different methods may strength the results.

1.2 Mixed methods research in the present study

Quantitative and qualitative research represent different paradigmatic orientations, epistemologically and ontologically. There are important differences in these paradigms and a combined approach, "the third paradigm" [129], is no guarantee of a perfect study, but it creates an opportunity to minimize the weaknesses and maximize the strength of a study. The ideal of objectivity is a useful goal in both quantitative and qualitative research, but subjective decisions throughout the research process are often unavoidable in spite of the methods that are used [129].

In our study of Swedish pediatric oncologists, we chose both quantitative and qualitative analysis in a mixed research approach and the underlying research questions guided the choice of method in each study. Previous research has described a "priority-sequence model", i.e. one method should be principal and the other complementary, or a combination of methods avoiding priority decisions [163]. We felt that the different methodological approaches were equally valid and useful, without a sequence decision, when it came to obtaining a more comprehensive image of the phenomenon of "being a pediatric oncologist". The thematic qualitative analysis (Paper I) was used to obtain knowledge of professional crisis management and the experiences of pioneers in pediatric oncology to create a study-specific instrument. Questionnaires, analyzed with quantitative methods (Papers II and III), were selected to make it possible to perform the first Swedish nationwide study of pediatric oncologists. Furthermore, the aim was to present the results of the study-specific questionnaire with methods similar to those that have previously been reported using the established psychometric instruments [153,154,159,164]. However, in a study with a small sample size (n=90) every conclusion must be drawn with caution. The classical qualitative inductive method of grounded theory (Paper IV) was chosen in order to penetrate certain areas of the questionnaire in depth, in particular the central question of the pediatric oncologists' main concern and personal experiences in a field where little is known to date.

We are aware that two of the authors' (MS and IM) preconceptions as pediatric oncologists studying pediatric oncologists may be regarded as bias influencing the data in our study. The third author (KP) is a psychologist with no previous connection with pediatric oncology. She has consistently raised comments and questions relating to these preconceptions. In addition, the step-by-step procedure that was used to create the study-specific questionnaire involved a multiprofessional expert panel outside this research field. The interviews with experienced physicians (Paper IV) were performed by students in psychology with no personal relationships to pediatric oncology/oncologists. The authors analyzed the data solely in coded form. None of the authors has any financial interest that could inappropriately influence this study.

1.2 Reliability and validity

In this thesis, the reliability of the variables in the study-specific questionnaire and the psychometric instruments was examined by Cronbach's alpha (Paper I and Table V).

1.3.1 Pediatric Oncology Coping Questionnaire (POCQ)

The questionnaire, which was specifically designed for this study (Paper I), included six variables constructed from a theoretical basis with Cronbach alpha values varying between 0.65 and 0.87. The variables of "Factors of motivation" (Paper II) and "Work-related aspects" (Paper III) had the lowest internal consistency, 0.65 (n=18) and 0.70 (n=20) respectively. These levels are acceptable but not good and indicate that the data might be instable. Random errors may arise from ambiguously formulated items. Reliability, measured by a test-retest process, would probably have reduced this risk. On the other hand, such a procedure may induce reactivity, i.e. a "change in the phenomenon itself" [134] between the two administrations. Another risk with retest processes is memory-related overestimation. Random error may even be generated in the process of coding, but we have tried to minimize this risk by having two researchers (MS and KP) controlling the data fed into the statistical program. Non-random error, i.e. a systematic biasing effect, may be present and, in a study comprising participants active and previously active in pediatric oncology, a recall bias cannot be ruled out. Another core question related to validity deals with the theoretical concept itself. Non-random error prevents the indicators from representing the concept of interest. The POCQ performed well with very few missing values and no comments about the instrument being difficult to complete, but the process of face validation and qualitative analysis when constructing this instrument represents solely the first steps on a long journey to develop a valid and reliable instrument.

1.3.2 Sense of Coherence (SOC)

This "is a valid, a reliable, and a cross culturally applicable instrument for measuring health" [62] In the literature (124 studies), the Cronbach alpha value of the SOC-29 scale ranges from 0.70 to 0.95 and the means from 100.50 (SD 28.50) to 164.50 (SD 17.10) [152]. The pediatric oncologists' mean value of 152.2 (15.2) is regarded as a high value, pointing to a strong sense of coherence and the results are presented as a uniform scale due to the fact that the subscales are intertwined [26].

1.4.3 Coping Resources Inventory (CRI)

The normative groups in Sweden (n=33) and in the US (n=843) show similar mean values except for the spiritual/philosophical dimension, i.e. a lower value in Sweden, which is thought to be culturally dependent. Validity investigations (American population) indicate that the total scale, as well as the cognitive and the physical scale, can predict the incidence and onset of stress symptoms. Our results were in line with normative groups in Sweden and the United States.

1.3.4 Ladder-of-Life (L-o-L)

The computed alpha value of the total scale is 0.83. The results are presented with mean values and in hierarchical regression models. The average mean values in the whole group for the single items were 7.7 to 8.1 and this is in accordance with normative groups. There are no clear cut-off points between low and high life satisfaction, but we have regarded these values as high.

1.3.5 Symptom Check List (SCL-90)

In Table IVA (Paper II) and Table III(Paper III) the answers of the study-group, concerning the subscales of the SCL-90 (anxiety, depression and somatization), are given on a five-point Likert scale, ranging from 1 (not at all) to 5 (very much), presented as mean values for each subscale. The most used ranging is from 0 (not at all) to 4 (very much) and this version, with new mean values, is presented in Table V. Different versions of the SCL have previously been used to address mental distress in physicians [17,165,166]. The mean values in the present study were low compared with the normative group (Table V). The Cronbach alpha was 0.73 for each scale, which is regarded as good but not high, and this may indicate that this is not a homogeneous group. Conclusions in this study must be drawn with caution, as only one instrument, on one occasion, was used to measure mental distress. We need to be aware that a low rating cannot be equated with good mental health and self-rated depression is not the same as a clinical diagnosis of depression. On the other hand, it is a well-known fact that a strong sense of coherence is related to low levels of perceived depression [62], especially among persons scoring high on SOC [62,158].

1.3.6 The HP5i (Health-relevant Personality 5 (Five-Factor Model = FFM) inventory)

The Hedonic Capacity in this study had a low internal consistency, but was comparable with the normative sample (0.54 and 0.65). Reported explorative factor analysis of the 5HPi, in the original version, indicated that the hedonic capacity scale was not homogenous [66,68]. In a new version of the instrument two new items are included [66]. The correlation between the original version and the new revised form was 0.77 and the mean inter item correlation coefficient was 0.25 and 0.36, respectively. However, as the level of negative affectivity was comparably low, we assume that this finding together with the results in the whole group point to the direction of extraversion.

1.3.7 The Grounded Theory study

In the process of validating the grounded theory study (Paper IV) the credibility has been judged by the following terms; fit, relevance, workability and modifiability [147,150]. According to the methodological guidelines of GT saturated data is presented. However, this decision is a subjective judgment and more of relevant data could have emerged if we had performed some more interviews. Modifiability, i.e. openness to future research is necessary to develop or alter this theory.

2. General Discussion

Over the years, the physician's professional role has been influenced by a series of scientific, medical, social and economic progressions and changes. The struggle for growing knowledge and advanced research has produced tremendous success in terms of the treatment outcome and previously fatal diseases in childhood can now be cured. Today, the goal in pediatric oncology is to improve the survival rate for serious conditions still further, but physicians are also confronted by new challenges. The consequences of modern treatment strategies include severe and sometimes lethal side-effects and there is an accelerating public expectation of cure. It is therefore not surprising that previous research has shown that pediatric oncologists display signs of strain and depression [80,99,114,116,117]. Little is known about resilience and personal satisfaction among physicians in the practice of pediatric oncology. This thesis presents the first Swedish nationwide study of pediatric oncologists. The theoretical framework of salutogenesis was chosen to focus on factors promoting well-being. Interviews were performed to create a study-specific questionnaire (Paper I) and, together with five psychometric instruments, it was possible to demonstrate factors associated with the outcome measures, i.e. their stress resilience (Paper II) and life satisfaction (Paper III). Their ultimate challenge appeared to be the difficult role of messenger (Paper IV). The outcome measures (Papers II and III) were studied against the role of experience (more/less than 10 years) and the numbers of patients cared for/type of medical center. Factors influencing stress resilience were identified as the role of motivation, low levels of depression and aspects of their social coping capacity. The pediatric oncologists' total life satisfaction was explained by being a male physician, working at an academic medical center regardless of gender, having a hedonic personality and low levels of depression. Time pressure was a reality for every physician. New interviews, entering deeply into the results of the questionnaire, focused on the physicians' main concern and the way they handled their hurdles (Paper IV). The analysis revealed the challenge of breaking bad news. Strategies that were used to handle the messenger role were related to constantly striving for knowledge, support-seeking sources, the role of building a close relationship with the patients and their families and at the same time avoiding coming too close and working on one's attitude to central life issues.

The major focus of this research, performed with mixed methods and a cross-sectional design, was to describe personal resources and the difficulties associated with being a pediatric oncologist. The concept of salutogenesis represents a positive approach/psychology to these queries, but focusing on factors promoting well-being is not to the same as closing one's eyes, or minimizing or neglecting the troublesome aspects. Salutogenesis is instead a reflection of an attitude to the way individuals can face and deal with difficulties and challenges, rooted in reality and negotiating hope [167,168]

2.1 The study population of pediatric oncologists

Eighty-nine percent of the members of the Swedish Pediatric Oncology and Hematology Organization participated. At least 3 months of clinical practice within pediatric oncology was required. This is too short a period to fulfill the certificate criteria and to be clinically experienced as well. On the other hand, the study mean value for years of experience was 15.6 and only 3 participants had worked for less than one year (4 months, 6 months and 9 months), indicating that the majority matched the specialist criteria and were clinically experienced [87,99,145] Their family situation was characterized by being married or having a partner (90%) and the mean value for numbers of own children was 2.73. Some had worked within other social/health care professions (6%) and some had another education (16%). One of the goals in this project was to perform a population-based study, defined here as all the physicians in Sweden who share the experience of working or having worked with pediatric oncology patients for at least three months. In order to use this term, a broad and ambitious approach was used. The procedure nominated a number of physicians who did not belong to the defined target population and we still do not know for sure that we reached every presumptive participant. This raises the question of what the real decline is. In the articles (Papers II and III), we have chosen to focus on the fact that the majority of participants, 88/89%, were members of the official organization, i.e. a high response rate [169,170] in the self-evident target population. Nonetheless, the fact remains that non-respondents might have had interesting and different thoughts and experiences which we never captured in this study.

The well-being of pediatric oncologists

Resilience, satisfaction and choice of specialty

The intrinsic motivating factors influencing the stress-resilience capacity included intellectual challenges and continuous education, relatedness to colleagues and a multi-professional team, together with a sense of professional growth, competence and autonomy with the responsibility for working in preferred areas (Paper II). Furthermore, pediatric oncology positively influenced their personal development, in spite of the workload and emotional and existential challenges (Paper III). This is in accordance with the theory of "flow" which proposes that an individual selectively cultivate a limited subset of activities, values and personal interests. When the intrinsic motivation, high involvement, deep concentration, and a perception of high challenges are matched by adequate personal skills this achieves "flow" promoting well-being [171,172]. It has been suggested that intrinsic factors promote job satisfaction [61]a term that is also used synonymously with motivation [173], and career resilience in physicians requires this kind of intrinsic motivation rather than minimizing the effect of negative extrinsic factors [63]. On the other hand, it is difficult to known how and to what degree intrinsic and extrinsic factors interact [63]. When our study group rated the solution-seeking challenges as stimulating (84%) and at the same time as stressful tasks (37%), we concluded that overtime probably affected the physicians, although half the population did not rate this as a high score. This may be due to variations in the physician's perception of his/her work. It might even reflect the role of the intrinsic generator directed at positive emotions or being a real sign of resignation when facing too much work. All the analyses were performed at group level, but potential individual differences are expected to be present.

Physicians with more than ten years' experience reported a higher impact from motivational factors, as well as overall life satisfaction related to the past. It is suggested that life satisfaction is relatively stable across life [174], but the role of experience and age, domains that are partly related, is not obvious. According to Pastor [55] and Austrom [175] subjective well-being tends to be higher in older physicians, while the life satisfaction of medical oncologists was higher in physicians aged 50 years or less [19]. In our study group there was no statistically significant difference related to experience. When discussing the term "satisfaction" it is important to emphasize that professional satisfaction differs from life satisfaction but they may interact [47]. Together with marital satisfaction [47,176] these three domains are essential for subjective well-being [47]. However, marital status was not a significant variable in this study.

Focusing on specialty and professional satisfaction, previous research has revealed that pediatricians are more committed and satisfied than physicians in other specialties [177-179]. The present results point to a high degree of satisfaction among pediatric oncologists (subspecialists), but with no control group this may be related to the fact that they all are pediatricians. In line with the literature [180], half the study population had pediatrics as a career goal solely during their medical education, probably due to a certain interest in children [86]. Furthermore, gender, personality traits (expressiveness), and life goals (satisfying social relationships) have an impact on the choice of specialty [181], although the research relating on influencing factors presents “varying and inconsistent results” [182]. However, even the care-takers benefit from the physicians’ job satisfaction, as patients are more likely to follow medical advice if the physician shows satisfaction in his/her practice and takes time, while a low level of professional satisfaction and .may negatively influence the quality of care [183].

The role of personality and gender

The life satisfaction of the study group was influenced by being extrovert, being a male and not being depressed. In the total overall life satisfaction, personality and gender were significant variables and remained significant even when adjusting for emotional distress. Extroversion can predict life satisfaction [8-11], and being a male has been associated with increased overall well-being in medical oncologists [19]. Male physicians in our study had a high subjective present life satisfaction but also the highest rating in terms of being under time constraints when working at academic centers. One hypothesis is that the lack of time may create difficulties for male physicians, as it reduces their opportunity to realize professional goals when it is suggested that their identity is centered on knowledge and competence [38]. However, they appear to balance this problem by being motivated and satisfied with life, which gives them the strength to continue in pediatric oncology.

The physician-patient relationship and communication

Pediatrics is known to be one of the specialties in which the patient-physician relationship plays an important role [184] and building this relationship was central for the pediatric oncologists, regardless of place of work and gender (Paper IV). The building process was described in great detail, as a well-thought-out procedure focusing on the sick child and establishing contact with the whole family. However, this relationship in oncology is characterized by several challenges related to communication [81,82] including cultural aspects [83]. In our study group, the most common strategy for handling the difficult role of messenger was to communicate and build a relationship, and listening intently to the patient’s story can break boredom and burnout in physicians [25].This patient-doctor communication is regarded by the parents of terminally ill children as a principal determinant of high-quality physician care and, when appropriate, it also allows for communication directly with the child

[88]. This method has mostly been practiced by physicians in western countries [85,89]. A direct approach, talking about the cancer diagnosis and death with the child or the adolescent, presupposes cultural sensitivity [83,90]. At the same time studies of parents whose child is undergoing treatment for cancer [88] and parents who have experience of losing a child to cancer [91] emphasize openness and talking. Our pediatric oncologists practiced bedside communication training with role models. This framework is a promising way of teaching communication [92], as it is defined as a core clinical skill [93,94]. Other ways of learning communication are interactive workshops [185-187] and training courses [85], including narrative training for professionals in pediatric oncology [188]. This is important as medical education based solely on lecture-style presentations has failed to change physician behavior [189].

Communication through humor and laughter was sometimes used by the participants in this study. These are globally established relational tools and, if they are used with sensitivity and respect, they may reduce anxiety in stressful situations and build bridges between patients and professionals in cancer and palliative care [88,190,191]. Humor is also a way of negotiating that hope and hopefulness is an important psychosocial issue especially in adolescence [192]. Furthermore, the balance between the hope of a cure and the hope for integrity and comfort is a goal of pediatric end-of-life care [167] and every terminally ill child with cancer has the right to have a margin of hope [168]

Empathy and Identification

Our results indicated that a close relationship was worth pursuing, but it was also important to realize the difference between empathy and identification. Empathy is a term first defined in psychology as a way of understanding the inner feelings and the internal framework of another person [193]. In psychosocial oncology caregivers empathy plays a special role, when patients are facing life-threatening illnesses and end-of-life issues [194]. An open, warm and listening attitude is a necessary dimension of human science and practice, but it is also evident that patients and families need support to grow and develop in spite of their severe situation. When professional identification comes too close it may impede a development of this kind and increase the burden. Distancing may even act as protection for the caregiver from overwhelming emotions enabling him/her to have the energy to go on working [84,145]. Empathy combined with medical and psychosocial competence in the appropriate setting, i.e.

surroundings with a multi-professional team and colleagues, can support the therapeutic power and protect physicians from burn-out [195]. A varying degree of closeness and distance is defined as professional ethics and is probably necessary when working in pediatric oncology [145].

Meaning-focused coping and pro-active coping

Life-threatening conditions and death in childhood contradict the order of nature [25,45]. In pediatric oncology, these difficult circumstances are constantly present and may often have a detrimental effect on healthcare professionals, sometimes described as an ongoing grieving process [25]. However, the physicians' open-minded approach to existential issues of life and death, emphasizing the importance of having "a carefully prepared view", may have possible implications related to meaning reconstruction which plays an important role in the grieving process [46]. Meaningfulness has also been described previously as a work-related feeling when meeting seriously ill children [47,48], i.e. in accordance with the theory of positive and negative emotions co-occurring in the stress process [38]. In other words, this perception of "meaning" promotes job satisfaction in pediatric oncology [196,197] and probably mobilizes an adaptation function under severe circumstances by broadening the perspective, the attention and the behavioral repertoire, i.e. a way of replenishing the physicians' coping resources [39]. In this process of meaning, spirituality and religion are known to be essential as well [176,198]. Our study group had a high SOC; this concept includes a dimension of meaningfulness, which is suggested to be the most important domain [25], and individuals with a strong SOC are more likely to develop a greater variety of general resistance resources (GRRs) [151].

The history of pediatric oncology is the history of pro-active coping. Focusing on the future and its potential, the pioneers kept on working. Collaboration, i.e. the role of social support [41], probably acted as a protector from stress. As a result of research and clinical work, there has been a dramatic change in the survival rate. Collaboration and pro-active coping are still needed to face the challenges of today.

Work-related aspects: facilitators and obstacles

The role of the medical center and time constraints

The majority stated that their work was emotionally and intellectually demanding but manageable and not more emotionally demanding than they had anticipated (Paper III). The academic medical center influenced the total life satisfaction but did not remain significant when controlling for depression. An optimistic attitude towards the future contributed to the resilience in the whole group, particularly among physicians at academic medical centers. These pediatricians meet 25-90 new patients a year, the majority are cured and this probably contributes to their confidence in the treatment and the future. Furthermore, at the pediatric oncology centers, several colleagues share the experiences, difficulties and rewards and they are supported by multi-professional teams which some of their colleagues at non-academic medical centers lack. These factors are well-known sources that promote job satisfaction [199]. However, the academic environment could generate a certain perceived stress related to demands associated with publications, academic rank and grant support, which may reduce the professional satisfaction, with a risk of exhaustion [18].

The suffering of the children and their families constituted burdensome aspects of their job, but it was also the lack of time within regular working hours that created difficulties. "Work-related aspects" influenced the present and future satisfaction, indicating that objective/environmental factors play a minor role in explaining their life satisfaction. We did not explicitly ask the participants to give their weekly working hours, but the majority worked full time and, according to the Swedish labor legislation, that is equal to 40.0 hours. Time constraints are a well-known source of frustration for many doctors [55,74,96,200-202]and work stress is known to be a predictor of well-being in physicians, but with varying impact [17,19,53]. However, working hard has not been shown to be a powerful indicator of dissatisfaction [179] and, with several cultural differences, it is not possible to draw common conclusions solely regarding the number of working hours. Despite the fact that the whole study population indicated time constraints, 82% stated that they were satisfied with their areas of responsibility, probably reflecting the "demand-control effect" [75] and the role of "flow" [171,172]. Contributory factors making pediatric oncology emotionally demanding were economic discussions, although few participants found that economy influenced their potential for providing satisfactory care. This is probably explained by the fact that the Swedish social insurance system guarantees every child the same care, regardless of their parents' financial status. On the other hand, the physicians are constantly expected to economize, because institutional care is very expensive. Organizational aspects were also demanding factors for one in three, as was the risk of making incorrect medical judgments and ordinations. These are core questions for pediatric oncologists facing some specific challenges related to the lack of evidence-based medicine within their field, e.g. aspects of chemotherapy dose administration in childhood. The employers play an essential role in creating an organization which is secure and effective, because dealing with treatment toxicity/errors and the stress of being overloaded are factors associated with an increased risk of developing psychiatric disorders [22].

Breaking Bad News

The main concern of pediatric oncologists revealed their strained position of "being a messenger of life-threatening conditions" (Paper IV). To tackle this challenge, the physicians searched every available source of knowledge, regarding this struggle as part of their professional ethics. Strength and resources were saved by seeking multidimensional support being aware of the need for a work-life balance. The role of messenger was described as a balance between difficult choices and the need to make carefully prepared decisions, sometimes combined with a feeling of loneliness, and the specific challenge of meeting seriously ill teenagers. These findings revealed similarities with the present knowledge of doctors' agony about being trained to cure but being forced to break bad news, feeling that they failed to reach this goal, living in a society fearing death [78]. Communicating bad news is therefore a stressful task [79]and may contribute to the oncologist's anxiety and depression and lack of personal fulfillment [80]. Relapse has been identified as the most stressful message, because it could be the signal of a terminal phase [84]. The physicians' sense of powerlessness could be described as a medical and psychological problem and, the physician is lost for words to express his/her feelings [86]. The fear of being blamed for the message and the fear of facing personal illness and death may even be present [85]. To regain control, the strategy of developing expertise is known to be one way of improving the oncologist's self-esteem [87]. Challenges are not equal to threats, i.e. tackling the tasks as challenges is a way of reformulating the disease and its consequences into soluble problems [87].

The Need of Support and Self-care

In addition to these cognitive aspects, our results indicate that there is a need for multidimensional support and actively cultivate personal interests [19,199]. Physicians in cancer care often seek support from colleagues [87] but some physicians can be reluctant to show emotions [84]. Professional and personal relationships, including colleagues/teamwork/family/partner/friends, and personal boundaries, are sources that prevent burn-out in end-of-life care [191]. Another essential aspect is that studies of burn-out in oncologists suggest that many physicians believe that their choice of specialty negatively influences their private lives, because work-related stress may spill over leading to dissatisfaction and feelings of guilt [18,84]. These findings emphasize the need for time for recovery, time to build non-professional relationships and time for physical training, reading, and hobbies, i.e. aspects known to increase physicians' well-being [19,84,191,199].

Emotional distress of pediatric oncologists

Emotional distress

The group is characterized by low levels of mental distress. The low level of depression explained half the variance in the total overall life satisfaction and the cognitive and physical coping resources, i.e. domains essential in the stress process [37]. Physicians with less than 10 years' experience had a salient level of somatization. A strong sense of coherence is related to low levels of perceived depression [62] and low levels of life satisfaction can predict depressive symptoms [53]. Consequently, emotional distress is strongly intercorrelated with life satisfaction and therefore, in the statistical analyses, these concepts are handled in different linear regression analyses (Paper II) and in hierarchical models (Paper III).

Studies of burnout suggest that younger physicians have an increased incidence compared with older doctors [80,98,203]. We would like to offer the hypothesis that somatization in the less experienced group is a result of a heavy workload resulting in too little time being spent with patients and families. One contributory factor could be that, in a community in which children are expected to live to adulthood, the death of a child is an existential provocation which the more experienced group was able to balance with their higher motivational factors and past overall life satisfaction. One in ten has had to seek professional help because of perceived stress related to his/her job. Female physicians at non-academic hospitals scored highest. This difference was not statistically significant but, according to previous research, female pediatric oncologists/physicians are more likely to be depressed [84,101] and less likely to report a high degree of overall well-being [19]. It has been suggested that women's identity development is formed in part by relational connectedness [38,39]. It is possible to speculate about whether this relational identity could make female oncologists especially vulnerable to psycho-social issues of childhood cancer, in particular when team support is lacking and work-home interference is present [203]. Exhaustion may increase the risk of developing cynicism [18], a condition that threatens empathy and commitment, and burnout may cause suboptimal patient care [203]. In our study, 10% had experienced severe illness and/or death during their own childhood. Some regarded this as a resource, while others said that it could increase an individual's vulnerability and predict distress [84]. Conclusions relating to mental distress must be drawn with caution, as only one instrument, on one occasion, was used to measure the domain. We need to be aware that a low rating is not equal to good mental health, nor is self-rated depression the same as a clinical diagnosis of depression.

However, in spite of the stable emotional status of the population, the time pressure and work load have to be seriously addressed in the future, as they are known to result in stress for oncology healthcare professionals [10,24], may lead to psychiatric morbidity [25], negatively influence the physician-patient relationship [26], and could lead to committed physicians leaving the field.

Implications and recommendations in the daily work in pediatric oncology

The role of experience-based knowledge

A higher impact from motivational factors, overall life satisfaction related to the past and lower levels of somatization were reported by more experienced physicians. This highlights the role of clinicians with emotional life experience and a genuine interest in their work. At the bedside, they can act as role models, contributing their medical knowledge and introducing new colleagues to the world of psychosocial pediatric oncology. This kind of clinical teaching includes radiating hope, the hope of always being able to do something and ways of creating a close relationship with one's patients without coming too close. Guidance from professionals could complement these role models. When facing the demanding task of delivering bad news, we would suggest some practical implications and a structured way of handling the situation (Table XX).

Table XX. Practical implications for pediatric oncologists' breaking bad news

Implications
• Discuss with colleagues to "exhaust" every prospect of knowledge" and to obtain support
• Arrange a meeting informing the staff including nurses of the results of the investigations and the planned strategy
• Inform the child and his/her parents about the condition/the relapse/the incurable disease, i.e. break the bad news, but do not leave the room before indicating what is now going to happen
• Talk to both parents and to the child at his/her age level
• Prepare a project of care and involve the family doctor/the primary health care professionals, if appropriate
• Re-evaluate the project over the time according to the child's condition
• Prepare home assistance, individually adapted to the child and his/her family
• If the child is dying from the malignant disorder, organize a post-death meeting with the family [49].

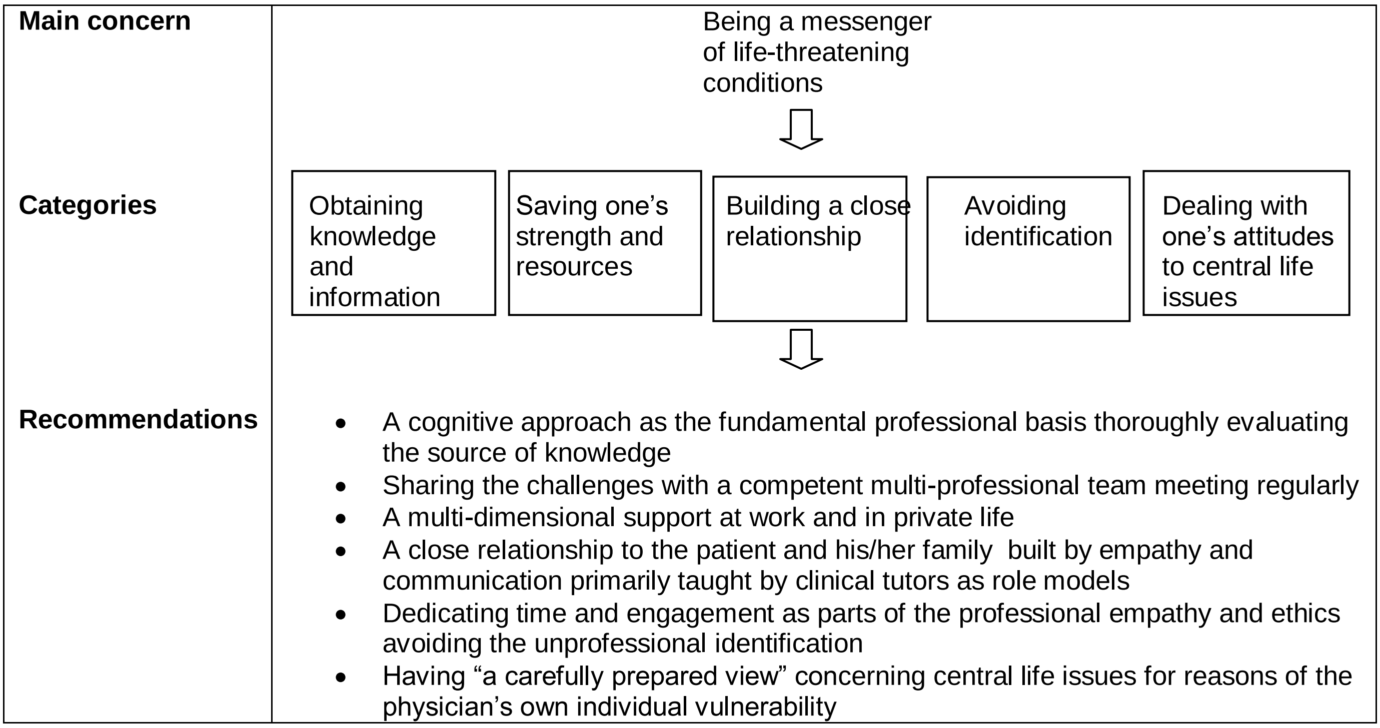
The role of the workplace

The expected future life satisfaction was higher among physicians working at academic medical centers. The majority of the physicians who had had to seek help for work-related psychological problems worked at non-academic centers. Time pressure was present, regardless of the place of work. Pediatric oncology in Sweden is based on close cooperation between the different types of center. In spite of this, the need for more support appears clear. Today, support is given by frequent personal contact with colleagues through telephone calls and e-mail, educational sessions in different parts of the country and at a national level. Another way of facilitating clinical support is through training at academic medical centers, thereby establishing personal relationships with colleagues and meeting many cured children, essential aspects from both a medical and a psychological angle. Grant support for periods of training of this kind is given by the Swedish Children's Cancer Foundation. At the local hospital, we would suggest that at least two physicians are educated in the field in order to share the workload. Employers need to be aware of the need for an organization based on a multi-professional healthcare team when working in pediatric oncology.

The role of work-life balance

Experienced physicians serve as role models even when it comes to the balance between personal and professional priorities and responsibilities, i.e. work-home interference and the risk of burnout [203]. Medical oncologists with a high level of well-being had developed an approach to dealing with death and end-of-life care, had struck a balance between personal and professional life, had spare time with different activities and reported greater career satisfaction [19]. Being prepared for the main concern, "breaking bad news", implies strategies which include the perspective of a work-life balance. Figure 3 presents physician-related recommendations which might help committed doctors to stay in pediatric oncology, acting as role models and attracting new colleagues to this specialty.

Figure 3. Main concern, categories and recommendations for the physician-related personal psychological way of handling



Main concern	Being a messenger of life-threatening conditions
Categories	Obtaining knowledge and information Saving one’s strength and resources Building a close relationship Avoiding identification Dealing with one’s attitudes to central life issues
Recommendations	• A cognitive approach as the fundamental professional basis thoroughly evaluating the source of knowledge • Sharing the challenges with a competent multi-professional team meeting regularly • A multi-dimensional support at work and in private life • A close relationship to the patient and his/her family built by empathy and communication primarily taught by clinical tutors as role models • Dedicating time and engagement as parts of the professional empathy and ethics avoiding the unprofessional identification • Having “a carefully prepared view” concerning central life issues for reasons of the physician’s own individual vulnerability

Strengths and limitations

The *strength* of the study is the nationwide approach, with 89% of the members of the official Swedish Pediatric Oncology and Hematology Organization (SPP) participating and covering 40 years of pediatric oncology. The design is mixed-methods research, implementing both a qualitative and quantitative approach, i.e. different perspectives when studying the research question. The study includes several psychometric instruments and concepts in an attempt broadly to reflect the theoretical framework of salutogenesis, i.e., in this thesis, health-promoting factors for pediatric oncologists.

In the discussion, some of the *limitations* have already been mentioned. The main limitation is the cross-sectional study design with a selected single group of physicians without a control group. This design was chosen because of some specific challenges in pediatric oncology related to the lack of evidence-based medicine within certain areas. The risk of socially desirable answers is present and, due to the wide range of age and experience, some participants may have had a recall bias when answering the questionnaire. We must also consider the fact that our results might not apply in other countries or in a medical culture other than that in Sweden. On the other hand, a single group study may contribute knowledge that makes it possible to conduct new studies comparing the challenges in other groups of physicians within the same culture. If the study-specific questionnaire is to be used in studies of this kind, an adapted version and further testing of reliability and validity are necessary. Physicians in different parts of the world probably face several varied circumstances that influence their life satisfaction, such as academic pressure, insurance companies and aspects of legal provisions. Differences like this would still be difficult to evaluate even with a control group.

CONCLUSIONS

❖The general impression emerging from this study is that the majority of the pediatric oncologists are able to handle their different work-related impediments, but there seems to be a certain degree of vulnerability in the less experienced group and among physicians working at non-academic centers. The role of gender needs to be taken into consideration.

❖To tackle the challenges, the physicians search for every available source of knowledge (problem-focused coping) and work on the process of building a strong patient-physician relationship with empathy and commitment (emotion-focused coping), avoiding identification with this struggle as part of their professional ethics.

❖Strength and resources are saved by seeking multi-dimensional support, being aware of the need for a work-life balance and having a carefully prepared view of central life issues (meaning-focused coping).

❖Intrinsic motivation when facing demanding challenges, being active and prepared for the task (the theory of "flow") but also reluctant to take risks, a stable emotional status with low levels of negative affectivity and a hedonistic approach promote their well-being. These factors are probably the main basic conditions that facilitate working in a profession facing life and death.

❖The group is also characterized by focusing on the future and its opportunities. They are encouraged by the successful developments in pediatric oncology, including further treatment improvements (pro-active coping).

❖Even if their personal accomplishment is high, pediatric oncologists need employers who understand the complex challenge of working with severely ill children and their families in order to retain experienced physicians and recruit new colleagues.

ONGOING AND FUTURE RESEARCH

❖Physicians who participated in the nationwide study in 2006/2007, when they had less than 5 years„ experience, are now (summer and autumn 2010) being interviewed in a qualitative follow-up evaluation based on their answers in the study-specific questionnaire. Interest focuses on their personal wellness-promoting strategies and the role of support and supervision.

❖The interviews with the pioneers (Part II) are going to be published. These analyses are being performed with grounded theory and focus on the personal process the physicians experienced during their career, while treating uniformly fatal diseases which became curable.

❖Further analyses and publications from the cross-sectional study with sense of coherence and coping resources, including their subscales, related to the physician-patient relationship, psychological handling and support, feelings about making mistakes, and physician-rated good qualities.

❖Studies to survey and evaluate the role of emotional support or supervision groups or other forms of reflection, including ethical discussions, for the pediatric oncologists of today and of the future.

❖Investigations of the well-being of physicians in other pediatric subspecialties and physicians in other specialties, i.e. surgeons and orthopedists facing severe illness and death in childhood.

❖Investigations of the well-being of pediatric oncologists in the other Nordic countries, preferably as prospective longitudinal studies with interventions to identify individual and environmental factors.

❖Investigations of children with cancer and their parents, focusing on the care-takers' needs and wishes in order to create the optimal patient-physician relationship.

SAMMANFATTNING PÅ SVENSKA

(SUMMARY IN SWEDISH)

Läkaryrket är ett av världens äldsta yrken och rollen har genom tiderna ständigt förändrats. Arbete inom barnonkologi innebär utöver medicinska utmaningar också ett ständigt möte med psykosociala och existentiella frågeställningar. Prognosen för långtidsöverlevnad för barn med cancer är idag god, men konsekvenserna av de moderna behandlingsstrategierna har lett till nya utmaningar. Dessutom är förväntningarna på bot idag betydligt större. I den första nationella studien med 90 läkare verksamma inom barnonkologi har de psykologiska aspekterna för läkare i arbete med svårt sjuka barn studerats.

Avhandlingens teoretiska begreppsram är salutogen, d.v.s. fokuserar på faktorer som främjar hälsa och välmående. Kvantitativa och kvalitativa delarbeten ingår. En studiespecifik enkät utvecklades 2006 baserad på intervjuer med 9 pionjärer inom barnonkologi, med upp till 40 års erfarenhet, och en litteraturgenomgång (delarbete I). Till enkätundersökningen kopplades 5 psykometriska mätinstrument vilka speglar gruppens copingresurser (CRI), känsla av sammanhang (SOC), livstillfredsställelse (L-o-L), personlighet (HP5i) och mentala stressnivåer (SCL-90, subskalorna depression/ångest/somatisering). En tvärsnittsstudie genomfördes 2006/2007 där 90 läkare (67% män och 33% kvinnor) deltog, varav 89% var medlemmar i BLF's sektion för hematologi och onkologi. Majoriteten arbetade på universitetssjukhus (57%) med 25-90 nya patienter per år medan 43% arbetade på länssjukhus med 3-20 nya patienter årligen. I delarbete II studerades stresståligheten i gruppen och i delarbete III livstillfredsställelsen och detta i relation till erfarenhet (mer/mindre än 10 år) och arbetsplats (universitets-/länssjukhus).

Enkätresultaten visade att optimala arbetsförhållanden inkluderar flera kollegor att rådfråga (98%) och ett multiprofessionellt team (95%). En rad olika copingresurser (kognitiva, emotionella, sociala, andligt/filosofiska och fysiska) användes. Gruppen karaktäriserades av en hög känsla av sammanhang, en genomsnittlig/hög livstillfredsställelse och låga nivåer av mental stress. Jämfört med kollegor på länssjukhus visade barnläkare på universitetssjukhus en större tilltro till framtiden. Läkare med längre tids erfarenhet redovisade större möjlighet att hantera stress medan kollegor med kortare tids erfarenhet skattade högre avseende somatiseringssymtom. En optimistisk och entusiastisk personlighet samt låga nivåer av depression bidrog till den totala livstillfredsställelsen. Arbetsrelaterade faktorer påverkade den aktuella och framtida förväntade livstillfredsställelsen. Drygt 10% av deltagarna, framför allt kvinnliga läkare på länssjukhus, svarade att de hade behövt söka professionell hjälp för arbetsrelaterade psykologiska besvär. Det största problemet i yrkeslivet för samtliga läkare var den höga arbetsbelastningen och ingen rapporterade att arbetet kunde avslutas inom normala arbetstider.

Delarbete IV, en kvalitativ intervjustudie med 10 erfarna barnonkologer, fokuserade vad läkarna upplevde som främsta psykologiska utmaning. Det var ”budbärarrollen”, i synnerhet vid recidiv och/eller övergång till palliativvård. Läkarna hanterade utmaningen genom ett brett sökande efter kunskap och stöd. De skapade nära relationer till barnen och familjerna, men försökte undvika identifiering. En genomtänkt syn på livet och döden var också en central strategi.

Sammanfattningsvis pekar resultaten mot att denna grupp barnonkologer har positiv livssyn, god livstillfredsställelse, stabilt emotionellt status och teamorienterat arbetssätt. Svårigheterna är relaterade till hög arbetsbelastning/tidsbrist, brist på kollegor, risk för mental stress bland mindre erfarna läkare eller anställd på länssjukhus, samt att förmedla svåra besked. Kunskap om läkarnas psykologiska hantering av arbetet förväntas ha betydelse för såväl en fördjupad patient-läkarrelation som för att behålla erfarna läkare och rekrytera nya specialister till området.

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APPENDIX

Interview guide I

Professionals expected to meet persons in a state of crisis, open interviews

1. What would you say is your greatest challenge when meeting severely ill persons in a state of crisis?
2. Why do you find this task so demanding?
3. What are your own personal reactions/feelings when meeting persons in a state of crisis?
4. How do you handle your own reactions/feelings?
5. What kind of support do you need when working with persons in a state of crisis?

Interview guide II, Part I

Pioneers in pediatric oncology, semi-structured interviews

(Part II will be published separately)

1. What would you say was/is your internal driving force when working with children with cancer?
2. What were/are the challenges?
3. How did/do you handle these challenges?
4. What were/are the most burdensome tasks?
5. How did/do you handle these burdensome tasks?
6. What do you think gave/gives the greatest satisfaction when working in this field?
7. What kind of psychological support would you say is needed when working with children with cancer?

8. What kind of supervision would you say is needed when working with children with cancer?

9. What are optimal working conditions for pediatric oncologists?

10. Please describe some personal traits you rate as essential when working with children with cancer.

11. Why are these traits essential?

12. What kind of relationship did you/do you want to have with the children?

13. What kind of relationship did you/do you want to have with their parents?

14. How did/do you relax when your work had/has been emotionally/medically demanding?

15. Did you/do you have any interests/hobbies "that gave/give you inspiration outside your job"?

16. How would you describe the role of your own family (spouse/children/relatives) during your years of working in pediatric oncology?

17. Please describe your view of the work-life balance.

18. Did/do you think questions relating to central life issues were/are important in this work?

Questionnaire

Code ……………………..
Date ……………………..

This questionnaire is being developed for use in a study with physicians who are working or have been working in pediatric oncology

The questionnaire consists of different types of question divided into one part with demographic variables, one part relating to the place of work and your choice of profession and one part relating to aspects of coping in your daily work. The questions can be answered by indicating a cross (X) on a five-point Likert scale. Free comments can be given in addition to each question. In the third and last part of the questionnaire, free-worded answers are presented. Version I has 12 questions (for physicians with more than 5 years in pediatric oncology), while Version II has 14 questions (less than 5 years). *The questions should be answered quickly with the ideas that cross your mind as you read the question.*

1) Gender
☐ Female
☐ Male

2) Age ………………………

3) What is your current family situation?
☐ Single
☐ Married/With a partner
☐ Another alternative? ....

4) Do you have children?
☐ Yes
☐ No

If the answer to question number 4) is "No", please proceed to question 8)

5) How many children do you have?..

6 a) How many girls do you have? ....
b) How many boys do you have? ....

7) The age of your child/children? ....

8) I was born in:
☐ Sweden
☐ Another Nordic country
☐ Another European country
☐ Outside Europe

9) I work at;

☐ An academic medical center
☐ A non-academic medical center
☐ Primary health care
☐ Other working place? Where?………………………………
☐ Retired

10) My first contact with pediatric oncology was: (you can mark one or several alternatives)

☐ I came in contact with a child with a malignant disease
☐ I got to know a pediatric oncologist
☐ I got to know health care professionals within pediatric oncology
☐ Lectures at medical school
☐ Participating in a round on a ward treating childhood cancer
☐ Working at a pediatric oncology department

☐ Another alternative, please state …………………….....................

Own comments: ……………………………………….................

11) In my private life, I have had experience of severe disease and/or death at the age of: (you can mark one or several alternatives)

☐ 0 to 7 years
☐ 8 to 14 years
☐ 15 to 25 years
☐ >26 years
☐ I have no such experience

Own comments………………………………………………………

12) Are you working within pediatric oncology today?

☐ Yes, fulltime
☐ Yes, Part time……%
☐ No, I am working at……………………………………………………..
☐ Retired

Own comments………………………………………………………

13) For how long have you been working in pediatric oncology?....................................

14) For how long have you been interested in pediatrics as a specialty?................................

15) Before you started to work in pediatric oncology, did you *consider* working in:
Another subspecialty within pediatrics?

☐ Yes, which………………………………………………………………………
☐ No…………………………………………………………………………………

Own comments……………………………………………………………………….

16) Before you started to work in pediatric oncology, did you *consider* working in:
Another specialty?

☐ Yes, which………………………………………………………………………
☐ No…………………………………………………………………………………

Own comments……………………………………………………………….

17) Before you started to work in pediatric oncology, did you *consider* working in:
Another profession in the social services?

☐ Yes, which………………………………………………………………………
☐ No…………………………………………………………………………………

Own comments……………………………………………………………….

18) Before you started to work in pediatric oncology, did you *consider*:
Another form of education?

☐ Yes, which………………………………………………………………………
☐ No…………………………………………………………………………………

Own comments………………………………………………………………………

19) Do you have a degree in another specialty?

☐ Yes, which………………………………………………………………………
☐ No…………………………………………………………………………………

Own comments……………………………………………………………………….

20) Do you have another kind of professional education:

☐ Yes, which…………………………………………..
☐ No

Own comments………………………………………………………………………

Indicate your following answers by drawing a circle around the number of choice

1 = Disagree completely **5 = Agree completely**

21) In pediatric oncology it is very essential with professional advanced knowledge when meeting the patients **1 2 3 4 5**

Own comments

…………………………………………………………………………

22) In pediatric oncology it is essential to take part in national continuation courses **1 2 3 4 5**

Own comments

…………………………………………………………………………

23) In pediatric oncology it is essential to take part in further international training **1 2 3 4 5**

Own comments

…………………………………………………………………………

24) In the daily work it is a *stimulating* challenge to keep on seeking solutions to difficult problems **1 2 3 4 5**

Own comments

…………………………………………………………………………

25) In the daily work established routines give a sense of security when managing different diagnosis **1 2 3 4 5**

Own comments

…………………………………………………………………………

26) In the daily work it is stimulating with improvisations **1 2 3 4 5**

Own comments

…………………………………………………………………………

27) It is a *stressfu*l challenge to keep on seeking solutions to difficult problems **1 2 3 4 5**

Own comments

…………………………………………………………………………

28) When you have to make decisions in severe treatment-related situations, it is very important to seek *support* from your *colleagues* **1 2 3 4 5**

Own comments

…………………………………………………………………………

29) When you have to make decisions in severe treatment-related situations, it is very important to seek *support* from *other professiona groups* within the health care system **1 2 3 4 5**

Own comments

…………………………………………………………………………

30) When I have to make decisions in severe treatment-related situations in my daily work, I usually have *access to colleagues* **1 2 3 4 5**

Own comments

…………………………………………………………………………

1 = Disagree completely **5 = Agree completely**

31) When I have to make decisions in severe treatment-related situations in my daily work, I usually have *access to other profession groups* within the health care system **1 2 3 4 5**

Own comments

…………………………………………………………………………

In my private life, when I face work-related emotional distress, I have access to:

32) Relatives **1 2 3 4 5**

33) Friends **1 2 3 4 5**

Own comments

…………………………………………………………………………

34) Pediatric oncologists need professional psychological supervision **1 2 3 4 5**

Own comments

…………………………………………………………………………

35) I have had access to professional psychological supervision when needed **1 2 3 4 5**

Own comments

…………………………………………………………………………

36) I have had to seek professional help for work-related psychological problems **1 2 3 4 5**

Own comments

…………………………………………………………………………

37) Building a close relationship with the child and the family is important for me **1 2 3 4 5**

Own comments

…………………………………………………………………………

38) It is natural sometimes to use humor in the caring situation in order to make contact **1 2 3 4 5**

Own comments

…………………………………………………………………………

39) It is natural sometimes to use humor in the caring situation in order to handle the serious aspects of a situation **1 2 3 4 5**

Own comments

…………………………………………………………………………

40) Periods without direct patient care are necessary to find the energy to go on working **1 2 3 4 5**

Own comments

…………………………………………………………………………

1 = Disagree completely **5 = Agree completely**

It is important for me that my work is appreciated by:

41) The sick children **1 2 3 4 5**
42) The parents **1 2 3 4 5**
43) My colleagues **1 2 3 4 5**
44) Other health care professionals I work **1 2 3 4 5**
45) My director/directors **1 2 3 4 5**
Own comments

…………………………………………………………………

Working with pediatric oncology is:

46) Emotionally demanding **1 2 3 4 5**
47) Intellectually demanding **1 2 3 4 5**
48) Time consuming **1 2 3 4 5**
Own comments

…………………………………………………………………

The problems I encounter working with pediatric oncology are:

49) Emotionally manageable **1 2 3 4 5**
50) Intellectually manageable **1 2 3 4 5**
51) Time consuming **1 2 3 4 5**
Own comments

…………………………………………………………………

52) Working with pediatric oncology is *more* emotionally demanding than I had anticipated **1 2 3 4 5**
Own comments

…………………………………………………………………

53) Giving a cancer diagnosis to a teenager is a *particularly* emotionally demanding task **1 2 3 4 5**
Own comments

…………………………………………………………………

54) Meeting the parents of children with different kinds of cancer is an emotionally demanding task **1 2 3 4 5**
Own comments

…………………………………………………………………

55) I often feel tired **1 2 3 4 5**
Own comments

…………………………………………………………………

56) My sleep is often restless and interrupted **1 2 3 4 5**
Own comments

…………………………………………………………………

57) I wake up early in the morning **1 2 3 4 5**
Own comments

…………………………………………………………………

1 = Disagree completely **5 = Agree completely**

58) Working in pediatric oncology gives you personal experience of managing crises that differ from experiences you may have when working with children with other chronic diseases **1 2 3 4 5**

Own comments

…………………………………………………………………………….

59) Experiences in my own private life during childhood and adolescence might have influenced my choice of working in pediatric oncology **1 2 3 4 5**

Own comments

…………………………………………………………………………….

60) I often worry about making incorrect medical *judgments* **1 2 3 4 5**

Own comments

…………………………………………………………………………….

61) I often worry about making incorrect medical *ordinations* **1 2 3 4 5**

Own comments

…………………………………………………………………………….

62) I often worry about different work-related tasks **1 2 3 4 5**

Own comments

…………………………………………………………………………….

63) I often feel strained thinking about my work-related responsibilities **1 2 3 4 5**

Own comments

…………………………………………………………………………….

64) I think that economic considerations influence my potential for providing satisfactory pediatric oncology care **1 2 3 4 5**

Own comments

…………………………………………………………………………….

65) I am able to perform my work within normal working hours **1 2 3 4 5**

Own comments

…………………………………………………………………………….

66) *Not* having the time to do my work within normal working hours is one of the reasons working with pediatric oncology is so demanding **1 2 3 4 5**

Own comments

…………………………………………………………………………….

67) Working with childhood cancer affects me even during my leisure time **1 2 3 4 5**

Own comments

…………………………………………………………………………….

68) It is important for me to be available to my workplace even during my leisure time **1 2 3 4 5**

Own comments

…………………………………………………………………………….

1 = Disagree completely **5 = Agree completely**

69) I find pediatric oncology work that affects me during my leisure time stressful **1 2 3 4 5**
Own comments
…………………………………………………………………………………

The following personal qualities are important when working as a pediatric oncologist:
70) Empathy **1 2 3 4 5**
71) Attention to detail **1 2 3 4 5**
72) Conscientious approach **1 2 3 4 5**
73) Ambition **1 2 3 4 5**
74) Resilience **1 2 3 4 5**
75) Effectiveness **1 2 3 4 5**
76) Target orientation **1 2 3 4 5**
Own comments
…………………………………………………………………………………

77) My employer gives me wanted responsibilities for areas corresponding to my wishes **1 2 3 4 5**
Own comments
…………………………………………………………………………………

78) My place of work is in a very good order taken as a whole **1 2 3 4 5**
Own comments
…………………………………………………………………………………

79) My employer supplies my need of further training in pediatric oncology **1 2 3 4 5**
Own comments
…………………………………………………………………………………

80) I can recommend this work to a younger colleague **1 2 3 4 5**
Own comments
…………………………………………………………………………………

81) I am contemplating to change my place of work **1 2 3 4 5**
Own comments
…………………………………………………………………………………

82) I have contemplated to change specialty **1 2 3 4 5**
Own comments
…………………………………………………………………………………

83) “Help and ease attitude” is part of my philosophy of life **1 2 3 4 5**
Own comments
…………………………………………………………………………………

84) In my daily work I am prepared to discuss questions about life and death **1 2 3 4 5**
Own comments
…………………………………………………………………………………

1 = Disagree completely **5 = Agree completely**

85) Meeting seriously ill and dying children makes me aware of essential issues in life **1 2 3 4 5**
Own comments
……………………………………………………………………………….

86) Working with pediatric oncology has an extremely stimulating effect on personal development **1 2 3 4 5**
Own comments
……………………………………………………………………………….

1 2 3 4 5
87) I am in good physical health
Own comments
……………………………………………………………………………….

I feel worried about severe diseases that might affect:
88) Myself **1 2 3 4 5**
89) Those individuals that are close to me **1 2 3 4 5**
Own comments
……………………………………………………………………………….

STUDYSPECIFIC QUESTIONNAIRE - FREE WORDING ANSWERS

Questions to physicians with more than 5 years' experience of pediatric oncology (Version I)

1. What do you think is the most burdensome task when working in pediatric oncology?

2. What do you think gives the greatest satisfaction when working in this field?

3. How do you relax when your work has been emotionally/medically demanding?

4. Is psychological support important when working in pediatric oncology?

☐Yes

☐ No

☐Partially

5. What kind of psychological support would you prefer when working in this field?

6. Is psychological supervision important when working in pediatric oncology?

☐Yes

☐No

☐Partially

7. What kind of psychological supervision is important when working in this field?

8. Do you think that questions relating to central life issues are important in this work?

☐Yes

☐No

☐Partially

9. How would you suggest that these discussions could be designed at your place of work?

10. Own comments?

Questions to physicians with less than 5 years' experience of pediatric oncology (Version II)

1. Why do you want to work with children with cancer?

2. At present, would you say that you are in need of *psychological support* when working with these patients?

☐Yes

☐No

☐Partially

If the answer to question 2) was “No”, please proceed to question 5

3. What kind of psychological support do you think you need when working in this field?

4. To what degree would you say that you need this kind of support? How often? How much?

5. At present, would you say that you are in need of *psychological supervision* when working in pediatric oncology?

☐Yes

☐No

☐Partially

If the answer to question 5) was “No”, please proceed to question 8

6. What kind of psychological supervision do you think you need when working in this field?

7. To what degree would you say that you need this kind of supervision? How often? How much?

8. What do you think is going to be your main concern when working in pediatric oncology?

9. What do you think gives the greatest satisfaction when working in this field?

10 What challenges do you think you are going to face in the future related to this work?

11. How do you relax when your work has been emotionally/medically demanding?

12. Do you think that questions relating to central life issues are important in this work?

☐Yes

☐ No

☐Partially

13. How would you suggest that these discussions could be designed at your place of work?

14. How long do you think you will work in pediatric oncology?

☐Months

☐Year