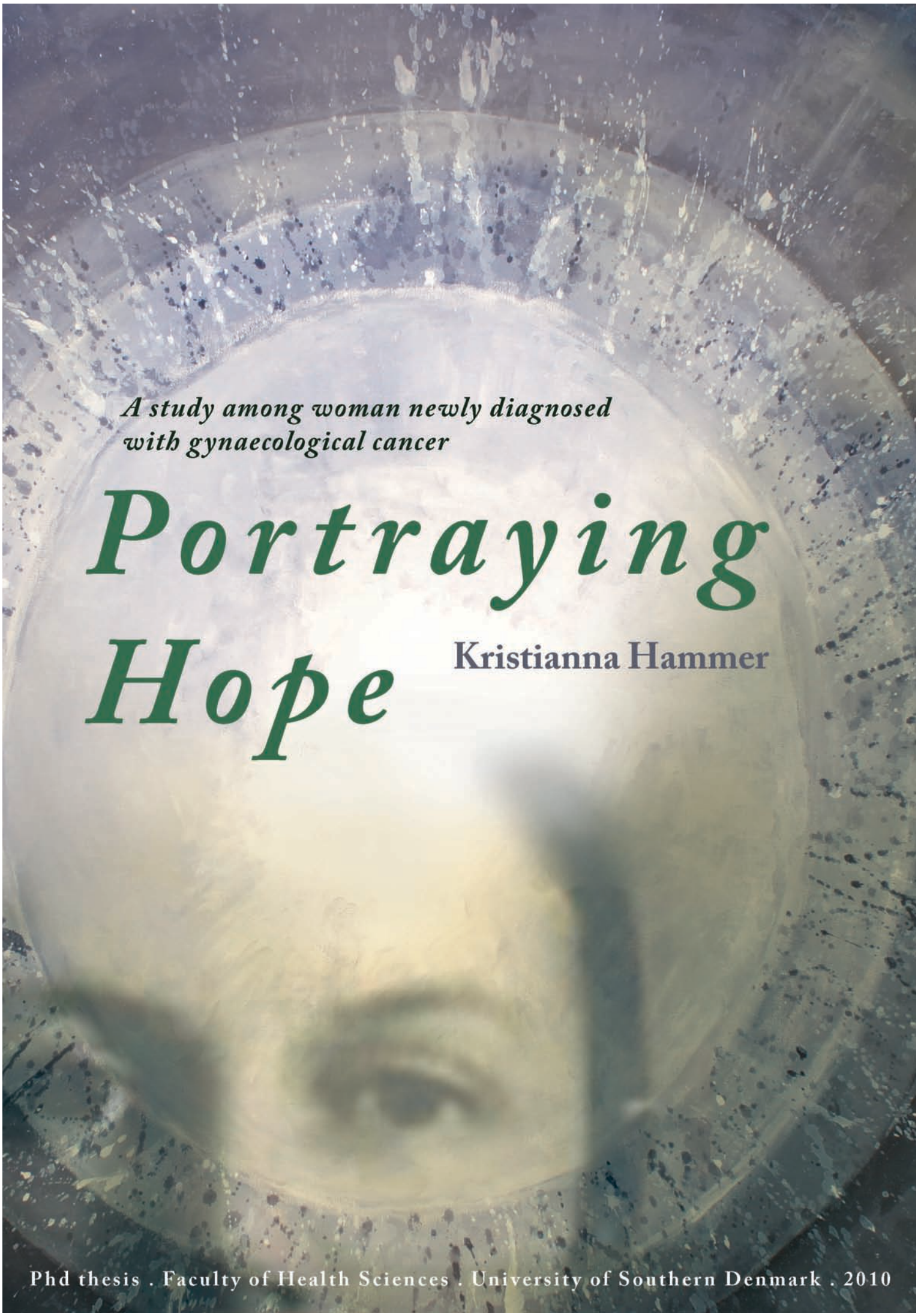

A study among woman newly diagnosed with gynaecological cancer

Portraying Hope

Kristianna Hammer

Phd thesis . Faculty of Health Sciences . University of Southern Denmark . 2010

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Hope is a united human experience essential to life. Understanding it is difficult as it is so integrate to human life. It is like a fish trying to understand the meaning of water. Water might be the last thing a fish is concerned about until it is taken out of it. Hope is so vital to life, that its loss is equated to the loss of life itself (Fromm 1968).

Original papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

I. Hammer K, Hall EOC, Mogensen, O. The meaning of hope in nursing research: a meta-synthesis. *Scandinavian Journal of Caring Science,* 2009 May; 23: 549-557.

II. Hammer K, Hall EOC, Mogensen, O. Hope as experienced in women newly diagnosed with gynaecological cancer. *European Journal of Oncology Nursing*, 2009 Sep; 13(4): 274-9.

III. Hammer K, Hall EOC, Mogensen, O. Hope pictured in drawings by women newly diagnosed with gynaecological cancer. (submitted)

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Acknowledgements

This study was carried out at the Gynaecological Department at the Odense University Hospital, Denmark. Thanks to the Gynaecological Department that allowed me access the research field which made this study possible. And thanks to the staff for being helpful throughout the study and I wish to thank you all.

I like to thank each of the participants of the study for sharing and for generously giving me your time – including your wholehearted contributions and the fine drawings.

My supervisor and "supporter" professor Elisabeth Hall, has given me excellent guidance, based on her long phenomenological experiences, deep understanding and insight. Thank you for sharing your scientific enthusiasm with me, for your constructive advising and your always wise perspective.

My supervisor and "supporter" professor Ole Mogensen. Thank you for your deep understanding and insight and always being so enthusiastic for my study.

Tanks to professor Karen Vibeke Mortensen for sharing her experience in the field of art and drawings.

Also, I owe many thanks to my loving family, my husband Eilif, our children and grandchildren who are the centre of my life. Also, a special thank to my son Fróði, who always was there to help me with his good advice and his expertise in the computer world. My daughter Turið for her support and many constructive discussions. And my son Runi for his theological reflections. Also, I owe many thanks to all friends and neighbours who have been supporting me through the whole process.

The study has been funded by Odense University Hospital, Department of Genecology and Obstetrics, 'Kræftens Bekæmpelse" and University of Southern Denmark. I am most grateful for this contribution.

1 Introduction

Hope is fundamental for life, health and during illness. Without hope life becomes meaningless and dull. The positive role of hope in human life, health, and illness is widely recognized. This is significant in nursing where the purpose is to promote health and well-being for all persons. This thesis is about hope and cancer, more specifically about hope when newly diagnosed with gynaecological cancer. Originally, the idea with the study was to investigate the lived experience of hope among women with gynaecological cancer over time; firstly when the women received the diagnosis, secondly six months later. This in order to follow the course of hope and add new knowledge about hope into the nursing field. However, because of time restraint, only the first part makes up this thesis.

The purpose of the thesis thus is to describe the lived experiences of hope in women newly diagnosed with gynaecological cancer. Inspiring hope is a basic value in nursing. When an individual is being diagnosed with cancer - a disease that can be life-threatening, mutilating and stigmatizing, often requiring intense treatment and causing insecurity - facilitating hope is a challenge for all involved; the patient, the family and the cancer care professionals. Knowledge about how the patients themselves experience hope might help nurses and other health professionals to act hopefully in critical situations. One such situation is the day that the patient receives the cancer diagnosis. The question is what matters for the patient then.

Cancer is a disease that may be life threatening but the disease can also be treated effectively. An increasing amount of patients with cancer are cured. Therefore, there are many good reasons to hope for cure. However, getting the diagnosis may activate stress. The individual could be shocked by the news, and the first impression could be “this is not true, this does not concern me”. The general assumption among theologians, many philosophers and humanistic oriented nurse theorists is however: hope is always there, is always present; Hope is part of the living life in a mysterious way. This mysterious way might be talked about in interviews and conversations and might be illustrated in drawings, symbolized in one way or another. Talks and

drawings are known to alleviate anxiety and stress among human beings. It is a way of managing happy and joyous feelings, as well as unhappy and awesome feelings. Knowledge about how patients express this mysterious feeling and desire through interviews and drawings would be a way for health care professionals to better understand the patients. The knowledge could contribute to quality in care and possibly add to the body of nursing knowledge.

Background

Facilitating hope is not a task that can be easily delineated in a clinical guideline; it demands knowledge, a caring attitude and respect for individual dignity and integrity. Caring matters, it qualifies our relationships with other persons and involves "to help him grow and actualize himself" (Mayeroff 1971:1). Whether this other is a person including oneself, an idea, an artwork or whatever, caring allows growth, maturity and development. Nurses play an important role in caring and inspiring hope in all kinds of contexts and relationships.

The impetus for studying the phenomenon "hope" as experienced on the day when a woman receives the diagnosis of gynaecological cancer, has several roots connected to clinical experiences, earlier studies and the development of nursing science in Denmark. One root comes from many years of working as a cancer nurse in the radiation therapy clinic. In those years, conversations with the patients, especially with women who were hysterectomied and in radiation therapy, taught me that having cancer in the reproductive area of the body was a threat to the female identity, womanhood, motherhood and sexuality as well as life itself. The women experience that life changed, that the diagnosis was a cutting line, and that they had to face a new life. Similar findings are reported in literature (Gamel et al 2000, Juraskova et al 2003, Larrison 2005). As a nurse I tried to listen and care, but as a woman I was touched. The women's stories impressed me. Some women saw the diagnosis through a pessimistic lens, others experienced hope in spite of the diagnosis. All were worried. Women with gynaecological cancer are described to worry more about their condition than patients with cancer in general (Corney et al 1992). Realizing that hope plays a therapeutic role while loss of hope and hopelessness place the patient at risk of

misadjusting to the diagnosis (Chi 2007, Owen 1989), it seemed most pertinent to study hope.

The study has a predecessor that deepened my knowledge of what constitutes hope and the meaning of hope in nursing care. My first study of hope was a theoretical survey of hope as expressed in the literature among chronically ill people (Hammer 2003; 2009). That study became my Master's Thesis. The background the study was an assumption that many patients were left alone with their hope or hopelessness. Hope-inspiring actions were not visible in nursing. How could that be when hope is central in holistic nursing which considers caring to be an ethical ideal and is supposed to be common practice in nursing? The study, with the title "Nursing between hope and hopelessness" aimed at enlightening the meaning of hope to chronically ill individuals and thereby to throw light on the possibilities which the nurses have to comply with hope and discourage hopelessness. Biographical stories were described and analyzed using the philosopher Gabriel Marcel's ontological notions of hope (Marcel 1965), the pedagogue Max Van Manen's phenomenological thoughts about "living in hope" (Van Manen 1990) and one of the first existential nurse theorists, Joyce Travelbee's, notions of hope in nursing (Travelbee 1971). The study concluded that hope is significant in coping but can turn into hopelessness, depending on the way the human being relates to the metaphysical choice between hope, life, hopelessness and – suicide. Nurses through good educational, communicative and personal qualities can guide the chronically ill person from hopelessness to hope through using "the terminology of hope", time and space to reflect and get the knowledge fixed.

Gabriel Marcel (1889-1973), often named the philosopher of hope (Knox 2003), cannot be neglected when studying hope. Marcel notes existentialism as a "bodily existence", meaning that one existence is related to another existence, like an engagement (Lübcke 2000). An essential feature in the existential philosophy is the view that the individual has to "compose one's life" (Skirbekk and Gilje 2000:583). By that kind of existential composure - when you as a person realizes your own death – the human being somewhat awakens, and the consciousness reaches deeper. If you cannot reach to the answer of the existential questions, "Where do we come from?

Who are we? Where do we go?" Then the consciousness is still left behind together with the mystery of life and the mysterious hope (ibid).

Further, my interest in hope as existential phenomenon arose due to the development in nursing toward a humanistic orientated nursing with caring as the core of nursing. Historically, early nursing theorists got inspirations to their theories from physiology, psychology, and sociology. Later they began to be inspired from philosophy (Hall 1997). This development speeded up in Denmark in the Nineteen Nineties much inspired by the Norwegian nurse theorist and philosopher Kari Martinsson who during five years was working in Denmark to establish the PhD education of nurses. Also lecturer and texts of the Danish nurse theorist and philosopher Merry Scheel about interactional nursing theory influenced the students in advanced nursing courses. This advancing was not limited to Denmark; humanistic oriented nursing was on the agenda around the Western world. Discussion about independence of the nursing profession, the epistemology of nursing and the substance and ontology of nursing took place (Paterson and Zderad 1988). By this, the discussion of hope, the being of hope and hope in clinical practice was initiated. This thesis is a follower to these discussions.

A third root that has influenced the design of the thesis is being an artist, a trained and experienced painter. Art in the form of painting means a lot to me; it colours all my life. My experiences as artist were a trigger to the design. Interviews as well as drawings were chosen as data collection tools. A mixed method was assumed to enhance validity, give a both broader and deeper understanding of the experience of hope and to create new frontiers (Polit and Beck 2006a). Most people use only a minimal part of their creative skills and abilities to create art. For many individuals art is able to tell a different story than words do, for example words in an interview. I like to refer to the American philosopher and psychologist John Dewey (1859-1952). Dewey believed that the creative process is a way of seeing, a language of its own and that word as media are not powerful enough; they are but characters that convey a vague and indefinite account of a phenomenon (Dewey 1980). Art is a medium to form or deform the human soul and life spirit (Parker 1987). Art captures humanity in all its forms (Chinn 1994). Art evokes spirituality, inspiration, imagination, creativity

and dedication. Art is the life spirit, Emerson (1982) said: *"Nature is the symbol of the spirit, nature always wears the colours of the spirit; art conspires with the spirit in search of beauty, wisdom, truth"* (p. 48). Others, such as McNiff (1998) see that art can help science to become more sensitive to the transformative effects of its interpretations, and that science can assist art-based research in becoming more systematic in its procedures and more attuned to the give and take in research. Different ways of looking and seeing complement one another (McNiff 1998). Art-based research might avoid a narrow perspective on research (McNiff 1998), and art needs to be studied phenomenologically (Rubin 1984). Research in art education (Beittel 1973) confirms that understanding and evaluating art-based research is a challenge. So, because art has a different kind of story to tell; interviews, drawings and interviews about drawings make up the data of this thesis. And the data are all analyzed phenomenologically as suggested by (Rubin 1984, Betensky 1995, Van Manen 1990, and McNiff 1998. Phenomenology aims are describing how phenomena present themselves in human existence (Van Manen 1990:184). This study will demonstrate how we can create research using the artistic process. The following chapters will explain this further.

Overview of the thesis

The thesis is organized as follows: A summary leading to *portrayal of hope*, and a framework of three papers (Papers I, II, III). The first six chapters give a picture of the background, the literature review and the aim. Chapter two concerns perspective on hope. Chapter three concerns perspective on cancer and gynaecological cancer. Chapter four is about perspective on art, drawings and art-based research. Chapter five and six delineate the rationale and the aims of the study. Chapter seven concerns the methodology methods used. Chapter eight presents a summary of the papers (I-III) that the thesis is based on, and in this chapter the results are presented. Chapter nine is the discussion, first about methodological issues, such as the approaches used trustworthiness and preunderstanding, then discussion about findings in relation to clinical nursing and nursing research. Chapter ten presents conclusions, based on the aim of the study and perspective in relation to clinical nursing and nursing research. The last chapter concerns practical, theoretical and methodological implications of the thesis.

2 Perspectives on hope

This study concerns developing an understanding of *the meaning of hope for women newly diagnosed with gynaecological cancer*. The study is undertaken in the context of nursing as a human caring science with caring as an ethical ideal (Watson 1979; 1989). In this context, hope is central. A life without hope is unbearable, and nursing has a social mandate to do well for a fellow human being who needs help and care (Kirkevold 2002).

In the following, ontological and epistemological aspects of hope of relevance for the study and a caring nursing context will be presented in three sections: the mystery of hope in life, hope in nursing philosophy and knowledge of hope from cancer nursing research. These aspects of hope matter when newly diagnosed with a disease such as cancer. The word *cancer* has a symbolic meaning, signalling not only a disease and a threat to health but also a threat to life itself. For some people cancer might be a symbol of death.

The mystery of hope in life

Hope is philosophically described as a mystery that is lived rather than a problem that has to be solved (Marcel 1951). Gabriel Marcel, the philosopher of hope, illustrates hope in an existentialphilosophical perspective, and his notions make the philosophical framework of hope for this study.

Marcel describes the human existence through the bodily (somatic) existence, relationship to another (dialogue)[1] and commitment[2]. He criticizes the impersonality

[1] *About the dialogue. Marcel mentions that the human existence is a relationship to others, to some one or the other. In the conversation with an unknown other, the other is not just another for me and I, another for the other, but I am also another for myself. The other is alien to me and I am an alien to the other. But at the same time I am an alien to myself in my relationship to the other. Only when we become familiar with each other or get to know each other, the real conversation or dialogue begins, where we talk to each other. The dialogue*

in the mechanical modern world, and argues that the human being has to return to the mystery of life. He maintains that human beings find their satisfaction in a God-centered communication, which is characterized by mutual fidelity and hope. He argues that hope is strong and will survive even a total collapse of the body, and he maintains that all physical theories of hope are absurd, because hope is a spiritual phenomenon, a mystery.

As a mystery, hope is beyond complete description and can not be fully defined, described or explained. Instead, hope is lived. Hope is a way to take part in the mysterious life. Such participation is to experience a wholesome life; it is something that we are involved in, present but is not easily described. However, Marcel describes hope. For him, hope is to get in to the mystery of existence, to be available for existence and to re-start existence. Hope is likewise the response to existence, a kind of fellow-feeling, communion. Hope is the entrance into human life, and through communion with fellow human beings hope is actualized. A person who lives in hope is no longer captive to the past.

The question in this study is how the women make meaning of life when hope is mysterious. Hope is spiritual in nature and arises in response to a personal trial, an captivity (Marcel 1951). Does this woman feel in captivity getting the diagnosis? Are they tied to the past? And how in such case will the spirit of hope arise for them? May hope, as described by the philosopher Mayeroff (1971), be compared to a coming spring, with growth, development and possibilities? Or is it that the mystery of life turns into an absurd situation where revolution, freedom and a manifold of possibilities stand in for hope, as Camus thinks (Lübcke 1982:341)? " … the less life is experienced as captivity, the less the soul will be able to see the shining of that

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may also lead a step further, a fellowship is established and my perspective is subjugated. "The other reveals me to myself" (Lübcke 2002: 299-306).

[2] *Regarding commitment. Marcel says that sensing is a direct participation, where the subject spontaneously interacts with the outside world. This participation is direct and spontaneous with the surroundings since there is no intermediary. There is no device that stands between the subject and me.*

veiled, mysterious light, which illuminates the very cater of hope's dwelling place" (Marcel 1951:32) .

Labeled with a cancer diagnosis feelings of despair and hopelessness may develop, feelings of whether to be cured or "loose the struggle" as often seen in necrologies. This closeness between hope and hopelessness again seems to be a mystery of life. However, there can be no hope, Marcel argues, "except when the temptation to despair exists. Hope is the act by which the temptation is actively or victoriously overcome" (Marcel 1965:9). A world without despair would be a world without hope. With Marcel's words "The truth is that there can strictly speaking be no hope except when the temptation to despair exists. The greater the despair, the more "unconquerable" hope can be (ibid). It seems that hope and hopelessness embraces the whole human existence in a mysterious way, and it is therefore pertinent to study hope in different contexts in order to develop knowledge of hope as experienced. How is it that women with a newly diagnosed gynaecological cancer go into the mystery of life and experience their existence?

Hope in nursing philosophy

Hope is present in nursing philosophies that embrace nursing as a human science and practice discipline. Nursing and caring are closely linked, also described as "nursing without caring is not nursing" (Scheel 2005), and hope is found to be part of caring. For Joyce Travelbee, Kari Martinsen and Jean Watson, some of many nurse scholars and theorists who have delineated nursing philosophies, hope is a natural and necessary part of caring.

For Travelbee, hope has a number of qualities but is specially characterized by the desire to get to or achieve a goal, combined with a degree of expectation that what you wish is within reach. The very process of hope is important, and not whether the person's goals are unrealistic or probably unattainable, unless a miracle was to happen. Further she states that the one that lacks hope, see no prospects for change or improvement in life; there is no solution to problems or ways out of difficulties (Travelbee 2002). For Travelbee hope is related to *courage* - the one that has courage has fears but is able to go beyond fear to achieve goals.

Courage as hope is likewise emphasized in Martinsen's philosophy of caring (Martinsen 1981). The basic premises for Martinsen's notions is that life is given to the human being, and that life, mercy, hope and open speech appear spontaneously and unrestrained in relations between human beings. In this, Martinsen's hope is closely connected to the notion of Løgstrup (1956). Caring is for Martinsen a moral, relational and practical enterprise in a complex and manifold reality, filled with paradoxes and "meeting-of-extremes". The meeting-of-extremes determine each other; they come together without mixing and without separating. The day a woman is diagnosed with gynaecological cancer might be a day where the meeting-of-extremes hope and hopelessness dialectically determine each other, such as Marcel also thinks. Typical of Martinsen's theory of caring is that sense perception is superior to reason. The nurse first is sensitive and open for the appeal from the suffering and sick human being and discloses the patient's fundamental life and suffering history. Next the nurse acts according to professional knowledge in order to give him a sense of life-courage or hope.

Watson's philosophy in developing of a caring science is gathered in carative factors (Watson 1979; 1989). One of them is instillation of faith-hope, without which nursing would fail, Watson argues. Instilling faith-hope is a therapeutic action that brings comfort, consolation and healing to the patient. As Marcel, Watson has a deep respect for both miracles and the mystery of life.

Seen in the light of this study, hope the day of a cancer diagnosis, it appears that very little, a short moment, a smile, a trust might make important impact on the hope or life-courage among patients. However, this implies that in any meeting between human beings there is an unspoken demand, a demand of taking care of a fellow human being's life, the life that has been put into your hands (Løgstrup 1956). To strengthen the hope is about promoting the life-courage. The nurse should do this through a moral-practical wisdom and professional judgment (Martinsen 1990). Instilling hope and faith in the future might give consolation and even healing (Watson 1988; 1999), understood as a better life situation. Hope as told by the women themselves therefore is pertinent to study in order for nurses to know and act properly, wisely and caring.

3 Perspectives on cancer and gynaecological cancer

Cancer as disease and metaphor

Cancer is the most common disease worldwide and the second leading cause of death. According to the World Health Organization's International Agency for Research on Cancer (IARC), there were 3,2 million new cases and 1.7 million deaths from cancer in Europe in 2006 (Grassi and Travando 2008). The incidence of cancer increased between 1950 and 2005, partly as a result of population growth and aging. Survival from cancer is also improving, with several million Europeans being cured or living with cancer for many years (Coleman et al 2003). Cancer nursing research is growing, however most studies have been found to focus on terminal cancer (Molassiotis et al 2006).

The word cancer is a metaphor that traces back to Hippocratc; he likened the veins radiating from bulbs in the breast to *crabs* (*cancer* in Latin, *karkínos* in Greek) indicating that cancer like crabs crawl everywhere and hollow the flesh and the lives of patients (Skott 2002). In early days, cancer was, in the talk of the town, a process in which the body was consumed or eaten. Cancer and tuberculosis were considered one and the same disease. They were not separated until the 1880s when tuberculosis was discovered to be a bacterial infection (Sontag 1988). Both diseases have been used in the literature as metaphors for the "unnatural" - that which cuts off life – in the individual as well as in a community or a society.

> *Throughout the nineteenth century, disease metaphors become more virulent, preposterous, and demagogic. And there is an increasing tendency to call any situation one disapproves as a disease. Disease, which could be considered as much a part of nature as is health, became the synonym of whatever was "unnatural" (Sontag 1988:74).*

Today, not only the cancer but the treatment as well is metaphorically seen as Eating of the body (Skott 2002). Patients might ask themselves if the cure will save of kill them. They know that all cells are affected by the chemotherapy or the radiation. There is, Skott says, a transition in the cancer metaphors, new metaphors are

developing. The diagnosis of cancer still creates fear - and hope. Thus, the diagnosis of cancer involves a series of dramatic changes that affects patient and family, as well as their environment.

Gynaecological cancer

Every year 1.800 women in Denmark are diagnosed with gynaecological cancer and 1.200 has their uterus removed because of this. Approximately 200 of these women are in their fertile age (Nordic Cancer Register/ANCR 2006), which makes gynaecological cancer to a common cancer diagnosis among women.

Getting the diagnosis affects the women in one way or another. Studies from Danish and international studies document that the woman might feel distressed over delayed diagnosis, and when the diagnosis is a fact, it brings along a "shockwave" striking not only the woman but also her family (Kübler–Ross 1969). The woman may experience pain, fatigue, menstrual and fertility changes and gastrointestinal distress but they might anyhow have a good bodily perception; they wish to be in control and are concerned about support and caring; and they hope for quick curative surgery, good communication and treatment (Akyüz et al 2008, Ekwall et al 2003, Ersak et al 1997, Esbensen et al 2004, Ferrell et al 2003, Hounsgaard et al 2007, Howell et al 2003, Pilkington and Mitchell 2004, Seibæk and Hounsgaard 2006, Velji and Fitch 2001).

Emotionally, the women react in different ways, some are intervening, others are cooperative or unsure (Wagner et al 2005). The women's well-being before treatment is a predictor of well-being afterwards and may predict length of survival (Elsemann and Lalos 1999, Gilbar 1996). In the course of the treatment, the women prefer sharing decisions with the doctors rather than making decisions on their own; they like to communicate with the nursing staff but might prefer to talk about their life, hobbies, families and friends rather than their health condition, strategies that seemingly are helping them to find meaning and hope for the future (Beaver and Booth 2007, Ekvall et al 2003, Kvåle 2007, Wagner et al 2005).

Studies about sexuality when diagnosed with gynaecological cancer show different results. Some studies express changes in sexuality as a prominent issue that negatively

affects the women's life (Anderson and Lutgendorf 1997, Fitch et al 2000, Guidozzi 1993, Steginga and Dunn 1997, Wilmoth and Spinelli 2000). Others, e.g. Ersak and colleagues (1997) found only 5 of 130 participants with ovarian cancer who expressed changes in sexuality or loss of perceived attractiveness. The women seem to adapt their sexuality to the life circumstances (Lamb and Sheldon 1994). Butler and colleagues (1998) in a qualitative study on women's experiences of sexual health after gynaecological cancer found that the women did not view the sexual functioning in isolation. Rather, sexuality seemed to be woven into the fabric of their identity. How women felt about this aspect of themselves was related to the entire context of their lives.

In conclusion, to be diagnosed with cancer seems to impress human beings even today when modern treatment to a great extent, and especially when it comes to gynaecological cancer, is able to cure or extend life. Cancer, however, is unnatural and treatment is aggressive. The hope for recovery and survival of disease and treatment are always present.

4 Perspectives on art, drawing and art-based research

Images came to us before the written word, so how did we use images to tell stories. (Nigel Spivey 2005)

The meaning of hope experienced by women newly diagnosed with gynaecological cancer is in this thesis also elicited by drawings (paper III). This was done much because I am an active artist and painter, and because art-based research brings a new research tradition with many possibilities (McNiff 1998). This chapter will present thoughts about art, drawing and art-based research, thus showing some of my preunderstanding as nurse and artist which is essential in the research approach used in this thesis, phenomenology.

The meaning of art in therapy and research

The representation of our human form and human production of art has been a preoccupation of artists through the centuries. Art portrays something of the universal human experience, which may or may not include the artist's emotion and expression in art (Bentensky 1995). It is expression that carries and conveys meaning. It is in art aspects of universal or subjective human experience find their expression in lines expressive of moods; in colours expressive of emotions; in shape expressive of weight, which also symbolizes the world; and in motion, stance or gesture expressive of vitality and feeling about self and aliveness. Expression is a given propensity which answers a human need to portray in individual ways feelings and thoughts about what one is, or, in certain cases, what one aspires to be (Betensky 1995).

It seems to me that phenomenological oriented art making comes close to the fulfilment of the task that Heidigger assigned to phenomenology: revealing the hidden aspect of man's Being as phenomena accessible to consciousness (Heidegger 2001/1954). Since phenomenology is an open-ended orientation with focus on a variety of phenomena-based themes, art expression and art-therapy qualify as legitimate themes for a phenomenological study. The emphasis on visually expressive self-projections with art materials of people in need to find themselves in the world,

makes art therapy uniquely suited to both the aspects of the philosophy and the method. In addition, phenomenology offers an answer to a long needed unbiased approach to art therapy in all its spheres: theory, training and professional practice (Betensky 1995).

When creating a piece of art, the artist must be involved in uncovering mental images and messages, recalling memories, making decisions, and generating solutions. Whether drawing or sculpting, creating art involves instant feedback. Each brush stroke that appears on the paper can promote future action as well as delight the artist. Creating art means that there is a concrete record of an inner process. This record can be discussed, altered and redrawn. Art is present in all activities that involve forming elements into a whole. Most instances of art are neither subjected to critical reflection nor valued as art. However, when we bring elements together to form a whole, we experience art (Chinn and Kramer 1999). This happens also in nursing.

Drawing is making an image; it is a visual art, using any of a wide variety of tools and techniques. The visual art focuses on the creation of works through drawing, painting, photography, printmaking, filmmaking and computer (Guillemin 2004). The visual is described as being the most fundamental of all senses because seeing comes before words (Berger 1972:7) and because "depiction, picturing and seeing are ubiquitous features of the process by which most human beings come to know the world as it really is for them" (Fyfe and Law 1988:2). Graphic illustrations as coloured drawings may represent collective reflection and expression of meanings of a phenomenon (Van Manen 1990).

In research of health and illness, drawings are used to picture the lived experience of a person's lifeworld when hit by illness (Salmon 1993, Guillemin 2004). Artistic expression and production of graphic illustrations were e.g. a vital process in understanding the experiences of living as survivors of Ebola virus in Uganda (Locsin 2002, Locsin and Matua 2002, Locsin et al 2003). Drawings done by patients with lupus have been used with diagnostic and therapeutic intentions (Nowicka-Sauer 2007). Drawings have been used to document health among myocardial infection patients (Broadbent et al 2004) and as a nonverbal method of measuring patients´ perspective of impact of illness (Büchi et al 1998).

Drawings are offering health care professionals a new perspective on caring - and thus also on hope. Drawings and visual interpretation of what is in the drawings are creative agencies, and they are important to examine because health care professionals work in image-based realities (Betensky 1995). Being engaged in creative acts creates hope and optimism; it helps people cope with debilitating problems (Lane 2005). In adults drawing may represent a creative confrontation with own preconscious imagery, and the drawing then functions as an initial ordering of confused experience (Naevestad 1996). A given patient may have a great ability for concretizing internal processes in pictures. Like an artist, the patient makes something invisible visible.

The meaning of art in nursing

The nurse scholar and feminist Peggy Chinn (1994) consider art as a part of all human experiences. Art expresses what words usually fail to express; it brings wholeness to human consciousness. Art moves consciousness into realms not imaged and realities not predicted. Art is feared and sometimes revered, because it is associated, in the depth of human consciousness, with women, with the ability to create, to generate, to bring forth life. Analogous to the act of giving birth, art brings forth, out of inner spirit, the essence of human imagination, that which has not existed before. Art expresses the powerful intention of the human spirit to move – to create revolution, to break free of constraints of political and social boundaries and to bring into awareness something that is possible but is not yet. Art is the mirror, the creator, and the record of each human being.

Turning to art as a way of "seeing" in nursing, we begin to remember what has been lost, and we comprehend knowing and doing (Chinn 2006). Turning to art as a medium to develop nursing knowledge is a medium to bring forward the potential of new knowledge. Art as medium, as act, as process, and as product becomes a carrier of wisdom; it becomes the expression of yearned-for wholeness, not only in the sense of encompassing all of human health experience, but in restoring within those who are nurses the wholeness that comes with linkage to ancient healing traditions that are rooted in women's ways of knowing (Carper 1975, Carper 1978, Chinn 1994, Chinn and Kramer 1994).

An issue of hope is the lived experience of art and healing with cancer patients. Lane (2008) examined the lived experience of art and healing with cancer patients and demonstrated an evolving spirit-body healing. New research shows that art in an intensive care unit relaxes patients. These patients used less pain medications and left the hospital earlier than those who did not have art in their rooms (McCaffrey and Locsin 2002, Prensner et al 2001, Kreitzer and Snyder 2002). Neurophysiologists now know that art, meditation, and healing all come from the same source in the body; they are all associated with similar brainwave patterns and mind-body changes. (Benson 1975). The process of making, viewing and reflect on art or listening to music can carry both the patient and nurse into another province.

Drawings with children are used for diagnostic, therapeutic and health promotion purpose (Champion et al 1999, Diem-Wille 2001, Fury et al 1997, Oakley et al 1995) or for studying children´s representation of themselves and their social world (Herth 1998). "The act of drawing moderates their narrative skills, providing the opportunity to organize and tell their stories using retrieval cues that are internally, rather than externally generated" (Driessnack 2005:421).

The aesthetic knowing which both Carper and Chinn and Kramer talk about, connects empirical, ethical and personal ways of knowing and gives a deeper meaning of a situation and "calls forth inner creative resources that transform experience into what is not yet real, but possible " (Chinn and Kramer 2004:193). The discipline of aesthetic is often simplistically associated with subjectivity and inconsistency, and this notion is paired with the assumption that there is an objective and constant reality at the core of human health experience. But, if there is a constant reality underlies all experience, science has shown that we cannot know it. Chinn and Kramer and Chinn talk about aesthetic curing in nursing, but not about aesthetic curing in research. The discipline of aesthetic is often simplistically associated with subjectivity and inconsistency, and this notion is paired with assumption that there is an objective and constant reality at the core of human health experience. It is time, however, to acknowledge that human experience cannot be completely understood through the scientific method and to apply the discipline, rigor and intelligencethat we commonly associated with science, to the process of aesthetic inquiry. How are the aesthetic curing different from scientific understanding? We need both scientific and aesthetic

knowledge, and the two have always complemented one another through human history as they continue to explore the unknown (Chinn 1994).

The meaning of art-based research

Art-based inquiry, like art itself, often includes carefully calculated studies, but the distinguishing feature of creative discovery is the embrace of the unknown. The way of research is self- selecting and not for everyone. However, it must be made arable for those artists who desire to use their skills and unique sensitivities to research their expertise (McNiff 1998).

Art-based research has developed out of creative art therapy (Betensky 1995, McNiff 1998) which in turn was an extension of psychology. McNiff, a painter, creates art therapy research and has done review of art therapy research. McNiff, a researcher and an artist, expresses other's experiences in art, making art and professional reflection on one's own creative art expression as basis of research. According to McNiff´s approach the process of investigation is still deeper. Self-reflective studies which grow out of own paintings, such as the researcher's relationship to her mother as the human body. Artistic self-inquiry is an inter-perspective research, a self-indulgent. Art-based research is a way of deeper and new removing practice through ward a prescript cases (McNiff 1989).

What Betensky has done is to provide us, not only with the kind of creative synthesis exemplified in her research work; she also introduced us to basic elements of symbolic expressions in art line, shape, colour and so forth – and how they can be viewed from a phenomenological perspective. Betensky has taught about phenomenology, about how she applies the methodology to art therapy.

McNiff (1998) defined art-based research as a method of inquiry which use the elements of the creative arts experience, including the making of art by the researcher. Art-based ways of understanding the significance of what we do within our practice (McNiff 1998:13). He likewise declares that art-based research has boundless possibilities. In keeping with the nature of creative expression, art-based research may encourage immersion in the uncertainty of life, finding a personally fulfilling part of

inquiry. Art-based research emerges understanding through an often unpredictable process of exploration (McNiff 1998). But we need to come to a better understanding of how artistic knowing is different from scientific understanding.

Summary

In summary, drawing is one of many devices used in visual art that can bring forward invisible or ineffable aspects of a phenomenon. Drawing is then a powerful medium in research and a carrier of wisdom; it integrates inner and outer, emotions and knowing to wholeness. Turning to art, drawing and art-based research as a medium for understanding meanings and experiences of relevance for nursing practice and nursing research is a way to gain wisdom and offer quality of care. Our emerging research tradition needs to reflect the interdisciplinary spirit which gave birth to nursing tradition.

5 Rationale of the study

There are several rationales for the subject and methods used in this thesis. The rationale for studying hope is because hope is considering being a life phenomenon (Delmar 2006) universal for human life and foundational to humanistic oriented nursing care. Hope is fundamental for life, health and during illness. Without hope life might seem meaningless and dull.

The rationale for studying hope in gynaecological cancer context is because cancer involving the female genitalia is considering affecting women in a unique way. The uterus, ovaries and vagina might have an effect on the way the women feel about femininity, womanhood and sexuality.

The rationale studying hope in the diagnostic stage is the consideration that patients with newly diagnosed cancer are especially vulnerable. There is an indication that the manner with which persons cope with uncertainty at this stage may have to do with how the person experiences the process of hope. It seems important to examine how the patterns of hope in the context of gynaecological cancer.

The cancer diagnosis puts patients at risk of psychological distress. Some see the diagnosis as a threat of life, others find hope in spite of a life threatening disease. Nurses may influence patients hope at this special period of time either by being a supportive, positive listener or by tearing hope away, creating hopelessness. Knowledge developed out of patients' own experiences of hope when newly diagnosed with a gynaecological cancer is valuable for good quality cancer nursing.

The rationale for the phenomenological approaches used in this thesis is that narratives and drawings are powerful verbal and visual expressions of life. A phenomenological approach is a particular mode of describing and understanding the contours of lived experience addressed in words and drawings. By a process of self-reflection and critical analysis the research explores various understandings of the phenomenon studied; it uncovers structure and meaning in order to come to a deeper

understanding of how elements found are intertwined in the essential of this special phenomenon.

6 Aims

The overall aim of this thesis was to elicit Danish women's experiences of hope when newly diagnosed with gynaecological cancer and to synthesize the findings into a bigger whole that effectively can be used in cancer nursing and cancer nursing research.

Specific aims of the different studies were:

- Identify recent nursing research about experiences of hope among people in health and during sickness as described in qualitative research and to condense these findings in a metasynthesis (Paper I).

- Investigate the lived experiences of hope among women newly diagnosed with gynaecological cancer as expressed through interviews (Paper II) and drawings (Paper III) of hope.

Paper I illustrates experiences of hope in more general terms. Thus, findings from paper I put the aims of paper II and III in perspective.

7 Methodology and method

Research design and approach

The study had different designs according to the aims of the study. An overview is seen in Table 1.

Table 1 – ***Overview of design, data, data collection and data analysis of the studies***

	Paper I	Paper II	Paper III
Design	Meta-synthesis	Phenomenological approach	Phenomenological approach
Sample	14 qualitative studies	15 women	15 women
Data collection	Literature search	Interviews	Drawings and post-drawing interviews
Data analysis	Meta-ethnography (Noblit and Hare 1988)	Hermeneutic phenomenology (Van Manen 1990)	Husserlian and hermeneutic phenomenology (Betensky 1995, Van Manen 1990)

Meta-synthesis

To identify recent nursing research about experiences of hope among healthy people and during sickness as described in qualitative research a *meta-synthesis* was performed (Paper I). Meta-synthesis is a research strategy to synthesise qualitative studies (Bondas and Hall 2007ab); it belongs to a group of meta-research methods with the potential to present comprehensive knowledge, to strengthen research based care and to facilitate the utilization of qualitative studies in health care (Estabrooks et al 1994, Paterson et al 2001). The trend of meta-research is seen as a new mode of knowledge development (Zhao 1991); the product of a meta-synthesis is supposed to

render a comprehensive theoretical argument for practice. The meta-synthesis study thus was done to give a broad overview of hope as experienced in different contexts.

Phenomenological inquiries

To reach the aim of the study, to investigate women's experiences of hope when newly diagnosed with gynaecological cancer, a hermeneutic phenomenological approach as described by Van Manen (1990) (paper II and III) and a Husserlian phenomenological approach as described by Betensky (1995; 2001) (paper III) were chosen. Before elaborating on these two phenomenological methodologies, I will present some general aspects of phenomenology as philosophy. This, to place the study in a context of philosophy of science.

Phenomenology is the science of phenomena. Hegel formulated phenomenology as the science in which we come to know *mind* as it is in itself through the study of the ways in it appears to us (Hegel 1977). When Husserl formulated phenomenology as a discipline that endeavours to describe how the world is constituted and experienced through conscious acts, as he uses the phrase *Zu den Sachen,* he sees phenomenology both as *going to the things themselves* and *lets get down to what matters* (Husserl 1982/1913).

Phenomenological research is a question about how human beings experience the world, in other words phenomenological research wants to know the world in which we live as human beings. According to van Manen the phenomenological research is a caring act:

> *We want to know that which is most essential to being. To care is to serve and share our being with the one we love. We desire to truly know our loved one's very nature. And if our love is strong enough, we not only will learn much about life, we also will come face to face with the mystery (Van Manen 1990:6).*

Phenomenology is both a philosophy and a methodology. As philosophy, phenomenology is supposed to describe experiences in essential terms (Carr 1999); it is the study of the lifeworld - the world as we immediately experience pre-reflected

(Husserl 1970/1954) and from there develop knowledge. As methodology, phenomenology aims at gaining a deeper understanding of the nature or meaning of the everyday life using a systematic and reflective description of experiences in life (van Manen 1990).

Since the Nineteen Seventies nurse researchers have involved phenomenology in describing human life experiences (Hall 1997, Kim 1999). The purpose is to provide ethical and living knowledge for nursing practice (Bergum 1994, Van der Zalm and Bergum 2000).

Phenomenology as philosophy

For Edmund Husserl (1859-1938), the father of the modern phenomenological movement, the objective of phenomenology was to develop epistemological knowledge of the essence of things. This should be done through turning to things themselves, *Zu den Sachen* (Van Manen 1990:31), meaning that the researcher actively explores the phenomenon in all its modalities and aspects using *reflection, intuition* and *insights* on different levels. The goal is as clear, illustrative, exact and cogent as possible to describe the phenomenon without preconceived apprehension. Presuppositions of any kind such as theories, abstractions and prejudices should be temporarily bracketed. Heidegger (2002), instead of asking how the essence of things are constituted in consciousness (as did Husserl), asked how the being of beings (things) show themselves to us. For Heidegger the phenomenological question became: How can we let that what shows itself be seen in the very way that it shows itself from itself (Heidegger 2002:53). Phenomenology then requires attunement to the modes of being, of the ways that things are in the world.

The word phenomenology derives from the Greek word *phainómenon* which means ‘that which appears” and *lógos*, meaning "study" (Denker 2000). Phenomenology does not claim that it can capture exactly what is known of an experience. Rather, it attempts to recreate a phenomenon as it appears to the participant. The meaning of an experience is not inherent in objects but is located in the individual’s life. Questions asked was what was significant of this experience to this person? And, what does she or he make of it? Specifically in this study was what was the significant experience of

hope for the woman and what did she make of it? Key concepts of significance for the research with a phenomenological approach are *essence, intentionality, lifeworld, meaning, reduction, lived experience, reflection* and *bracketing*.

The phenomenological theory of *intentionality* refers to the inseparable connection of human beings' consciousness with the world. To be conscious is to be aware of some aspect of the world, such as in this thesis the hope for something. According to Husserl, the basic intentional structure of consciousness is present whenever objects or situations in the world are experienced. For the researcher, the theory of intentionality is that every perception has a horizon "belonging to its object" (Husserl 1994:158).

Phenomenology is a study of *essence* (Merleau-Ponty 1962:vii) - a systematic attempt to uncover and describe internal meaning structures of lived experience of a phenomenon. In other words, phenomenology is the systematic attempt to uncover and describe an essential structure.

Phenomenological human science is the study of lived or existential *meanings*; it attempts to describe and interpret these experiential meanings we live as we live them (Merleau-Ponty 1962). Being of something is to inquire into the nature or meaning of the phenomenon.

The term *bracketing* describes the act of suspending beliefs and theories in order to study the essential structure of the world. *Bracketing* (also called epoché, the phenomenological reduction) is a term derived from Husserl for the act of suspending judgment about the natural world that precedes the phenomenological analysis. The concept can be understood as "unpacking" phenomena, or, in other words, systematically peeling away their symbolic meanings like layers of an onion until only the thing-in-itself remains. Thus, one's subjective perception of the bracketed phenomenon is the truest form of experience one can have in perceiving it. In other words, bracketing involves setting aside the question of the real existence of the contemplated object, as well as all other questions about its physical nature. The experience of seeing a horse e.g. qualifies as an experience, irrespective of whether the horse appears in reality, in a dream, or in a hallucination.

The *lifeworld* is an expression of the world in which we live, experience and act in our lives. The lifeworld is memories of the past as well as dreams of the future; it is an intuitive, common and pre-given world in which we act without reflection, in a natural way, without thinking too much about it. It is pre-given to us all quite naturally, as persons within the horizon of our fellow men, i. e. in every actual connection with others, as "the" world is common to us all (Husserl 1984/1936:122). The lifeworld is thus the pre-scientific and pre-reflective world of past, present and future.

Lived experience refers to the way persons experience and understand their lifeworld as real and meaningful; it describes those aspects of a situation as experienced by the person in it. In this study, the question is to understand the meaning women make of hope in a certain situation. Through interview questions and asking the women to draw, the women might start to reflect upon the matter that they earlier just took for natural, not being aware of. In this way knowledge about hope develops. The phenomenological description might reveal new aspects of this phenomenon.

The purpose of the phenomenological *reflection* is to grasp the meaning of a phenomenon. Phenomenological reflection is both easy and difficult. It is easy because to see the meaning of the *essence* of a phenomenon is something everyone does constantly. For example, when a nurse sees a patient, she does not just perceive a man or a women, she sees a person who differs from other men and women precisely in that respect which makes her talk of this person as a patient. The nurse has a notion of what a patient is. What is difficult is to come to a reflective determination and explication of what a patient is. This determination and explication of meaning is the more difficult task of the phenomenological *reflection.* To come to an understanding of the essential structure of something we need to *reflect* on it by practicing a certain *reduction. Reduction* is the technical term that describes the phenomenological device which permits us to discover what Merleau-Ponty (1962) calls the spontaneous surge of the lifeworld. In other words, the reduction is "the ambition to make reflection emulate the unreflective life of consciousness." (Van Manen 1990:185)

Phenomenology as methodology

The phenomenological approaches in this thesis are Van Manen's hermeneutic phenomenology (Paper II and III) originally developed for pedagogic practice (Van Manen 1990) and Betensky's husserlian phenomenology of art expression originally developed for art therapy in psychiatry and psychology practices (Betensky 1995) (paper III). Van Manen's methodology is known in nursing research (Hall 2000**)** and repeatedly used in nursing research to describe and interpret lived experiences in nursing contexts (e.g. Hall 2007, Lundqvist et al 2007, Van der Zalm and Bergum 2000). Betensky's methodology is less known in nursing research, and no nursing research study was found based exclusively on her approach to husserlian phenomenology. Van Manen and Betensky were chosen as their methodologies are human science oriented. The goal is to understand the deeper meaning of hope as told and illustrated by the informants themselves in a specific situation and context. The two aspects of the phenomenological methods of this study will be described in the following.

Hermeneutic phenomenology[3] *according to Van Manen.* The overall objective of Van Manen's hermeneutic phenomenology is ontological; it is to begin with the life itself, describing the lived experiences and interpreting the existential meaning and experiences, in this study, the lived experience of hope when newly diagnosed with gynaecological cancer. Van Manen sees the world as always interpreted; therefore his phenomenological approach is hermeneutic phenomenology.

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[3] *Hermeneutic is the theory and practice of interpretation. Hermeneutics is necessary when there is possibility for misunderstanding, Schleiermacher stated (1977). He opened up the idea of hermeneutics as a theory or technology of interpretation, especially with respect to the study of sacred (biblical and classical texts). Hermeneutic phenomenology tries to be attentive to both terms of its methodology; it is descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterrupted phenomena.*

By a process of self-reflection and critical analysis the researcher explores various understandings, uncovers their structure and meaning in order to come to a deeper understanding of the phenomenon – in this case hope when newly diagnosed with gynaecological cancer.

Van Manen (1990) refers to the Dutch phenomenologist Buytendijk who called phenomenology *The science of examples*. Van Manen states that when making a hermeneutic phenomenological study, you try to clarify the essence of a phenomenon through the analysis of the structural features of it. This clarification helps to highlight the phenomenon. Thus, the phenomenological description becomes an example or a picture of what the researcher attempts to describe. A strong phenomenological description allows us to see the deeper meaning of structures of the perceived experience, as described by the analysis, using proper units of identified themes and an accumulated thoughtfulness in the exemplary descriptions. Varied examples redirect the phenomenological theme, so that a handful of dimensions of the phenomenon itself will be illuminated (Van Manen 1990:121).

Van Manen's hermeneutic phenomenological approach is a dynamic interplay of research activities: (1) turning to the nature of lived experience, (2) investigating experience as we live it, (3) reflecting on essential themes, (4) the art of writing and rewriting, (5) maintaining a strong and oriented relation and (6) balancing the research context by considering parts and whole (ibid:30-34).

Husserlian phenomenology according to Betensky. The purpose of the Husserlian phenomenological research is to describe a phenomenon in depth to find out what really matters using the theory of intentionality and the phenomenological reduction.
For *Betensky*, phenomenology, due to its open-ended orientation and pursuit of an unbiased stance, lends itself to exploring art expression and art therapy. Phenomenological art therapy aims to assist people who are trying to find themselves. Art-making helps people through difficulties in life. Through phenomenological art therapy – as for example in this study, drawings and post-drawing interviews - people can transcend self-centeredness, and become participating members to the world (Betensky 1995; 2001). A good way to understand phenomenology is to look at it with reference to the oldest problem in philosophy, Betensky states. The oldest

problem is the relationship between the objective reality outside the human mind, and feelings and thoughts about that reality in the mind. In its approach to the dilemma of how these two worlds relate, phenomenology operates with two propositions. One proposition states that all inquiries must begin with phenomena of consciousness since they are the only things at our disposal, i.e., they are the only givers. The other proposition states that these phenomena can reveal to us what they really are. Looking at them with a concentrated gaze and with the purpose in mind and eye to see all that can be seen in them, we are getting closer to the deeper meaning. The phenomena of consciousness are many and all around us. They are things, thoughts, materials, persons, events, situations, feelings, moods, dreams, notions, fantasies, images, mental constructs, experiences, art expressions, and all that can be noticed on the art expressions, and material that come into consciousness from the level below it.

Phenomenology explores these phenomena by a three–step method. The first step is the *phenomenological intuiting* in which informant and researcher silently gaze at the art expression. Having just participated in the creative process where the informant was making his art-work and the researcher was participant observer, both now look at the finished art expression the way one studies a painting at an exhibition. The second step is the *phenomenological analysis*. This is including an examination of structural elements of the art expression: lines, form, colours, spacing, themes, tension and patterns. Together informant and researcher investigate these artistic means to convey personal meanings and symbols. The analysis leads to the third step, a reflection of the *whole experience* of the creative process. In this part, flashes of self-discovery, insights and AHAs occur.

Betensky and Van Manen both emphasize the importance of reflective dwelling in the data. Betensky (1995) talks about a process of silent intuiting of certain meaning in the art expression. Van Manen elaborates on silence, asking the phenomenological researcher to explore the silent, the unspeakable, and the taken-for-granted in the human experience. In this study, reflections of the meaning of interview and art data were long-lasting. I reflected in silence, alone and together with the participants and the supervisor about the meaning of what was said and the meaning of the drawings.

Coming close to the essence of a phenomenon, different modalities might be needed. Van Manen speaks for the use of different sources in investigating the experience as lived, such as personal experiences, art, literature, stories, observations and diaries. "The experience of something that appears ineffable within the context of one type of discourse may be expressible by means of another form of discourse" (Van Manen 1990:113). In this investigation, two discourses were used to express the meaning of the object of study, hope when newly diagnosed with gynaecological cancer, interviews and art expressions. These are but two of many variants that could have been used. What was wanted was to illuminate hope in this special context because of its value for the discipline of nursing.

Samples

Sample in paper I was 14 qualitative studies concerning the meaning of hope and identified using the keywords *hope* and *hopefulness* in literature searches as well as through reference lists in reviewed articles. The sample described the meaning of hope among healthy people (n=3), people with chronically illness (n=6) and people with terminal illness (n=5). The studies were published in nursing or allied health journals from 1990 to 2006 and were conducted in USA, Great Britain, Canada, Australia, Norway, Sweden and Finland. The total number of participants in the studies was 291. The methods of the studies were diverse, with one study using grounded theory, one using Q-method, and a third mixed method; the remainders were phenomenological, hermeneutical, or a combination of both.

In paper II and III, 15 women being newly diagnosed with gynaecological cancer participated. The women had a variety of cancer diagnoses, most of the women were married and had children, the youngest women were working, the eldest retired and housewives (Table 2). The median age of the women was 52 (range 24-87). The women were recruited from a gynaecological department at a university hospital in Denmark. Altogether, 27 women were contacted, however, 12 women declined, they were too emotionally influenced by the diagnosis. One of the declining women briefly participated but for emotional reasons discontinued the interview.

Table 2 – ***Data of the women in study II and III***

Age in years	Demographics	Diagnosis
24	Student, unmarried, no children	C. cervicis uteri
38	Working, married, children	C. cervicis uteri
40	Working, divorced, children	C. ovarii
40	Working, married, children	C. cervicis uteri
43	Working, married, children	C. cervicis uteri
44	Working, married, children	C. vulvae
47	Working, married, no children	C.cervicis uteri
52	Working, unmarried, no children	C. cervicis uteri
53	Working, divorced, adult children	C. corpus uteri
53	Housewife, married, children	C. cervicis uteri
54	Working, married, adult children	C. cervicis uteri
60	Housewife, married, children and grandchildren	C. corpus uteri
77	Retired, married, no children	C. ovarii
77	Retired, married, children and grandchildren	C. ovarii
87	Retired, widow, children and grandchildren	C. ovarii

Data collection

Data were collected using literature search, interview and drawings as seen in Table 1.[4]

[4] *To give a full picture of the data collection, I will mention here that in the second interview six months later, all accept one (the young 24 year old participant) agreed to participate and all of them again draw a picture of hope at that time. These data remain to be analysed.*

Literature research

A literature search was performed with the purpose to investigate what was known about hope and hopefulness (Paper I). The aim of this study was to develop a meta-synthesis of nursing research about hope as perceived by people during sickness and by healthy people. We reviewed 14 qualitative studies from seven countries following Noblit and Hare's (1988) methodology. The purpose of meta-synthesis is to develop new knowledge based on systematic attempts to analyze existing qualitative research findings of the phenomenon under study. Even though critical voices are heard regarding the representation of qualitative research synthesis studies (Bondas and Hall 2007a, Sandelowski 2006), the product of a meta-synthesis is intended to result in a more comprehensive and convincing theoretical argument for evidence-based practice (Thorne et al 2004).

Interview

Semistructured interviews (Kvale 1994) were used to collect data from the women in paper II. The women were interviewed the day they received the diagnosis. The interviews, lasting from 60-120 minutes, took place in a quiet room at a gynecological unit of the hospital. In this type of interview the researcher is the instrument through which the data are collected (Kvale 1994). Knowing that the women had just received a cancer diagnosis, the interviewer tried to create a pleasant atmosphere with candle light and coffee. To encourage the participants to continue telling about their experience the researcher was sensitive and listening. A semistructured interview guide governed the interviews and helped the involved to keep close to the issue. The initial question was: "Please tell about the situation when you got to know about the diagnosis and the operation. What did you think? What did you feel? What did you do?" Assuming that hope was a part of their life, the women were encouraged to speak freely about issues associated to life itself. All women spoke spontaneously of hope and their future. To increase hope and the significance of hope at this stage, I repeated my question abouth how they felt and thought and acted. During the interviews several women cried slowly, but most of them regained their composure and the interview went on. Each interview ended with the question "How do you see the future?" and a debriefing of the full interview.

All interviews were done by the first author who is a proficient cancer care nurse, experienced in consoling patients who are unhappy or crying. At the time of the interviews the interviewer had no connection to the cancer clinical practice where the study took place.

Drawing

Drawings (Betensky 1995) were likewise used to collect data from the women. In paper III, data were 15 drawings and 15 interviews with the art makers of these drawings straight after the art work. The drawings took place after the interviews. When the interviews (Paper II) had come to an end, the women were asked to express hope in a drawing. They were handed a blank unlined paper A5 (148x210 mm) and 12 coloured oil pastels. As the quality of the drawings tends to appear when the art-maker is ready to "let it flow" (Betensky 1995), the researcher left the room. After finishing the drawing, the participants explained the content of the drawing, the colours used and the composition. Together researcher and participant talked about the meaning of the drawing, like an inter-view (Kvale 1994).

Data analysis

Data in paper I were analysed using Noblit and Hare's (1988) meta-ethnographic approach which is a systematic comparison of studies where each study is interpreted with the other. This is done in a fashion similar to when an ethnographer is interpreting a culture and has the purpose of giving an expanded understanding of the phenomenon under study. The systematic comparison is done in a series of overlapping, parallel and repeating phases (Noblit and Hara 1988:26-29). A meta-synthesis is more than a systematic review of the literature (Schreiber et al 1989, Sherwood 1999) It has been defined as "bringing together and breaking down of findings, examining them, discovering the essential features, and, in some way, combining phenomena into a transformed whole" (Schreiber et al 1997: 314). The procedure in this study was

- identifying the topic,
- deciding what studies to be included,
- reading the studies included,

- determining how the studies were related,
- translating the studies into one another,
- synthesizing translations to a bigger whole,
- expressing the synthesis.

Data in paper II and III were analysed using phenomenology. Data from the interviews (paper II) and post-drawing interviews (paper III) were tape-recorded, transcribed verbatim and analysed following Van Manen's (1990) methodology. First, a *wholistic approach* to the data was done to get an overview of the full data source. Second, a *selective approach* was done. Elements and themes that occurred frequently in the text were identified. A detailed reading was again done with the purpose to reveal more aspects of the experience of hope in this situation. Then the individual themes were condensed into universal themes. Continuously, I was writing the phenomenological text, something Van Manen sees as a main object of the research process. In doing this I tried to maintain a strong and oriented relation to the phenomenon in question and to the discipline of nursing.

The drawings and the post-drawing interviews were both analysed apart and together using Betensky's (1995) phenomenological art therapy method and Van Manen's hermeneutic phenomenology.

To get an overview of data, drawings were looked at several times to achieve an overall picture of the meaning of the visual images of hope. In the second selective phase, the analysis focused on identifying elements in the drawings. Thereafter a phenomenological description was performed asking: What does the art-maker explain about her drawing? In the last two analysis phases, a matrix was developed to engage the understanding. Following this we condensed the individual interpretation and representation into universal interpretations. The questions asked to the data were: What does it mean? What is common and what is unique in the drawings? Are there symbols and metaphors? This approach was a reflective process and confirmed the phenomenological intuition earlier described. The next step was a phenomenological integration. The question to the data was: What does symbols, metaphors and interpretation mean? How is it possible to use this knowledge? During the analysis process a balancing between wholes and parts occurred in a dwelling in

and distancing from the data. This was done in an effort to present the results as complete, alive and intense as possible (Van Manen 1997).

Ethical considerations

Ethical guidelines followed those of the Northern Nurses Federation (NNF 2003) about informed voluntary consent, verbal and written information, and confidentiality. Before interviewing, the participants were informed of the research purpose and asked to sign a written consent form.

Permission to carry out the study was obtained before data were collected, and a number of orientation meetings were held at the hospital units. A description of the project was sent to the Regional Committee on Science Ethics and to the Data Surveillance Authority.

Ethical conduct in research is based upon the ethical principles of beneficence, respect for human dignity and justice. In this study these principles guided the research (Polit and Beck 2006b).

The interviews and drawings were carried out when the women were in a vulnerable life situation. There might be a risk that timing harmed the women. The diagnostic phase is a most difficult time, patients are vulnerable. But just because of their vulnerability it is important to develop nursing knowledge from the patients' perspective and assist nurses in further developing their role in relation to patients in the diagnostic phase and the complex and dynamic processes patients go through. Likewise, most patients admitted to hospitals for diagnostic investigations go through a challenging time of waiting. They are waiting for investigations and tests, preparing for undergoing them, and their waiting for their results. The time of waiting for the diagnosis is reported to be the most stressful time of illness experience (Mishel 1988, Benedict 1994, Neville 2003, Giske and Artinian 2007). It was possible that some patients would find it helpful to have someone to talk to, after having received the diagnosis, in this case a neutral and qualified person at this particular moment in their lifetime. According to the principle of beneficence, participants must not be subject to unnecessary harm and discomfort. The strategy to minimize harm included careful

awareness of the researcher when interviewing and asking about the drawings, recognizing her role as a not-harming researcher and the principle of beneficence.

Respect for human dignity, which in research ethics refers to the right to self-determination and the right to fully disclosure, was covered through following the NNF guidelines (NNF 2003). According to the principle of justice, the researcher must treat people who decide to participate in a non prejudice way and the researcher must demonstrate sensitivity and respect disrespectable of believes, lifestyles and cultures. Researchers should treat participants with courtesy and respect at all times (Polit and Beck 2006b). All interviews were done by the researcher of this thesis who is a proficient cancer care nurse, experienced in consoling patients who are unhappy or crying. At the time of interviewing the interviewer had no connection to the cancer clinical practice where the study took place.

The principle of justice likewise involves that the participants should be able to get in touch with the researcher during the study period. This was assured by leaving name, telephone number and e-mail address on the information sheet. Further, the principle of justice takes the right to have professional help if needed (Polit and Beck 2006b). In this study the researcher was in close contact with the unit staff; there was an agreement to assist. One of the women in the study made use of this professional assistance.

Preunderstanding

The problem of phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much, in other words, our preunderstanding knows too much. But how does one disregard everything one knows about an experience that one has chosen to study? Husserl used the term "bracketing" to describe how one must take hold of the phenomenon and then place it outside one's knowledge about the phenomenon (Husserl 1979). "We can't forget what we know, but we can to do it explicit" (Van Manen 1990:47). In hermeneutic and phenomenological literature you find that the self-awareness of the researcher is a prerequisite for effecting one´s preunderstanding and reaching a new understanding (Van Manen 1990, Gadamer 1991, Dahlberg et al 2001). Despite consciously trying

to put light on my preunderstanding as a nurse and an artist and demonstrate a fairly open and flexible mind, there were spots that were impossible to uncover for my consciousness. I tried to think critically about my approaches and method, tried to openly disclose processes, understandings and knowledge, to distance myself from own attitudes and experiences. Still, however, the interpretations of the phenomenon is coloured by the researcher's understanding and possibly her preunderstanding.

8 Results

The aim of the study was to elicit Danish woman's experiences of hope when newly diagnosed with gynaecological cancer and to synthesize the findings into a bigger whole.

In paper I, which illustrates lived experiences of hope in more general terms to put the main study in perspective, the findings of the meaning of hope among healthy people and people in sickness revealed hope to compose universal and specific dimensions. The universal dimensions were found to be being, becoming, relational, dialectic and dynamic. The specific dimensions were doing and situational.

In paper II, the findings from interviews with women newly diagnosed with gynecological cancer revealed that hope was essential for them at the time of the diagnosis. They hoped for being cured and able to continue their life as usual and to do that with loved ones, friends and relatives. The newly received cancer diagnosis made the women oscillate between hope and hopelessness, between positive expectations of getting cured and frightening feelings of the disease to take command.

In paper III the being dimension of hope penetrated the drawings. The being dimension involved three shades, an internal being or spirit, an external being or energy and a relational being or communion. All three shades of hope were nurtured through hopelessness. Hopelessness was a companion that followed hope like a shadow. An overview of the results is seen in Table 3. In the following paragraphs the individual results will be further described.

Hope among healthy people and people during sickness (Paper I)

The meta-synthesis of the meaning of hope among healthy and sick people revealed hope to compose universal and specific dimensions. The universal dimensions again were found to be being, becoming, relational, dialectic and dynamic. The specific dimensions were doing and situational.

Table 3 – *Themes and dimensions in the studies*

Paper	Themes	Dimensions
Paper I	Living in hope	Being
	Hoping for something	Doing
	Hope as a light in the horizon	Becoming
	Hope as a human to human relationship	Relational
	Hope versus hopelessness and despair	Dialectic
	Hope as weathering a storm	Situational/dynamic
Paper II	Hope as being cured, cared for and back to normal	Being
	Hope as being active and feeling well	Doing, being
	Hope as an internal power to maintain integrity	Being
	Hope as significant relationships	Relational
	Hope as fighting against hopelessness	Being, doing, situational
Paper III	Hope as a spirit to move on	Being (internal)
	Hope as energy through nature	Being (external)
	Hope as a communion through family life and relationships	Being (relational)

Living in hope – a being dimension

Hope had an internal being dimension called living in hope. Hope was something that was deep inside one's self which remains positive whatever happens. Thus it was a realistic optimism and an experience of being a whole human being. Willpower seemed to create energy and strength of being in faith and hope.

Hoping for something – a doing dimension

Hope had an external doing dimension that nurtured the internal mode of hope; it was a pragmatic, goal-setting entity which was reconstructed throughout life in response to situations. Achieving goals resulted in a deep feeling of satisfaction. Things hoped for included adequate food, having a place of one's own or expecting positive medical

outcome. Hope was the subjective probability of a good outcome for themselves or someone close to them, such as hoping for life after death.

Hope as a light in the horizon - a becoming dimension

Hope had a becoming dimension - a light in the horizon - a zest for life. This dimension was anticipating future possibilities such as living a little longer, expecting positive results, being cured from the disease or simply receiving a hopeful message from the physician. Hope as a light in the horizon was a help to remove hopelessness and see the significance of life.

Hope as a human-to-human relationship - a relational dimension

Hope had a relational dimension. The relationship was important. In this dimension hope was having a special someone to whom one could feel connected; it was a sense of mutual sharing, trust and unconditional positive regard. The human-to-human relationship was a promise of being loved and have someone to love, today, in the past and in the future.

Hope versus hopelessness and despair: two sides of the same coin – a dialectic dimension

Hope had a dialectic dimension that was referred to as hope versus hopelessness and despair, two sides of the same coin. The literature revealed that hope, hopelessness, and the core substance of health or vitality belong together. No matter what, hope is always there. Even if an individual seemingly has been robbed of hope, hope will be found again.

Hope as weathering a storm – a situational and dynamic dimension

Finally, hope had a situational and dynamic dimension that metaphorically was translated to “weathering a storm”. Like manoeuvring a ship in a storm, people, either healthy, chronically and terminally ill are searching to manoeuvre their life. They were hoping for good outcomes and better weather.

Hope as experienced among women newly diagnosed with gynaecological cancer (Paper II)

The analysis of the interviews with women newly diagnosed with gynecological cancer revealed that the presence of hope was essential for the women at the time of the diagnosis; they believed in being cured and able to continue their life as usual with loved ones, friends and relatives. The newly received cancer diagnosis made the women oscillate between hope and hopelessness, between positive expectations of getting cured and frightening feelings of the disease to take command. Five interrelated themes illuminate these findings.

Hope of being cured, cared for and getting back to normal

This theme highlights the importance of being cured, being cared for and getting back to normal. The women wished life to be the same as before the cancer, although their frame of reference was changed. This belief was often the very first thing that was told in the interview.

Hope as being active and feeling well

In addition to hope for cure the women envisioned the future as being active and satisfied. The women talked about the future and planned for the future. They wanted the future to be as before and they emphasized that even small things were important. Hope had to do with daily activities, doing small everyday chores and enjoying these things.

Hope as an internal power to maintain integration

This theme developed out of reflections late in the interviews and captures the spiritual mystery of hope. Hope was "something inside of me", something that contributed to "spiritual courage"; it was experienced to be a personal positive inner energy connected with strength and willpower and related to faith in God; it was a feeling of being a whole, human being with passion for life.

Hope as significant relationships

This theme captured the relational dimensions of hope. Hope grew out of love and relationship with significant others. Love, from husbands, children, grandchildren – and God, mobilized resources. The significant relationships confirmed a sense of value; the women felt being needed and good enough in spite of everything.

Hope as fighting against hopelessness

The women also experienced hopelessness. This theme was about the oscillating between hope and hopelessness. The diagnosis made the women realise that they had visible signs of cancer. For a moment they experienced loss, emptiness and hopelessness. It seemed as if hope was a fight against hopelessness, because as one woman said: "If hope disappears you have nothing".

Hope pictured in drawings women newly diagnosed with gynaecological cancer (Paper III)

In paper III, the womens' drawings, the succeeding descriptions of what the women saw in the drawings and the researchers' interpretation were condensed into three dimensions, revealing hope to be love, relationship, inner strength and a persistency to go on.

Hope as a spirit to move on

Hope had an internal being dimension. Hope was "something inside of me", something that contributed to "spiritual courage"; it was experienced to be a personal positive inner powerful feeling of being in faith and, thus it was a realistic optimism, an experience of being a whole human being. Hope was wholeness, *as a spirit to get moving on.*

Hope as energy through nature

Many of the women connected hope with nature, like getting energy through nature, that they felt themselves filled up with power after walking at the beach, in a wood or

leaning against a tree; it was a powerful feeling of being related to "mother earth". Tree, wood, water, see and flowers symbolised a peaceful awareness of life itself.

Hope as a communion through family life and relationships

Hope was related to a feeling of communion through family life and relation with relatives. Hope was a warm and powerful love for the family from whom they were getting support. This was expressed by one of the women as a feeling that the sun still was shining upon her and her family.

Synthesis of results

In summary, the synthesis of the studies identified conspicuous values of hope. Among healthy people and during sickness (paper I), hope had a multitude of dimensions being both universal and specific and seeing hopelessness as being dialectic to hope. The experience of hope when newly diagnosed with gynaecological cancer was synthesized to have situational, relational, doing and being dimensions (paper II). The core of hope was the being dimension. Hope was lived and hope appeared as having three shades, spirit (internal being), energy (external being), communion (relational being) and it was nurtured through hopelessness (paper III). These syntheses are illustrated in Figure 1. There hope is welding the lifeworld, past, present and future. Metaphorically hope is a prism. I see the lived hope as a prism with three sides. Hope is lived as spirit, energy and, communion and nurtured through their relationships and through hopelessness. Hope is shining through the prism and gives decisive results for each human being. Hope colours their lifeworld in their own specific way.

We live in a "broken world" Marcel says (Marcel 1995:15). And as I interpret it, the function of hope in this broken world is to weld the lifeworld, the past, the present and the future, every day, every minute and every second. Spirit, energy and communion are the motivating powerful forces. When some dramatic change is happening in our lifeworld, we need spirit, energy and communion to help us weld our dramatically broken world. No one can heal the broken world completely. But everyone can try to weld the broken world so much that the everyday life can be as close to a state of equilibrium as possible. I do not exactly see what Marcel means

with the broken world. Maybe he means that we live in a broken world and in this world hopelessness exists and without a world where hopelessness exists we do not know the world of hope. But one thing is true. To fight for hope is to fight against hopelessness.

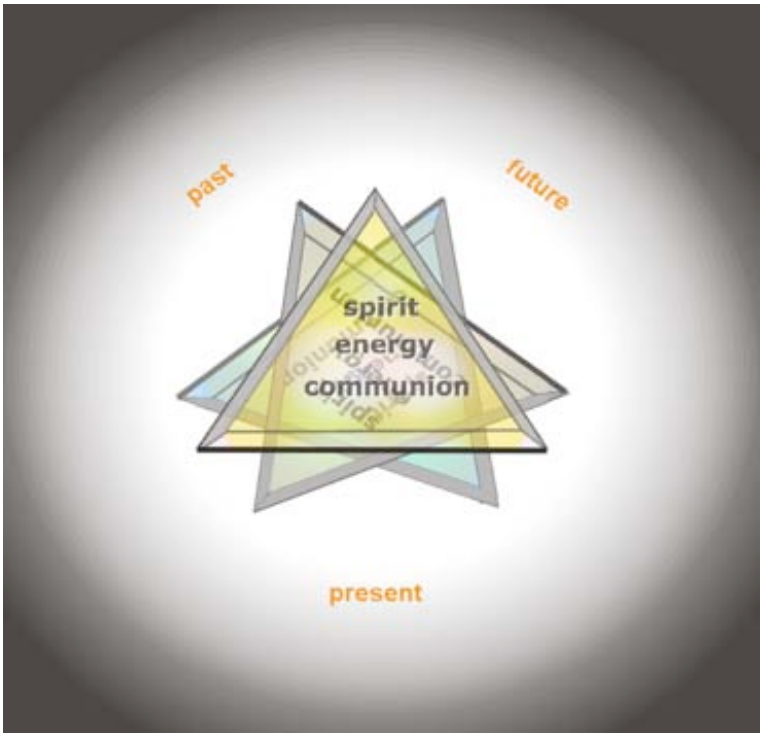

Figure 1 – Hope welding the past, present and future (lifeworld). The core of hope is the being dimension, metaphorically I see this being dimension like a prism with three sides. Hope is lived and hope appears as spirit (internal being), energy (external being), communion (relational being), and it is nurtured through hopelessness (Paper I, II, III). Hope is shining through the prism and gives decisive results for each human being; it will colour their lifeworld.

9 Discussion

In this chapter there will be a summarising discussion about central issues in the thesis. First, I will discuss methodological issues, the approach that was hermeneutic phenomenology, the trustworthiness of the study and the different designs and data collection methods. Second, substantial issues will be discussed targeting on the major concepts and phenomena that emerged, hope and hopelessness, communion, spirit and energy. The chapter ends with a summary and an illustration.

Discussion of methodologies

The hermeneutic-phenomenological approach

To get a deeper understanding of how the main methodology, hermeneutic – phenomenology, was used in this study, I will go back to Van Manen (1990) and his understanding of what characterizes this approach in qualitative research. I will compare his thoughts with what I have done in this study (paper II, III). Hermeneutic phenomenological research is the study of lived experience, the explication of phenomena as they present themselves to consciousness; essences; the description of the experiential meanings we live as we live them; a human scientific study of phenomena; and an attentive practice of thoughtfulness. To study the lived experience is to study the pre-reflective world as it is lived, to get to know what a special experience is like and to get insights (Van Manen 1990).

In this study, the phenomenon hope when newly diagnosed with gynaecological cancer was the lived experience studied. The women talked about hope (paper II), they made a drawing of hope and again talked about the drawing (paper III). During this process of reflecting on their lived experience of hope both the women and the researcher got deeper insights of what constitutes hope in this special situation. The women were allowed to talk freely and to draw in privacy. Consciousness is the access to the world, or as Van Manen states "it is by virtue of being conscious that we are already related to the world" (Van Manen 1990:9). Consciousness is always transitive; it is directed *towards something*; it is to be aware of some significant aspects of the world, to reflect on something that has passed or something that is lived

through (p.10). When the women got interviewed and draw there lived experience of hope at the day the women got the diagnosis, the women's consciousness of the cancer diagnosis was rather fresh; they lived through their experience or they were still living in the experience. Yet, the question was how well this timing was for reflecting on hope as phenomenological research is retrospective and not introspective? The literature emphasizes that receiving the diagnosis of gynaecologic cancer is a dramatic and worrying experience (Akyüz et al 2008, Hounsgaard et al 2007). A certain distance to the actual event would have given different data. More women then would have been more composed but still with clear memories of their experience of hope that day.

A limitation in both paper II, the interview study, and paper III, the drawing study, was that many women declined to participate. More participants might have given a more diverse picture of hope or it might be that hopelessness would have been still more prominent. However, in phenomenological studies the number of participants is not decisive, rather it is the way the experiences are lived that matters. Likewise a diversity of experiences matters as well as the openness of the researcher to detain preunderstandings and theories and let the experience kind of flow in itself to show itself. In spite of the declination of quite a few participants, the women in this study constituted a varied group of women in all ages, civil status and with different kinds of gynaecological cancer diagnoses. The women both talked about and draw their experience which added to the strength of the study. To approach the essence of the lived experience of hope in this situation, the study grasped the particular phenomenon in a full and deeper meaning as close to the focus as possible, at the particular moment when the women got their diagnosis.

My preunderstanding and belief was that hope is a mystery (Marcel 1965) but always present in one way or another especially during worry and insecurity. The design then was intentional and performed in deep respect for the fragile situation the women were in.

Hermeneutic phenomenological science, as all sciences, should be a matter of being systematic, explicit, self-critical and intersubjective (Van Manen 1990). During data analysis, I systematically was questioning and reflecting on data both alone and

together with the supervisors and co-authors and the research process was explicitly presented. It was intersubjective through dialoguing with other researchers and writers such as Marcel. It might be that the self-critical is not as explicit in this study. But the self-critical issue penetrated all the study through several re-analyses and rewritings before reaching to satisfaction and agreement.

Meta-synthesis as method

In paper I, data consisted of 14 qualitative studies about hope. The studies included were analysed and presented in a meta-synthesis. The purpose of meta-synthesis is to develop new knowledge based on systematic analysis of existing qualitative research findings of the phenomenon under study (Bondas and Hall 2007a). Meta-synthesis in qualitative research goes back to the growing amount of qualitative studies conducted from the 1980s and forward. It is a call to nurse researchers to accumulate knowledge from "one-shot" research studies not situated in larger research programs (Estabrooks 1994:510, Sandelowski 1997). A meta-synthesis is different than a systematic review of the literature. The systematic review (Cooper 1988, Kirkevold 1997) may be seen as a predecessor to meta-synthesis. Meta-synthesis is also inspired by meta-ethnography which was developed by Noblit and Hare (1988) to synthesize the body of field research within anthropology. Likewise, meta-synthesis can be compared to the quantitative meta-analysis, a term representing a research strategy in which the results of quantitative studies using similar instruments, data sets, and analytic methods are reanalyzed and aggregated (Glass, MacGaw and Smith, 1981). Further, meta-synthesis shares many features with the research strategy secondary analysis. However, in secondary analysis, the researcher has access to the primary data, a difference compared to meta-synthesis (Heaton, 2004; Thorne 1994; 1998). A shortcoming of the meta-synthesis is a dependence on the quality of the primary research publications and not having been involved in the research design and the initial data collection.

Interview as method

The purpose of using the phenomenological interview as a method was to obtain rich descriptions of the women's lifeworld, to catch a variety of views and thematic to describe a manifold of experiences (Van Manen 1990). The interview is a dialogue,

where the interviewer is using herself as an instrument and need to reflect of herself as such, her way of being, her values and beliefs and her interview technique (Hall 1996, Fog 1994). In this study, the interviewer tried to be sensitive, listening and humble, asking broad questions and refraining from leading questions. The interviews were long-lasting, they lasted from 60 to 120 minutes and they were characterized by a good tone, openness and pliability. Some women were softly crying, but at no point of time did I have a feeling that the participation was a nuisance for the women. On the contrary, the interview sometimes seemed to be as therapy to them. The limit between interview and therapy is difficult to make, there is a grey zone (Fog 1994). Both modes of interviews plan to disguise experiences, feelings and desires with the purpose to contribute to deeper understanding, both are about reflection and self-reflection. However, there are target differences. The purpose of a research interview is knowledge development; the purpose of a therapeutic interview is personal growth and development. In this study, I was aware of this difference, and tried to keep the research purpose in the foreground.

Drawing as a research method

The purpose of using the visual phenomenology and asking the women, after the interview, to draw their experience of hope and then talk about the drawing with me, was to get a deeper understanding of the meaning of hope in this situation. Using drawings in combination with interviews was original in thought and considered to be a strength of the study; it was a form of art-based research described by McNiff (1998) to have a variety of forms with many possibilities for knowledge development. In approaching the truth of a phenomenon different modalities might be needed. “The experience of something that appears ineffable within the context of one type of discourse may be expressible by means of another form of discourse” (Van Manen 1990:113). Hope when newly diagnosed with cancer is definitely an example of an ineffable phenomenon that lends itself to study through different discourses. Van Manen is asking the phenomenological researcher to explore the unspeakable and the taken-for-granted.

The visual phenomenology used was a modified version of the US. art therapist Mala Gitlin Betensky’s (1995) art therapy method. Her method is less known but

acknowledged and elaborated on among some later research groups using drawings and art in research (McNiff 1998). Betensky (1995), as Van Manen, talks about the meaning of silence, the process of silent intuiting of certain meanings in the expression. Silence was considered in this study, letting the women be by themselves during drawing and giving them ample time to make the drawing.

The strength of Betensky's method is that there is a common talk about the drawing, a self-interpretation together with the researcher or the therapist. To draw is a matter of aesthetics (Betensky 1973). Betensky and also Chinn (1994) consider aesthetic activities to bring wholeness to human consciousness. Art moves consciousness into new realms and images. With other words, to draw and to interpret drawings are ways of seeing, remembering, comprehending and developing knowledge. Guillemin (2004) considers drawings to be bound up with power relations, social experiences and technological interactions. The process of drawing is informed by the lifeworld of the drawer. Drawings are as much about the drawer's history as it is about present and future (Guillemin 2004). Thus, the drawing as a visual product is not only a record of how the women in this study understood hope at that particular place and time, the drawings also in one way or another illustrate their lifeworld, their memories of past experiences, their present social and family state and their dreams and desires of the future.

Trustworthiness

Criteria for validity in qualitative research are delineated as establishing trustworthiness (Lincoln and Guba 1985, Polit and Beck 2006a) and including criteria of credibility, dependability, confirmability and transferability.

Credibility is to carry out the study in a way that the findings will be credible. It involves member check, repeated contacts, peer debriefing, a search for difference in the unique, source triangulation and theory triangulation. In this study credibility was assured through researcher familiarity with the chosen research and methodologies. A pilot interview was done to practice the interview ability. Also the credibility lies in the researcher's aesthetic and artistic knowing (McNiff 1998). The credibility should be seen in the light that the supervisor was experienced in the method chosen in paper

I (Bondas and Hall 2007a; 2007b, Aagaard and Hall 2008) and that there was a close cooperation between the authors of all papers in reading and analyzing the data, a kind of peer debriefing. However, several of the credibility issues mentioned by Lincoln and Guba were not effectuated in this study. Member check e.g. is a controversial credibility issue not always seen as useful. Kvale (1994) advises against member (participant) check, suggesting the researcher to take full responsibility of the findings.

Dependability refers to data stability over time and conditions; it involves a search for coherence, consistent statements, and method triangulation. In this study dependability as a search for coherence and consistent statements was considered all through the research process. Methodological triangulation was also practiced, using different approaches to reach deeper understanding of the phenomenon under study.

Conformability refers to data accuracy, relevance and meaning. In this study, the researchers, alone and together reflected upon each step in the research process. In the data analysis, matrices were used to give overviews of the thoughts and reflections. Data analysis and findings further were presented for nurse researchers both in local and national seminars and international conferences and seminars. Findings have been discussed, reflected on and recognized.

Transferability refers to the extent to which the findings can be transferred to other settings and groups and involves purposeful sample selection, rich data and data descriptions. In this study (papers I, II, III), the research process was described in detail. The specific phenomenon was hope when newly diagnosed with gynaecological cancer. The synthesis of the results must be said to be rather abstract and therefore possibly transferable to other similar research and practical settings. Lincoln and Guba however, suggest that the responsibility to transfer a generated theory to other contexts belongs to the reader or buyer of the results. A well described and processed research could be a starting point for continuous research in the field. To facilitate transferability of the findings, they were presented both in words and in figures.

Some limitations of the study have to be addresses. A number of women turned down the invitation to participant; they were too overwhelmed by the cancer diagnosis. The women who agreed to participate might be strong women belonging to the intervening or cooperative type (Wagner et al 2005) while the women who declined to participate might be more uncertain, anxious and fearful. The findings of the study thus might give a too positive picture of the experience of hope among this group of woman.

Preunderstanding

Repeatedly, it has been emphasized in hermeneutic and phenomenological literature that the self-awareness of the researcher is a prerequisite for effecting one´s preunderstanding and researching of a new understanding (van Manen 1990, Gadamer 1991, Delmar 1999, Dahlberg et al 2001, Hall 2007). In this study, the cultural, theoretical and visual preunderstanding most often was explicit and there was a self-awareness that was helpful in the interpretation work, the preunderstanding of being a nurse, a women and an artist. An open-minded and reflective position is a "must" in hermeneutic phenomenological studies. The deeper understanding of a phenomenon studied develops out of the preunderstanding from which we cannot free ourselves. (Lindseth and Norberg 2004). Though, despite conscious trying to be open for the phenomenon itself and because of my preunderstaning there were blind spots that were impossible to recognize (Wackerhausen 1992). Personal and professional experiences of hope and hoping through a life as a women, wife, mother, grandmother and nurse influenced my pre-understanding of the phenomenon.

Discussion of the findings

Findings from the three studies (paper I, II, III) were described to encompass three shades: spirit, energy and communion. The three shades demonstrate a living hope. Hope was lived through these three, the internal (spirit), external (energy) and relational (communion) shades and often pictured as a sun. At the same time, a sense of hopelessness was present as a dark cloud on the sky. In the following these areas will be further discussed.

Hope and hopelessness nurture[5] *each other*

Hope and hopelessness did not only exist side by side but they nurtured each other, they were like two sides of the same coin (paper I). Being newly diagnosed with gynaecological cancer made the women oscillate between hope and hopelessness (paper II). The diagnosis made the women realise that they had signs of cancer, and for a moment they experienced loss, emptiness and hopelessness. But at the same time hope was always present, even though hopelessness was pushing from all sides as I have pictured in Figure 1. These findings are comparable to Lindholm's (2005) study of Finnish women suffering from breast cancer. The author found that hope, hopelessness and the core substance of health belong together and set vitality in motion. No matter what, hope is always there. Even if an individual has been robbed of hope, it will be found again (Turner 2005). In the situation described in this thesis, the newly diagnosed women were fighting against hopelessness using internal, external and relational forces.

Marcel's (1965) notion is that there is a fundamental relationship between hope and hopelessness – a tension field wherein human beings live and have to make an existential choice. A world without opportunities or without despair would be a world without hope. Even the most desperate hopelessness – thoughts of suicide – can become the starting point for hope. Marcel (1965) speaks of two forms of hopelessness – more correctly that hopelessness affects two different shades of being. One kind of hopelessness affects the specific hope and another kind affects the universal hope. The universal hope for Marcel is metaphysical, transcendent, tied to the soul, and is even strengthened when hopelessness arises. It is therefore easy to claim that hopelessness is caused by something concrete non-metaphysical which first and foremost affects the specific hope. In this study, this non-metaphysical concrete was the diagnosis of cancer.

A way of seeing hope and hopelessness nurture each other is when Marcel (1965) introduces two ways to comprehend hopelessness; *surrender and acceptance*. By

[5] *I use the word nurture to demonstrate the mutual nourishment of the relationship. Bergum (1994) describes nurturance as "fostering growth in one another ... nurturance always occurs in reciprocation, through interaction" (Bergum 1994:77).*

acceptance you comprehend your situation, but you are still actively fighting against self-destruction. You remain yourself and refuse to be reduced to what the situation entitles. You protect yourself. When surrendering, the self is dissolved. This sense of hopelessness, Marcel claims, has a metaphysical element and therefore it can affect the universal hope. The individual is fascinated by the idea of own death to such a degree, that he/she actively contributes to it. This is what Marcel defines as the true (metaphysical) hopelessness, a hopelessness that is not tied to something concrete which affects the specific hope. When there is no more hope, the soul is left to a state of drowsiness, where one actively destroys oneself. This supports the thought that patients losing hope are worse situated than patients who are able to sustain hope.

In this study, the women did not show signs of surrender; they protected themselves, tried to comprehend the situation and were actively fighting hopelessness in an acceptance. This example points to the dialectical engagement of hopelessness and hope—where there is hope there is always the possibility of hopelessness, and only where there is the possibility of hopelessness can we respond with hope. Hopelessness or despair says Marcel, is equivalent to saying that there is nothing in the whole of reality to which I can extend credit, nothing is worthwhile. “Despair is possible in any form, at any moment and to any degree, and this betrayal may seem to be counselled, if not forced upon us, by the very structure of the world we live in” (Marcel 1995:26). Hope is the affirmation that is the response to this denial.

Communion

Not only hope and hopelessness were nurturing each other. Being in relationship was most important for hope in this situation. Relationship or communion with loved ones was essential. Hope as communion was an essential shade of hope (papers I - III). The word communion in Latin *communio* means community, solidarity, generally, public (Jensen 1978). Significant relationships confirmed a sense of value; the women felt being needed and good enough in spite of the diagnosis. The women illustrated hope related to a feeling of communion through family life and relationship with near and dear, such as husband and children. Warm and powerful love for the family, with whom they were getting support, gave the women a feeling that the sun still was shining upon them and their family (Figure 2).

Figure 2 – Hope as ”a feeling of communion through family life”

Similarly, others (Herth 1998, Benzein 1999, Lindholm et al 2005, Turner 2005) have found that this shade of hope, having a special someone with whom you feel a connection, a sense of mutual sharing and trust and unconditional positive regard, is imperative. It is documented that the family plays a very important role for patients suffering with cancer (Penrod and Morse 1997, Herth and Cutcliffe 2002). You know you are loved and can love in return; you have family memories that remind of the past, give joy and stimulate a future life (Turner 2005). Meaning in life and communion with others are the sources of hope that give strength to love and endure hopelessness. Communion belongs to the realm of being, a reciprocal love and a unity, where two people become a *we.* In communion moments “silent spirituality” can be active, through prayer, meeting with God and by reading the Bible (Benzein 1999:40). The silent spirituality is important also for non-religious people. Every person has spiritual needs, whether that person has a religious conviction or not. According to Gabriel Marcel (1965:67) hope requires communion, availability and transcendence. Hope is the response to being, a kind of fellow-feeling that Marcel calls communion. Hope is the entrance into being, and through communion hope is actualized. A person who lives in hope is no longer captive to the categories of the past. Therefore, the value and the depth of the human existence are determined by living in hope, because hope is a way to take part in the mystery of being. Such participation is to experience a wholesome life. Meaning in life and communion with others are the sources of hope that give strength to love and endure hopelessness (Lindholm et al 2005: 37). Benzein (1999) finds that when physical changes progress,

the values change from defining future by time, to finding the greatest meaning in friends and family.

Spirit and body

Hope as spirit and hope as energy represent two shades of hope in this thesis. The participants used different expressions in these two shades even if they are very closely linked to each other and in the literature often are used as synonyms.

First some words about spirit. The word spirit in Latin *spiritus* means, airing (Jensen 1978). Hope as spirit was an inner, mysterious, spiritual hope, "something inside of me", something that contributed to "spiritual courage"; it was experienced to be a personal positive inner force connected with strength and willpower and related to *faith in God (*In the Bible *faith in God* is related to Hope)(1. Corinth; Chapter. 13), it was a feeling of being a whole human being with passion for life. The women in the study showed that they *had a spirit to move on (Paper III)*. Hope was a powerful internal feeling that was welding present, past and future; it was like being a fish trying to swim further despite currents and waves (see Figure 3). The young woman diagnosed with ovarian cancer who pictured hope as a fish in troubled water, commented on her drawing, "I am still swimming" (Figure 3).

Figure 3 – Hope "was like being a fish trying to swim further despite currents and waves".

To understand hope as a spirit, we need to know more. Hope as spirit was as having an internal power to maintain integrity. Spirit is closely linked to the expression spirituality which has to do with human existence. Although there is not yet an agreed

definition of spirituality in the literature (Meraviglia 1999), preliminary definitions indicate that spirituality is broader than religion (which it often is compared to). Spirituality relates to the universal quests to make sense out of existence (Bernard 1988, Benson 1997, McGrath 2005), a characteristic of human being (Frankl 1973, Saunders 1981). Thus every person is spiritual and dealing with questions of meaning and purpose (O'Connor et al 1997), and hope is, according to Marcel, a spiritual phenomenon and as such a mystery.

Spirit or spirituality likewise had to do with the bodily existence, so essential for the women in this study. Marcel believes that human existence is an embodied, incarnated existence - our body is not something we can ignore. The body is not something we have in the same way as we have an instrument; it is not available as an instrument; it is the condition for which we can use instruments; we are our bodies. The body is, as my body, a fundamental perspective in the lifeworld. But temporarily, the body is also an object, equal with other objects. Therefore, the bodily has an ambiguity for Marcel (Knox 2003). In this study the hope for cure had this ambiguity; it was a hope for getting well and regain the earlier bodily existence. One drawing specially exemplified the bodily existence, the close relationship between body, life and hope in this situation (see Figure 4).

Figure 4 – Hope illustrated as "a happy uterus" representing the close relationship between body, life and hope.

When patients are facing a life-threatening disease such as cancer, they have a need to talk with other about their experiences. Finding meaning in cancer diagnosis through spirituality helps the patient to cope and maintain hope (Taylor 1998). Similarly to this study, Mickley and colleagues (1992) described hope as having a spiritual dimension and documented that hope and spiritual well-being belong together. Furthermore, spirituality has been described as an aspect of quality of life for patients with cancer that encompasses not only religious but also other dimensions such as hopefulness, transcendence and purpose (Burton 1998, Ferell 1996). Herth (1990:1256) defined hope in her study of terminally ill people as "an *inner power that facilitates the transcendence of present situation and moment new awareness and enrichment of being"*. However, they encounter many obstacles to communicate because there is no language available for spirituality (McGrath 2005). Spirituality and religious beliefs are reported to help the individuals find meaning, and maintaining hope was found in this and other studies (Herth 1990, O'Conner et al 1990).

Nurses have an important role in assessing spiritual well-being in oncology care. Nurses have to acknowledge the role of spiritual and religious beliefs when coping with cancer. Talk and listening encourage efforts to find meaning in life despite the diagnosis. According to Benson (1995), it is the belief that it is the common ingredient; it does not seem to matter if the beliefs are spiritual or religious precepts, beliefs in caregivers, or belief in medicine or all at the same time; all have the same effect to create meaning and coherence for the patients. In the study of spiritual, religious and personal beliefs and distinctive to assessing quality of life in health, O´Connell (2009) concludes that spirituality makes a significant and distinctive contribution to quality of life, assessment in health and should be assessed routinely in health care populations.

Energy through Nature

Hope as energy from Nature was the third shade of the core of *hope* found in this study. The word energy is in Latin *vigor* meaning vitality, liveliness. Hope as energy was an external factor to discern meaning from the cancer diagnosis and create hope in this situation of being diagnosed. Energy from nature gave hope. Drawings

reflected a need to get out in the nature, go to the beach, walk in the forest or enjoy the garden (Figure 5). There was an obvious closeness between hope as spirit and hope as energy from nature.

The closeness of spirit and energy that was found is seen in earlier studies, however often different from here. Owen (1989) e.g. describes energy among patient with cancer as hope in a somewhat different way. Hope was an *energetic driving force*, being determined and being a fighter; it was a matter of keeping the illness in its place through fighting knowing that a future exists no matter the seriousness of the condition. Energy thus was a spirit of energy, an inner force. Our study though confirms Kim and colleagues' (2006) study that external sources are involved in hope. Nature so to speak acts as a healing landscape. Travelbee (1971) also describes hope as linked to energy but again more linked to the internal than the external, and Herth (1993) found among older adults that inner strength and energy were important aspects when revealing the meaning of hope.

Figure 5 – Hope as Energy from nature.

Energy from Nature as demonstrated in the drawings in paper III was not earlier described as such. Scarles (1960) however, argues that Nature plays an important role in mental health; Nature is a link between the conscious and the subconscious. We receive important signals from Nature even though we may not consciously preserve them. Similar reflection is documented by Ottosson (2001) in his perception of nature during rehabilitation following a traumatic head injury. For him, being alone with Nature was different from when he shared the experience with others. It was a way of coping with the crisis (Ottosson 2001). Face to face with nature, we all are equal. Even the strongest has to give in. Ottosson's impressions from nature surroundings are connected to forests, paths in the woods and especially to stones. "Lying on the warm stone surface and looking out over the forest and up at the clouds drifting by, or examining the smallest detail, gave him the greatest pleasure.... It is as though the stone could absorb sorrow …" (Ottosson 2001:167). Out in Nature - to which people have been attuned since time immemorial – we experience more basic sensation and we perceive more basic signals that penetrate more directly our psyche (p. 172). In this study not stones but trees and flowers, the beach and the garden were places to experience energy, to facilitate hope and to receive the feeling of hope. This might be cultural. Denmak has miles and miles of beaches, and lots of people enjoy gardening. Ottosson is Swedish, a country with rocks, forests and stones. The importance is the external energy felt in Nature, something not very much researched. I agree with Annerstedt (2009:49) who argues that science cannot dispense from the dynamics of living, culture and nature, they belong together. "Only by working with this premise as a point of departure, can former criteria and old traditions in science be challenged and subsequently ameliorated."

Summary

The phenomenon of hope when newly diagnosed with gynaecological cancer is in this thesis portrayed as three-dimensional. Hope is found to encompass three shades, spirit, energy and communion linked together like a prism as illustrated in Figure 1. Figure 6 shows a circle, or more precisely, it has a multidimensional spherical shape. The colours vary from white in the centre, symbolising hope, to light grey outwards which then turns into coal-black symbolizing hopelessness, which always is present.

A self-reflection (McNiff 1998) on this my art-expression is powerful. The figure tunes my mood and lifts me up to another level of consciousness, – *"the province where hope lives"*. The power of the figure is the dialectical perpetual movement from dark to light. Looking at the figure, I feel drawn towards the centre into the light, the hope, the energy, the joy and peace where lightness rules and where I am in communion with my precious family.

The prism-like shape symbolizes the three aspects of hope: spirit, energy and communion which were prominent in this study. The figure is in movement as it moves around the circle both inwards and outwards. The movements are symbolizing that hope is in perpetual movement also in time. Hope is welding the lifeworld, past memories, present state and future desires into a wholeness of existence (Figure 6).

According to Marcel (1965) hope is being able to re-start existence, it is a continuous new start in life after an impressive experience. Hopelessness is however always present, in this figure illustrated by the dark surroundings. Every moment of our life is "the presence and at the same time the distance ... which is in reality my being" (Marcel 1951:31). Hope as spirit, energy and communion is a time-related phenomenon synthesizing the memory of the past with future perspectives of a bodily existence in communion with loved ones.

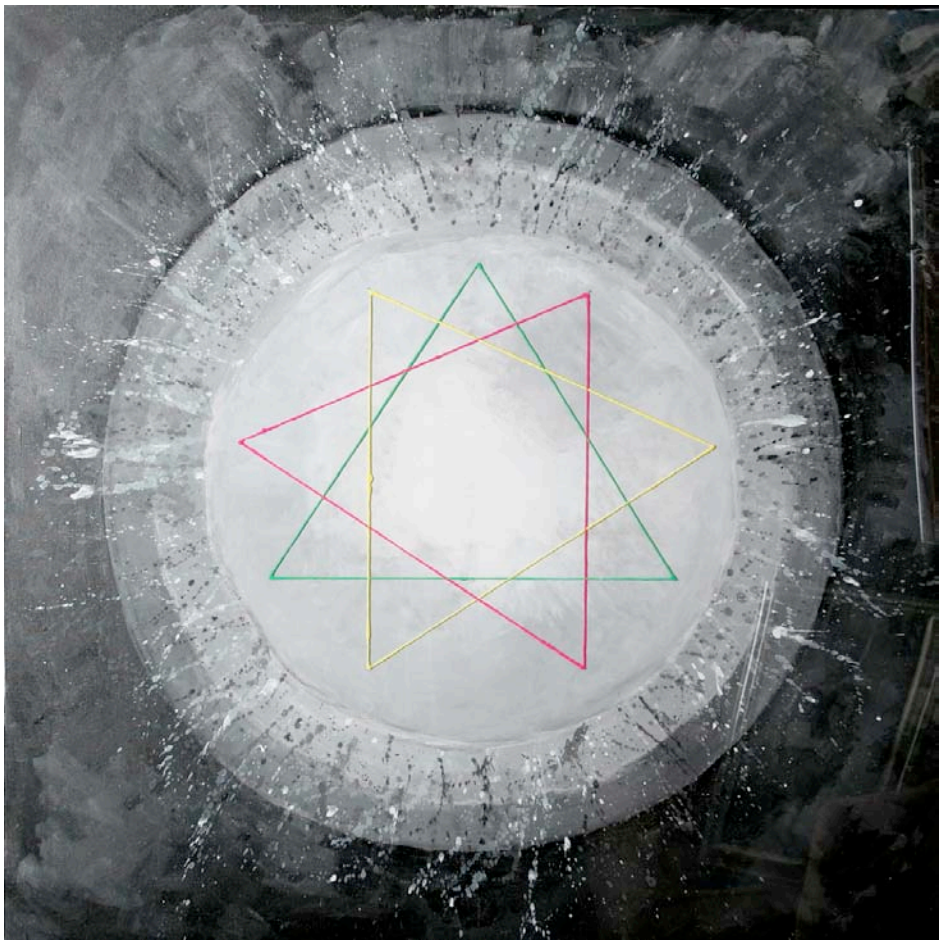

Figure 6 – The living hope with the prism-like shape symbolizing the three aspects of hope: spirit, energy and communion and with an every-threatening hopelessness trying to penetrate the living hope.

10 Conclusion

Referring to the specific aims to investigate the lived experiences of hope among women newly diagnosed with gynaecological cancer as expressed through interviews and drawings and identifying experience of hope in a meta-synthesis, the following conclusions can be drawn.

- Hope among women newly diagnosed with gynaecological cancer is a feeling of *hope.* Women hope for cure, care and a normal life, they want to be active and feel good and they hope for relationship with their near and dear.

- Hope among women newly diagnosed with gynaecological cancer is an internal willpower, a spirit to maintain integrity, hope is energy through nature and hope is communion with loved ones.

- Hope among women newly diagnosed with gynaecological cancer is a continuous fight against hopelessness. Hope and hopelessness are two sides of the same coin, they nurture each other and therefore hopelessness is a necessity for hope.

- Hope among women newly diagnosed with gynaecological cancer is movable, perpetually in motion in a multidimensional tension field of hope and hopelessness, past, present and future and spirit, energy and communion (Figure 1 and Figure 6).

- The innovative qualitative research methods, meta-synthesis and visual phenomenology which were used in this study, are effective methods to elicit new knowledge in cancer nursing research.

11 Implications and Future Research

A challenge in cancer care is to communicate and inspire hope to patients all through their illness trajectory from receiving the diagnosis and further on in the process. The findings from this study document hope among women newly diagnosed with gynaecological cancer. The findings have practical, theoretical and methodological implications and point towards new research studies.

I will particularly stress *the dialogue* as conclusive for this study's meaning for nursing practice. Generally the dialogue takes part in the dissemination of any research findings. In dialogues people exchange points of views, their understandings change and they may alter their actions based on the new understanding. The rationality of the human science is to believe in "the power of thinking, insight and dialogue" (Van Manen 1990:16). Through dialogue, human beings can make things understandable to each other; they can share their lifeworlds and thus become more human.

In dialogues among *researchers* and *clinical nurses* findings from this study, such as abstractions, quotations, drawings or figures, can be mirrored against the real world in practice, with what nurses experience in their daily work and when caring for newly diagnosed patients. How does the nurse or the health care professional then inspire hope for the patient? The clinical nurses might acknowledge or refute the findings from this study and be stimulated to acquire further knowledge. In the dialogue the researcher may contribute with findings from other similar studies and the nurses have a chance to be critical. The awareness of the mystery of hope thus might be greater or the dialogue might make knowledge visible, knowledge which the dialoguing partners already might hold without knowing (Figure 7).

Dialogue *among researchers* takes place on different levels, on individual, national and international levels through talks, seminars, conferences and publications. The dialogue between researchers is extremely important and essential for a living

research. Generally the significance of research findings withers away and dies if not talked about in some kind of dialogue pattern.

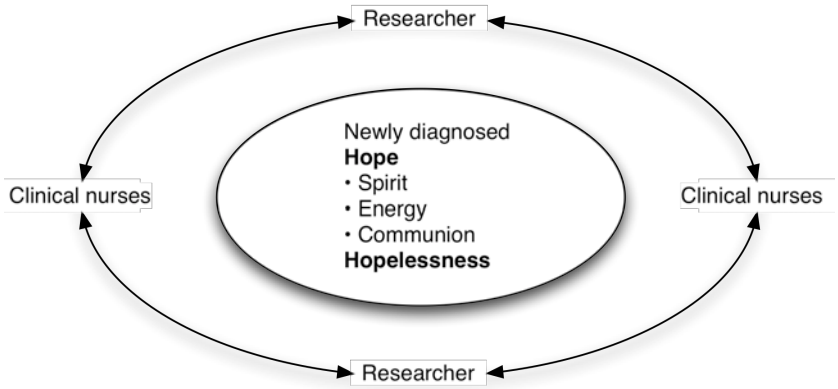

Figure 7 – The dialogue among researcher and clinical nurses.

Study findings provide awareness that hope is communion. Women newly diagnosed with cancer regarded communion with their near and dear as extremely important. That is because people matter to each other and because, according to Marcel (1951), the human existence is relationships to others. Only when we become familiar with each other or get to know each other, the real conversation or dialogue can begin and a fellowship can be established.

A theoretical implication achieved through this study could be the use of Marcel's philosophy of hope as a framework in research and education. Marcel's philosophical foundation which is penetrating all through this thesis provides a suitable theoretical framework from which to study and understand hope in other nursing contexts. This study has contributed to an understanding of the mystery of hope, hope in the context of being newly diagnosed with gynaecological cancer. Marcel's thoughts about hope helped sharpen the understanding of the ineffable involved in the issues of hope and hopelessness. His ontological and religious notions of hope can be a point of departure for many different humanistic oriented nursing care activities. Marcel demonstrates in a beautiful way that hope is fundamental in order to reach an agreement with oneself and one's life no matter what happens. The mystery of hope embraces the whole human existence and shows itself most clear when despair gains access.

The study provides a novel methodological approach for qualitative studies. Paper III was based on a visual methodology that was not earlier found in nursing research. This methodological approach provided a helpful tool when combining interview and drawing for a deeper understanding of hope. The significance of nature for hope was clarified through this approach. Drawings illuminated what words failed to express. Future research designed to explore ineffable and essential nursing matters such as hope, caring or pain might very well involve the visual art as methodology. This approach will contribute to the knowledge development in nursing. Thus a visual methodology such as the one used in this study might bring wholeness to a mysterious life phenomenon. In previous research of health and illness, drawings have been used to picture the lifeworld of individuals when hit by illness. More research is however needed.

Likewise, drawings, when dialoguing among each other or when talking and listening to patients' stories of illness and suffering, might offer the involved new perspectives on hope.

This thesis identifies a novel combination of dialogue in practice, Marcel theoretically and drawing methodologically for empirical studies in qualitative nursing research. It is my special interest to disseminate knowledge about this combination in future research into the patients' perspective (Figure 8).

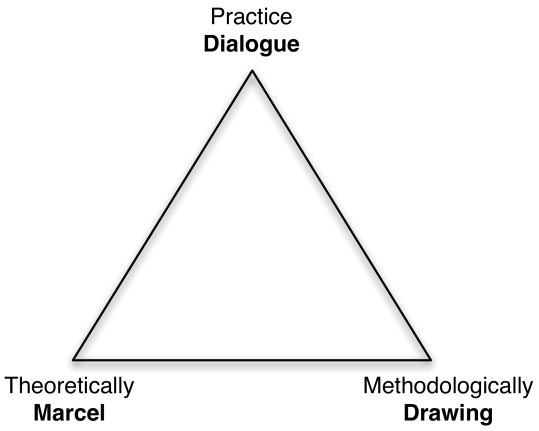

Figure 8 – Model of a combination of dialogue in practice, Marcel theoretically and drawing methodologically for empirical study.

Hope research needs to be visible and reflected in relevant policies within health and cancer care. The fundamental acceptance of the professional nurse's role is to help the patient to experience hope in order to engage him/her in mastering the illness and suffering. Experienced nurses intuitively know that hope affects the cause of recovering; yet, there seems to be limited knowledge from clinical interventions designed to support the development of hope. Focus must be on this issue within organizations that deliver patient care. The question of how we can help the patient to see hope within our work setting must be addressed. The nurse cannot present hope to others but she can intervene enabling the ill to find hope. Knowledge about how the nurse should intervene is limited and needs further attention.

I suggest for practices to consider *hope delivering plans* as technical devices in cancer nursing. A hope delivering plan is a critical component of nursing practice when the life of the patient is threatened. The nurse should be capable of producing a plan of care that includes a range of interventions and attitudes that are specifically designed to increase or maintain a person's hope from the very beginning of the cancer trajectory. Although many assessment tools and scales purpose to measure hope to clinical practice, a need exists for developing strategies that more closely are linked to the actual cause or states of developing and inspiring hope. Then, nurses will be better prepared to assess the dynamic process of hope and hopelessness and to devise individualized care early in the process.

This thesis has produced new knowledge about the lived experiences of hope in women newly diagnosed with gynaecological cancer. However, this knowledge gives rise to another concern, whether hope is experienced in the same way or different for men and women? We live in a gendered society that influences how we and others perceive our lifeworld. Consequently, relationships and particularly issues of dependency are experienced differently by women and men (Gilligan 1982:8). Males tend to have difficulty with relationships, while females tend to have problems with individualism.

Further research is needed into the lived experience of hope among men newly diagnosed with cancer. Siddiqui (2010) e.g. found in his study of 1365 patients treated for non-operative non-small cell lung cancer in a radiation therapy oncology group,

that males had a significantly higher mortality than females. Gender seemed to be the most significant factor influencing survival results. I am inspired by this gender difference of mortality. We know that genetic biology plays a role in cancer knowledge. And we know that the social and psychological plays a role too, but that gender is of such significance is interesting. The issue needs to be targeted in new ways of investigation. What I mean is that it would be interesting to know whether and how the lived experiences of hope in men newly diagnosed with cancer are different from the lived experiences of hope in women newly diagnosed with cancer. According to the Danish philosopher Simon Sjørup Simonsen (2004) men respond with isolation when diagnosed with a life threatening disease like cancer. He compares this behavior with elephants because, according to a myth about elephants, when they feel that they are dying, they leave the herd to die alone, in isolation (Simonsen 2004).

Nursing involves multiple ways of knowing, and as such, educational institutions have a responsibility of assisting students in gaining knowledge in non-traditional ways. Visual knowledge should be regarded as equally important as empiric knowledge. I suggest that drawing is used in nursing education to help student nurses gain insight into illness from the patients' point of view. Artists could be invited to conduct powerful hope workshops. Using the visual knowledge may help students to a better understanding of life with a life-threatening illness such as a cancer disease. More research concerning the meaning of visual knowledge is needed. This is a new challenge in a practice discipline such as nursing which needs further attention. We need to know how art, aesthetic and visual knowledge can help nurses and student nurses to gain insight into ineffable and individualized life phenomenon such as hope.

Dansk resumé

Portræt af håb hos kvinder med nydiagnosticeret underlivskræft

Formålet med afhandlingen *Portræt af håb hos kvinder med nydiagnosticeret underlivskræft* er at undersøge, hvordan håbet opleves den dag man får diagnosen underlivskræft. Håb er en del af livet, det er en naturlig del af det at være menneske og være forpligtet til livet. Håbet er også tæt knyttet til håbløshed, og den dag man får kræft kan være en dag med følelsesmæssigt kaos og en fornemmelse af, at man har mistet kontrol over livet. Håbløsheden kan nemt indfinde sig. Men netop fordi håbet er en del af livet selv, så er håbet tilstede i en eller anden form.

Baggrunden for undersøgelsen er forståelsen af, at sygeplejen er en praksisdisciplin placeret i spændingsfeltet mellem natur-, human-, samfunds- og sundhedsvidenskab. I dette spændingsfelt er sygeplejen ved at udvikle sit eget kundskabsfelt med egne teorier og metoder. Denne afhandling er en del af denne udvikling. At hjælpe en patient til at finde håb i sygdom og lidelse er en af grundpillerne i humanistisk orienteret sygepleje, hvor også værdighed, respekt, integritet og omsorg er overordnede værdier. Viden om, hvordan patienten selv oplever håb på diagnosetidspunktet vil styrke sygeplejens kundskabsbase og den vil øge forståelse og handlemuligheder for kliniske sygeplejersker.

Kræft er en almindelig og ofte livstruende sygdom, og desuden kan ordet kræft have en stigmatiserende betydning. Kræft i underlivet er en blandt de mest hyppige kræftformer hos kvinder. Diagnosen kan føles som en trussel ikke bare på livet selv men også på kvindens identitet, seksualitet eller ønske om at blive mor. Forskning om håb hos kvinder med underlivskræft viser, at kvinderne ønsker at blive behandlet og at få fjernet kræften hurtigst muligt, de ønsker god kommunikation og støtte i sygdomsforløbet, og de ønsker snarest at vende tilbage til det almindelige liv med arbejde og familie.

Afhandlingen bygger på tre artikler.

I artikel I, *The meaning of hope in nursing research: a meta-synthesis,* er formålet at udvikle en meta-syntese af sygeplejeforskning om håb som det opleves i sundhed og ved sygdom. Undersøgelsen er et litterært baggrundsstudium og, med hjælp af en meta-etnografisk metode, bliver resultater fra 14 kvalitative undersøgelser om håb set i patientperspektiv, syntetiseret til seks temaer.

- A*t leve i håb* hentyder til en positiv indre styrke og følelse, realistisk optimisme og tillid til livet.
- *At håbe på noget* betyder at man sætter mål, har konkrete ønsker og tænker pragmatisk.
- *Håbet er et lys i horisonten* viser, at man trods sygdom og trusler på livet kan se det positive i livet her og nu.
- *Håb som en menneskelig relation* hentyder til, at mennesket er relationelt og afhængigt af andre. Temaet peger på betydningen af at være elsket og at have nogen at elske.
- *Håb og håbløshed, to sider af samme mønt,* peger på at håbløsheden altid står på lurenkik og at håbet så at sige opstår på grund af håbløsheden. Der er et dialektisk forhold mellem håb og håbløshed.
- *Håb er at være på vagt* hentyder til, at den syge manøvrerer sit liv ved sygdom på lignende vis som kaptajnen manøvrerer sit skib i stormvejr; det hentyder til at være en fighter og ikke lade sygdommen tage over i hverdagslivet.

Overordnet ses håbet altså at have mange facetter, det har at gøre med at være og at være sammen med andre, at handle, at have mod og at kæmpe. Undersøgelsen viser også at håb og håbløshed påvirker hinanden dialektisk.

I artikel II, *Hope as experienced in women newly diagnosed with gynaecological cancer,* er formålet at undersøge hvordan kvinder, der lige har fået diagnosticeret underlivskræft, oplever håb. Undersøgelsen har en hermeneutisk-fænomenologisk tilgang og femten kvinder i alderen fra 24 til 87 år bliver interviewet den dag, de får diagnosen. Kvinderne havde fået konstateret kræft i livmoderen, livmoderhalsen eller

æggestokkene. Kvindernes oplevelser af håb bliver efter en hermeneutisk-fænomenologisk analyse samlet i fem temaer.

- Håb er at blive rask og alt skal blive normalt igen
- Håb er at være aktiv og have det godt
- Håb er en indre kraft for at opretholde integriteten
- Håb er at have pårørende
- Håb er en kamp imod håbløshed

Vigtigst er at blive behandlet og få fjernet kræften. Det er oftest det første kvinderne nævner i interviewet. At blive rask er målet. Det som desuden særligt står frem i denne undersøgelse er, at håb er stærkt knyttet til det at have pårørende, at have nogen at elske og selv at blive elsket. Kærlighed og nære relationer synes at aktivere positive tanker og følelser. Det giver håb om at være betydningsfuld trods alt. Et andet væsentligt fund i denne interviewundersøgelse er, at kvinderne svinger mellem håb og håbløshed. Tanken om at få fjernet livmoderen og ikke kunne få børn er en trussel for nogle af de unge kvinder i undersøgelsen. Der er en tynd tråd mellem at opleve håb og ligesom at "falde ned" i håbløshed. Håbet er så at sige betinget af håbløsheden; uden håbløshed, intet håb.

I artikel III, *Hope pictured in drawings by women newly diagnosed with gynaecological cancer,* er formålet at undersøge hvordan kvinder, der lige har fået diagnosticeret underlivskræft, tegner håb og hvilken betydning, de lægger i tegningen. Samme 15 kvinder der indgår i artikel II deltager i denne undersøgelse, idet tegningerne bliver foretaget lige efter at interviewene med kvinderne er afsluttet. Tanken, både at tale med kvinderne om håb og at bede dem tegne håb var med en forventning om, at få en dybere forståelse af oplevelsen af håb i denne kritiske situation. Data i denne undersøgelse er derfor 15 tegninger af håb samt 15 efterfølgende båndoptagede samtaler med kvinderne om deres tegningerne den dag de får diagnosen underlivskræft. Data bliver analyseret fænomenologisk og samlet i tre temaer.

- Håb er en indre kraft (spirit)
- Håb er en ydre kraft (energy)

- Håb er fællesskab (communion)

Tegningerne viste, at der var flere variationer af hvert tema. Håb som en indre og ydre kraft var en ukuelig vilje at komme videre, at svømme som en fisk i modstrøm, at være sammen med familien. Det var også at hente nye kræfter i naturen, ved stranden, haven eller skoven. Også i tegningerne stod kærligheden og fællesskabet til familien tydeligt frem og var ofte symboliseret ved røde hjerter eller blomster. Håbløsheden som så tydeligt havde vist sig i de første to artikler var ikke fuldt så fremtrædende i tegningerne. En enkelt tegning har dog en stor sort sky hængende over hus og hjem.

I afhandlingen bliver håbet samlet i en helhedsforståelse, hvor indre og ydre kraft samt fællesskab udgør tre sider, og hvor håbløsheden ses som en mørk skygge i en omkreds om den triangelformede konstruktion (se Figur 1 i afhandlingen). Resultaterne bliver diskuteret i forhold til tidligere undersøgelser og særligt til eksistensfilosofiske tanker om håb og håbløshed præsenteret af filosoffen Gabriel Marcel (1889-1973) og sygeplejeteoretikeren Joyce Travelbee (1926-1973). For Marcel er håbet et mysterium, dog lige væsentlig for livet som det at trække vejret. Travelbee ser håb som et mentalt vilkår, der hjælper et menneske at mestre forandring ved sygdom og lidelse. Det er sygeplejerskens opgave at styrke denne tilstand.

Undersøgelsen er en af de første i Norden der undersøger håb hos patienter ramt af cancer og den første der undersøger dette allerede på diagnosetidspunktet. Fundet af det nære sammenhæng mellem håb og håbløshed understøtter behovet for at sygeplejersker og andet sundhedspersonale støtter patienter i at finde håbet helt fra diagnosetidspunktet. Viden om at håbet genopbygges via håbløsheden kan hjælpe sygeplejersker og andre sundhedsprofessionelle at følge patienten ”ned” i håbløsheden. Bare at være til stede er en støtte, der kan styrke håbet.

Nyt i denne undersøgelse er at bruge interview og tegninger i kombination og at håbet stimuleres via ydre kraft hentet i naturen. Tegninger og samtaler om tegningerne gav en dybere forståelse af fænomenet ”oplevelse af håb”. Tegningerne talte så at sige deres eget sprog. Det var gennem dem, at den ydre side af håbet stod så tydeligt frem. Håb som en ydre kraft var hentet i naturen.

Undersøgelsen, som skaber ny viden om patienters oplevelser om håb generelt, og som beskriver håbet ved nydiagnosticeret underlivskræft, har betydning for klinisk sygepleje. Resultaterne kan danne udgangspunkt for diskussion mellem sygeplejersker og sammenlignes med egne erfaringer. Metaforer som er beskrevet i afhandlingen både i ord og billeder, for eksempel "håb og håbløshed, to sider af samme mønt" (artikel I) eller " at være en fisk i modstrøm" (artikel III) kan ligeledes diskuteres i forhold til brug af metaforer ved sygdom og i sygeplejen. Ordet metafor kommer fra græsk og betyder overføring. En metafor er sigende, den peger på virkeligheden i overført betydning. Der forekom mange metaforer i tegningerne, der kan mane til uddybet forståelse af tegningers betydning, når emnet er så uhåndgribeligt og vanskeligt at sætte ord på som håb. Måske kunne farvekridt og tegnepapir indgå som standard i klinisk sygepleje ved samtale med patienter om håb eller andre eksistentielle emner. En kombination af samtale og tegning kunne virke terapeutisk og forklarende på de involverede.

Til sidst; håb er et grundvilkår i livet, og at inspirere til håb er grundlæggende for god sygepleje. Plejepersonalet kan styrke patienternes indre følelse af håb ved at inddrage naturoplevelser og de nære og kære i omsorgen for patienten. Derved vil de tre nuancer af håb, den indre kraft at gå videre, den ydre kraft gennem naturen og fællesskabet med familien og andre pårørende, kunne holde håbløsheden på afstand. Håbet kan give livskraft - enten patienten er nydiagnosticeret eller på anden vis har brug for støtte og omsorg.

English Summary

Portraying hope. A study among women newly diagnosed with gynaecological cancer.

The aim of the thesis *Portraying hope among women with newly diagnosed gynaecological cancer* is to examine hope experienced the day the woman get diagnosed with cancer. Hope is a part of life; it is a natural part of being human and being committed to life. Hope is also closely linked to hopelessness, and the day you get a cancer diagnose can be a day of emotional chaos and a feeling that one has lost control over life. The feeling of hopelessness can easily appear. However, precisely because hope is a part of life, hope is present, in one form or another.

The background of the study is an understanding of nursing as a practice discipline, placed in the field of tension between the natural-, human- and social- and health sciences. In this field of tension nursing is about to develop its own knowledge field with its own theories and methods. This thesis is a part of this development. Helping a patient to find hope in illness and suffering is one of the cornerstones of humanistic-oriented nursing where also dignity, respect, integrity and caring are overarching values. Knowledge of how patients themselves feel hope at the time of diagnosis will enhance the nursing knowledge base and will increase understanding and opportunities for clinical nurses.

Cancer is a common and often life-threatening disease and also the word cancer have a stigmatizing meaning. Gynaecological cancer is one of the most frequent cancers among women. The diagnosis can be felt as a threat not only to life itself but also to the woman's identity, sexuality and desire to become a mother. Research on hope in women with gynaecological cancer shows that women want to be treated and to get the cancer removed as soon as possible, they want good communication and support in the disease course and they want to return to normal life with work and family.

The thesis is based on three papers.

In paper I, *The meaning of hope in nursing research: a meta-synthesis,* the purpose is to developing a meta-synthesis of nursing research on hope as it is experienced in health and illness. The study is a literature study, with the help of a meta-ethnographic method; results from 14 qualitative studies of hope seen in the patient perspective are synthesized into six themes.

- *To live in hope* alludes to a positive inner strength and sense of realistic optimism and confidence in life.
- *To hope for something* means that you set goals, have concrete wishes and think pragmatically.
- *Hope is a light at the horizon* shows that patients despite illness and death threats can see the positive in life here and now.
- *Hope as a human relationship* refers to that the human being is relational and dependent on others. The theme highlights the importance of being loved and having someone to love.
- *Hope and despair, two sides of the same coin* suggests that hopelessness is always on lurking and hope so to speak, occurs because of hopelessness. There is a dialectical relationship between hope and hopelessness.
- *Hope is to be wary* alluding to the sick manoeuvring his life in a similar way as the captain manoeuvre's his ship in stormy weather. It alludes to being a fighter not letting the disease take over in everyday life.

Generally, hop have many facets, it has to do with being and being together with others to act, to have courage and to fight. The study also shows that hope and hopelessness influence each other dialectically.

In paper II, *Hope as experienced in women newly diagnosed with gynaecological cancer* the aim is to examine how women experiencing hope the day they are diagnosed with gynaecological cancer. The survey has a hermeneutic-phenomenological approach and fifteen women aged 24-87 years are interviewed. The women had been diagnosed with cancer of the uterus, cervix or ovaries. The women's experiences of hope are after a hermeneutic-phenomenological analysis grouped in five themes.

- Hope is getting well and everything should be back to normal
- Hope is to be active and feel good
- Hope is an inner force to maintain the integrity
- Hope is to have relatives
- Hope is a struggle against hopelessness

Most important to be treated and have the cancer removed. It is usually the first issue the women mentioned in the interview. Being healthy is the goal. Also hope is to have someone to love and to be loved. Love and close relationships seem to activate positive thoughts and feelings. It gives hope to be something for others. Another important finding in this interview study is that the women fluctuated between hope and hopelessness. The idea of getting a hysterectomy and not being able to have children is a threat to the young women in the study. There is a thin line between hope and the experience to 'fall' into hopelessness. The hope is, so to speak dependent upon hopelessness. Without despair, no hope.

Paper III, *Hope pictured in drawings by women newly diagnosed with gynaecological cancer,* aims to examine how women diagnosed with cancer, represents hope and the importance they place in the drawing. The same 15 women included in Paper II participated in this study, because drawings were conducted immediately after the interviews with the women had been completed. The idea that both speak to the women and ask them to draw their experiences was an expectation to get a deeper understanding of the experience of hope in this critical situation. Data in this study is therefore 15 interview and 15 drawings as well as 15 interviews about their drawings. Data is analyzed phenomenological and collected in three themes.

- Hope is an internal force (spirit)
- Hope is an external force (energy)
- Hope is the community (communion)

The drawings showed that there were several variations on each theme. Hope as an internal and external force was an irrepressible desire to move forward, to swim like a fish counter current and to be with family. Also it was to catch power from the nature, the beach, garden or forest. Also in the drawings it was love and communion with the near and dear in the family stood clearly forward and often was symbolized

by red heart or flower. Hopelessness, as so clearly had shown itself in the first two papers were not quite so eminent in the drawings. One drawing, however, had a big black cloud hanging over her home.

In this dissertation hope as collected in a synthesis showing three sides, an internal, an external and a commotional force are belonging together, and where hopelessness is seen as a dark shadow in a circumference of the triangle shaped design (see Figure 1 in the dissertation). The results are discussed in relation to previous studies and particularly the existence of philosophical thoughts of hope and hopelessness presented by the philosopher Gabriel Marcel (1889-1973) and nursing theorist Joyce Travelbee (1926-1973). According Marcel hope is a mystery, however, equally essential to life as breathing. Travelbee sees hope as mental conditions that help a person to master change by disease and suffering. The nurse's task is to strengthen that state.

This study is one of the first in Scandinavia to examine hope for patients suffering from cancer and the first to examine this already at time of diagnosis. The findings discovered of the close relationship between hope and hopelessness supports the need for nurses and other health care to supports patients find hope starting from time of diagnosis. Knowledge about the hoped rebuilt through hopelessness can help nurses and other health professionals to monitor patient 'down' into hopelessness. Just being here is a support that can strengthen hope.

New in this study is to use interviews and drawings in combination and that hoped stimulated by external force loaded from the nature. Drawings and conversations about the drawings gave a deeper understanding of the phenomenon of "experience of hope." The drawings speak their own language. It was through them, that the outer side of hope was so clearly. Hope as an external force was loaded from the nature.

The study, which creates new knowledge about patients' experiences of hope in general and describes hope in newly diagnosed gynaecological cancer, are importance for clinical nursing practices. The results may create a platform for discussion between nurses and compared with their own experiences. Metaphors as described in the thesis, both in words and in drawings, for example 'hope and hopelessness, two sides of same coin (Paper I) or “to be a fish in counter current” (Paper III) can also be

discussed in relation to use metaphors in nursing health care practices. The word metaphor comes from Greek and means “transfer”. A metaphor is meaningful, it points to the reality in transferred meaning. There were many metaphors in the drawings, which can evoke to deeper understanding of the impotents of drawings, when the topic is so intangible and difficult to put into words as hope is. Perhaps crayons and drawing paper could be included as standard in clinical nursing practices when interview with patients about hope or other existential topics are actual. A combination of interview and drawing could have a therapeutic and explanatory of those involved.

Finally, hope is a basic condition of life and to inspire hope is fundamental to good nursing. Professionals can enhance patients' internal sense of hope by including natural experiences and the close and dear in caring for the patient. Thus, the three shades of hope the inner force to move forward, the external force through nature and communion with family and other relatives could keep the hopelessness at bay. Hope could give life force - whether the patient has newly diagnosed or otherwise in need of support and nursing care.

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Paper I

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The meaning of hope in nursing research: a meta-synthesis

Scandinavian Journal of
Caring Sciences
THEORETICAL STUDIES
doi: 10.1111/j.1471-6712.2008.00635.x

The meaning of hope in nursing research: a meta-synthesis

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Scand J Caring Sci; 2009; 23; 549–557

The meaning of hope in nursing research: a meta-synthesis

The aim of this study was to develop a meta-synthesis of nursing research about hope as perceived by people during sickness and by healthy people. A meta-synthesis does not intend to cover all studies about hope; rather it tries to synthesize qualitative findings from different contexts, cultures and times to provide a global picture of the phenomenon under study. Noblit and Hare's meta-ethnographic approach was used. The approach is a systematic comparison of studies where each study is translated into the other. Data were 15 qualitative studies published in nursing or allied health journals and conducted in USA, Great Britain, Canada, Australia, Norway, Sweden and Finland. The meta-synthesis resulted in six metaphors that illustrate dimensions of hope. These metaphors permeated the experiences of hope regardless of whether the human being was healthy, chronically or terminally ill. They comprise the complexity of hope and were: living in hope, hoping for something, hope as a light on the horizon, hope as a human-to-human relationship, hope vs. hopelessness and fear: two sides of the same coin, and hope as weathering a storm. Knowing the multidimensionality of hope and what hope means from the patient's perspective might help nurses and other healthcare professionals to inspire hope as Florence Nightingale did when she walked with the lamp through the dark corridors and spread hope and light to the patients. We suggest that nurses working with patients with serious conditions such as cancer reflect on the meaning of the metaphors.

Keywords: chronically ill people, healthy people, hope, hopefulness, meta-ethnography, meta-synthesis, qualitative studies, terminally ill people.

Submitted 27 May 2007, Accepted 29 April 2008

Introduction

The positive role of hope in human life, health and illness is widely recognized and this is significant in nursing where the purpose is to promote health and well-being for all persons. The meaning of hope to human beings has been described by numerous philosophers, theologians, psychologists and nurse researchers (1–8). Even if there is not consensus about the attributes of hope, some matters seem to be common in the literature. Hope is both universal and specific (1, 9). Universal hope is a general belief in the future, a defence against despair, and a safeguard for the human being by illuminating life itself. Specific hope is connected to time and object; for example, a person might hope for something such as a treatment to be successful in curing disease. When the specific hope is threatened, universal hope might help the human being to avoid giving up. However, in the western world, hope as phenomenon is reduced to a specific hope for miracles, a hope detached from reality. 'Human beings that do no longer hope have lost the courage to be … and their life project might be to take away the hope from others' (10, p. 38).

Because of its abstract and elusive nature, the phenomenon of hope has received limited attention in clinical nursing research. However, hope is a basic value in nursing, belonging to the philosophy of nursing (7, 11–13). Hope is not a gift to another person but the nurse can arrange the environment in a way that allows the patient to experience hope (7). To instil hope is described as a disposition of the nurse: 'The nurse inspires hope; she does it by what she is more than what she does' (12, p. 273). In doing this, the nurse allows patients and relatives to live a complete life in spite of biological restrictions and disabilities. Koopmeiners et al. (14) studied how health personnel influence the experience of

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hope among patients with cancer. They found that hope was closely linked to the way the staff had time for the patient, their way of giving information, their politeness, caring and helping attitude, just 'being there' and showing honesty and respect. The most important reason for failing to instil hope was linked to the way the information was given. McCann (15) found that nurses used two strategies to enable young schizophrenic clients to uncover hope for the future: (i) enhancing motivation and (ii) developing pathways to wellness. Further, as hope seems to have a positive effect on the immune system (16, 17), inspiring hope and following the patient through hopelessness to a realistic hope (18) characterizes good quality nursing. Other scholars have developed hope scales to measure nursing strategies (19) and develop intervention programmes (19) but this has been critiqued as being too limited an approach. Professional nurses would benefit from knowing peoples' lived experiences of hope to better understand hope in the middle of illness and other critical life situations (20).

Our interest in hope derives from an ongoing hermeneutic phenomenological study of hope in women experiencing hysterectomy for cancer. A literature search for research about hope in this perspective revealed a gap in documentation. Other studies dealing with the experience of hope in different contexts were found. An extensive search of the subject was performed with the purpose of examining research regarding the experience of hope during different conditions and situations. A meta-synthesis of qualitative studies involving hope was intended to provide a deeper understanding of the nature of hope.

Literature concerning the meaning of hope among chronically ill persons show that hope gives quality to life (21), as well as a new greater existence (22), that people with a 'fighting spirit' have a better prognosis than people who react with fatalism and helplessness (23), that exercise positively helps lung cancer patients to envision a better future (24), and that the chronically ill develops strategies to maintain (25) and strengthen (17) hope. Overall, experiential, relational, spiritual and cognitive relationships are important strategies that patients use to encourage and maintain hope during chronic sickness and suffering (26). Still there seems to lack a clear description of what constitutes hope. Further work to clarify the phenomenon is needed (8, 20, 27, 28). This study provides a meta-synthesis of qualitative studies of experiences of hope perceived by people during sickness and by healthy people. The aims were to identify nursing research about this phenomenon and to synthesize the findings into a bigger whole that effectively can be used in clinical nursing.

Meta-synthesis

Meta-synthesis is more than a systematic review of the literature (29, 30). It has been defined as 'bringing together and breaking down of findings, examining them, discovering the essential features, and, in some way, combining phenomena into a transformed whole' (31, p. 314). The origin of meta-synthesis in qualitative research goes back to the increased number of qualitative studies conducted in nursing and other health sciences since the 1980s (32, 33) followed by urgings to accumulate knowledge from 'one-shot' research studies not situated in larger research programmes (34, p. 510). Sandelowski et al. (32) critique single shot studies; each can be viewed as reinventing the wheel and has little impact on evidence-based practice. The purpose of meta-synthesis is to develop new knowledge based on systematic attempts to analyse existing qualitative research findings of the phenomenon under study. Even though critical voices are heard regarding the representation of qualitative research synthesis studies (33, 35), the product of a meta-synthesis is intended to result in a more comprehensive and convincing theoretical argument for evidence-based practice (36). As with all kinds of qualitative studies, creativity is essential for recognizing the links and patterns among study findings and shaping new theoretical knowledge (37). Several methodologies for meta-synthesis of qualitative data have been developed to achieve rigour (30, 32). A growing body of knowledge is developing based on meta-synthesis of qualitative studies (36–39), and there is an ongoing discussion of the challenges of this method (33, 35, 36). Generally, the goal among qualitative researchers is that meta-synthesis of qualitative data can contribute to practice that will support delivery of the best possible care to patients and relatives.

Method

Noblit and Hare's (40) meta-ethnographic approach was used in this meta-synthesis. The method is well described and frequently used among meta-syntheses (39). The approach is a systematic comparison of studies where each study is interpreted with the other. This is done in a fashion similar to when an ethnographer is interpreting a culture (40, p. 7) and has the purpose of giving an expanded understanding of the phenomenon under study. The systematic comparison is done in a series of overlapping, parallel and repeating phases (40, p. 26–29).

- Getting started: The research group identified the topic that qualitative studies might inform and considered which audience to direct.
- Deciding what is relevant to the initial interest: The research group justified which studies were to be included in the meta-synthesis.
- Reading the studies: The studies were repeatedly read and discussed in the research group, interpretative metaphors were noted, and close attention was paid to the details of the studies.

• Determining how the studies are related: In this phase, the studies were organized in categories using a matrix; the research group compared key metaphors, themes, phrases and concepts and was discussing the relationships within and between the studies.
• Translating the studies into one another: This part of the process involved a weaving together of the studies following Noblit and Hare's words: 'An adequate translation maintains the central metaphors and/or concepts of each account in their relation to other key metaphors or concepts in that account. It also compares both the metaphors or concepts and their interactions in one account with the metaphors or concepts and their interactions in the other account' (40, p. 28).
• Synthesizing translations: A synthesis refers to making a whole that is bigger than just the parts themselves imply. In this phase, the research group compared the synthesized whole as well as was analysing competing interpretations.
• Expressing the syntheses: Finally, the research group decided on how to communicate the meta-synthesis in an appropriate form.

Sample

The studies included in this meta-synthesis were identified using the keywords hope and hopefulness in literature searches as well as through reference lists in reviewed articles. A meta-synthesis does not intend to cover all studies about the phenomenon studied; rather it tries to synthesize qualitative findings from different contexts, cultures and times to provide a global picture of the phenomenon under study (35). Studies of hope as perceived by both healthy and sick people were selected according to the above criteria as well as because of their focus and methodological comparability (32). Therefore, studies found concerning healthcare professionals' and relatives' experiences of hope were not incorporated in this study. The final sample consisted of 15 qualitative studies (Table 1), which is plenty for a meta-synthesis (35). In comparison, in a meta-method study including 45 meta-synthesis studies, the majority were found to include from nine to 18 studies (39). The methods of the studies were diverse, with one study using grounded theory, one using Q-method, and a third mixed method; the remainders were phenomenological, hermeneutical or a combination of both. The studies were published in nursing or allied health journals over a period ranging from 1990 to 2006 and were conducted in USA, Great Britain, Canada, Australia, Norway, Sweden and Finland. The total number of participants in the studies was 291. For practical reasons, the studies were grouped into three categories that described the meaning of hope among healthy people, which is people not diagnosed with any illness, chronically ill and terminally ill people.

Healthy people. Benzein et al. (41), in a phenomenological–hermeneutic study, explained the meaning of the lived experience of hope in healthy nonreligious Swedes. The authors found that the experience of hope included internal and external components related to being and doing, and changing according to the individual's place in the lifespan. The internal process was related both to the self and being in the world in the past, present and future. The doing component was an external process of hoping for something, setting long- and short-term life goals, and expecting positive results of significance for the well-being.

Herth (42), in a phenomenological study, investigated the meaning of hope and strategies to foster and maintain hope during dire circumstances among homeless US children living in shelters. The essence and process of hope were envisioned as a multifaceted evolving process of creating and recreating hope in the midst of life's constant changes. Hope was conceptualized as an inner core of hope and an outer ring of flexible directed hopes. Five themes of hope emerged from data collected through drawings and interviews: connectedness, internal resources, cognitive strategies, energy and hope objects.

In a phenomenological study of hope seen through the eyes of Australian young people, Turner (43) identified hope as an anticipation of future possibilities and a driving force for the young people, and she found four horizons of hope. They were: an experience of at-one-with, a driving force, having choices, connecting and being connected.

Chronically ill people. Cohen and Dawson Ley (44) conducted a hermeneutic phenomenological research of patients' perspectives of having antilogous bone marrow transplantation. The prevailing theme presented in this study was fear of death and hope for survival. Hope was increased and fear reduced through knowledge of the different treatment steps. As one of the participants said 'so far so good' (44, p. 475).

Ersek (45) wanted to explore the processes of hoping in adult men and women who had undergone bone marrow transplantation for leukaemia. She found that the central strategy of maintaining hope was a dialectic between dealing with the illness through appraising the illness as a threat, allowing an emotional response, working it through and moving on, and keeping the illness in its place through fighting and accepting the illness while managing uncertainty and control.

Little and Sayers (46), using narrative interviews, described the meaning of hope among cancer caregivers and survivors who had undergone life-saving treatments and thus had 'mortal extreme experiences' (46, p. 1331) and 'death salience' (46, p. 1332). The authors explained hope as a subjective probability of a good outcome and identified two hope discourses among cancer survivors: one concerned life and death and the other concerned meaning in

Table 1 The meaning of hope among healthy, chronically ill and terminally ill people

References	*The meaning of hope among healthy people*	*Qualitative design/ data analysis method*
Benzein et al. (41)	24 healthy adults aged 18–80 years (Sweden)	Phenomenological hermeneutics
Herth (42)	60 homeless children living in shelter (USA)	Phenomenology
Turner (43)	10 young people of both sexes, aged 18–25 years (Australia)	Phenomenology
	The meaning of hope among chronically ill people	
Cohen and Dawson Ley (44)	20 adult survivors of antilogous bone marrow transplantation (USA)	Hermeneutic phenomenology
Ersek (45)	20 men and women, who had undergone bone marrow transplantation (USA)	Hermeneutics
Kim et al. (48)	32 chronically ill patients suffering from cancer, cardio vascular diseases, addiction and chronic renal disease (USA)	Q-methodology
Lindholm et al. (47)	50 women suffering from breast cancer (Finland)	Hermeneutics
Little and Sayers (46)	15 cancer survivors with large bowl, liver, breast cancer, Hodgkin's lymphoma and leukaemia (Australia)	Grounded theory
Lohne and Severinsson (49, 50)	10 patients who had undergone acute spinal cord injury studied first year and 1 year after injury (Norway)	Phenomenological hermeneutics
	The meaning of hope among terminally ill people	
Benzein et al. (54)	11 patients with cancer in palliative home care (Sweden)	Phenomenological hermeneutics
Buckley and Hearth (55)	16 terminally ill persons (Great Britain)	Mixed method
Flemming (52)	4 individuals suffering from advanced cancer and with uncertain prognosis (Great Britain)	Phenomenology
Hall (56)	11 individuals with HIV and diagnosed as terminally ill (USA)	Grounded theory
Wong-Wylie and Jevne (53)	8 terminally ill patients with HIV (Canada)	Phenomenological descriptive analysis, CI technique*

*A method for documenting and understanding human experience and interaction.

life. Because of the mortal extreme experience hope was different among patients and caregivers.

Lindholm et al. (47) conducted a study involving Finnish women suffering from breast cancer. They investigated the significance of hope and hopelessness for these patients' vitality and found that in connection with threats to life, hope and hopelessness belong together and set vitality in motion. Thus, hope and hopelessness presuppose each other and together nourish vitality (47). Also, hope was tied to what was meaningful in everyday life, and an open attitude toward life was important if hope was to grow. Therefore, meaning in life and communion with others are sources of hope that give strength to live and endure hopelessness.

Kim et al. (48) revealed hope in five different patterns in chronically ill patients and found that hopeful patients attributed different meanings to the their life because of different circumstances and orientations. Hope patterns were: (i) externalism orientation, (ii) pragmatism orientation, (iii) reality orientation, (iv) future orientation and (v) internalism orientation. These patterns show the subjective experiences of the patients and depend on how they decide to focus on different dimensions of meaning. Furthermore, these five patterns were differentiated through two axes: (i) external and internal orientation and (ii) present and future orientation.

In a phenomenological–hermeneutic study of Norwegian patients who had undergone an acute spinal cord injury, Lohne and Severinsson (49) found hope to be Longing and getting out of the Vicious Circle. Likewise hope was interpreted to be 'the power of hope' and two subthemes, will, faith and hope, and hoping, struggling and growing (50). The power of hope was interpreted as the individual having experienced meaning mainly expressed through willpower. Hope was personal and an inner adventure of strength, independent of context.

Terminally ill people. Hall (51) explored hope as it was lived by persons with HIV and diagnosed as terminally ill. She found that individuals with HIV struggled to maintain hope and that health professionals easily could cause loss of hope. The dilemma of hope for diagnosed terminally ill persons was how to establish a connection between the present and the future and a feeling of optimism when facing dire predictions. The author described having hope in four main themes: having a future life in spite of the diagnosis, having a renewed zest for life, finding a new reason for living, and finding a treatment in the

professional or alternative care system that will contribute to survival.

Flemming (52), in a phenomenological study, described the meaning of hope to palliative care cancer patients. She identified influential areas of hope during terminal illness. The most important factor was control of disease progression in order not to get worse. Each individual wanted to maintain control of some part of life and presented individual definitions of hope such as living another month, 'provided I'm not a nuisance to anybody' (52, p. 17). Hope was maintained by nursing and medical staff as being there and showing an interest in each individual as well as by knowing that the family was loving and close.

Wong-Wylie and Jevne (53) investigated patient hope by looking at the interaction between physicians and terminally ill patients with HIV/AIDS. Findings included five paired categories of opposing valences: being known as human/being known as a case, connecting/disconnecting, descriptive/prescriptive, welcoming/dismissing and informing/poorly informed. The relationship between a person diagnosed with HIV/AIDS and his or her doctor was central to the hope potential; the physician held the power to either diminish or enhance hope in each interaction with the patient.

Benzein et al. (54), in a phenomenological–hermeneutic study, examined the meaning of the lived experience of hope among Swedish patients with cancer in palliative at-home care. Narrative interviews revealed a tension between hoping for cure and living as normally as possible, and living in hope and reconciliation with life, the disease, and the forthcoming death. The presence of confirmative relationships such as self, significant others, milieu, pets and a transcendent relationship were important dimensions of hope.

Buckley and Hearth (55) investigated the meaning of hope for terminally ill persons, with cancer or motor neuron disease. The findings implied that hope remained present regardless of proximity to death. Two categories of hope were formulated: hope-fostering and hope-hindering. Hope-fostering included love from family and friends, spirituality/having faith, setting goals and maintaining independence, positive relationships with involved abandonment and isolation, uncontrollable pain and discomfort, and devaluation of personhood.

Results

The qualitative studies that was included in this meta-synthesis revealed hope to have several dimensions and a rich number of metaphors. During the phases of determining how the studies were related, the meta-synthesis collapsed these dimensions into six metaphors which permeated the experiences of hope regardless of whether the human being was healthy, chronically or terminally ill. The inter-related metaphors are as follows with reference to the included studies.

Living in hope – a being dimension

Hope has an internal 'being' dimension that we call living in hope (41, 54). Hope is something that is deep inside one's self that remains positive whatever happens (42); it includes a realistic optimism and an experience of being at-one-with (43). Hope involves knowing that things are right in the world, confidence that life will go well for self and others, and that the possibility exists for success, increased prosperity, education and absence of sickness and suffering (43). Hope is a vital force in adaptation and has been associated with a higher quality of life (45). Hope is illustrating basic human needs. Willpower seems to create energy and strength of being in faith and hope (50).

Hoping for something – a doing dimension

Hope has an external 'doing' dimension that nurtures the internal mode of hope; it is a pragmatic, goal-setting entity (48) that is reconstructed throughout life in response to situations (41, 43). Achieving goals results in a deep feeling of satisfaction. Goal-setting changes from long- to short-term in different situations in response to being healthy or ill, young or old. Things hoped for include adequate food, having a place of one's own (42) or expecting positive medical outcome (51). Hope is the subjective probability of a good outcome for ourselves or someone close to us, such as hoping for life over death (46).

Hope as a light on the horizon – a becoming dimension

Hope has a further 'becoming' dimension that we call a light on the horizon; that is, having a zest for life (51), anticipating future possibilities such as living a little longer (52), expecting positive results (41), being cured from the disease (46) or simply receiving a hopeful message from the physician (53). Hope as a light on the horizon is a driving force such as spirituality (43, 55); it is an opportunity to move beyond the immediacy and reality of the past and live fully in the present while projecting a different future (43). The light on the horizon is brighter and stronger through knowledge, relationships and a positive attitude toward life when undergoing life-threatening treatment (44). The light on the horizon helps to remove hopelessness and see the significance of life (47), and it resembles stepping through an archway into the unknown where it is scary, but where passions lead and things come together. This dimension of hope might lead patients to exclude persons in the social network who are not positive about possible outcomes (56). Sensory impressions, such as listening to birds, hearing the sound of waves, being outside and seeing the beauty of flowers foster this dimension of hope (54).

Hope as a human-to-human relationship – a relational dimension

Hope has a 'relational' dimension that we see as a human-to-human relationship. In this dimension hope is having a special someone with whom you feel a connection, a sense of mutual sharing and trust and unconditional positive regard (42). You know you are loved and can love in return; you have family memories that remind of the past, give joy and stimulate a future life (43). Relational hope is being known as human (53), and may be encouraged by caregivers' positive attitude, confidence and confirmative relationships (47, 54), by nursing and medical staff 'being there' and showing interest and concern, and knowing that one's family is loving and close (52). Meaningful interpersonal relationships, faith, affirmation and support confirm a sense of worth, feeling needed and 'good enough,' and help a person experience hope (48).

Hope vs. hopelessness and despair: two sides of the same coin – a dialectic dimension

Hope has a 'dialectic' dimension that we refer to as hope vs. hopelessness and despair, two sides of the same coin. Hope, hopelessness, and the core substance of health or vitality belong together (47). No matter what, hope is always there. Even if an individual seemingly has been robbed of hope, hope will be found again (43). Thus hope and hopelessness are closely linked to living in fear of dying (44) or other kinds of despair (49). Interactions with health professionals hold the power to diminish or enhance hope (50, 53).

Hope as weathering a storm – a situational and dynamic dimension

Hope has a situational and dynamic dimension that we metaphorically have translated to weathering a storm. Like manoeuvring a ship in a storm, healthy, chronically and terminally ill persons are searching to manoeuvre their life (47, 51), hoping for good outcomes and better weather (46). Hope in this understanding is having an energetic driving force (42, 43, 50), being determined and being a fighter (51, 55); it is a matter of keeping the illness in its place through fighting (45) knowing that a future exists no matter the seriousness of the condition (52). Nevertheless, hope is circumstantial and changeable because of lifespan, disposition and life experiences (48).

Discussion

The aim of this study was to develop a meta-synthesis of nursing research about hope as perceived by people during sickness and by healthy people. A meta-synthesis of qualitative studies determines how studies are related and how the findings of the studies cumulate and make up a bigger whole than the singular studies. However, meta-synthesis research has the limitation that the detailed descriptions that validate the quality of the original qualitative studies are lost. A limitation of this study might likewise be the variety of methodologies used in the sample. However, the authors believe that the usefulness of synthesizing available qualitative studies related to a broad understanding of the meaning of hope justifies this limitation. Actually, the strength is that a meta-synthesis is telling a new story through a rigorous description and translation process where the study findings are related to each other. This study identifies dimensions and metaphors of hope across contexts, cultures and times. Thus, the meta-synthesis presents a universal picture and has generalizability with stronger power for evidence-based practice than each of the studies included.

We reviewed 15 qualitative studies from seven countries following Noblit and Hare's (40) methodology. The review resulted in six metaphors that illustrate dimensions of hope, a being, a doing, a becoming, a relational, a dialectic, and a situational and dynamic dimension. These results comprise the complexity of hope and extend Marcel's (1) notions of hope as specific and universal. The dimensional findings of our meta-synthesis likewise are differently structured than those of Cutcliffe (57), who described hope to be complex and multidimensional, encompassing spiritual, physical, intellectual, emotional and social dimensions. Likewise, Kaasa and Masterstvedt (58) discussed hope among terminally ill and dying patients in three dimensions: hope on a daily basis, hope concerning a possible eternity and hope based on unrealistic premises. These studies, as well as ours, show the multidimensionality of hope and are examples of how health researchers as well as clinicians try better to understand the meaning of hope in health care. We see the relational dimension as very important in caring sciences. Both in health and when chronically ill or terminally ill, people need to feel trust, connections and closeness with others. Nurses can inspire this dimension of hope just by being there and showing interest in their fellow human being, be they colleagues, patients or relatives. This dimension of hope can be seen in the light of Løgstrup's (59) notion that humans are relational beings who are interdependent throughout life. 'The interdependence is so deep that without it individuals would not be human' (59, p. 65).

One finding of this meta-synthesis is that hope has an internal being dimension that we call living in hope, knowing that things are right in the world and having confidence that life will go well for self and others (43). Another finding was that hope is not only achieved, it might be an endeavour, a struggle or fight, and these external doing and situational dimensions nurture the internal being dimension. Further, the findings show that

hope has a dialectic dimension of hope and fear. During hopelessness and despair there is no hope. Hope, however, has not disappeared, but is hidden. As in the mythological story of 'Pandora's box', where hope was all that was left, hope might suddenly pop up and give new strength in life. Because hope and hopelessness are dialectics they belong together (60). When doing so hope shows as 'a light on the horizon' with future possibilities. Hope might transcend the despair and hopelessness and give beauty to life.

The last metaphor in this meta-synthesis was hope as 'weathering a storm'. This dimension of hope is circumstantial and changeable because of the lifespan and life experiences (48). The literature repeatedly emphasises that hope has a situational and dynamic dimension connected to the individual's potential. Hope is situational and dynamic but always there. After stormy weather there is calm. We see hope as the force of the wind; the sail is the soul that provides the ship's drive and spirit, and the wheel is the knowledge which safeguards the direction of the ship. Thus hope is found to have both a futuristic meaning as shown in the dimensions living in hope, hoping for something and hope as a light in the horizon, and hope has an everyday life meaning as demonstrated in the dimensions: hope as a human-to-human relationship, hopelessness and hope as two sides of the same coin, and hope as weathering a storm. The findings highlighted the importance of maintaining a future orientation as well as a here-and-now everyday orientation when working with people in any life circumstance. However, further clarity is needed about the meaning of these two orientations.

Implications

The aim of this study was further to synthesize the findings into a bigger whole that effectively can be used in clinical nursing. Based on the above findings and inspired by the authors of the studies included in this meta-synthesis, we see implications for achieving the outcome of hope. One suggestion is that caregivers discuss findings of empirical studies among the staff, comparing their experiences to the literature. A dialogue between nurses about recent knowledge development can facilitate and strengthen the evidence-based practice of existential matters such as hope. This is important as hope is a behaviour and everyday concept that is essential to nursing but that is broad and abstract and needs to be described in its volume (61). The metaphors presented in this study might likewise be discussed. Metaphor is Greek and means transmission; it represents reality in a figurative sense and is often used as a tool to articulate threats or other experiences when talking about serious conditions (62). We have used metaphors in interpreting or translating the studies into each other. Patients frequently use metaphors to describe their experiences. We suggest that nurses working with patients with serious conditions such as cancer listen carefully to the patients' metaphors and reflect on the implicit meaning of them. In this way nurses might be able to respond to patients' needs in a most caring fashion (63), helping the patients to see the light in the horizon and helping them to realize that hope and hopelessness are two sides of the same coin. Recognizing the multidimensionality of hope and the meaning of hope from the patients' perspective might help nurses and other healthcare professionals to inspire hope in the way Florence Nightingale did when she walked with the lamp through the dark corridors and spread hope and light to the patients.

In addition to dialoguing of the meaning of hope among colleagues, our suggestion for nurturing a hope-centred care in nursing is using a care delivery plan that encompasses both the metaphors and the dimensions presented here in a guided hope intervention plan. Together nurse and patient could plan short-, longer- and long-term goals of the different dimensions using the metaphors of this meta-synthesis as structure. A guided hope intervention plan would strengthen the nursing agency relevant to hope, inspiring and documenting otherwise tacit and taken-for-granted nursing actions and beings with the patient. We agree with Herth and Cutcliffe (28) that hope research needs to be visible and reflected in relevant policies within health care. We also believe that meta-syntheses of qualitative studies contribute to evidence-based practice (39), and we suggest future research be conducted using this challenging method to document qualitative studies and strengthen the knowledge development in other existential nursing matters. For the sake of this study, however, nurses need first to make clear the importance of hope in caring for chronically and terminally ill people and the role nurses play as caregivers not only in care of the patient during illness but also for the well-being of the patient regardless of health status.

Author contributions

Kristianna Hammer and Elisabeth O. C. Hall were together responsible for the design, data collection, analysis of data and writing of the manuscript. Ole Mogensen participated in the writing and in critical reviewing of the manuscript. Elisabeth O. C. Hall and Ole Mogensen supervised the study.

Funding

This study was funded by Institute of Clinical Research, Department of Gynaecology and Obstetrics, Odense University Hospital, Denmark and The Danish Cancer Society, Copenhagen.

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Paper II

Hammer K, Hall EOC, Mogensen, O.

Hope as experienced in women newly diagnosed with gynaecological cancer

European Journal of Oncology Nursing 13 (2009) 274–279

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Hope as experienced in women newly diagnosed with gynaecological cancer

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Keywords:
Cancer
Experience
Hope
Hopelessness
Marcel
Newly diagnosed gynaecological cancer
Cancer nursing
Phenomenology
Van Manen

A B S T R A C T

Aim: This article presents findings from a hermeneutic-phenomenological study with the aim to investigate the meaning of the lived experience of hope in women newly diagnosed with gynaecological cancer.

Method: Fifteen women were interviewed the day they were receiving the diagnosis at a gynaecological department of a Danish university hospital. The women, aged 24–87 (median 52 yrs), were diagnosed with ovarian, endometrial, cervical and vulvar cancer.

Results: Hope was found to be connected to both diagnosis, cure, family life and life itself and closely tied to hopelessness. The newly received cancer diagnosis made the women oscillate between hope and hopelessness, between positive expectations of getting cured and frightening feelings of the disease taking over. Five major interrelated themes of hope were identified: hope of being cured, cared for and getting back to normal, hope as being active and feeling well, hope as an internal power to maintain integration, hope as significant relationships and hope as fighting against hopelessness. Thus, hope was woven together with hopelessness in a mysterious way; it took command through inner strength and courage based on a trust in being cured and of being in relationship with significant others.

Conclusion: The findings of the close relationship between the shades of hope and hopelessness support the need for nurses to continue to practice hope-inspiring nursing. Nurses need to understand the complexity of hope and its close connection to hopelessness when newly diagnosed with a threatening disease as cancer; and the findings might help nurses assist patients in fighting hopelessness.

Introduction

This study investigates how women newly diagnosed with gynaecological cancer experience hope. Receiving the diagnosis of gynaecologic cancer is a dramatic (Akyüz et al., 2008) and worrying experience (Corney et al., 1992; Hounsgaard et al., 2007). When diagnosed with a life-threatening malignant disease people's perceptions of life change, and they try to adjust (Howell et al., 2003a, Mishel et al., 1984; Reb, 2007). Hope then plays a therapeutic role (Chi, 2007) while loss of hope places the patient at risk of maladjusting to the diagnosis and treatment (Owen, 1989). Patients with newly diagnosed cancer oscillate between uncertainty, optimism and control (Mishel et al., 1984). Nurses are invaluable resources in inspiring patients to find hope in life when diagnosed with cancer. However, the patients are the 'experts' of their lived experience; their own words of what constitutes hope are important for cancer nursing knowledge development.

What is hope?

Hope, being essential to people being diagnosed with cancer, triggered us to ask the questions: What is hope? What does hope mean to people? The theoretical framework for this study comes from the philosopher of hope Gabriel Marcel (1889–1973) who connects soul and hope. Marcel answers the first question: "…hope is for the soul what breathing is for the living organism. Where hope is lacking the soul dries up and withers. It is no more than a function …" (Marcel, 1978, p. 11). Marcel's answer to the second question is that hope embraces the whole human existence and being, and hope comes into being only when the possibility for despair gains access. Hope is fundamental to get into agreement with oneself and one's life; it is not turned inward towards oneself but outwards, openly, towards the other in a communion. Hope

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doi:10.1016/j.ejon.2009.02.004

thus reveals a close human-to-human relationship and a dialectic relationship to despair. Hope is restored through despair.

Hope in cancer nursing research

In cancer nursing research, hope is described as complex, multidimensional and dynamic and a powerful factor in healing (Cutcliffe, 1997), coping (Felder, 2004), and quality of life (QOL) (Esbensen et al., 2004; Ferrell et al., 2005; Post-White et al., 1996). Hope's relationship to caring and healing is evident in Cutcliffe's (1997, p. 330) definition: "Hope is a multi-dimensional, dynamic empowering state of being, that is central to life, related to external help and caring, oriented towards the future and highly personalised to each individual". Hope as a structure comprises several interrelated dimensions such as being, doing, becoming, relational, dialectic, and dynamic dimensions (Benzein and Saveman, 1998; Cutcliffe, 1997; Hammer et al., 2008) thus making it possible for individuals to experience hope in manifold ways (Herth and Cutcliffe, 2002); the dimensions relate to each other "like the units in a mobile" (Benzein, 1999, p. 7).

Qualitative approaches such as phenomenology, grounded theory and ethnography are increasingly used in cancer nursing research (Molassiotis et al., 2006). Using these approaches, cancer care professionals have studied hope in the perspectives of broad cancer populations (Kvåle, 2007; Moadel et al., 1999; Nekolaichuk et al., 1999), palliative care (Benzein et al., 2001; Bowes et al., 2002; Buckley and Herth, 2004; Duggleby and Wright, 2005, 2007; Flemming, 1997; Kennett, 2000), cancer survivors (Persson and Hallberg, 2004), patients in treatment for haematological cancer (Post-White et al., 1996; Saleh and Brockopp, 2001; Cohen and Ley, 2000) and parents of adolescents with cancer (Kylmä and Juvakka, 2007). In all studies, hope was dynamic and important for finding meaning in the experience. Likewise, researchers have addressed hope among cancer patients and other critical conditions through surveys using hope instruments (Ballard et al., 1997; Benzein and Berg, 2003, 2005; Duggleby and Wright, 2007; Herth, 1992; Miller and Powers, 1988). In these hope scores were relatively high among patients with cancer regardless of hope intervention and closeness to death. Few studies have concerned hope when being recently diagnosed with gynaecological cancer. However, Winterling and colleagues (2004), in a phenomenographic study of changes in life among patients with newly diagnosed advanced gastrointestinal cancer and their spouses, found hope to be one important way of handling the situation. Patients and spouses hoped for a long life, for being healthy and staying together. Other acts of handling the situation were reconciliation, can't complain, making the best of it, preparation, avoidance and isolation. Reb (2007), in a grounded theory of 20 women's experiences of an advanced ovarian cancer diagnosis found hope to play a key role. Hope was necessary for finding meaning; hope changed over time and was associated with the ability to return to a normal life. Other studies document that in the diagnostic phase patients balance between hope and despair (Giske and Artinian, 2008) and they feel distressed over a delayed diagnosis (Ferrell et al., 2003b; Reb, 2007). Further, spirituality and faith are most helpful in maintaining hope throughout a life-threatening illness (Edser and May, 2007; Ferrell et al., 2003a).

Hope and women with gynaecological cancer

Generally, the quality of life of women with gynaecological cancer is more or less affected (Ersak et al., 1997; Esbensen et al., 2004; Ferrell et al., 2005; Pilkington and Mitchell, 2004); the women wish to be in control; they are concerned about caring and treatment (Howell et al., 2003b; Velji and Fitch, 2001) and prefer sharing decisions with the doctors rather than making decisions on their own (Beaver and Booth, 2007). Ekwall and colleagues (2003), in an interview study of 17 Swedish women in treatment for gynaecologic cancer, found that the women first of all hoped for quick curative surgery, good communication and support. Danish women in rehabilitation after cervix cancer operations experienced life positively; they had a deeper bodily perception and were active in the rehabilitation (Seibæk and Hounsgaard, 2006). In a study of ten women's experiences of short admission for hysterectomy (not cancer), Wagner and colleagues (2005) identified three types of women, an intervening, a cooperative and an unsure type. The women described emotional reactions, and as in Ekwall and colleagues' (2003) study, the women hoped for dialogue with the nursing staff. Though, women might distance themselves from the illness, preferring to talk about their life, hobbies, families and friends rather than their health condition, these strategies seemed to help them to find meaning and hope for the future (Kvåle, 2007).

In summary, even though cancer nursing researchers have studied hope among patients with various cancers and likewise studied women with gynaecological cancer, there has been less focus on hope as perceived in the pre-surgical period. A study of these experiences seems relevant. Being diagnosed with gynaecological cancer might be a threat to women's identity, their sexual life and a life as a mother as well as being a threat to life itself. Thus, the aim of this study was to investigate the meaning of the lived experience of hope in women newly diagnosed with gynaecological cancer. The research question was: How do women experience hope when being newly diagnosed with gynaecological cancer?

Method

Setting and design

The study was conducted at a gynaecological department of a Danish university hospital; it was designed as a qualitative interview study (Kvale, 1994) with a phenomenological approach (Van Manen, 1990). Phenomenology addresses human beings in their natural attitude; it is interested in describing and constituting the meaning of the human lifeworld in its many variants. The point of departure in this study was being newly diagnosed with gynaecological cancer. The subject matter was how the phenomenon (the experience of hope) unfolds in this special situation. Through a phenomenological approach we wanted to get a deeper understanding of the phenomenon. The phenomenological text, through varying examples and a poetic touch in writing that puts the study in-between art and science (Van Manen, 1997), is intended to bring forward a renewed understanding of the phenomenon studied. The text should further help the reader to see the phenomenon in a new shape. The rigor and exactness of this approach is constituting the meaning of the phenomenon "through working with intuitive insights and reflections on different levels of recognition all along the research process" (Hall, 1996, p. 5).

Participants

Twenty-seven women were approached from a gynaecological department at a university hospital in Denmark. Women meeting the inclusion criteria of being newly diagnosed with gynaecological cancer and anticipating hysterectomy, having Danish as first language and willing to tell about their feelings of hope, were consecutively contacted about participation. The women were asked to participate in the study and were given written and verbal information about the study when receiving the diagnosis by the involved gynaecologist. Twelve women declined, leaving a group of 15 women as participants of the study. This amount is considered enough when searching for a deeper meaning of qualitative

interview data (Kvale, 1994). The reasons for refusal were usually that the women were too emotionally influenced by the diagnosis. One of the declining women briefly participated in the first interview but for emotional reasons discontinued the interview. The median age of the women was 52 (range 24–87); ten were married, one was a widow, two were unmarried and two were divorced. Four were diagnosed with ovarian cancer, eight with endometrial cancer, two with cervical cancer and one with vulvar cancer. Two of the women's spouses participated in the interview.

Data collection

The women were interviewed the day they received the diagnosis and the message that they had to undergo hysterectomy. The interviews, lasting from 60 to 120 min, took place in a quiet room at a gynaecological unit of the hospital. In this type of interview the researcher is the instrument through which the data are collected (Kvale, 1994). The interviewer (KH) knowing that the women had just received a cancer diagnosis, tried to create a pleasant atmosphere with candle light and coffee. To encourage the participants to continue telling about their experience the researcher was sensitive and listening. A semistructured interview guide governed the interviews and helped the involved to keep close to the issue. The initial question was: "Please tell about the situation when you got to know about the diagnosis and the operation. What did you think? What did you feel? What did you do?" The women were encouraged to speak freely about issues associated with cancer, hysterectomy, family and life itself. During the interviews several women cried slowly, but most of them regained their composure and the interview went on. Each interview ended with the question "How do you see the future?" and a debriefing of the full interview.

All interviews were done by the first author who is as proficient cancer care nurse, experienced in consoling patients who are unhappy or crying. At the time of the interviews the interviewer had no connection to the cancer clinical practice where the study took place.

Ethical considerations

Interviewing patients the day they are receiving a diagnosis of cancer demands attention to ethical issues. The researchers in this study were aware that the participants were vulnerable but did not regard the interview as violating the women's integrity. Ethical guidelines followed those laid down by the Northern Nurses Federation (NNF, 2003). Participants were informed of the research purpose, asked to sign the consent form and told that they could step out of the interview. Permission to carry out the study was obtained before data collection, and a project description was sent to Regional Committee on Science Ethics, and Data Surveillance Authority.

Data analysis

All interviews were tape-recorded and transcribed verbatim and analysed. A phenomenological analysis was used, inspired by Van Manen (1990) and carried out in several steps (not necessarily in this order).

- First, a wholistic approach to the data was done. Data were read through several times to discern an overall meaning of the experienced hope.
- Second, a selective approach was done focusing on identifying elements and themes in the text. Questions asked of the data in this approach were: How is hope described? What phrases stand out? Do sentences or part-sentences seem to be thematic of the experience of hope? For example, the expression "bright spots in daily life" was found, and the researchers asked themselves: What does the woman mean when she says bright spots in daily life? In this step sentences were condensed and reformulated into meaning units, making essential themes in each data source.
- Third, individual themes were condensed into universal themes. Questions asked of the data were: What themes are common to all interviews and fundamental not only for the phenomenon but also for the context?
- In the fourth phase meaning units were condensed in a way that was pertinent for the discipline of nursing. The question of the data was: What does this meaning unit reveal of the nature of hope in this situation seen from a nursing perspective?
- Finally, intuitively, reflectively and mindfully, the researchers tried to create a sensitive phenomenological text that could serve health care professionals working with this group of patients.

The first author conducted the first analysis, and after that all authors together or in groups of two were dwelling in the analysis, moving back and fourth between the data excerpts and the output of the analysis, reflecting on, refining and validating the writing of themes, quotes and the text in general. Thus, research and writing became one indistinguishable process; it was a way of describing hope as experienced by the women as well as a measure of own knowledge, reflexivity and thoughtfulness (Van Manen, 1990).

Findings

The analysis revealed that the presence of hope was essential for the women at the time of the diagnosis; they believed in being cured and able to continue their life as usual with loved ones, friends and relatives. Still, the newly received cancer diagnosis made the women oscillate between hope and hopelessness, between positive expectations of getting cured and frightening feelings of the disease taking command. Five interrelated themes will be presented to illuminate the findings.

Hope of being cured, cared for and getting back to normal

This theme highlights the importance of being cured. The experience of hope when newly diagnosed with gynaecological cancer was a belief in being cured, being cared for and getting back to normal. The women wished life to be the same as before the cancer, although their frame of reference was changed. This belief was often the very first thing that was said in the interview. The women had a deep desire to be treated and cured, and some prayed to God for health and recovery. Hope was woven into this desire of being cured; it was connected to positive outcomes and expectations of getting rid of the cancer. The women were hoping for recovery and for resuming their previous lives. Hope was thus experienced as a will to be alive, to be part of life and find meaning in this situation. The professional treatment and care strengthened the belief that everything was under control and taken care of. The way doctors and nurses were giving information, answering questions and creating a positive atmosphere affected the impression of being treated with respect. There was hope to be cured. The following short quotes illuminate this theme.

"Hope is related to be cured, getting rid of the illness".
"Hope for me is that my everyday life is working as usual".
"I feel hope when the doctor tells about the program and I sense that everything is under control".

"I feel hope when the doctor and nurse create a positive atmosphere between us".
"I feel hope when I pray to God that my operation will go well".

Hope as being active and feeling well

In addition to hope for cure the women envisioned the future as being active and satisfied. The diagnosis initiated thoughts about the future, the women talked about and planned for the future. They wanted the future to be as before emphasizing that even small things were important. Hope had to do with daily activities such as exercising, eating healthy food, thinking actively or talking about recovery; it was doing small everyday chores and enjoying these things such as walking at the beach or in the woods or walking barefoot. The women talked about just being satisfied with life and "bringing positive spots into the daily life". Hope then was associated with being free to choose, to challenge oneself and be in control. Quotes that illuminate this theme are:

"Hope is related to a willingness to go on challenging myself".
"I feel hope when I am eating healthy food and exercising".
"Hope is when I am talking about getting better".

Hope as an internal power to maintain integrity

This theme developed out of reflections late in the interviews and captures the spiritual mystery of hope. Hope was "something inside of me", something that contributed to "spiritual courage"; it was experienced to be a personal positive inner energy connected with strength and willpower and related to faith in God; it was a feeling of being a whole human being with passion for life. Hope was fundamental to life itself, a will to be, to live and find meaning in life.

"I feel hope when I am filled with positive energy, a powerful feeling".
"Hope is related to a willingness to go on with challenges of life".
"Hope connects me to life; it gives me power to go on living, to see more of life".
"When you have hope, you have a passion for life".
"I believe that hope is something everybody needs until they take their last breath".

Hope as significant relationships

This theme captures the relational dimension of hope. The diagnosis made the women think of their loved ones and talk about their love and connectedness to children, husband and family. Hope was emotional and a practical support from significant relationships. Hope grew out of love and relationship with significant others. Love, from husbands, children, grandchildren – and God, mobilized resources. The significant relationships confirmed a sense of value; the women felt being needed and good enough in spite of everything. However, what they thought of themselves or accomplished on their own did not seem to be as important as giving hope, love and care to others. Hope then was a give and take in significant relationships, just knowing having trustworthy people around nurtured hope. The following quotes illuminate this theme:

"My love for my husband and my love for my daughter give me hope and power to move on".
"My love for my family means everything for me".
"Giving love and being loved give me hope".
"I feel hope thinking that everything lies in the hands of God".
"I feel hope thinking that everything is for a purpose".

Hope as fighting against hopelessness

The women also experienced hopelessness. This theme is about the oscillating between hope and hopelessness. The diagnosis made the women realize that they had visible signs of cancer, and for a moment they experienced loss, emptiness and hopelessness. They wished to run away from the diagnosis and return to their former familiar life. Yet it seemed as if the women instantly switched hopelessness to hope. Hope was restored after touching hopelessness; it activated hope through planning for the future and thinking about positive outcomes. It seemed as if hope was a fight against hopelessness, because, as one women said: "*If hope disappears you have nothing*". The feeling of hope dominated experiences of hopelessness. The women might focus on the present in order to keep the uncertainty at bay. "*Nobody knows what the future may bring*". The process of trying to make sense of the old and new reality seemed complex. The uncertainty about their future functioning resulted in a modification of hope in order to cope with the reality.

"I feel hopelessness when I think about my children … I feel awful getting cancer. Then I think maybe they can remove all of the cancer. Then I feel hopeful".
"I feel hopeless when I think that I can't get more children … I feel hope again when I pray for the operation to go well. I might be able to get children after all".
"When I think about how my children will react on "mom has cancer" I feel hopelessness. But so I make new plans for us, doing things together like going on a holiday – then I feel hope again".
"When you don't have hope it is hard just going on with your life … but I hope there is something for me afterwards when I have had the surgery".

Discussion

The aim of this study was to investigate the experiences of hope among women newly diagnosed with gynaecological cancer. Fifteen women of all ages participated. A phenomenological approach was used to extract the meaning content of experiences of hope in this situation. Overall, hope was found to be multifaceted, with physical, relational and existential tendrils, being connected to both diagnosis, cure, family life and life itself and closely tied to hopelessness.

Some limitations of the study have to be addressed. A number of women turned down the invitation to participate; they were too overwhelmed by the cancer diagnosis. The women who agreed to participate might be strong women belonging to the intervening or cooperative type (Wagner et al., 2005) while the women who declined to participate might be more uncertain, anxious and fearful. The findings of our study thus might give a too positive picture of the experience of hope among this group of women. Hopelessness might be more prominent than found here. When diagnosed with serious illness, all women might not manage as well in their fighting against hopelessness as the women in our study seemed to do. Or as the philosopher Marcel (1951) puts it: some women might refuse to accept the offer of hope. Another issue that might have limited rich data collection was the timing. It might be that the women, as the women in Reb's (2007) study recalled, were in a state of shock and chaos after the recent diagnosis and that a certain distance to the actual event would have given richer data. The women then would have been in a state of after-shock but still with clear memories of their experience of hope that day.

An expected finding was that the women hoped for being cured from their disease. Being cured was a goal for them. The will to be cured and go on living is earlier described among cancer patients (Benzein et al., 2001). Our results concur with a Swedish study of 17 women's description of what was important during their interaction within the health care system (Ekwall et al., 2003). The most urgent need for the women was to have their tumor removed quickly. In our study, getting the very best care involved maintaining hope of a rapid cure after treatment. It was clear that being cured and go on living normally depended on assurance of help from others such as doctors and nurses. Confidence in treatment was a significant dimension of hope as earlier described from nurses' perspective (Benzein and Saveman, 1998).

Prominent in our study was that hope was related to love and being loved. Love and close relationships activated thoughts and feelings of well-being and released hope into energy and actions. Hope was knowing that there was someone to love and care for. As the interviews took place the same day the women got the cancer diagnosis, the hope as significant others might be interpreted as reaching out for help. In Reb's (2007) grounded theory study, women with advanced ovarian cancer retrospectively recalled the day of diagnosis as a day of death threat; they were in a state of flux, interpreted as reverberating from the impact of the diagnosis, sensing the threat, succumbing to the vortex and trying to survive the emotional chaos (Reb, 2007). If this was the case for the women in our study, no wonder they experienced hope as having significant relationships. Hope depends on a belief in help and support from others. Family and significant others are important for feeling inter-connected (Benzein, 1999) both to oneself and others.

Another finding was that hope was intertwined with hopelessness. All women experienced both hope and hopelessness instantly at the time of the diagnosis. Bearing in mind that the women in this study were newly diagnosed with cancer, it is understandable that they were fighting hopelessness. As in our study, patients during the pre-diagnostic phase are found to use different strategies in maintaining hope (Giske and Artinian, 2008); they were balancing between hope and despair, seeking and giving information, interpreting clues, handling the existential threats and seeking respite. The close relationship between hope, despair and hopelessness seems to be an inevitable characteristic of hope. Hope and hopelessness are inseparable because they alone can give rise to unconquerable hope (Marcel, 1956). Hope is restored through despair; it is "a memory of the future" that endures almost everything. We are, Marcel (1951) says, given the opportunity to hope; the possibilities are there, waiting for us to find them while feelings of uncertainty and hopelessness due to suffering prevent us from so doing. In our study, when being in hopelessness, the woman expected to receive the required assistance from nurses and other health professionals in order to maintain hope and avoid hopelessness. It could be that they experienced both hope and hopelessness at the same time. One woman experienced hopelessness when thinking she could not became pregnant and have children but instantaneously prayed for the operation to turn out well with possibility to become a mother. In a review of the literature, Aylott (1998) found evidence that it is conceivable to simultaneously experience hope and hopelessness. Feelings of hopelessness might be suppressed by coping strategies until inner strength and resources are exhausted, the author states. Hope then is an inner strength but could be activated through outer forces. Anybody who has the power of inspiring hope has the power through action to bring about hopelessness, either temporarily or forever (Flemming, 1997). Health care professionals thus can communicate hope as well as hopelessness – a single word or the tone of voice might be decisive; they can trigger meaningful possibilities in life as well as meaninglessness. Professionals are able to help release hope into energy and activate thoughts and essential feelings in a continual balance between hope and hopelessness.

The question remains whether the findings are valid and generalizable. In lifeworld studies, validity has to do with being open and sensitive to the phenomenon in focus, and to present the study coherently with an inner logic that makes it possible for the reader to follow the process (Kvale, 1994). In this study, the researchers tried to describe the research process in detail, tried to group the themes in a coherent way, and used examples and quotes as validity tools to portray the meaning of hope among women newly diagnosed with gynaecological cancer. Validation in qualitative studies is also a communicative and pragmatic enterprise (Kvale, 1994). The researchers dialogued with each other during the analysis and writing-up process thus validating the findings. However, a lifeworld study cannot be judged by the authors only, others (readers, listeners) have to validate the findings for accuracy, coherence, value and usefulness. "A good phenomenological description is something that we can nod to, recognizing it as an experience that we have had or could have had" (Van Manen, 1990, p. 27).

Generalization in lifeworld research is to supplement what we already know with new dimensions (Jørgensen, 1996). Together new and old knowledge might interact with renewed depth; the new knowledge has provided a somewhat better understanding of the world of human beings. The point of generalizability of a qualitative study like this then lies in the fact that the new understanding in other contexts can catch the many nuances of the human lifeworld. In this study, hope was seen in the context of Danish women newly diagnosed with gynaecological cancer who were composed enough to participate in the interview, and data were interpreted by a group of health care researchers and presented in five themes. Due to the special Danish context, the findings might be considered not generalizable or maybe even as unique anecdotal Danish experiences without scientific value. However, anecdotes always contain aspects of the universal (Van Manen, 1990). For example, the themes 'hope as fighting against hopelessness' and 'hope as an internal power to maintain integrity' seem to be universal experiences of hope but might likewise provide new understanding of the meaning of hope in this special context. The understanding might be valuable and useful in cancer nursing; it might foster changes in attitudes among nurses working with cancer patients and their families.

Conclusion

The findings of the close connection between hope and hopelessness support the need for nurses to continue to practice hope-inspiring nursing. Nurses need to recognise that they are invaluable professional resources in this respect. Knowing that hope is restored through hopelessness might help nurses follow the patients "down" in hopelessness as a caring support. Just being present might trigger hope and might activate inner strength and power.

Hope in our study was multifaceted, involving hope for treatment and cure, being active and satisfied, giving and opening for care, love and relationships. Hope was a belief in the future, an inner willpower to be an integrated human being and an acceptance of being interdependent, being one in relationships with family, friends and God. Hope was woven together with hopelessness in a mysterious way; it took command through inner strength and courage based on a trust in being cured and of being in relationship with significant others. The findings not only add to new knowledge about hope but also about hopelessness and especially about the close relationship between the two when newly diagnosed with a threatening and malignant disease such as

gynaecological cancer. Findings are important as they help nurses understand the complexity of hope and its close connection to hopelessness; they help nurses assist patients in fighting hopelessness. More research concerning hope-giving nursing in this context will however validate the findings.

Conflict of interest

All authors of the article *Hope as experienced in women newly diagnosed with gynaecological cancer* hereby disclose any financial and personal relationships with other people or organisations that could inappropriately influence their work.

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Paper III

Hammer K, Hall EOC, Mogensen, O.

Hope Pictured in Drawings by Women Newly Diagnosed with Gynaecological Cancer

Hope Pictured in Drawings

by

Women Newly Diagnosed with

Gynaecological Cancer

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Abstract

Background. In mysterious ways hope makes life meaningful even in chaotic and uncontrolled situations. Hope, when a person is newly diagnosed with gynaecologic cancer, is ineffable and needs exploring.

Objective. The aim of the study was to investigate the lived experiences of hope among women newly diagnosed with gynaecological cancer as expressed in drawings.

Method. Fifteen women who on the same day had been diagnosed with gynaecological cancer participated. They were between 24 and 87 years old (median 52) with a variety of diagnoses. Data from drawings and post-drawing interviews were analysed using visual and hermeneutic phenomenology outlined by Betensky and Van Manen and assembled in themes.

Results. Three themes emerged in the study. hope as a spirit to move on, hope as energy through nature, hope as a communion with family life and relationships.

Conclusion. Combining interviews, drawings, and post-drawing conversations for a deeper understanding of hope is a new and rare research method. The method offers health care researchers a new perspective of hope different from when interviewing patients. The patients themselves become the experts from whom to learn directly or indirectly.

Implication for Practice. Visual representations make new opportunities for nursing knowledge of the lifeworld. The use of drawing in clinical practice and research can change nurses' and other health care professionals' perception of the individual patient; make them free from schematic thinking, and enforce individualized care. Drawings as other visual representations are suitable tools in understanding an ineffable phenomenon such as the nature of hope when diagnosed with cancer.

Keywords*:* Hope; gynaecological cancer; newly diagnosed; drawing; phenomenology; women

Introduction

The day a person is diagnosed with cancer is a day of emotional chaos and a feeling of losing control of life.[1] Hope is, however, present, because philosophically speaking: "hope is not a kind of listless waiting; it underpins action or runs before it, …"[2(p342)] Hope in a mysterious way makes our existence bearable and meaningful even in chaotic and uncontrolled situations. This study explores how women express hope in drawings when the diagnosis of a gynaecologic cancer is disclosed to them. The word cancer has a stigmatising meaning in society, being more than only a disease, and the diagnosis might be a threat to the female identity and dream to become a mother.[3,4] Picturing hope in drawing is a way of expressing the chaos as well as life itself now and in the future. Drawing is a way to deepen the understanding of hope. Drawings are visual devices representing personal and collective reflection; they are ways of expressing a subject not easily talked about.[5-7] Knowledge from drawings of hope might help nurses and other health care professionals understand what matters for patients when they are diagnosed with cancer.

Theoretical framework

The theoretical framework of this study is the existential philosopher Gabriel Marcel's (1889-1973) notions of hope. Marcel unites soul and hope. "… hope is for the soul what breathing is for the living organism. Where hope is lacking, the soul dries up and withers. It is no more than a function …".[8(p11)] Hope is fundamental to get into agreement with oneself and one's life; it embraces the whole human existence and being and comes into being only when the possibility of despair gains access. Hope does not turn inward towards oneself but outwards, as an opening towards the other in a communion. Hope thus reveals a close human-to-human relationship and a dialectic relationship to despair. Hope is restored by means of its interdependence with despair.

Literature review

Literature searches in PubMed, CINAHL and SCOPUS using the words hope, newly diagnosed, gynaecologic cancer, and drawings separately and in combination were done. Studies found in the search as well as in the reference lists of the literature, demonstrated that when struck with cancer, hope is a powerful factor in healing, coping and quality-of-life.[9,10] Quite a few nursing and other health care researchers have studied hope across the cancer trajectory. Cancer nurse researchers have addressed hope using instruments to measure hope in different contexts.[11,12] These studies have identified hope from outer perspectives. The concept of hope has been e.g. divided into experiential, relational, spiritual, and rational dimensions.[13] Qualitative cancer care researchers have addressed hope from an inner perspective, letting the patients' own words be heard. Thus, experiences of hope are identified broadly,[14-16] when being in palliative cancer care,[12,17,18] or being a cancer survivor.[19,20] In a meta-synthesis of 15 qualitative studies on hope experiences in health and during illness, authors identified six themes: living in hope, hoping for something, hope as a light on the horizon, hope as a human-to-human relationship, hope vs. hopelessness and fear: two sides of the same coin, and hope as weathering a storm.[21]

When newly diagnosed with cancer, people are tired, they might be depressed, their quality of life is changed,[22] and they oscillate between hope and despair.[23,24] Receiving the diagnosis is a dramatically distressing experience and a change in life, which the women have to adapt and adjust.[3,25] Authors in an interview study found that hope, when newly diagnosed with gynaecologic cancer, was connected to diagnosis, cure, family life and life itself, and closely linked to hopelessness.[24] The importance of the family, significant other persons and support is apparent.[24,26] Being given a cancer diagnosis in old age is described to disturb the family balance.[27] The family is a support but can simultaneously be a burden, and patients try to protect family members from worry and concern.[28,29] Spirituality is found to be

important when newly diagnosed with cancer. Spirituality was a strong predictor of social, emotional, and functional well-being in a study investigating quality of life in newly diagnosed cancer patients.[30] Women newly diagnosed with breast cancer try to maintain and restore their spiritual equilibrium by fighting and thinking positively about the disease,[31] they may share their experiences with others, obtain and give support and examine their life priorities.[32] Hope is an important way of handling the disclosure of the cancer diagnosis,[33] the level of hope actually increased when the diagnosis was disclosed compared to when not knowing the diagnosis.[34] In a survey to examine the relationship between uncertainty, optimism, seriousness of illness, control over physical function, and adjustment in women newly diagnosed with gynaecological cancer, Mishel and colleagues[35] found uncertainty to be a detriment of keeping the newly diagnosed patient hopeful. With a higher level of uncertainty, patients had more sad feelings and negative expectation about the future; they were less motivated to get what was wanted and had more adjustment problems. Uncertainty was also associated with disruption in family relationships. Patients with more uncertainty and less optimism experienced more problems with their immediate and extended family relationships.

Isolated studies were found that document hope and other health experiences through drawings. Herth[36] used drawings together with interviews to investigate the meaning of hope in homeless children and to identify strategies that children used to foster and maintain their hope. Locsin and colleagues, [37,38] in a phenomenographic study using drawings and interviews as data, described how people experienced surviving the Ebola virus epidemic in Uganda 2000-2001. The disease was pictured as horrible ghosts, sometimes in the shape of evil tortoises. Surviving this highly lethal viral disease was categorized as an escape in peaceful awareness, hoping for a world outside of fear; it was persistence in defying death and a constant fear of dying. In order to understand the negative effects of long-term psychiatric

hospitalization, Ornellas Pereira and colleagues[39] used drawings and interviews in a study of the experiences of four Brazilian women. The analysis disclosed sadness, emotional suffering, and social exclusion among the women and also dreams and hope for the future. One of the women said about one of her drawings, ”The sun rises for everybody who believes and hopes that one day they will live in a home, in a protected lodging”. [39(p129)] In drawings from women with systemic lupus erythematosus, the disease was illustrated as a monster “that sometimes bites but still has human shape”, a many-faced creature and a kind of octopus that unpredictably attacks somewhere in the body.[40(p8)] Pain was illustrated by horrible teeth, and generally there were feelings of fear. What will happen next?

The literature thus demonstrates that hope is involved in one way or the other when newly diagnosed with cancer. Drawings can be powerful illustrations expressing metaphors and feelings of matters, such as hope, that are not easily spoken of. They so to speak tell a story in their own language. Drawings were not found used to illustrate hope among women newly diagnosed with gynaecological cancer. Drawings give further knowledge about the experience of hope and help health care professionals towards a deeper understanding of what matters for women when newly diagnosed with gynaecological cancer.

Aim of the study

The aim of the study was to investigate the lived experiences of hope among women newly diagnosed with gynaecological cancer as expressed in drawings. The study is part of a comprehensive study designed to get a deeper and richer understanding of hope among these women[24] and to further the knowledge into hope-facilitating nursing strategies. The first author’s experiences as a cancer nurse and a professional painter contributed to the design of the study.

Method

Setting and design

The study was conducted at a gynaecological department of a Danish University Hospital and had a visual phenomenological[41,42] and a hermeneutic phenomenological[7] approach. The approaches helped investigate the visual expression (drawings) in many variants and how the drawings were understood by the "art makers" themselves. The drawing, as any anecdote included in a phenomenological study, portrays something of the universal human being, and at the same time aspects of the subjective human experience.[7] Through colours, objects, lines and shapes, the drawing expresses emotions, moods, motions, stance, gesture; it might express aliveness, vitality and feelings about self. Of special interest for the researcher is to notice which elements in the drawing that mostly evokes the phenomenon studied. The point of departure in this study was the situation of being newly diagnosed with gynaecological cancer and the way in which hope was experienced in this situation. The drawing itself occurred in silence. The researcher then kept back. Later, the researcher helped the art maker to look at the drawing, see the essence of her work, and listen to her story based on the drawing of hope.

Participants

Twenty-seven women were contacted after having received their diagnosis. Twelve of them declined to participate; they were too emotionally influenced by the diagnosis. Fifteen women thus were recruited. The women were between 24 and 87 years old (median 52 years) and had a variety of diagnoses as shown in table 1. The women were given written and verbal information about the study when receiving the diagnosis by the involved gynaecologist, and the same day they were interviewed and asked to make a drawing.

Data and data collection

Data were 15 drawings and 15 post-drawing interviews made with the art makers immediately after the art work. The drawings took place in prolongation to interviews with the women.[24] When the interviews had come to an end, the women were asked to express hope in a drawing. The researcher supplied the women with a blank paper and oil pastels, and she asked them to draw what they were hoping for at this moment. As the impetus of drawing tends to appear being alone and given ample time,[41] the researcher left the room. After finishing the drawing, the researcher and the informant talked about the meaning of her drawing, the substance, the colours used, and the composition.

Ethical considerations

Ethical considerations followed those laid down by the Northern Nurses' Federation,[43] guaranteeing anonymity, confidentiality, and free participation. The women were informed of the research purpose and asked to sign a consent form. A protocol was sent to Regional Committee on Science Ethics and to Data Surveillance Authority, and permission to carry out the study was obtained before data collection. The researcher was aware of the vulnerability of the newly diagnosed women and did her utmost not to violate their integrity.

Data analysis

Post-drawing interviews were audio taped and transcribed verbatim. Drawings and post-drawing interviews were analyzed apart and together, inspired by visual and hermeneutic phenomenology.[7,41] Firstly, and to get a overview of data, drawings were looked at, and post-drawing texts were read through several times to achieve an overall picture of the meaning of the visual images of hope. Secondly, a direct experiencing of the visual data was done. In this phase, the analysis focused on identifying elements in the drawings. The question asked to the

visual data in this approach was: What do we see? Thirdly, a phenomenological description, a process of artwork and creating of the phenomenon, was done. Question asked to the data was: What does the patient explain about her drawing? This was a description of what was in the drawing, in other words, what did the drawing represent. In these two phases of analysis, and to get a deeper understanding, a matrix was developed. Fourthly, the phenomenological intuiting was done. This was a reflective process where the researchers were dwelling in the data condensing the individual interpretations and representations into universal interpretations. The questions asked to the data were: What does it mean? What is common in the drawings? Are there any symbols and metaphors? The next step was a phenomenological integration. The question to the data was: What does this mean seen from a nursing perspective? What do symbols, metaphors and the art makers' own interpretation mean? During the analysis process the researchers were alternately dwelling in and distancing from the data in an effort to present as complete, alive and intense findings as possible.[7]

Findings

Being diagnosed with gynaecological cancer was a change in every day life. Suddenly the women's life world was broken, and the sense of security was lost. In this situation hope presented itself as a peaceful awareness of love, relationship, inner strength, outer resources and a persistency to move on. It was as if the women were living in infinite hope, and their hope had different shades due to life experiences. The drawings were colourful. The women used different colours in their drawings, mostly red, yellow, blue and green, but also black. In some drawings the colours were symbols for hope, healing or hopelessness; red seemed to be the colour of love, blue and green the colours of hope, black the colour of threat to life and despair. Metaphors for hope were frequent such as a shining sun, a red heart, a green tree, a sailing ship, a house, my home, or a fish in troubled water. We identified three shades of hope each elucidating a deeper meaning of the drawings which in turn pictured the women's lived

experience of hope. One shade demonstrated hope as internal, as a spirit to move on in spite of a threat hanging as a cloud over life. Another shade of hope came from outer forces, it was external. The women got energy to move on, sustain the diagnosis and the insecurity connected to the future within the nature, such as from being in the woods, at the beach or in the garden. The drawings showed trees, water, garden and flowers as symbols for the meaning of the nature. Further, hope had a relational shade which was linked to human relationships and human interdependence. The significance of others who loved the women and whom they loved was obvious. Hope grew out of communion in family life and close relationships with loved ones. Pictures of hearts, houses and family members closely together illustrated this shade of hope. In the following, the three shades of hope will be elaborated.

Hope as spirit to move on

Five drawings combined with post-drawing interviews and informant interpretation constituted the internal shade which we interpreted as hope as spirit to move on. The pictures were colourful and had different motives. There were a handful of variations of hope. In one picture, the cancer diagnosis was hanging as a big black cloud over an orange house and a tree, and it was raining heavily (Figure 1). The art maker, a young girl diagnosed with cancer of the cervix, commented on her drawing.

> I have cancer. It is as if the troubles are raining over us. I am afraid that I cannot have children. I wish to have children, it is my greatest desire. Of course I hope that they won't remove everything so I can have children in spite of everything.

The drawings showed that in spite of the threat, there was willpower and hope to get cured and have children, to move on as a fish in troubled water, to get a healthy uterus, and to sail

out in the world with family and friends willing to weld life in the future with life in the past, knowing that life will be different. One woman in her fifties diagnosed with cervical cancer said about her drawing, “I have pictured a happy uterus and some ovaries, a happy uterus with eyes and nose, and a sun. I am happy, my uterus is happy”. The young woman diagnosed with ovarian cancer who pictured hope as a fish in troubled water, commented on her drawing “I am still swimming”.

Hope as energy through nature

Another five drawings combined with post-drawing interviews and informant interpretation constituted the external shade which we interpreted as hope like energy through nature. The drawings pictured hope as a positive force that was fetched in close contact with well-known experiences in the nature, the view from the window at home, the summer cabin, or the feeling of strength because of closeness to the ground when leaning up a tree. A bouquet of colourful red tulips with green leaves symbolized the future. The woman said “Spring is in the air, and it is time to open the summer cabin, just as usual”. In one picture the sun was mirrored in the water and there were trees around the sea. Trees and the beauty of the sunset meant a lot; they were energy forces that helped fight for life. The sun symbolized hope to experience more in life and hope that life would be the same as before. Thus, the spirit to move on seemed nurtured by close contact with nature, sun, sea, trees, and flowers. Hope grew out of experiences, recollections and plans that had to do with external environmentally known matters. A woman who pictured her house and garden said that she was aiming at a life without hopelessness. She did not want to think about illness and death; she wanted to see the light, the flowers, the garden; they filled her with hope, peace, and growth. One middle-aged woman diagnosed with cervical cancer drew a tree and commented, “I like to lean to a

tree. I take my shoes off so that I can feel the energy from the ground run through my body. I am just standing there without thinking. It's health, isn't it?"

Hope as a communion with family life and relationships

The third group of five drawings combined with post-drawing interviews and informant interpretation constituted the relational shade of hope which we interpreted as hope as communion with family life and relationships. The drawings described the women's deep relationship with their nearest and dearest, the meaning of love, togetherness, and family. Hope as a spirit to move on was nurtured through togetherness with family and other close relationships. The future was the family. The women felt happiness when being with husband and children; they hoped that the happiness would come back and that the family could be together and happy as a family. The drawings were made with red colours symbolizing love. Green colours and gardening were symbolizing growth and development. Hearts were symbolizing love, and love was imperative to feel hope. The shining sun was warming the relationship and made the women feel confident and secure. One woman commented on her drawing that constituted four red intertwined hearts embraced by a couple of green leaves under a shining sun and a small bluish cloud (Figure 2).

> This is my family – we are together. My family means everything to me, they keep me up. I love my husband and my daughters. The sun is shining and I expect the happiness to return to us. Green, the colour of hope, embraces our little family.

Discussion

Just as the researchers of this study found literature involving drawings to be powerful, they found the drawings of hope in this study to be powerful. The drawings gave new perspectives

on hope. The study showed that the simplest drawing portrayed hope as experienced in the situation. An advantage in the design was the post-drawing conversation when the women interpreted their drawings and expressed in words what mattered to them. The post-drawing interpretation was an indispensable partner to the drawing itself. The conversation about the drawing of hope was not only a research matter but unintendedly resulted in therapeutic value. In a phenomenological sense,[41] the women were the ones that experienced the process of looking at the self-made drawing as it appeared to their senses and consciousness. Thus, they themselves arrived at the subjective meanings, and not the researcher. The women talked about what mattered to them in this new situation, they deepened the substance of the drawing while the researcher was listening. Therein lies the therapeutic matter.

An important finding in this study was that hope had several shades. Out of the reflective and intuitive process grew a deeper understanding of hope as more than what was found when first interviewing the women of hope. Then the authors identified hope as a trust to be cured, cared for and getting back to normal; it was being active and feeling well, an internal power to maintain integration, be in significant relationships and fighting against hopelessness.[24] The visual display deepened the meaning of hope. Together with the post-drawing conversation between the researcher and the participants about their drawing and the following analysis, we found that internal spirit, external energy, and communion with loved ones were the factors that gave hope to the women newly diagnosed with cancer.

The most important finding was that the women's families and loved ones were primary sources in hoping for health, cure, and a normal life in this special situation. Hope was in communion with others. A spirit to move on was nurtured through communion with family and other close relationships. The future was in the communion with loved family members. Hope as communion through family life and relationships as found in this study is, however, not new. Hope requires communion,[2] affirmative relationships confirm the

humanness and helps experience hope,[44] and family plays an important role for patients' suffering[24-27]. You know you are loved and can love in return. You have family memories that remind you of the past, give joy and stimulate a future life.[45] Drawings and stories of hope made by homeless children, irrespective of their age, all included the presence of a significant other person, a parent, a teacher or a friend demonstrating the desire for connectedness.[36]

The intrinsic spirit shade of hope was the inner power that facilitated the transcendence of the present critical situation and gave new awareness and enrichment to the women. It was the very fabric that the soul of the human being is made of.[2] For Marcel hope is a mystery and difficult to understand. Hope cannot be reasoned or felt; it is not an emotion, and it is more than acceptance. It has, among other things, to do with patience. Where you cannot be cured of your illness, you do not give up, but persevere as the one you are. In a most peculiar way the strongest hope can be born out of the deepest despair, because there is no hope, unless the temptation of despair is possible.

In this special situation of being newly diagnosed with gynecological cancer the women were in a state of transition between being healthy and being ill. Receiving the diagnosis is in other studies described to be a change in life requiring adaptation and adjustment.[3,25] Transition denotes a change in life that requires a person to redefine, consider and hope for a new life.[47] In this situation individuals need special care (transitional care) and understanding. Nurses' tasks are to listen patiently, to facilitate individuals' strength and to restore the individuals to optimal health and self-fulfilment enhancing healthful living.

We found that nature had an impact on hope, nature popped up as an external energy field. Spending time in nature was a strategy to cope with the diagnosis, and to believe in a positive outcome. Living and nature belonged together. The drawings reflected a desire to get out in the nature, go to the beach, walk in the forest or enjoy the garden. The nature gave energy. We interpreted this as an external hope; it was an outer resource that contributed to a

persistency to move on with life. Our study confirms Kim and colleagues' study[44] that the nature of hope is composed of several patterns and that external sources are involved and intrinsically linked together. Nature so to speak acts as a healing landscape where hope flourishes.

The interpretation of the drawings identified frequent use of metaphors to symbolize hope. Metaphors are used to catch a meaning, describe a complex condition or illustrate the meaning of a phenomenon difficult to talk about. Metaphor is a word that characterizes a matter and is transferred to another matter.[46] A more common daily word is used instead of the specific phenomenon. In this study, the sun, red hearts, green trees, a sailing ship, a house and the home were metaphors for hope, a cloud on the sky was metaphor for the pending threat to life that the diagnosis meant, and a fish in troubled water was the metaphor for the struggle between hope and hopelessness in an uncertain time. The women used red and green colours to symbolize hope and black colours to symbolize hopelessness and despair. Metaphors can also be used to express silent knowledge, or they can be used to express a matter in a poetic language allowing intense emotions.[7] The woman who commented "I am still swimming" to her drawing impressed us; the metaphor was expressive and had long-lasting effect. The metaphor "swimming as a fish in troubled water" was there to impress us, and it was, as says the philosopher Løgstrup,[48] carried forward through the atmosphere of the situation. Metaphors are seen used in studies involving drawings[37-40] or persons being newly diagnosed with cancer. The diagnosis releases "a personal emotional journey", the patient needs "time-out" to reflect on life and the new situation.[29]

A limitation in this study was that no data were obtained from the women who declined to participate. Knowing some demographics would have given comparable data concerning age, civil status and diagnosis. The women who agreed to participate might be strong women, while the women who declined to participate could have had a more serious

diagnosis, or they could be more uncertain and experience more problems with their family relationships.[35] Also, the refusal could have to do with the timing of the participation. However, when contacting the patients, the researcher explained the purpose and the method of the study with deliberate gentleness and the ethical considerations in mind,[43] and more than half of the contacted persons accepted the invitation to participate.

Questions remain about validity and generalizability of the findings. In phenomenological studies of lived experiences, validity concerns a sensitive openness to the phenomenon in focus as well as to own preconceptions and interpretations. Validity likewise has to do with presenting the study coherently with an inner logic that makes it possible for the reader to follow the process. In this study, data were assembled in very abstract entities, and these were illustrated through examples and quotes on a more concrete level, thus giving body to the abstractions. Further, the researchers all through the research process critically dialogued with each other, questioning interpretations, comparing them with earlier findings[24] and jointly re-writing the text. "A good phenomenological description is something that we can nod to, recognizing it as an experience that we have had or could have had".[7(p27)] Thus validity of the study was continuously evaluated. Generalizability of a qualitative study like this lies in the fact that the understanding reached also in other contexts can catch the many nuances of the human lifeworld and supplement what is already known with new dimensions. In this study, hope was seen in the context of Danish women newly diagnosed with gynaecological cancer who were composed enough to participate in an interview, picture hope in a drawing, and talk about the meaning of hope as expressed in the drawing. The research group interpreted the data and presented them in three themes. Due to the special Danish context, the findings may be considered as not generalizable or maybe even as unique anecdotes without scientific value. However, phenomenology does not aim to explicate meanings typical for particular cultures as ethnography does. Rather, "phenomenology

attempts to explicate the meanings as we live them in our everyday existence, our lifeworld".[7(p11)] The three themes "hope as spirit to move on", "hope as energy through nature" and "hope as communion with family life and relationships" all are lifeworld experiences of hope in analogy with what literature of hope has earlier documented. The themes could, however, provide new dimensions of the meaning of hope in similar contexts. The understanding might be valuable and useful in cancer nursing, fostering changes in attitudes and actions among nurses working with cancer patients and their families.

Implication for practice

Nurses working with cancer patients are in a unique position to help enabling hope because of their continuous contacts with the patients.[49] Findings of this study have special implications for nursing practice designed to enable hope when the diagnosis of gynaecologic cancer is disclosed to the women. Hope was found to have several shades, and nurses can take these into account in caring for newly diagnosed cancer patients. Clinical nursing interventions that should be examined in enhancing hope among these women include support and care. Women diagnosed with gynaecological cancer are reported to have a variety of needs[50] and promoting closeness and presence of loved ones such as family and friends seems to be a most desired need. Nurses here serve as the ones establishing and encouraging vital relationships. Disclosure of a cancer diagnosis is a change in life, a transition between health and illness where much uncertainty is involved, and patients need gentle transitional care. The diagnosis of cancer inevitably promotes feelings of despair. If we assume with Marcel[2] that there is no hope unless the temptation of despair is possible, it is a challenge for nurses and other health care professionals to follow the patient in hope and despair, knowing that for the deserted there is no hope. The strongest hope can be born out of the deepest despair. The findings of this study also highlight that drawings and post-drawing interviews give a deep and broad understanding of the experience of hope. The use of drawing in clinical practice and research

can change nurses' and other health care professionals' perception of the individual patient; make them free from schematic thinking or "frames". Drawings as other visual representations, are suitable tools in understanding ineffable phenomena in people's life world; they make new opportunities for nursing knowledge of the lifeworld when a person is diagnosed with cancer; and they may reveal metaphors used. Drawings and post-drawing conversation used in nursing education can help student nurses learn more about metaphors and gain further insight into the meaning of art and metaphors in situations of illness and disability.

Conclusion

The findings of this study lend support to the lived experience of hope and contribute to a growing body of knowledge related to hope expressed in drawings when newly diagnosed with gynaecological cancer. We can conclude that enabling hope is essential when newly diagnosed with cancer. Hope is an ineffable and basic human phenomenon and as such it has capability to become more effable when pictured in drawings. Hope has different shades and a most important shade of hope lies in the communion with family and other close loved ones. When being diagnosed with a life threatening disease such as cancer, hope lies in being in relationship. Future research designed to explore ineffable and essential nursing matters such as hope, caring, anxiety, responsibility or pain might involve the visual art as methodology. Combining interview, drawing and post-drawing conversation for a deeper understanding of hope is both therapeutic and effective. Drawings followed by post-drawing dialoguing and interpretations are offering health care professionals a new perspective in research and care. The patients themselves become the experts from whom to learn directly or indirectly. The visual is fundamental because seeing comes before words. Drawing and post-drawing conversation express what words might fail to express, and bring wholeness to a mysterious

life phenomenon such as hope. What matters for people in the diagnostic phase of cancer is gentleness, a gentle truth about the reality, not being deserted and some loved ones around.

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Table 1. Demographic data of the participating women

Age in years	Demographics	Diagnosis
24	Student, unmarried, no children	C. cervicis uteri
38	Working, married, children	C. cervicis uteri
40	Working, divorced, children	C. ovarii
40	Working, married, children	C. cervicis uteri
43	Working, married, children	C. cervicis uteri
44	Working, married, children	C. vulvae
47	Working, married, no children	C.cervicis uteri
52	Working, unmarried, no children	C. cervicis uteri
53	Working, divorced, adult children	C. corpus uteri
53	Housewife, married, children	C. cervicis uteri
54	Working, married, adult children	C. cervicis uteri
60	Housewife, married, children and grandchildren	C. corpus uteri
77	Retired, married, no children	C. ovarii
77	Retired, married, children and grandchildren	C. ovarii
87	Retired, widow, children and grandchildren	C. ovarii

Texts to Figure 1 and 2 which are in separate files

Figure 1. I have cancer. It is as if the troubles are raining over us.

Figure 2. This is my family. We are together.