Preparative waiting

a grounded theory study
of gastroenterological patients
going through the diagnostic phase
in a university hospital

Tove Giske

Dissertation for the degree doctor politicarum (dr. polit.)

at the University of Bergen

2007

Teach us to number our days aright,

that we may gain a heart of wisdom.

Moses

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

The research project presented in this dissertation has been carried out at a regional university hospital in Norway. I am grateful to the participants who shared their thoughts and experiences in a vulnerable time of their lives. Your stories have taught me more in depth that illness is so much more than a bodily experience. I also appreciate the interesting discussions and good collaboration with nurses, nurse assistants, and physicians at the ward during data collection and analysis data.

Deaconess University College has been my employer for many years. I am grateful for the trust the different headmasters have shown me from the beginning plans and through out the whole process of completing this doctor politicarum (dr. polit.) study. Thank you Jorunn M. Johnsen, Ivar August Bye, Ole Georg Hoaas, and Jørn Henning Theis.

Professor Barbara Artinian, in 2001 at Azusa Pacific University, CA, introduced me to grounded theory (GT) when I was searching for both a topic and a supervisor for my doctoral dissertation. She showed a great deal of trust in me when she offered to be my supervisor after just 5 days of knowledge of me and my project. She has supervised me all the way through the project and shared generously her knowledge and experience of being a GT researcher. She also has been patient enough so I could grow and learn on my own. She opened her home for me and made me a part of her family. Barbara also took time to come to Norway many times to mentor me, to teach GT, and to share her expertise at workshops in Bergen. Her care for doing GT right also made her eager to share her expertise with other dr. polite candidates here in Bergen. Her mentoring made us realise that we needed to come together and form our own GT research group.

Professor Eva Gjengedal, University of Bergen (UiB) has been there for me from day one. After looking at my project Eva became interested in my topic and trusted that I would manage to fulfil the task, so she took me on as her student at the

good conversations on highways around Los Angeles. Bethany Cone is thanked for excellent work in improving my written English.

Anonymous referees are also thanked for giving thoughtful comments that challenged my thinking resulting in improved papers.

My family is important; Ane, Åse Marie, Johannes and Jarl. Åse Marie's challenging question at the outset: "Why are you doing this study?" helped me make my priorities mostly right. Thanks to Jarl for support and many developing discussions along the way, even though you do not know qualitative methods.

Finally I am grateful for economic support, in the beginning and in the end from Bergen Deaconess University College. I also thank Western Norway Regional Health Authority who made it possible for me to be a full time scholar by their 3 year doctoral scholarship, and lastly Centre for Clinical Research which made it possible to finish.

Bergen, October 4th 2007

Tove Giske

ABSTRACT

To go through the diagnostic phase is reported to be the most stressful time of the illness experience. There is a growing body of knowledge about how women going through diagnostic workups for breast abnormality experience their situation; however, little research is done with patients in gastric wards with as open outcome of the investigation as in this study.

The aim of the study was to gain a better understanding of how patients coming to a gastroenterological ward for diagnostic investigation experienced and handled their situation. It was also to learn, from the patients' perspective, how nurses and other health care professionals could help such patients in the best way.

The study used a classical grounded theory design. Data were derived from 18 in-depth interviews from 15 patients at a gastroenterological ward at a Norwegian University Hospital during 2002- 03. Data collection and analysis were done jointly, and participants and focus of the interviews were chosen in accordance with the development of the theory. Data were first coded openly. As the participants' main concern and the core category emerged, constant comparison went on to selective coding. Lastly theoretical coding was conducted where the substantive codes were related to each other so they fitted data, let the processes in the field emerge, and worked to explain what was going on in the area studied.

The participants' main concern was found to be how they could prepare themselves for the conclusion of the investigation and for life afterwards. The core category was named "Preparative waiting". The substantive "Preparative Waiting Theory" (PWT) explains how they handled their main concern. The theoretical code of "Balancing between hope and despair" integrated the theory, and had four patterns: controlling pain, rational awaiting, denial, and accepting. These patterns guided how participants balanced between the categories of the theory which are "Seeking and giving information", "Interpreting clues", "Handling existential threats", and

"Seeking respite". These findings are compared and discussed in light of theories and empirical research.

To be in the diagnostic phase meant to be in a process of continuously attempting to make sense of one's situation. The search for a realistic interpretation was balanced with looking for hopeful signs. The process of interpreting and handling the situation was conjoint, and influenced by their relationship to family, friends, fellow patients, health care professionals, and God. Since much of patients' inner preparative work was concealed due to the vulnerability of the situation, it was apt to be overlooked by nurses and physicians in a busy ward. To the extent trust developed between patients and health care professionals, patients could reveal their experience of the situation without feeling exposed or embarrassed. Nurses and physicians are the most powerful part in the hospital, and carry a professional responsibility to develop a culture that fosters the ability and willingness to take care of such vulnerable patients.

PWT can assist nurses and other health care professionals in assessing how patients prepare themselves differently for getting a diagnosis. Patients would find it helpful to be followed up by a designated contact person at the ward, who could provide adjusted information, coordinate care and examinations, respect privacy, and inquire about existential concerns. This would promote patients' ability to prepare for receiving diagnosis and life afterwards, and patients using mostly the patterns of controlling pain and denial would benefit the most from such support.

Key words:

Grounded theory, theoretical codes, diagnostic phase, balancing, uncertainty, coping, hope, trust, vulnerability, power, nurse-patient interaction, interpersonal communication, gastro-enterological nursing

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to by their Roman numericals:

I Giske, T., & Artinian, B. (2007). Patterns of "Balancing between hope and despair" in the diagnostic phase. A grounded theory study of patients at a gastric ward. (Accepted for publication October 3rd 2007 in *Journal of Advanced Nursing*).

II Giske, T., & Artinian, B. (2007). A personal experience of working with classical grounded theory. From beginner to experienced grounded theorist. (Revised manuscript sent to *International Journal of Qualitative Method*, September 2007).

III Giske, T., & Gjengedal, E. (2007). "Preparative waiting" and coping theory with patients going through gastric diagnosis. *Journal of Advanced Nursing, 57*(1), 87-94.

IV Giske, T., Gjengedal, E., & Artinian, B. (2007). The silent demand in the diagnostic phase. (Accepted for publication September 21st 2007 in *Scandinavian Journal of Caring Science*).

ABBREVIATIONS

EANS, European Academy of Nursing Science

GT, Grounded theory

HELTEF, Stiftelse for helsetjenesteforskning (Foundation for Health Services

     Research)

ICD-10, International Classification of Diseases, 10th version

ICN, International Council of Nursing

NOU, Norges offentlige utredning (Official Norwegian Reports)

NSD, Norsk samfunnsvitenskaplig datatjeneste (Norwegian Social Science Data

     Service)

NSF, Norsk Sykepleierforbund (Norwegian Nurses Organisation)

PWT, Preparative Waiting Theory

REK, Regional etisk komite (Regional Ethical Board)

SI, Symbolic interactionism

UCSF, University of California – San Francisco

UiB, University of Bergen

LIST OF APPENDICES

Appendix 1: Characteristics of participants

Appendix 2: Potential questions to be used in interviews

Appendix 3: Examples of coding

Appendix 4: The constant comparative process of the study

Appendix 5: Certificate of acceptance from REK

Appendix 6: Certificate of acceptance from NSD

Appendix 7: Information letter to patients

Appendix 8: Informed consent form

1.0 INTRODUCTION

Most people will at sometime in life have a suspicion of being seriously ill, often related to a bodily change. Some of them are admitted to hospital for medical investigations. To be admitted to hospital for medical investigation without a final diagnosis explaining what kind of disease they have, how serious it is and whether it can possibly be treated, is distressing. Interpretation of both present and future become unsure, and this gives the patient a feeling of uncertainty. Selder (1989) states that uncertainty forces a person to confront his vulnerability and that this vulnerability again heightens the experience of uncertainty. Uncertainty together with pain and other problems put significant pressure on these patients in the diagnostic phase. A high degree of uncertainty is related to high emotional distress, anxiety, and depression (Mast, 1995; McCormick, 2002; Neville, 2003).

The diagnostic phase can be defined as the interface between suspicion of an illness and medical confirmation (Poole, 1997, p. 274). Poole (1997) refer to Sontag and writes about "health and illness [as] being two different kingdoms to which all people hold dual citizenship; the 'passport of the well' and 'the passport of the sick' enabling passage into either domain" (p. 274). Poole extends this analogy to embrace the investigation process and continues: "the diagnostic phase [is] as a stormy ocean through which people are buffed and tossed, until they are washed upon the shore of either kingdom: the well or the sick." This analogy vividly describes how the diagnostic phase can be experienced.

Irving (2001) analysed the concept of waiting and defined it as "a stationary, yet dynamic, and unspecified time-frame phenomenon in which manifestation of uncertainty regarding personal outcome remains in suspension for a limited time, but for the definite purpose of something to be expected" (p. 135). In the diagnostic phase, the entire situation is filled with waiting; waiting for investigations and tests to be decided, preparing for them, undergoing them, and finally waiting for results and interpretations. Waiting in uncertainty puts the patients' lives on hold. This is

challenging since they tried their uttermost to interpret and understand what is going on and what it might mean for their future life.

The diagnostic phase, when nothing is final, can be demanding for nurses and physicians too, as they relate to patients and their family. Health care professionals tend to know and understand more than patients, and communication can be experienced as difficult until such information has been conveyed to the patients and all parties have the same knowledge. On the way it can be tempting for professionals to delay contact and building of relationship with patients until their case becomes clearer.

The advanced literature review was conducted to become aware of gaps in knowledge of the area. In the planning of the study we were aware that there was limited research on patients going through the diagnostic phase, except for women investigated for breast cancer (Heskestad & Tjemsland, 1996; Poole, 1997; Ambler et al., 1999; Thorne et al., 1999; Poole & Lyne, 2000). At the outset we knew that waiting for a diagnosis had been reported to be the most stressful time of the illness experience for patients. In her review, Mishel (1997) found that patients who went through diagnostic procedures had higher levels of uncertainty than other medical and surgical patients. Neville (2003) reported that patients living with an undefined illness, such as no distinct diagnosis, could not categorise their problems sufficiently and were left living with uncertainty. This waiting for a clarification of their situation was the most difficult time of the illness. For patients waiting for the report about a breast biopsy, the time between discovery of breast mass and definitive diagnosis was reported to cause considerable anxiety for many women (Benedict et al., 1994). Thorne et al. (1999) found that women experienced waiting as intense and agonizing, and that a lot of energy was bound up in waiting for the verdict. Woodward & Webb (2001) recommended that greater attention should be given to the emotional experience during the diagnostic phase, and Poole (1997) pointed to a general consensus in research related to the period surrounding diagnosis of breast cancer that

this time is the most stressful time both for women and their partners, and she requested more qualitative explorations of reasons for this distress.

Research related to women going through diagnostic workups show that experienced nurses and physicians can reassure and provide patients with valuable information (Benedict et al., 1994). Heskestad & Tjemsland (1996) recorded that how women were met, welcomed, and informed by physicians in the hospital were related to their feeling of being safe and ability to trust. Fridfinnsdottir (1997) found that nurses could be of service to women by giving information and emotional support, and Ambler et al. (1999) reported that breast care nurses could help women think through and face reality in the situation. Thorne et al. (1999) reported that coordination of service was important and that women longed for being seen and treated as a person. These findings are in accordance with Official Norwegian Report (NOU) 2 (1997) which points to the importance of the quality of meetings between patients and health care workers where the individual patient must be seen and met from a holistic perspective. In aims and plans for university hospitals, target areas are set to obtain patient satisfaction and quality of treatment (Report 26, 1999 – 2000 to the Storting [Stortingsmelding]; Ministry of Health and Care Service, 2006, 2007). It is regarded as fundamental for hospitals to keep their focus on the patients and involve them in care and treatment. To be able to reach these aims, health care professionals working in hospitals need to develop a practice that incorporates wishes and viewpoints from patients and their next of kin both in individual cases and as a part of the ongoing planning and development.

There is a growing interest and focus on patients' contribution and collaboration in investigation, treatment, and care. This interest can be understood as an increased acknowledgement of patients' autonomy, and that their experiences, knowledge, values, preferences, and interests must be taken into account in matters relating to patients health and life. Paternalistic attitudes of nurses and physicians can reduce a patient's ability to take part in such decisions (Peter & Morgan, 2001). Real collaboration challenges health care professionals to develop professional roles and practices that are in accordance with the requested patient collaboration (McQueen,

2000), and this leads to a change in roles from professional distance to one in which personal involvement is seen as central (Playle & Mullarkey, 1998).

Western Norway Regional Authority initiated a research project where patients were asked to evaluate their stay in hospitals in the region by responding to a questionnaire which was built on 10 additive indexes related to information, personnel, organising of service, and standard of care and treatment. The study was carried out by Foundation for Health Services Research (HELTEF). 2,880 patients responded and they were in general satisfied (HELTEF, 2003). The report gave an average picture of how patients evaluated the different hospitals in the region. In addition to such evaluations we also need more specific knowledge about different groups of patients, such as for example being patients in the diagnostic phase. These patients are vulnerable due to the uncertainty they go through, and they can easily become invisible in the hospital system. Since they have no diagnosis, they do not belong to any patient associations that can stand up for them. To have more systematic knowledge about how patients experience the diagnostic phase would help to ensure quality in health care.

This thesis consists of seven chapters. After introduction, the main purpose of the study is presented. In chapter three, nursing perspectives and the knowledgebase of nursing are outlined, and in chapter four grounded theory with key concepts of the method and criteria for evaluation of the generated theory are introduced. The participants of this study and how data collection and analysis were carried out, together with ethical concerns are also described in this chapter. In chapter five, the main findings of the study are presented as a brief account of the four Papers this thesis is based on. Chapter six holds the discussion of methodological considerations, findings, implications of the study, and suggestions for further research. Chapter seven concludes the research project.

In the thesis I change between using "we" and "I" in the writing. "We" is used in relation to the planning of the study, analysis of data, and the articles, since this was done more or less in collaboration with my supervisors. "I" is used in relation to

data collection and decisions related to the study, for which I take the full
responsibility.

2.0 MAIN PURPOSE OF THE STUDY

In planning of this research project we were aware of the need for more knowledge related to patients' experience of going through the diagnostic phase. We therefore decided to study patients in hospitals going through medical investigations, since improved knowledge in this area would be highly relevant for nursing practice. The diagnostic phase in this study is therefore defined as more delimited than Poole (1997) did; from patients were admitted to the hospital for medical investigations till the conclusion about their situation was ready to be unveiled to them.

After the study was decided to be related to patients in the diagnostic phase in hospital, a more defined group of patients to investigate had to be chosen in order for the study to be accepted of the Regional Ethical Board (REK). We were looking for a group of patients who would probably experience uncertainty to a great extent and could have a mixture of possible diagnostic outcomes. Patients coming to a gastroenterological ward seemed to be a good choice since they were admitted with a diversity of symptoms and problems, and came on both scheduled and emergency admission. Even though such patients do not receive diagnoses of malignant diseases, their problems can be chronic, painful and influence their lives to a great extent.

The main purpose of the thesis therefore became to

- Gain more knowledge and a better understanding of how patients coming to hospital for medical investigation because of symptoms in stomach-intestine area experience and handle their situation (Paper I, III).
- To learn more about, from the patients' perspective, how nurses and other health care professionals can help such patients in the best way (Paper IV).

After having analysed data, the main concern of patients going through the diagnostic phase at a gastroenterological ward was identified and the research question for this study could be stated as:

- How do patients in the diagnostic phase prepare themselves for the concluding interview and life after receiving a diagnosis?

The substantive grounded "Preparative Waiting Theory" explains how patients work to handle their main concern and also how nurses and physicians can assist them in doing so.

3.0 THEORETICAL BACKGROUND AND PERSPECTIVES

In this chapter the focus of nursing is presented as to be concerned about how patients' experience and handle being ill. Further the key elements in caring are displayed before the knowledgebase of nursing is outlined as to be diverse enough to cover human existence in relation to health and illness. Lastly Kim's analytic framework of four domains of nursing phenomena is presented.

3.1 Nursing perspective

Through education and practice nurses learn the perspectives of the discipline. They learn how to ask questions, to observe, to interpret, and to think. These frames of references are used more or less consciously in selection and organisation of information judged as important for care and treatment of patients (Visintainer, 1996; Fawcett, 2000; Alligood, 2006). The nursing perspective is on people's experience of being ill and receiving treatment, and how health problems influence their basic needs and their activities of daily living (Henderson, 1961; Travelbee, 1971; Artinian, 1997). Nursing focus is not on diagnosis or treatments as such. To build bridges between the illness experiences of patients, their values and preferences, and the bio-medical world, especially in hospitals, is important for patients and a work where nurses can be central (Henderson, 2006).

The illness perspective refers to how lay people perceive, appraise, interpret, live, and respond to subjective symptoms and problems (Kleinman, 1988; Bury, 1997). Peoples' experiences of illness affect their disease by emotions such as hope, fear, sorrow, and despair. Diseases can also affect their experience of illness (Sheel, 2005). The illness perspective is subjective and different from the disease perspective where professionals try to organise symptoms objectively to fit a given diagnostic taxonomy (Kleinman, 1988; Bury, 1997; Hydèn, 1997).

Most nursing theorists understand nursing as a relational and moral practice, built on professional knowledge (Henderson, 1961, 1998; Travelbee, 1971; Artinian, 1997; Martinsen, 1996; Alvsvåg & Gjengedal, 2000; Alvsvåg, 2006). Nursing can be described as a process of interaction between patient and nurse with the aim to come up with a common understanding of the situation and a mutual plan of care. An important aspect of this interaction is for the nurse to acknowledge the inequality of power between a patient and a nurse in the hospital system (Milligan-Hecox et al., 1997; McQueen, 2000; Sellman, 2005; Scantz, 2007). The focus on caring in nursing highlights that nursing is more than what nurses do (following guidelines and standards); it is always related to how they best can carry out their work. Attitudes, relational qualities, and use of clinical judgement is fundamental so nursing care can be planned and carried out in according to the actual situation. Due to knowledge and power, nursing care is never morally neutral. This is in accordance with Løgstrup's poetic expression that we hold some of the other person's life and destiny in our hands (Løgstrup, 1956). Patients want health care professionals who are able to combine knowledge and clinical expertise with relational qualities such as attentiveness, the ability to listen, to be available, and to show support (Schattner et al., 2004; Shattell, 2004; Sjöling et al., 2005; Delmar, 2006; Sørlie et al., 2006). Extensive time is not always necessary to form such relationship (Shattell, 2004). In the nursing literature there have been discussions related to which professional qualities are needed under labels such as nurse-patient interaction (Shattell, 2004), relational competence (Brøbecher & Delmar, 2007), presence (Finfgeld-Connett, 2006), advocacy (McGrath, 2006), compassion (Dietze & Orb, 2000; Schantz, 2007), and partnership (McQueen, 2000).

In a meta-synthesis of caring, Finfgeld-Connett (2007) outlines key areas of nursing care and what it takes of the individual nurse and the working fellowship. It takes an expert nursing practitioner to assess patients' and/or families' situation and to plan and carry out interventions physically, psychosocially and spiritually in a way that patients feel advocated and empowered. A great range of interpersonal qualities such as presence, patient centred, going beyond routines, showing attentive listening,

and to be creative are listed. Caring is intimate relationships building on mutual trust where the nurse is deeply involved and protects the patient. At the same time there is enough distance so the nurse does not get emotionally overwhelmed. Caring takes maturity of the nurse, which enables him or her to draw a line of involvement to prevent exploitation of self.

Caring must be learned, cultivated, and supported by a conducive environment. It takes time and resources, and the individual nurse needs to experience recognition and receive support to validate care herself. The outcomes of caring for both patients and nurses are reported to improve mental well-being, and for patients to enhance mental and physical well-being (Finfgeld-Connett, 2006), increase health and healing (Brilowski & Wendler, 2005), security (Sørlie et al., 2006), ameliorate distress, and induce trust (McQueen, 2000).

Patients without a diagnosis often feel vulnerable and tired, and they come in contact with the existential threat of a possible menace to their lives. When they have few concrete needs for care, they can withdraw to protect themselves and are thereby easy to overlook in a busy ward. Physicians, often specialists with in-depth knowledge in their area, are central in investigating and concluding a diagnosis in hospitals. Physicians therefore often become important for patients in the diagnostic phase. Nurses, carrying a generalist perspective in the hospital (Vike et al., 2002), valuing relational knowledge, caring, and empathy, can also be a valuable resource for patients in assessing and meeting their individual needs for support, information, continuity, and coordination in the midst of uncertainty in the diagnostic phase. Different cultures of caring in wards can improve or hamper the individual professional in their relation with patients as it influences values affecting language, observations, topics to report and discuss, and how professional responsibility is understood (McQueen, 2000; Edvardsson et al., 2005; Martinsen, 2006; Norheim, 2006; Schantz, 2007).

3.2 Knowledgebase of nursing

The knowledgebase of nursing sees the person, both the patient and the nurse, as a meaning-seeking being, who constitutes a wholeness of body, mind, and soul living in relation to self, others and the environment. Knowledge needed in the nursing profession aims at giving nurses "the broadest possible understanding of humanity and the world in which they live" (Henderson, 2006, p. 30), and is therefore developed under different paradigms and with a variety of methods (Kim, 2000; Scheel 2005). Nursing stands in a dynamic interaction between natural sciences, behavioural sciences, and social sciences, and nursing science thereby creates an important knowledgebase related to possibilities and limitations of human existence in relation to health and illness (Sheel, 2005). This understanding of need for diverse knowledge in theory and practice is built into the nursing education program (Kim, 2000; Henderson, 2006; Ministry of Education and Research, 2005)

Kim developed a metaparadigm framework, which is a typology that can guide delimiting conceptual and theoretical issues of importance for nursing (Kim, 2000, p. 7). Her framework is an analytic tool used to classify phenomena in nursing into four domains. This framework could easily be applicable for other health professions in order to organise their key concepts and perspectives. The four domains are: 1) The client domain which is concerned with theoretical issues concerning clients. By understanding what is important for clients, nurses can understand more and gain better knowledge about what is important for them and according to this deliver more effective and needed nursing care to clients (p.42). 2) The client-nurse domain deals with phenomena rising out of encounters between client and nurse in the process of delivery of nursing care. Three particular phenomena are identified: contact (physical and/or connection), communication (use of language and other symbols), and interaction phenomena (client and nurse as social agents) (p. 104 – 105). 3) The domain of practice encompasses phenomena and concepts related to what nurses do in their nursing work, and it refers to cognitive, behavioural, and social aspects of fulfilling the professional nursing role (p. 45 – 46). 4) The domain of environment

refers to the common external world that constitutes the context of the client-nurse interchange and practice. It is a common source of understanding for client and nurse, and is composed of spatial and temporal aspects, and qualitative aspects of physical, social, and symbolic components (p. 46 – 47).

The present study took place in the client domain (Kim, 2000). We did not study the interrelation between patients and health care professionals directly, nor professionals' experience and handling of being responsible for the planning and carrying out of the investigation process. In practice factors related to the individual patient (client domain), the nurse (practice domain), the interaction between them (client-nurse domain), and the environment have an interactive, modifying, and dynamic affect on each other (Kim, 2000, p. 213). Environmental conditions, for example such as where patients sleep and how patients staying in the patient's hotel are planned into the ward's space and activity, influence the quality of information exchange at the doctors' rounds. Environmental conditions also impact on privacy, ability to rest, and how patients take care and feel responsibility for fellow patients.

In this thesis knowledge about phenomena important for patients going through medical investigations in hospital will be presented and discussed in relation to nurses, and to some extent also other health care professionals' role and responsibility.

4.0 METHOD

4.1 Choosing method

The aim of the study was to gain more knowledge about patients' experience and handling of their situation, and a qualitative method was required to reach these goals. GT, which is widely used in nursing (Pursley-Crotteau et al., 2001), was chosen as the method to develop knowledge about these patients. The term "grounded theory" refers to both a method and to the product of the research. GT is most useful when little is known about a topic or phenomena and is best used in analysis and identification of complex and hidden processes (Morse, 2001) which was true for gastric patients in the diagnostic phase at the outset of this study. It is a method that offers a systematic approach to study the richness and diversity of human experience, interaction, and meaning, and it generates a theory that can be used to understand the contextual reality of problems and processes (Hutchinson & Wilson, 2001; Holloway & Todres, 2006). The requirements of the method as to develop concepts that should be related to each other into a dense and parsimonious theory (Glaser, 1978) appeared attractive.

The founders of classical GT were Anselm Strauss (1916 – 1996) and Barney Glaser (1930 -), who were recruited at the University of California – San Francisco's (UCSF) School of Nursing in the 1960s when they developed their doctoral program in nursing. Strauss came from the University in Chicago and had studied Mead and Blumer, and he became steeped in the philosophy of symbolic interactionism (SI). Strauss recruited Glaser from Columbia University to UCSF. Glaser studied quantitative analytic methods, but he was also interested in developing sociological theory based on real world situations. They shared a common interest in developing new concepts and generating theories that could explain patterns of behaviours in the area studied rather than verifying established theories (Glaser & Strauss, 1967; Stern & Covan, 2001; Milliken & Schreiber, 2001; Reed & Runquist, 2007). Their classical

work *"Awareness of dying"* (Glaser & Strauss, 1965) made them realise that the method they were using was different, and they named their new method Grounded Theory. In GT they tried to bring together the best of rigor and logic from quantitative methods with the rich and interpretative insights from the symbolic tradition (Glaser & Strauss, 1967; Glaser, 1998; Milliken & Schreiber, 2001; Stern & Covan, 2001).

4.2 Grounded theory and symbolic interactionism

Grounded theory is rooted in the SI tradition of social psychology and sociology. SI will guide the researcher and thus be fundamental to the whole research process (Glaser & Strauss, 1967; Chenitz, 1986; Chenitz & Swanson, 1986; Glaser, 1998; Annells, 1996; Milliken & Schreiber, 2001; Jeon, 2004; Holloway & Todres, 2006). SI focuses on the meaning events have to people in their natural, everyday settings. Glaser (1998) describes how he learned about SI through Anselm Strauss: "Through Anselm, I started learning that social construction of realities by symbolic interaction making meaning through self indication to self and others. I learned that man was a meaning making animal" (Glaser, 1998, p. 32).

Herbert Blumer (1900 – 1987) was the originator of the term "symbolic interactionism". He wanted to present a theory that could be an alternative to uncritical behaviourism and extreme positivism of the structural functional perspective. He builds on Mead, but in his theory about SI, less emphasis is put on the common and inter-subjective meaning of the symbolic universe (Jeon, 2004). According to Blumer (1969, p. 2), SI rests on three basic premises:

The first is that *"human beings act toward things on the basis of the meaning that the things have for them"*. These things can be objects, other human beings, institutions, guided ideals, activities of others and situations (Chenitz & Swanson, 1986). SI argues that there is a conscious thought and cognitive meaning between stimulus and response and /or between feelings and actions (LaRossa & Reitzes,

1993). The second premise refers to the source of meanings and states that the *"meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows"*. Meanings are seen as social products growing out of the experience of how others act towards and speak about the thing. Meaning must be shared. The third premise is that *"these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he or she encounters"*. The process of interpretation involves the person communicating with himself about things that have meaning, that he can interpret the meaning, and thus be able to choose actions the person finds fit the situation.

SI is a theoretical perspective that illuminates the relationship between the individuals and society. Humans are active in their own experience through interpreting the experience and they act according to their interpretation. People plan, project, and revise their thoughts and behaviours in relation to others, and their behaviour must therefore be understood in relation to others as well as the context (Holloway & Todres, 2006). People use symbols to denote, indicate and constitute objects. This use of symbols allows communication and shared meaning to develop. To understand behaviours, the researcher must go behind the outer behaviour to the underlying meaning that motivates the behaviour. The shared meaning, the foundation of culture, makes the interaction of people predictable to some degree. This gives stability to relationships and social interactions. At the same time differences in personal experience and meaning give every situation an aspect of unpredictability and uncertainty (Milliken & Schreiber, 2001).

Glaser (2003, 2005) has, in the last several years, distanced himself from SI and argues that stating GT as rooted in SI limits the openness and sensitivity of the GT researcher to choose theoretical codes with the best fit to data. He admits though that qualitative data tend to be SI oriented, but that SI often accounts for only parts of data and therefore lacks strength in explaining how social structures, authority structures, systems or cultures influence social action. This has caused discussion amongst researchers doing GT of how basic SI actually is to the method. The conclusion so far is that SI is inherent in GT research whether the researcher is aware

of it or not, and that it guides the epistemology and methodology, method and techniques of grounded theory (MacDonald & Schreiber, 2001; Milliken & Schreiber, 2001; Reed & Runquist, 2007). For this study, where interpretation of meaning and purposeful action and interaction are central, I see SI as fundamental to the research process and cannot see that it limits the choice of other theoretical perspectives in discussing our substantive GT.

SI has been criticised for overestimating the power of the individuals to create their own realities and to ignore that we inhabit a world not of our own making. SI gives too much weight to the actors` definition of the setting and overlooks the fact that there is a reality out there independent of how we define it (LaRossa & Reitzes, 1993; Annells, 1996; MacDonald, 2001). In PWT these aspects became important conditions to the theory, as we have discussed in Paper IV and in subsection 6.2.3.

4.3 Key methodological concepts

GT is a general, inductive method based on a concept-indicator model (Glaser, 1999, 2005). In this dr. polit.-project, GT was used as a qualitative method. The aim of GT is to generate new theory from data, to develop a theory that is grounded in data, and to focus on processes going on in the field of study. According to Fawcett (2000), a theory is one or more described concepts and propositions that state the concrete and specific relations between the concepts (p. 18). Two levels of theories can be generated in GT; substantive and formal. A substantive theory is grounded in research in one particular substantive area and the comparative analysis is done between or among groups within this empirical field. Formal theory is more general; it is developed by comparing different kinds of substantive areas. Both levels of GTs are grounded in data (Glaser & Strauss, 1967). A substantive theory is more closely linked to the area studied, has a more intimate relation to the empirical field, and is therefore easier to apply for those working in the field (Hartman, 2001). Substantive theories have general implications and relevance, and especially the core category,

the highest level category of the theory, can become a springboard to develop formal theories (Glaser & Strauss, 1967; Glaser, 1978).

According to GT methodology, the researcher, independent of how much knowledge and experience he or she has at the outset, enters the field of study with an attitude that he or she does not know the participants' main concern (Glaser, 1998). This attitude is taken in acknowledgment that participants in a study do not necessarily share the professional view of their problem. Such initial openness is a principal attitude because openness in early data collection and analysis will best allow the participants' main concern to emerge as appropriately and quickly as possible (Glaser, 1992).

The aim of data collection and analysis, which is done concurrently, is to develop a conceptual account for how participants act to solve their main concern (Glaser, 2001). GT alternates between working inductively and deductively. Collected data are analysed inductively. Ideas, questions, possible connections and relationships among categories, as well as theoretical considerations, are written down in memos, guiding where and for what to sample next (Hartman, 2001). In GT this is called theoretical sampling and is how the researcher is lead by the developing theory in further data collection (Glaser & Strauss, 1967). As the theory develops, the researchers' theoretical sensitivity increases, assisting her in understanding what is important and useful in data analyses. This in turn increases her ability to conceptualise and formulate a theory (Glaser & Strauss, 1967). Hartman (2001) points to different sources of theoretical sensitivity. One important source is the researcher's growing understanding of the participants' main concern by working with data, another source is the researcher's theoretical knowledge, and experience both professional and personal, combined with a conscious attitude of openness towards data. Working and discussing the developing theory with others, and the changing perspective of different projects at different stages, can also be sources of sensitivity in the research process.

In GT, the researcher generates theory systematically from data by the constant comparative method. It is patterns of behaviours, and not people, that are categorised, and she looks for ways in which participants work to handle their main concern. Data are coded systematically, first by open coding where the researcher codes incidents for as many open codes as possible without preconceived ideas or thoughts of relevance. When the researcher understands the participants' main concern and how they work to solve it, she can start naming the core category. At this point the open coding ceases, and selective coding begins (Glaser, 1978). In selective coding, coding is delimited to variables related to the core variable, and further data collection is also guided by this understanding. The core variable, which is the highest level category, relates the other categories with their properties to each other. The core category accounts for most of ongoing activities and behaviours in data (Glaser, 1998). In selective coding the researcher works to develop concepts that are both analytical and sensitive (Glaser & Strauss, 1967). In this way the growing theory is more than just description of relationships and processes in a given study. Due to the analytical concepts, the developing grounded theory transcends individuals or groups of individuals in a given time and at a given place (Glaser, 2003). The last stage in analysing data is theoretical coding, which conceptualises how the selective codes may relate to each other to constitute a grounded theory. Theoretical codes weave the fractured story, turned into concepts, back to an organised whole; it is what creates a theory. Theoretical codes give scope and new perspectives, they are flexible, and several theoretical codes may fit the same data (Glaser, 1978, 1998).

When new data no longer contributes to further developments of categories and their properties, theoretical coverage is reached. Such saturation is determined by empirical limits of data, the integration and density of the theory, and the researcher's theoretical sensitivity (Glaser & Strauss, 1967). At the same time, it is important to underline that a substantive grounded theory only has partial closure since new ideas and more data can modify the theory (Glaser, 1978). A substantive grounded theory is not the same as the truth, but it is one way of presenting data that can possibly be true (Starring et al., 1997).

4.4 Criteria for evaluation of a grounded theory

A theory must meet four criteria in order to be called a grounded theory: fit, work, relevance and modifiability (Glaser, 1978; Hutchinson & Wilson, 2001). 1) The categories of the theory cannot be forced or be selected out of the pre-conceived understanding of the phenomena studied; they must *fit* the data. A GT does not account for everything happening in a unit or in the data; it focuses on how participants solve their main concern. Concepts relevant for that purpose are generated systematically as they are fitted and refitted to data. Later in the analysing process concepts are validated and fitted together to form a dense and parsimonious theory that fits the substantive area (Glaser, 1978, 2001). Lomborg & Kirkevold (2003) point to the criterion fit as the most important for evaluating the validity and the truth of the grounded theory, and therefore fit is on more of an ontological level than the other three. Fit can either be interpreted from a realist position where it corresponds to reality, or it can be interpreted from a socially constructed point of view as a matter of coherence, consensus or pragmatic usefulness. It was of importance to Glaser and Strauss to distance grounded theory from the grand theories dominated in social science in the 60s (Glaser & Strauss, 1967). It is not clear how the criterion fit was meant to correspond to reality from the beginning. Annells (1997) and Lomborg & Kirkevold (2003) argue that classical GT and Glaser's direction of grounded theory take a critical realist view which means they believe that there is a reality out there to be discovered, but that this recognition depends on perception and cognition done by individuals (Mautner, 2000). 2) The criterion *work* means that the theory must be able to explain what happens in the data, predict what will happen, and interpret what is happening in the area studied. Workability is related to how well a GT accounts for how participants solve their main concern (Glaser, 1998). 3) A GT must also be *relevant* by allowing core problems and processes in the area studied to emerge. A theory is relevant and has a good grab for participants and practitioners in the substantive field in so far as it allows core problems and processes in the area to emerge. In addition a GT is also evaluated according to the density and the integration of the theory. A well-generated GT must

have few abstract, but sensitive concepts that are systematically related to each other. 4) The fourth criteria is *modifiability*. A substantive GT has only partial closure since new ideas and more data can modify the theory. Modifiability is therefore an ever-ongoing process and as more data appear, the theory will be enhanced.

4.5 Choosing field and setting the inclusion criteria

We chose a medical gastro-enterological ward at a larger university hospital as the setting for our study, since patients admitted to this ward came with a diversity of symptoms and with various possible outcomes. The gastric ward had 21 beds in a few one-bed rooms, two-bed rooms and some four-bed rooms. It was not unusual that patients had to have their bed in the corridor due to lack of vacant beds in patient rooms for a shorter or longer time. Patients had the opportunity to serve themselves drinks and meals from a buffet in the hallway. To the degree which health and investigation program permitted, the physician could suggest that the patient stay at the nearby hotel (5 min. walking). In the hotel, patients would have an individual room and meals served in a restaurant area. Both options of stay were fully covered by the Social Security System. The hospital had a separate medical investigation ward and a x-ray unit, which both were bottle-necks in carrying out an efficient investigation program.

Before the study started, it was decided to interview patients while they were in the midst of the investigation process, which was a stressful and challenging time for patients. Many studies have investigated the diagnostic phase retrospectively, asking participants to look back at the diagnostic phase (Benedict et al., 1994; Heskestad & Tjemsland, 1996; Thorne et al., 1999; Poole & Lyne, 2000; Logan et al., 2006). Retrospective recalls when knowing the outcome give patients a lens to view and evaluate the investigation process through which the experience can be turned or twisted. Momentary accounts also has their shortcomings by tending to be concrete and missing the broader picture (Folkman & Moskowitz, 2004).

When I contacted the gastric ward in the planning stage, the project was met with interest and welcomed by the unit. The senior physician and the head nurse judged it as an important initiative and they acknowledged the need for more knowledge about how patients experienced the time of waiting for a diagnosis, which would enable their staff to assist patients even better during the process. During data collection I had regular contact with the head nurse and two nurses at the unit in recruiting participants for the study.

The inclusion criteria for the research were chosen to be as open as possible, giving the freedom to sample for participants as the study developed:

- Patients hospitalised for medical examination in the stomach-intestine area. The patient knows that he/she is admitted because of such investigation.
- Patient 35 years or older.
- As equal a distribution between men and women as possible
- The patient's physical and mental condition is such that it is justifiable to take part in an interview.
- The patient has received oral and written information about the study and is willing to participate.

The age of 35 and older was chosen because at this age most people are settled into many of the important roles in their lives.

4.6 Participants

Participants were chosen in collaboration with two contact nurses and the head nurse at the unit. The sample was chosen in accordance with the development of the theory (theoretical sampling) and to have variation in gender, age, duration of current health problems, emergency and scheduled admission, length of stay in the hospital, and if they stayed in the unit, at the patient's hotel, or slept at home.

15 patients were interviewed and three of them were interviewed twice. There were eight women and seven men, all ethnic Norwegians, and their age ranged from

35 – 84 years, with an average of 54 years. All participants had at least upper secondary education, and the older the participants were, the less education they had (Appendix 1, Table 2). Nine of the participants stayed at the hospital ward, four at the patients` hotel nearby since their health condition and the investigation program allowed this, and two slept at home. All participants were able to wash and dress themselves, and they served themselves meals from a buffet in the hallway. This meant that they were rather self-sufficient and did not need practical nursing care.

Some of the participants had gone through many earlier examinations prescribed by their general practitioner, some as outpatients at clinics, and others in hospitals. They came to the hospital with a variety of bodily symptoms such as bleeding from the rectum, ongoing decrease of blood percentage, blood in the stool, feeling limp, having fever, different kinds of pain, diarrhoea, nausea, loss of weight, enlarged liver, and icterus. They were tired, weary and vulnerable and had a sense of fear and uneasiness due to the uncertainty of the situation.

They went through tests and examinations such as a variety of blood samples, x-rays, gastro-, recto-, and coloscopies, ultrasounds, and biopsies were taken. To be in hospital for investigations meant that in many cases there would be just hours between decisions about a test or sample to be taken, related preparation procedures to be carried out, and examinations to be accomplished, before results could be communicated. This could be experienced as both safe and threatening.

Eight of the participants came in by emergency admission. They had experienced their health problems from one day to six months and two of them had been hospitalized earlier for the same problems. They had stayed an average of 4 days in hospital when interviewed. Seven of the participants came by scheduled admission and they had lived with their health problems from 13 weeks to nine years and five of them had been hospitalized earlier because of the same problems. They had stayed an average of 11 days in hospital when interviewed. In this sample women were older than men and they were more often admitted to the hospital on emergency admission (Appendix 1, Table 1, 3).

Some patients came to the hospital for a so called "second opinion"; a right they have according to the Patients' Rights Act (Ministry of Health and Social Affairs, 1999) to have their case evaluated a second time by the specialised health care (hospital). Due to the same act, patients have the right to choose which hospital in Norway to be admitted to, and some patients choose to come to this particular University hospital. Their motivation for so choosing came from acknowledging that physicians at this hospital had a special expertise in the gastroenterological area, and that they could offer special examinations.

It has not been possible to identify how many patients, or the percentage of patients at medical wards at this hospital, who are admitted, acute or elective, for medical investigations. All patients admitted to a hospital come with a diagnosis, either a symptom-diagnosis or a diagnosis in the International Classification of Diseases system (ICD-10). In ICD-10 there is no diagnosis called "Investigation". To find the percentage of patients in medical wards who go through an investigation process, we would have to find the number of patients who had changed their diagnosis from admittance to discharge, a process that turned out to be theoretically possible, but practically very demanding, so we did not go through with it.

Being admitted to the hospital meant to be away from familiar surrounding, routines and family members, and most patients shared a room with other patients. Sense impressions such as sounds, smells, and sight of staff, fellow patients, equipments, and just being in the hospital environment were something they commented on as especially challenging.

Nine of the participants lived together with a partner and six of them lived alone because they were divorced, single, or widowed (Appendix 1, Table 1, 2, 3). The participants' relationship to family and friends varied. Some lived together with a spouse who was supportive and one to lean on, others felt they had to protect the spouse and children while they went through the diagnostic phase. Some had smaller children, others had children who could support them and help them receiving some information from the hospital. Other characteristics of the participants were that three

of them were retired, two were not working due to their health problems, four had been working until the day they became hospitalized, and six were on sick leave when hospitalized.

For more details about the participants, see Appendix 1, Tables 1 – 3. These Tables were worked out after the theory was generated, and give some perspectives on how age, admission and gender organise the participants. There were no parallels found between patterns of "Balancing" and types of admission, and due to the small sample, we drew no conclusions related to these findings. The tables might be of interest for future research.

4.7 Data collection and analysis

Paper II presents and discusses how the study was conducted in more detail. In this paragraph, therefore, I just briefly present how the key methodological aspects of the method were followed and give some examples.

PWT grew from constant comparison of 18 interviews of 15 patients and observations recorded in memos. Three of the participants were interviewed twice because they went through a longer examination process with gave me the opportunity to contact them again and to learn more about how they experienced this process. The interviews were done during three periods of time in 2002 - 2003. 16 interviews were taped and transcribed and two written by hand. They were conducted in different rooms at the hospital such as the bath, examination room, office of the head nurse, and the patients' room. Two interviews were conducted at the participant's room in the patients' hotel, and one was done by phone to the participants home. The interviews had an average length of 56 minutes, with a maximum of 120 minutes and minimum of 10 minutes. The shortest interview was done by phone to the patient's home in the evening, due to difficulties at reaching her during the day. The other short interview was 15 minutes, because the patient was called for to start preparation for an investigation earlier than first announced.

Qualitative interviews were chosen as the best method for learning about how patients experienced and acted in the diagnostic phase (Kvale, 2001; Fog, 2004). In preparing for the study, possible open questions were worked on so that they contained no key words that might guide how the participants would respond. It was not meant, nor used, as a series of questions to be asked during the interview; rather it became an important preparation for me on how to formulate open questions during interviews (Appendix 2).

Data collection and analysis were done jointly. In the beginning participants told their stories about why and how they came to the hospital, how it was for them to be in the hospital and go through investigations and wait for more and more feedback on their situation (baseline data). In the interviews, I had to be sensitive to patients' wishes and abilities to express how they experienced their situation, and to accept their need to protect themselves from threatening prospects for the future. It was in these situations that I learned to understand how they handled enduring the distressful uncertainty of waiting (interpreted data). A few times patients focused more on telling me what they thought I was looking for (properline data) (Glaser 1998, 2002).

Interviews were coded openly, by hand, and with as many codes as possible for what was going on in data. In the beginning I was not able to see any patterns or find ways of organising data, and it was not clear to me that I should be looking for the participants' main concern. Due to the hidden nature of the study topic, it took a long time before we were able to start naming the main concern and the core category. Therefore, the openness of data collection and the time of open coding went on for the first spring and summer of the study.

My sensitivity for the field grew as more patients were interviewed and coding conducted, and memos were written for the whole duration. Reflections, ideas, hypotheses, and possible connections were stated in the memos. Here is an example of a memo from September 2002 with the heading "Crises also offer opportunities":

"Not knowing opens the door to uncertainty. Most of them walk through the door into a landscape where they feel that there are many options for the future. One calls himself a realist, so he chooses to relate to what is when he gets the final information about it. He is the only one so far not mulling over his situation. Most of them have been looking at multiple outcomes, and know something about what they fear for. It seems like the longer time they have been waiting; the harder it is for them.

But this time of uncertainty can also carry something good. The threat of something seriously wrong makes patients and their close ones reflect about life. It is as they stop and realise a little more what really matters in life, a kind of value clarification in life."

Theoretical sampling was conducted both in relation to which participants to interview next and in areas about which to learn more about. One participant stated that it was better to know than not knowing, however bad it could be. This lead to sampling around questions such as: what do they want to know, is knowing always favoured before uncertainty, do all of them want to know. Another topic for theoretical sampling turned out to be what advantages they saw in getting a diagnosis.

When patients' main concern and the core category became clearer, we moved over to selective coding for variables related to the core. For selective coding software NVivo 2.0 (QRS International, 2002) was used. Coding reports for every concept lead me back to line-by-line coding in data. By this constant comparison, validation of the core category and related concepts emerged from data. This constantly returning to data helped to let go of previous understanding and preconceived ideas and to look for the main concern of the patients. We searched for naming concepts that would be analytic and sensitive, fitting our data, be relevant to what was going on in our data, and which would work well to grasp what patients in the diagnostic phase worked with. One example of developing a concept is "Trying to make sense", which was further developed into "Challenging uncertainty". To

improve the sensibility of the concept it was renamed to "Seeking and giving information". For more examples of open and selective coding, see Appendix 3.

Towards the end of validating the participants main concern as "How to prepare themselves for the concluding interview and life afterwards" and the core concept as "Preparative Waiting", we went on to theoretical coding were we searched ways of relating the categories we had developed to each other. Sorting of memos aided the process of developing the final concepts and to relate them to each other. We also used models as a tool to present how the concepts could be best related to each other in order to fit data. 13 models were developed before we were satisfied with a model that could best explain to others how patients worked to solve their main concern. The final analytic step was done when using the theoretical code of "Balancing", which showed how the four patterns of "Balancing between hope and despair" organised the way different patients prepared themselves for receiving a diagnosis and what life would be afterwards (Paper I). The whole process of sampling data and generating PWT is illustrated in Appendix 4.

To increase validation and transparency in the analysing process, interviews, the development of categories, and the growth of the theory were discussed with both of my supervisors. Six of the interviews were translated into English so that my American supervisor could have as direct access to some of the data as possible. The analysing process and the developing theory have regularly been discussed with a group of dr. polit. candidates using GT in the Bergen area. The substantive grounded theory of "Preparative Waiting" has been presented at international nurses' conferences. Feedback from participants (from Portugal, England, USA, Taiwan, Korea, and Ghana) was that they acknowledge the process of "Preparative Waiting" as familiar to their own experiences of going through the diagnostic phase and from working with patients going through diagnostic workups.

4.8 Ethical considerations

The study was approved by the Regional Ethical Board (REK III 020.02, Appendix 5), reported to the Norwegian Social Science Data Service (NSD No 8971, Appendix 6), and welcomed by the medical ward. Participants were recruited to the study in accordance with the developing theory. Who should be asked to participate was discussed with the head nurse or one of the two contact nurses at the ward. In the beginning, patients fitting the inclusion criteria were asked orally and in writing (Appendix 7) to take part, and later on variations related to age, gender, time of having problems, acute and/or planned admission were sought. When a patient agreed to participate in the study, the ward informed me so that I could make an agreement with the patient about when and where to meet for the interview. When we met we introduced each other and signed the consent form before the taped interview began (Appendix 8). In the beginning of the interview, the participants were asked to give themselves a name that could be used to make them anonymous in the interviews. To maintain confidentiality of data, the list connecting interviews with real names was kept separate from data in the nursing university college's safe. All names of staff and other people that came up in the interviews were changed in the transcripts to protect privacy (Johnson & Long, 2006).

In all contact with participants, ethical discernment is needed in qualitative research so that the person's integrity is not violated (Helsinki Declaration, 2004; Foss & Ellefsen, 2004; Johnson & Long, 2006). In a research interview there must be a high awareness related to how to ask questions and of the dynamics in the interaction between interviewer and interviewee as well as a critical attitude towards what is said (Kvale, 2001, p.31). During the interviews, I had to balance between on one side trying to create an open atmosphere so participants could feel as free as possible to share their thoughts and experience of being in the diagnostic phase, and on the other side respecting their need for protecting themselves from opening up too much about what they feared were possible threats related to the future. As interviews developed, the sense of openness or the need for protection and distance changed, and

I had to be sensitive to these changes marked by tone of their voice, gesture, and the whole atmosphere in addition to changes in themes. Different participants showed different ways of talking about and handling being in the diagnostic phase, which later came through as different patterns of "Balancing" (Paper I).

Before the study started, the possibility that some patients would need following up after interviews was discussed with the head nurse. The ward agreed to be sensitive and look for such needs. No such needs were reported; on the contrary many participants expressed the feeling that the interview had been personally beneficial for them by enabling them to put their experiences into words. This is not an unusual experience (Kvale, 2001).
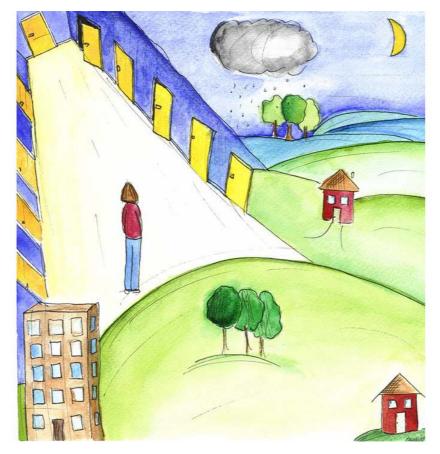
5.0 SUMMARY OF MAIN FINDINGS

The two main purposes of this study were to develop knowledge about how patients admitted to a gastric ward, going through the stressful time of diagnostic investigations, experienced and handled their situation, and how health care professionals could best help. Our findings, discussions and suggested implications are presented in four papers. All the papers were written after data were collected, analysed, and PWT was generated.

The substantive grounded "Preparative Waiting Theory" has no steps, and the concepts are integrated into each other. We therefore found it difficult to divide the presentation of PWT into parts in different papers. Instead we decided to present, in Paper I, how the theoretical code of "Balancing" integrated PWT and how the four patterns of "Balancing between hope and despair" explained how different patients prepared themselves differently for the concluding interview. Paper II outlines how we applied principles of classical grounded theory in this study. Paper III and IV are papers discussing PWT in relation to other theories. PWT and methodological aspects are therefore just briefly presented in these papers. Paper III focuses on how patients handle the investigation process and discusses this in light of Lazarus & Folkman's (1984) stress and coping theory, which we found to give a fruitful theoretical perspective on patients joint activity of appraising and coping in the diagnostic phase. In Paper IV we change focus from patients to health care professionals, and to implications this study has for relationships between patients and nurses and physicians. The vulnerability and dependency patients expressed in relation to physicians and nurses made us choose a theoretical perspective that was explicit about the ethical demand in recognising the appeal of being taken care of in power relationships. The choice of the writings of the Danish philosopher Knud Ejler Løgstrup (1956, 1983, 1988, 1997) and the Norwegian nurse philosopher Kari Martinsen (2006, 2007) assisted us in highlighting the importance of health care professionals' relations to patients

Before each paper is more extensively presented, three pictures developed along the analysing process will be presented. These pictures were developed together with the artist Gunhild Øverli, and became important in facilitating our process of conceptualisation of what was going on in the study. They may aid the readers in getting a better understanding of how patients in the diagnostic phase experience their situation; see Picture 1, 2, and 3.

Picture 1. The patient is admitted to the hospital for diagnostic workups. The patient is alone in the hallway, walking towards the door at the end of the corridor; a metaphor for the concluding interview when the medical team will reveal the conclusion of the investigations. The doors along the corridor symbolise what the patient hopes and fears. Some doors are ajar, others are shut. The patient does not walk into these rooms; he or she just knows more or less what is inside them and what might become their reality. Painted by Gunhild Øverli.

Picture 2: Some patients have had their health problems for a short time when admitted to the hospital.
Painted by Gunhild Øverli.

Picture 3: Some patients have been waiting for a long time and gone through former examinations and hospitalisation before they were admitted to the hospital this time. The way they have come is long, and their troubles have increased over time.
Painted by Gunhild Øverli.

5.1 Patterns of "Balancing between hope and despair" in the diagnostic phase (Paper I)

Paper I presents the main findings of the study, and aims at showing how the theoretical code of "Balancing" moved PWT to a fully integrated grounded theory. Theoretical codes are abstract and flexible models that integrate GTs so they become more plausible, relevant and enhanced. "Balancing between hope and despair" is a dynamic and complex activity decisive for how patients prepare themselves for receiving the conclusion of the investigation process. The balancing patterns of controlling pain, rational awaiting, denial, and acceptance are briefly presented and followed through in this article. These patterns guide how participants used the categories of PWT: "Seeking and giving information", "Interpreting clues", "Handling existential threats", and "Seeking respite". Patterns are strategies, so one person could use more than one pattern.

Patients sought information related to preparation and outcome of investigations to try to judge their situation. They wanted nurses and physicians, preferable one main contact person, to provide them with information and to follow them up during the stay. In the process of evaluating their case, they interpreted clues from their own bodies, diagnostic procedures, collaboration with staff, and priority given in the system. To be kept in uncertainty about the outcome of the investigation process and consequences for the future, made them consider what was important in life and be more aware of their view of life. To be able to keep oneself occupied with something else than the constant tension of uncertainty, helped the waiting time pass on, and provided participants with renewed strength.

In the last part of the paper, PWT is compared and discussed with other research. Other studies reporting on patients in different kinds of situations, hallmarked by the phenomena of waiting, gave support to our findings related to different patterns used in "Balancing between hope and despair". We outline briefly some implications for care for patients using different patterns of balancing, before more general implications related to the concepts of the theory are discussed. The

importance of credible authorities for information exchange and coordination of the investigation process is widely reported. How patients' feed different kinds of clues into their interpretation process to assist them in making sense of their situation, is also noted by other studies. Others discuss the existential threat triggered by considering a possible mortal outcome of the investigation as well, mostly in relation to putting one's life in God's hand and by praying. How patients used respite to divert their attention from the undefined situation they were in, was also identified as a coping strategy in some other studies.

By understanding how the patterns of "Balancing between hope and despair" relate the other strategies of PWT to each other, nurses and other health care professionals can better understand how they can assist patients in the diagnostic phase in hospitals. Nurses can offer invaluable support for patients and thereby strengthen their confidence and hope. More research is needed, especially related to how nurses can assist patients using mostly patterns of <u>rational awaiting</u> and <u>denial.</u>

5.2 Learning classical grounded theory (Paper II)

Paper II outlines how the principles of classical grounded theory were followed in data collection, analysis, and development of a substantive grounded theory in this study. According to GT methodology, the credibility of a GT is evaluated according to how well it fits the substantive field, works to explain and account for how the participants solve their main concern, and is relevant by letting the participants' core problems and processes emerge.

This paper shows how we worked for quality in data collection by beginning openly, without pushing our own ideas on the participants. Data collection and coding were done concurrently, and new data were compared with already coded data. Along the process, our theoretical sensitivity grew and guided further theoretical sampling, such as which participants to choose and what to sample for. Initially, data was coded openly without thoughts of relevance. Later, when the participants' main

concern and core category became clearer, we moved on to selective coding and limited coding to variables related to the core category. Memos were written throughout the process, containing questions, and connections, as well as ideas for further data collection to saturate the categories.

The conceptualisation was aided by developing paintings which expressed our early understanding of the participants' situation. Working on theoretical coding meant that we related the concepts of the theory to each other so that it could be presented in a dense and parsimonious way. In theoretical coding, we used models and theoretical codes to present a GT that fitted the field, had grab, and worked to explain to others how patients experienced the diagnostic phase.

Due to classical GT methodology, literature in the early stage of data collection and analysis was read in other areas than uncertainty and waiting for a diagnosis. This was done to enhance openness to data until the substantive theory was generated. In the later stage, theories and research relevant to the findings were read and compared with the substantive grounded theory of "Preparative waiting".

5.3 "Preparative waiting" and coping theory (Paper III)

Paper III discusses our findings in relation to Lazarus and Folkman's (1984) theory about appraisal, stress, and coping, and to Lazarus' (1999a, 1999b) later writings. Appraising means to evaluate the meaning and significance of a situation to self and others. Antecedent conditions, coping resources, and options available are assessed, resulting in judgement of the situation, which leads to the emotional outcome of the primary appraisal. Stress occurs when a situation is appraised as taxing available resources and the wellbeing of self and others is endangered. Problem-focused coping is to manage and/or change the environment, as emotional-focused coping deals with handling the emotional response to problems.

All participants in our study appraised the diagnostic phase as a threat to their well-being, but it could also hold combinations of appraisals as harmful, challenging,

and beneficial. These combinations gave a blend of negative and positive emotions, which were handled by "Balancing between hope and despair".

Appraisal and coping were seen as joint activities for the participants, as they were kept in the process of making sense of their situation over a shorter or longer period of time. Cognitive coping, where they interpreted their lives in new perspectives, is an example of how appraisal and coping were intertwined, lowering and rising of awareness in evaluation and handling of the situation are other examples. They strove to appraise the situation as realistically as possible, but also to see enough hope to be able to endure the waiting time.

To manage the ambiguous time of waiting, participants used problem-focused coping to the degree that they found it amenable. By preventing conflict with staff, being prepared for rounds, and using the time at the medical unit they tried to promote access to relevant, personalised and accurate information. They also provided staff with information they thought was relevant for the investigation. Secondly they tried to reduce the time of waiting, and promote correct preparation and carrying out of medical examinations.

Emotional-focused coping dealt particularly with promoting hope and handling anxiety. Hope was seen as important to be able to endure uncertainty in waiting, but too much made them become ill prepared, as too little hope could leave some at the edge of despair. To reduce the appraised threat, assessment of the situation and the belonging emotions could be moved to a less conscious level. The rest and restoration they found in respite was also seen as important in emotional coping.

According to Lazarus and Folkman (1984), coping contains both intra- and interpersonal processes. Patients waiting for a diagnosis hold many concurrent possibilities regarding needs, wishes, frustrations, hope, fears, weakness and strength, and which ones come forth depend on conditions and qualities patients consider be present in relation to family, close friends, God, and to health care professionals in

particular. In this way, the staff can influence how patients evaluate their situation, what resources they assess as available to them, and how they manage their way toward the concluding interview.

5.4 The silent demand in the diagnostic phase (Paper IV)

Paper IV discusses how health care personnel can help patients in the diagnostic phase to make their situation more bearable. The illness perspective of waiting for a diagnosis displays the patients' vulnerability, dependency, and the possibility to be harmed if nurses and physicians fail to acknowledge the appeal for being taken care of.

This paper briefly presents PWT, emphasising the internal and invisible ways of preparing for receiving a diagnosis before discussing it in relation to Løgstrup's (1956, 1983, 1988, 1997) and Martinsen's (2006, 2007) writings. Løgstrup writes about the ethical, silent and radical demand, and how people appeal for being taken care of while put in the hands of others. Life utterances, which are basic phenomena carrying our lives, such as trust, openness, and the zone of untouchability are discussed in relation to being in the diagnostic phase. Trust is fundamental to our lives, and by revealing ourselves we become vulnerable and power can be misused to insult and embarrass the other. Openness brings us closer to our motives and emotions and stands in a unified opposition to the zone of untouchability, which takes care of the strangeness and integrity of the other person. Together they keep our lives flexible and prevent stiffness and simplifications. In addition to life utterances, our lives take shape in accordance to laws, morals, and conventions in our culture.

The study reveals that patients felt vulnerable and therefore were careful to whom they opened up. A patient returning back to the ward after a leave of absence exemplifies how easily the silent appeal of being seen as vulnerable can slip away for staff. Nurses and physicians working with patients in the diagnostic phase hold some of the other person's life and destiny in their hands, and thereby they carry the

responsibility of taking care of the patients' best interest. Staff possesses a position of power in the hospital, and how patients and health care professionals sense each other by tone and gesture lay the ground for building of trusting relationships.

Løgstrup argues that we only have the right to make ethical demands to others insofar as they are conditioned by social norms, moral, legal or conventional criteria implied in our lives together. The Patients right Act (Ministry of Health and Social Affairs, 1999) and the Codes of conduct (Norwegian Nurses Organisation [NSF], 2001; International Council of Nursing [ICN], 2006) are in accordance with the ethical demand, and place the responsibility on professionals to take care of patients in their best interest due to the knowledge and power they have. The illness experience relates to persons as a whole, and goes beyond the objective and bodily focus found in the bio-medical model. In addition patients' conditions vary, so it is not possible to outline how to follow the norms. Professionals are left to use their judgement, built on knowledge, experience, and imagination, based on the motive of wanting the best for patients. It is a professional responsibility for individuals and leaders to develop and maintain a culture where conventions, procedures, and guidelines are practiced so that life utterances can come alive and patients feel taken care of while put in our hands.

6.0 DISCUSSION AND IMPLICATIONS

The main aim of this research was to develop knowledge about how patients admitted to a gastroenterological ward, experienced and handled going through the diagnostic phase. In the following sections methodological considerations of the study will be discussed together with findings and implications of the research. Lastly areas of further research are suggested.

6.1 Methodological considerations

In this section SI's role in GT are discussed together with how the key concepts of classical GT methodology was carried out in this study.

6.1.1 Grounded theory and symbolic interaction

Symbolic interactionism, as presented in section 4.2, explains how individuals create meanings and act. Without limiting ourselves to SI as the only theoretical code fitting our data, we see the process of creating meaning through inner dialogue and through interpretations and interactions with others to be at the centre of the process which patients in the diagnostic phase go through. How they act can be understood as the background of how they interpret and define others' actions within the context of the hospital system. As researchers we must go beyond the participants' behaviours and look at the meanings and motives underneath which form patients' choice of actions in the diagnostic phase. The four identified patterns of "Balancing" can be a tool to understand how different patients interpret and act differently (Paper I).

Some GT researchers argue that as far as GT builds on SI, it places itself within the constructivist paradigm (Charmaz, 2000; Milliken & Schreiber, 2001). This paradigm views reality as pluralistic and relativistic. Reality is created in the minds of individuals where truth is based on consensus rather than on objective facts

and it does not relate to an external reality. A constructivist stand in research causes the scientific reasoning during the research process to fall apart, argue Lomborg & Kirkevold (2003), since everyone can maintain the theory they prefer, based on their own construction of reality. In contrast, a realist would argue that there exists a world, a single reality, independent of our knowledge, and that this reality can be discovered (MacDonald & Schreiber, 2001). In their first book on grounded theory, Glaser & Strauss (1967) were not clear on how they understood truth, validity and reality. Glaser has to a limited extent taken part in the discussion about ontological and epistemological questions concerning GT (Lomborg & Kirkevold, 2003; Jeon, 2004). Some support that Glaser's writing builds on a critical realist view (Annells, 1996; MacDonald & Schreiber, 2001; Lomborg & Kirkevold, 2003) as he argues that there is a real reality out there waiting to be discovered (Glaser, 1978, 2002). Critical realism refers to positions that maintain the existence of an objectively, mind-independent reality whilst acknowledging that perception and cognition always is done by a subject (Mautner, 2000; Wikipedia, 2007). According to Wilson & McCormack (2006, p. 48), critical realism looks for causal mechanisms and how they work under different conditions. Different from in positivism, causality is understood to take place within a complex and open system which acknowledges that social phenomena are fundamentally meaningful. Meanings cannot be measured or counted, but must be investigated by interpretative methods. Critical realism is anti-positivistic as qualitative approaches are used to offer insight into social contexts by seeking to understand reasons for why things happen. Based on Annells (1996), SI sees time and place as constructions, but "the natural world has a reality apart from these constructions" (p. 386). Such a stand offers the possibility to see SI as fundamental to GT and at the same time hold on to critical realism (Annells, 1997).

Charmaz's (2000) presentation of GT as a constructivist method was answered by Glaser (2002), in which he argued that a grounded theory could be generated from a realist point of view. His requirements of doing GT from a realist perspective are to apply an open attitude in the initial data collection combined with the tedious work of the constant comparative method. As open coding moves on to selective coding, data samples according to the generating theory, and developing concepts are fitted and

refitted to data. By making a point of fit, Glaser points to the GT's correspondence to the social reality as fit serves as the function of external validation of research of social processes to take place (Lomborg & Kirkevold, 2003, p. 199). Glaser (2002) acknowledges that bias, personal predilection, and biography influence data collection and analysis, but argued that this bias can be controlled for in the theory by continuously fitting generated concepts against data. In GT concepts build the bridge between data and the substantive theory generated (Starrin et al., 1997), and by this abstraction a grounded theory gives an account of patterns of behaviours relevant for the area under study (Glaser, 1978; Starrin et al., 1997; Hartman, 2001). Due to different theoretical sensitivities researchers collect different data showing different aspects of the empirical field. Because of this a GT must be open to modification. In classical GT, the researcher works to make data objective by looking for the main concern of participants, comparing and conceptualising patterns that emerge in data, and searching for the core category. In this way the researcher's ideas either drop out as irrelevant or are found in data and by that earn their way into the theory. A grounded theory generated in line with classical GT methodology will therefore be understood as aiming at presenting knowledge about phenomena in a substantive field that exists and can be discovered independently from participants and researchers.

As presented in section 4.3 there are two levels of grounded theories: substantive and formal. In this study we sat out to study a particular area, namely patients in the diagnostic phase in a hospital and we collected and compared data limited to patients admitted to a particular ward. The theory we have developed is therefore a substantive grounded theory. Since PWT is conceptual and not descriptive, it bridges data and theory and has a more general relevance (Starrin et al., 1997). The literature that was researched showed that the processes patients go through and the concepts we have generated are recognised in other studies with other groups of patients admitted for medical investigations (Leydon et al., 2002; Sjöling et al., 2005; Moene et al., 2006; Sørlie et al., 2006) as well as for out-patients going through the diagnostic phase (Benedict et al., 1994; Heskestad & Tjemsland, 1996; Fridfinnsdottir, 1997; Thorne et al., 1999; Poole & Lyne, 2000; Drageset &

Lindstrøm, 2003, 2005). The core category of our substantive theory, "Preparative Waiting" may have relevance and implications for wider groups of people than gastroenterological patients waiting for a diagnosis, and the process of "Preparative waiting" can be recognised in diverse situations such as preparing for an exam or a dissertation, preparing for giving birth, or for changing jobs.

Kim (2000) discusses which philosophical and epistemological stand serves nursing best. She argues that the ontological foundation for nursing must fit human nature, ways of living, and practice, and that to do so we need philosophical and theoretical pluralism. Her nursing epistemology is a combination of realism and constructivism: "reality or the essence of reality must be considered to exist *a priori* to any science, but is 'obtained' for knowledge development by contextually (historically and socially) situated specific human agents who engage in producing knowledge within given hermeneutically constrained horizons" (p. 235). By discussing and critiquing each others work and writing, we can contribute to development of knowledge and theories that can aid nurses in developing our knowledgebase closer to what truly exists.

6.1.2 Critical conditions in doing GT

As stated in chapter 1.0, little was known about these patients at the outset of the study, and GT is a good choice for studying the illness perspective, how patients search for meaning, and how they act as they go through this challenging time of uncertainty (Holloway & Todres, 2006). In addition to generating a substantial grounded theory about patients in the diagnostic phase, I also have learned the method by reading about it, doing data collection and analysis, writing out the theory, and discussing the whole project with other researchers (Paper II).

This study followed classical grounded theory methodology (Glaser, 1978, 1992, 1998, 2005; Hartman, 2001; Cutcliffe, 2005). Wilson & Hutchinson (1996) point to criteria that must be met before a research project can be called a GT study. The study must start with no pre-conceived framework, and data collection and

analysis must be done concurrently. Data collection must be done purposely, analysis must reach a conceptual level with theoretical codes, and the substantive grounded theory, with its generated concepts must contribute to theoretical knowledge in a specific substantive area. Pitfalls in using GT can be to develop an incomplete theory without density due to too premature closure in data collection and analysis. If there is a lack of a core variable, a study will be descriptive and not a GT study. To be able to develop a conceptual GT, the researcher must be able to think conceptually and to discover ideas in data (Hutchinson & Wilson, 2001). As described in Paper II, we will argue that this study meets these criteria and can be called a sound substantive grounded theory study.

To study patients in the diagnostic phase was not the easiest initially, since the distress of uncertainty made their main concern and the way they handled it partially hidden from themselves and therefore also partially hidden for me in the interviews. In this study, interviews were the best data source to give insight about how these patients experienced, thought and understood their own situation (Fog, 2004). To find data that were as reliable as possible, creating mutual contact during the interviews was important (Fog, 2004). A decisive aspect of creating such contact was to balance openness with respect for the individual patient's limits for opening up to threatening future perspectives. This balance was an ethical concern in most of the interviews. During the interviews, I tried to have a high awareness related to how questions were asked and listen to what was said (Kvale, 2001). There is always a risk that the interviewees mainly give baseline or properline data (Glaser, 1998), speak in general terms, or present themselves as how they want the researcher to see them. In many of the interviews, participants opened up; in tears and laughter, they shared how distressful their experience was and how they managed to save face and endure the time of waiting (interpreted data). Many also expressed that it was helpful to have someone outside the ward to talk to, since I was not one of the team and did not take their critical considerations personally. Having said this, I acknowledge that just having interviews as the main data source can weaken the focus on context of the study, and that field observations could have added to the understanding of how

interactions with hospital staff impact on patients. To study interaction with staff was not the aim of this study, but the study revealed that patients' interaction with physicians and nurses influenced the experience of their situation to a great deal.

The researcher's pre-understanding, knowledge, and experience at the outset of a study influence to some degree how the study develops. Different researchers bring different theoretical sensitivity to a study (Glaser, 2002), and the ability to conceptualise also differs (Hutchinson & Wilson, 2001). My background as a nurse and being a nursing teacher with experience of doing bedside nursing together with student nurses in different clinical placements in hospitals, had given me many experiences with patients in the diagnostic phase. My interest over many years in spiritual care in nursing also formed my theoretical sensitivity (Giske, 1993, 1995, 2005). The working out of possible questions to ask patients displayed what we thought could be relevant to gain knowledge about in the study (Appendix 2). This list must not be seen in opposition to the deliberate openness in data collection and analysis, but rather as openness about our understanding at the outset of the study. My theoretical sensitivity grew out of interviewing patients and analysing data, and openness towards data was also stimulated by reading literature in related fields (Glaser, 1978, 2005), such as suffering, grieving, ambiguous loss, philosophy of science, during periods of open and selective coding. As more data were collected and selective coding went on, the theoretical sensitivity guided theoretical sampling in relation to what to sample and from whom, which again influenced the ongoing selective coding and development of the theory. In this way, constant comparison became more focused on relation to the participants' main concern and the core concept. Data not relevant for the core category were left out of the further analyses. An example of such data was how some participants had struggled to receive referrals from their general practitioner to out-patient investigations earlier on.

In theoretical coding we used a number of different models to work out how best to relate the categories of the theory to each other so that the theory became dense and saturated, fitted the data, showed the participants core problems and

processes (relevance), and worked to explain what happened in data (Artinian, 1982; Glaser, 1978). Late in the process of theoretical coding, I finally understood how to use theoretical codes (Glaser, 1978, 1998). The theoretical code of "Balancing" wove the whole theory together, and a coherent presentation of how the different strategies of "Preparative waiting" influenced how patients prepared themselves for the concluding interview could be written out (Paper I). There is potential to go on generating and possibly modifying the theory further by sampling more data and analysing them in accordance with the four patterns of "Balancing".

GT has been criticised for isolating itself from former knowledge and not taking part in building on the body of knowledge in a substantive area. Hutchinson & Wilson (2001) argue that the literature review before the study starts can only provide the researcher with sensitising concepts and the gaps in knowledge in an area. In this study, no systematic literature review was conducted before the study started, but we were aware that little research was done amongst patients in the diagnostic phase. After PWT was generated, we knew which concepts to search for, and could judge the relevance of research and other theories for our study. This made the literature review and evaluation of it easier. In Paper I, PWT is contrasted and compared with other research and written into the body of knowledge about patient's experience of going through the diagnostic phase.

Another criticism of GT has been that it neglects social structure and culture's influence on human action and interaction (Holloway & Todres, 2006). Similar criticism was also raised against SI (see section 4.2). GT is a general inductive method that can be used on any type of data (Glaser, 1999, 2005), and not limited to use as a qualitative method on a micro level. In constant comparison of data, the researcher generates concepts and looks for how they vary under different conditions (Glaser & Strauss, 1967). In this way conditions are always taken into consideration in the analysing process. If it emerges from data that social structure is the best way to present how participants solve their main concern, than that would give the best fit, relevance and workability of the grounded theory (Glaser, 1978; Reed & Runquist,

2007). In this study, the focus was on how people handled being in the diagnostic phase in hospital, and PWT presents how individual patients handled their situation. The study set out to examine micro-level-processes such as meaning and experiences. As a part of the theory, we have presented how different contexts such as where patients slept, how coordination of investigations were carried out, how continuity of staff, and how the doctors' round were prepared all influenced how patients endure and prepared for receiving the diagnosis. Dependency of physicians and nurses and patients' lack of power in the hospital system came through as important and is discussed in more detail in Paper IV and in subsection 6.2.3.

The theory is generated from 18 interviews with 15 patients, all native Norwegians. Other participants were not excluded from the study, but they were not actively sought, nor were they present in the wards when participants were considered. The theory of "Preparative waiting" has been presented at international conferences with participants from different countries. People's feedback in the role of nurses and patients has unambiguously been that they recognise the process of "Preparative waiting" in their own lives. This we take as a sign of having generated a substantive theory that has fit and grab, and that it is abstract of people, units, and time (Glaser, 1978).

6.2 Discussion of findings

This research was done in the client domain (Kim, 2000), and the substantive PWT offers new insight into what patients with gastroenterological symptoms see as their main concern in the diagnostic phase as well as how they handle their situation. The concepts of the theory are supported by research of comparable groups of patients (Bendict et al., 1994; Heskestad & Tjemsland, 1996; Fridfinnsdottir, 1997; Thorn et al., 1999; Leydon et al., 2002), but have not been presented earlier as related and integrated as in PWT.

After PWT was developed, we looked for relevant theories in relation to which we could discuss it. Lazarus & Folkman's (1984) and Lazarus' (1999a) theory of appraisal, stress and coping offered a fruitful perspective to discuss ways patients handled uncertainty and endured going through the diagnostic phase in hospital (Paper III). Løgstrup's (1956, 1983, 1988, 1997) and Martinsen's (2006, 2007) writings about the ethical demand, trust, power, and the unified oppositions between spontaneous life utterances as openness and the zone of untouchability offered meaningful concepts and a presentation of how we are put in the world together. This gave a helpful way to understand patients' vulnerability and the professionals' power and responsibility in perspective on individual and organisational levels (Paper IV). Both theories are well in accordance with nursing as it is understood as moral and relational practice (section 3.1).

In the next section I will elaborate more on one area that got limited room in the papers due to the restricted words available in an article, namely how the experience of their body fed into their interpretation of what was at stake in the situation. Then the discussion continues with looking more into existential coping and lastly into vulnerable relationships in health care

6.2.1 Making sense of the body

In the patients' process of making meaning of their situation, understanding and evaluating of the body were important This is briefly presented and discussed as a part of the category "Interpreted clues" (Paper I), but deserves a greater focus than the delimited words in an article allowed. When focusing on the body, it is important to remember that the illness experience relate to person as a whole being and goes beyond the objective and bodily focus of the bio-medical model (Paper III). In the literature we found reports discussing how patients in the diagnostic phase worked to interpret all kinds of clues that could assist them in revealing what was at stake in their case, such as health care professionals' nonverbal expressions, investigations,

and schedule patterns (Heskestad & Tjemsland, 1996; Thorne et al., 1999; Poole & Lyne, 2000). Just one article dealt with how patients tried to make sense of their bodily symptoms (Rhodes et al., 2002).

In our study, participants worked to interpret their symptoms, to understand changes in them, and to elucidate their meaning as they compared their actual situation with former experiences in their own and others' lives. During hospitalisation they went through preparations for investigations that made them become more aware of their body due to feeling hunger when they fasted, or feeling unpleasantly "watersome" when they had to drink a great deal. Some of them went through investigations such as biopsy and laparoscopy which left them with blue marks and added bodily pain. Many of them also felt dreadful for investigations such as gastroscopy and colonoscopy.

The participants, who had lived with symptoms and problems for some time without having found means to interpret them and to receive help, became concerned about how they should understand their problems. When it turned out to be difficult to find something objectively in their body, and the problems lasted over time, the question surfaced in patients and in relation to their general practitioner that these bodily problems might be better understood from a psychological point of view. When this became a theme in the hospital, most of the participants were rather clear about the order of their problems. It had started out as bodily symptoms such as pain, diarrhoea, or loss of weight, and as these problems lasted over time they drained the person of energy to carry out their normal life and they became worried, sad, and depressed. To the extent that it turned out to be difficult to establish objective findings in tests and investigations in the hospital, and by asking if the patient had had problems before they got ill, patients felt that the puzzle of their situation were given back to them. When that happened, it became important for patients to prepare themselves for the concluding interview so they could handle an outcome of no objective findings and therefore no diagnosis, without falling apart. Similar challenges are discussed in another study (Rhodes et al., 2002), showing that patients felt alienated and trapped in their problems as long as nothing visible or measurable

showed up as wrong in their body. This dilemma can be expressed as what patients describe cannot be heard and believed by the physicians before some evidence of it can be seen. Just one participant in our sample was considering that his situation could perhaps best be understood as caused by psychological challenges in his life. This possibility made him prepare himself and his family for continued examinations related to how he handled his life after he was discharged from the somatic hospital.

6.2.2 Existential coping

To be in the diagnostic phase makes patients become more aware of ultimate situations in life, as presented and discussed in Paper I under "Handling existential threat". Folkman & Moskowitz (2004) state that in coping research, religious coping has received little attention until recently. This is not so in nursing research, where spiritual care has gained a growing body of knowledge (Simsen, 1985; O'Brien, 1999; Taylor, 2002; Kelly, 2004, Ross, 2006; Miner-Williams, 2006; McSherry, 2006).

Patients in the diagnostic phase are kept on hold as they do not know how serious their situation is or what changes it may lead to in their lives. They try to establish meaning in what they go through and to comprehend what significance it might have in their lives. In this process, patients become more aware of values and what really matters in life, but data indicate that even though this is a time of value clarification, this is not the time for making changes in their view of life (Paper I). Balk (1999) points to three aspects in life that must be present for a life crisis to make spiritual changes, and it is interesting to compare this with patients living with an unsure situation, such as going through the diagnostic phase. The three aspects are: 1) the situation must create a psychological imbalance readily resisting stabilisation, 2) there must be time for reflection, and 3) the person's life must forever afterward be coloured by the crisis. Balk works within the bereavement tradition. Bereavement is a life crisis that threatens a person's well-being, but at the same time holds the potential

for both growth and harm. PWT has similarities with bereavement as patients go through a complex process of relating to potential changes in their lives as they prepare themselves for what is waiting at the concluding interview. Patients in the diagnostic phase do not know if or to what extent their lives will be changed by the concluding interview. Their situation is not final as in a grieving situation, but they touch and taste "what if" (Poole & Lyne, 2001) to a varied degree and thus come in contact with the spiritual aspects that fundamental changes in their lives represent. Regarding the second aspect, the waiting patients have abundant time to reflect on their situations since so much of their time is tied up in waiting for investigations, further plans, and results. As shown in PWT, they try to reduce their time and focus on reflection about their situation by "Seeking respite", which offers them rest and passing on of time (Paper I). According to Balk's last aspect, the person's life must forever be coloured by the crisis. Some patients who go through the uncertainty of waiting for a diagnosis in hospital experience this process so distressful that it holds the potential to mark them for lives, for others it will not. According to the patterns identified in "Balancing between hope and despair" (Paper I), there was a huge difference between participants using mostly the pattern of <u>controlling pain</u> and those mostly using <u>rational awaiting</u> in relation to how they handled the existential threat, and the former pattern will colour the person's life more than the latter one. Patients waiting for a diagnosis in the hospital do not face an imbalance long enough to cause spiritual changes, and the uncertainty they live through prevents them from taking their worst fear as a reality. Until they know, it seems that their level of hope varies as they reside in uncertainty.

To go through the diagnostic phase makes patients judge their situation as accurately as possible to try to determine their future. The situation can be either understood as harmful, a threat, a challenge, a benefit, or combinations of these as discussed in Paper III. To the extent it could be interpreted as also holding a challenge and/or be beneficial, it could also hold positive emotions. Patients in this study shared about positive emotions and potentials for growth as they discussed their own reflections and a growing clarity related to what was of real importance in life,

which again helped them to make better priorities and in some cases to work through conflicts (see quote from memo related to this in section 4.7). Some also shared what they had learned from talking to fellow patients in the hospital, and that they were grateful for the perspectives they had gained on their own life and situation. Talking and listening to fellow patients combined with helping some of them out can also be understood as a way of engaging in positive and meaningful events to increase one's own sense of meaning, which again could offer respite from distress. To be kept on hold in the diagnostic phase in hospitals offers a two-sided opportunity. It is possible to come into more contact with the distressful and sometimes anxiety-related emotions due to the ambiguous situation they go through, and at the same time to feel alive, to be thankful for opportunities to acknowledge what is of importance, and to be able to make priorities right in life. The possibility of including positive emotions in a stressful life situation is described as a new development in the field of coping (Folkman & Moskowitz, 2004).

6.2.3 Vulnerable relationships in health care

Early in the process of theoretical coding, one of the categories was named "Vulnerable dependency on staff and system" (Paper I and II). This category contained experiences and strategies patients used in relation to physicians and nurses, and as being a part of the hospital system. This was later taken out as a category and built into the whole theory, as it described conditions of being a patient in the diagnostic phase. In Paper III, we briefly touched on how relationships to family, health care professionals, fellow patients, and God had an impact on how they judged their situation, what recourses they considered available for them, and how they managed their way toward the concluding interview. Participants in this study had different relations to significant others. Some missed intimate supportive talk with their spouses, some felt it was good to not have to relate too closely to the worry of their loved ones. Others did not have close family or friends nearby. Social support

is argued to assist a person in making sense of the illness experience (Mast 1995). For most of our participants, social support from family and friends was limited to short visits and phone calls. Our findings indicate that they neither received significant support from talking with fellow patients nor involved their social network as reported in studies where participants undergo breast diagnosis (Benedict et al., 1994; Heskestad & Tjemsland, 1996; Fridfinnsdottir, 1997; Drageset & Lindstrøm, 2003; Lebel et al., 2003), or when the diagnosis was known (Mishel & Braden, 1988; Mast, 1995; Isaksen & Gjengedal, 2006). Thorne et al. (1999) reported that some women protected family and friends by keeping secrets, and Logan et al. (2006) found that women attempted to isolate themselves to allow time to concentrate and reflect on their lives, and to prevent themselves from being overwhelmed by depression. This matches our findings where participants, independently of patterns used in "Balancing", wanted to restrict information about being in the hospital for diagnostic workups to close family, and not to burden others until they knew more about the outcome.

In Paper IV, we discussed the ethical demand in the diagnostic phase. In section 3.1 we presented nursing as being focused on the illness experience of patients, and that it is a relational and moral practice built on professional knowledge. In section 3.2 we introduced Kim's (2000) four domains of nursing, of which the client-nurse domain was one. The client-nurse domain deals with phenomena rising out of the encounter between patient and nurse in the process of care. In this section the relationship between vulnerability, trust, power, uncertainty, dependence, openness, zone of untouchability, and wanting the best for the other will be discussed, and how the way they are lived out in the hospital impact patients' experience and handling of their situation. It should be remembered that the participants in this study needed little practical care. This led to fewer meeting-points for practical tasks to be carried out, which again resulted in more challenges for nurses to see the individual patient in a busy medical ward.

As humans, we are vulnerable in relation to each other (Løgstrup, 1956, 1997), and this is a part of ordinary vulnerability we face in life. Vulnerability can be described as a function of exposure to harm and a person's ability to protect himself (Sellman, 2005, p. 5). Sellman sets up three types of risks of harm that are related to vulnerability: 1) harm a person can prevent, 2) harm when a person must rely on actions of others for protection, 3) harm we are powerless to protect ourselves from since it occurs unexpectedly. Patients in this study are vulnerable to type two, since they are dependant on health care professionals to plan and carry out what it takes for them to come to a conclusion about their case, and on type three since they possibly have a disease that can threaten their well-being. Sellman points out the intimate relationship between vulnerability and trust. Being a patient means to have one's vulnerability exposed, and to trust health care professionals increases patients' vulnerability (Sellman, 2007). This is supported by Irurita (1999), who found that patients' core problem in hospital was vulnerability related to inability to retain control of their life and their situation, and to protect themselves against threats to integrity. Patients can feel vulnerable if their dignity and autonomy is threatened, if their bodies are exposed for examinations, and if personal information is disclosed, and patients can feel anxiety, uncertainty, and distress in hospital (McQueen, 2000). Patients also have reported that they are confused in relation to what is going on, and have uncertainty related to diagnosis, prognosis and possibly treatment (Sørlie et al., 2006).

All these findings are supported by data in our study. Being in the hospital meant to be in an unfamiliar environment with reduced possibility to control one's surroundings and timetable. Patients shared space with fellow patients in their rooms, in the living room, in the hallway, and in the smoking room. To protect their vulnerability, patients tried to hide their distress. Relationships with professionals were important and to the extent they experienced professional qualities, good will, and continuity in following through, trust was built. When it was lacking, vulnerability was increased.

According to Løgstrup (1956, 1997), we have power over each other's life. Relationships are power-relationships, and we need to be willing to listen to the demand of how to use our power in the best way to take care of the other. Health care professionals have power over patients in hospitals due to patients being ill, lacking knowledge, and the experience of being in the hospital system (McQueen, 2000; Schantz, 2007); patients often have less influence on the decision making process (Shattell, 2004). Patients in the diagnostic phase become more aware of what is at stake in their lives, and what is of value to them (subsection 6.2.2). Their senses become more alert to tones and gestures from nurses and physicians, and their vulnerability makes them more aware of power differences, dependency, and the importance of trust. Patients are the most unprotected, exposed, and dependent partly due to being the ones coming to the hospital with their problems to receive help. Our participants also shared that the insecurity they felt in the patient role related to how much initiative they should show in carrying their case forward without showing mistrust of staff. Patients are the most vulnerable and hold the greatest possibility for harm in the hospital system (Milligan-Hecox et al., 1997; Sørlie et al., 2006; Sellman, 2007). It is a moral challenge for nurses to exercise power in relation to patients so that trust is taken care of (Sjöling et al., 2005; Delmar, 2006, Martinsen, 2006). How we carry out the power we as nurses and physicians have, is of utmost importance for patients. We need to recognise their appeal to be taken care of and followed up. The challenge is that the demand is silent and that it is not obvious how we best can fulfil it (Løgstrup, 1956, 1997). It takes knowledge, judgement, and creativity in every situation.

Trust is a life phenomenon and we are put in the world dependent on trusting each other to have a good life (Løgstrup, 1956, 1997). In health care, trust can be seen as reliance on others' competence and willingness to look after rather than harm, which is what is important to patients as they are entrusted to the care of others (Peter & Morgan, 2001). This is similar to what Løgstrup (1997, p.17) said: "we are each other's life and destiny as we hold more or less of each others' lives in our hands". Patients in hospital are dependant on health care professionals; they hope to be able

to trust them to follow through, and they are left to trust that others have their good as the primary consideration. In our study, we saw that patients and staff sensed each other and interpreted each other's tone of voice, body language, and gestures (Paper IV). In this process it is important to balance inviting openness and respectful distance according to the patient's zone of untouchability, which will keep the patient unharmed, make vulnerability more bearable, and increase trust (Paper IV). Trust is fundamental for care, and this responsibility is placed on health care professionals (Brilowsky & Wendler, 2005; Delmar, 2006; Brøbecher & Delmar, 2007). This is also in accordance with the Patients' Rights Act (Ministry of Health and Social Affairs, 1999) and professional codes of conduct (NSF, 2001; ICN, 2006).

In the literature, many aspects of nursing competence and expertise are outlined related to care that addresses the needs of the whole person (Dietze & Orb, 2000; Brilowsky & Wendler, 2005; Schantz, 2007). Nursing is a relational and moral practice (McQueen, 2000; Austgard, 2006), which takes personal and professional maturity (Finfgeld-Connett, 2006, 2007). Kim (2000) discusses skill development in nursing in relation to the clinical decision making in practice (practice domain). She discusses the complex cognitive, behavioural, social, and ethical aspects involved in professional actions, and the importance of using clinical judgement. Brøbecher & Delmar's (2006) way of organising relational competences into three levels can assist in creating an overview of this area. According to them relational competence holds some basic attitudes, will, and ability related to the moral, relational, and practical aspects of caring. 1) The first level is the exterior, visible level which concerns professional knowledge and experience displayed in concrete action and skills. This is connected to the ability to perform professional judgement, to see the other person, and to make therapeutic use of self (Travelbee, 1971). 2) The second level is less visible and unfolds the ability to see the other as a unique person and to be able to observe patients openly and professionally. Interactions with patients build on personal knowledge, the ability to reflect on and share experiences, and to develop a deeper professional understanding. 3) The inner aspects of relational competence are related to the person's understanding of self, the nurse's own image of self, his/her

contact with own vulnerability, and the ability to move between closeness and distance. The nurse needs to be authentic, take responsibility for the relationship, and oblige oneself to act professionally in the best interest of the other. To have the other person's good as the primary consideration is seen as fundamental to caring and nursing (McQueen, 2000; Edvardsson et al., 2005, Sellman, 2005; Finfgeld-Connett, 2006; Schantz, 2007).

This might seem like big words, but the participants in this study can testify that these qualities are making a huge difference in their stay. These three levels of competencies were also built into their wish for a contact person at the ward. To the extent they felt their case was followed up by professionals with knowledge and experience, who cared for them as a person rather than a number, they felt carried through the system. Likewise, to the extent they felt their case was moved forward by chance, nobody knowing or engaging in their matter, they felt ignored, carrying the impossible responsibility to move their own case forward in the hospital system. These wishes are all in line with official documents underlining the importance of patient focus and respect for integrity (NOU 2, 1997; Ministry of Health and Social Affairs, 1999; Ministry of Health and Care Services, 2006, 2007). After having compared PWT with literature, we see that there is a close connection between the more vulnerable patients are, the more they value emotional and relational qualities in care, and treatment combined with competence, knowledge, and technical skills.

There is a connection between how patients are treated and the values fostered and supported in a ward and an organisation (Paper IV; Finfgeld-Connett, 2006, 2007). Kim (2000) writes about how "exogenous factors" (p. 221) such as organisational structure, norms, and culture influence how nurses carry out their work. Holm (2005) discusses the importance of relationships in an organisation under the label of parallel processes. Relationships between leaders and employees influence relationships between employees and patients. This works partly through "how I am treated, I treat others", partly through self-image and self-esteem, and through tolerance for frustrations and affectations. That the attitude in the ward, and

the tone set by the leaders, has implications for the relationship between nurses and patients, is also acknowledged by other researchers (McQueen, 2000; Edvardsson et al., 2005; Norheim, 2006; Schantz, 2007).

A hospital is a place where conflicting values meet. Hospitals aim at utilising staff and equipment efficiently, and to shorten a stay in hospitals due to cut of costs. If the cost-benefit focus becomes the most important value and patients are related to as consumers without acknowledging patient's vulnerability or the difference in power between the staff and the patient, then compassionate care will suffer (Dietze & Orb, 2000). Then it is of little use to have well formulated aims in strategic documents valuing patients' perspective, cooperation, and holistic care. To the extent that this is the actual value driving the organisation, patients can easily feel reduced to a number in a huge system. Some of the participants in this study felt, at times, reduced to such a number. How the individual health care professional is able to balance these conflicts depends on how personal qualifications are acknowledged and fostered in the ward (McQueen, 2000; Schantz, 2007), and how the organisation supports colleagues to balance cost-benefit and technological focus with psychological and spiritual concerns of the patients. A good balance will lead to increased mental well-being for both patients and nurses (Finfgeld-Connett, 2006).

6.3 Clinical and educational implications

The present findings offer knowledge about how patients at a gastroenterological ward worked to prepare themselves for getting a diagnosis. PWT has clinical relevance as it fits the clinical area, presents the core problems and processes in the area of study, and works in explaining how patients handle going through the diagnostic phase. PWT offers guidance to health care professionals in how to prevent and relieve patients from vulnerability and despair, and how to promote their hope. Our theory has implications not only for nurses, but for all working with patients in the diagnostic phase. In particular PWT may be relevant for physicians since they are

responsible for planning, carrying out of much of the diagnostic procedures, and most importantly to conclude about the individual patients' case.

Three areas to ensure quality in relation to patients in the diagnostic phase stands out as important: 1) the investigation process is as little distressing as possible for patients. 2) The investigation process goes smoothly and ends with the right conclusion about the individual patient's case. 3) Patients become as well prepared for the diagnostic outcome as it can be, which will make them as ready as possible to hear and accept the conclusion and go on with possible treatment.

In the coming sections general and more specific implications related to clinical and educational implications will be outlined.

6.3.1 General implications

Since patients in the diagnostic phase seldom express openly how they experience uncertainty and waiting, it can be awkward for nurses and physicians to grasp their vulnerability and appeal, which make it demanding for them to know how to act. Nurses and physicians, as well as patients, know that they can not influence the outcome of the investigations by supporting patients in the diagnostic phase. However, the experience of distress of uncertainty in waiting can be eased by a trusting relationship. This can prevent put-downs and ameliorate the uncertain waiting-time (subsection 6.2.3, Paper IV), which might influence how realistically patients are able to prepare for the final conclusion and further to cope with life after diagnosis (Heskestad & Tjemsland, 1996; Widerman, 2004; Drageset & Lindstrøm, 2005).

The participants in this study had one overall clear suggestion that they believed would relieve their situation, enhance speed, and quality in the investigation process: to organise the ward so that every patient going through the diagnostic phase got assigned a knowledgeable and experienced contact person. This could be a nurse

or a physician. This had to be a dedicated person who could be the patient's spokesman and advocate, one who was responsible for having an overview and to follow up on the case. A contact person for each patient would make it more likely that the professionals' powers were used in the best interest of the patients, it would improve the likelihood that patients had a say in decisions, and that uncertainty and vulnerability were reduced to a minimum for them.

Such credible authority (Mishel, 1988, 1997) would also facilitate good quality in the other actions that could be suggested from PWT. Adjusted flow of accurate information related to practical conditions of the stay and in accordance to investigations, would make the stay as predictable as possible for patients. Health care professionals should also be aware of the intense interpretation activity patients conduct in relation to all possible clues that can help them to make sense of their situation. In the hospital staff are observed and interpreted; what they say and don't say and how their bodies; eyes, facial expressions, body postures speak of hope or seriousness. What kinds of investigations they go through are considered as is also the priority they experience they are given in the system. Nurses and physicians should also be aware of possible existential threats patients work through as they face the uncertainty of not knowing what their future holds. By listening to and recognising different ways patients can express existential concerns and by trying to understand what kind of world views, traditions or religious faiths patients' belong to, health care professionals can acknowledge and support such work. By showing thoughtfulness and acknowledge patients' needs for respite to rest and restore their strength, practical arrangements can be carried out for the individual patient. This can for example be to give patients leave from the ward when possible, to make agreements to call them by cell phone when they have to be present at the ward, and so on. How a contact person can support patients in the diagnostic phase with information and emotional support is also reported by others (Fridfinnsdottir, 1997; Ambler et al., 1999; Thorne et al., 1999; Woodward & Webb, 2001; Drageset & Lindstrøm, 2003; Lebel et al., 2003; Sjöling et al., 2005; Logan et al., 2006)

6.3.2 Implications related to patterns of "Balancing"

In the papers (Paper I, III, IV) we argued that by understanding how the theoretical code of "Balancing", and the patterns of <u>controlling pain</u>, <u>rational awaiting</u>, <u>denial</u>, and <u>accepting</u> related the strategies of PWT to each other, health care professionals could more easily be sensitive to how patients worked to protect themselves from despair and to maintain hope as they prepared for the outcome. Such understanding makes the patients' situation easier to grasp, but it will still be demanding for nurses and physicians to act and to develop dynamic and mutual interactions with these patients.

In the end of this thesis some implications, sufficiently detailed that nurses and physicians working with such patients can evaluate their applicability for practice will be suggested in relation to patients using different patterns of "Balancing" (Paper I). We would like to underline that a person could use more than one pattern depending on personality, their total situation, the actual situation, and how quality of relations to nurses and physicians were experienced by the patient (Paper IV, subsection 6.2.3).

An important question to consider is to what extent nurses and physicians mainly should follow patients patterns, or if they should challenge or work against one or more of them. Another question to reflect upon is if some patients need more careful follow up than others due to patterns of "Balancing" they mostly use. Such considerations lead us to look at ideas, theories, and frames of references health care professionals consciously or unconsciously build on in clinical judgements. In section 3.1 we pointed to frames of references that a discipline learns in theory and practice that guide practice and provide professionals with a perspective in which to observe, interpret and describe patients' situations (Visintainer, 1996; Fawcett, 2000; Alligood, 2006). Two examples of questions related to such perspectives or frames relevant for patients in the diagnostic phase are; 1) is it best for patients to work

reciprocally with cognitive and emotional aspects of such stressful situation, or is it also possible to prepare well without having too much contact with emotions related to contingently outcomes? 2) Is it better to work on problems and challenges in a conscious and explicit way than to use less awareness and/or a more silent and internal way? How the individual health care professionals and the attitude in the team relate to such questions will colour the meeting with the individual patient.

Patients using mainly the pattern of <u>accepting</u> seems to be the ones easiest to relate to and those handling their situation best. They were able to appraise their situation realistically and combine it with some peace by trusting there would be enough resources for them so they would be able to cope with whatever the outcome would be. The situation of uncertainty and waiting is distressing for these patients too, and a contact person, a well coordinated investigation program, and continuity of physicians and nurses would make the situation more predictable for them and thereby ease their way through the diagnostic phase.

Patients using the pattern of <u>controlling pain</u> to a large extent, go through a very harsh time with a lot of emotional pain, and the distressful experiences of going through diagnostic workups are most easily recognised with these patients. Building of trusting and caring relationship together with continuity of few key professionals would offer these patients health care resources to lean on that would support their hope and help them feel more carried through the investigation process. Awareness of the existential distress they go through together with their need for pulling themselves back from thinking about the worst scenarios should make nurses and physicians aware of how to protect these patients from potential possibilities along the process. To assist patients in reaching respite would be a way to help them gain a break from the anxiety provoking uncertainty they go through. Such break would give them renewed strength to endure the diagnostic phase.

Patients predominantly using patterns of <u>rational awaiting</u> have limited conscious contact with emotions related to the uncertain situation they go through. They try to appraise the situation as realistically as possible, and seek facts about

their case. They extend emotional processing of their situation until they know the outcome. In relation to these patients, nurses and physicians have to consider to what extent they see it as helpful for patients to relate emotions to the preparative cognitive work they carry out, and thus make a better connection between the cognitive and the emotional aspect of their situation. If it is possible to go healthy through a distressing experience without an emotional catharsis, as newer bereavement theories seem to imply (Stroebe et al., 2006; Guldin, 2007), patients using predominantly this pattern may prepare well for the conclusion of their case without being too bothered by distressing emotions. To the degree this is right, these patients would best be supported by receiving accurate and adjusted information, that conditions for finding respite to "kill" the time of waiting were promoted, and simply by not asking them too many questions.

Patients using mostly <u>denial</u> tend to distort the judgement of their situation to protect themselves from emotional distress of threatening scenarios for the future. This leads to a less realistic appraisal of the situation and thus to a poorer preparation for the diagnostic outcome. To the extent nurses and physicians earn these patients trust; they strengthen patients' hope and thereby reduce their need for denial and distortion (Paper IV). By demonstrating competences, continuity of care and following up of patients, health care professionals can assist patients in a more realistic evaluation of their situation and thus contribute to a more accurate preparation for the concluding interview and life afterwards.

6.3.3 Implications for teaching

PWT provides knowledge about how patients with gastroenterological symptoms experience and handle going through the diagnostic phase in hospital. It also lays out how nurses and physicians can promote or hamper the way patients work to prepare themselves for the concluding interview and life afterwards. By making this knowledge available in education, health care professionals can understand more

about how this vulnerable time in patients' life is experienced and can be supported. Teaching this substantive grounded theory to nurses and physicians can foster the ability and willingness to focus on the interpersonal relationship between them and the patient as a means to exchange information and support patients.

6.4 Suggestions for further research

This research aimed at answering how patients in the diagnostic phase at a gastroenterological ward experienced and handled their situation. A GT has just partial closure, since it often generates new ideas that can be investigated further, and as one gathers more data, the substantive grounded theory can be modified (Glaser, 1978). In this research, generation of PWT answered our initial questions but it also led us to new questions that could be further explored.

To sample more data in accordance to patients using different patterns of "Balancing" could improve our understanding of how health care professionals could work differently with patients as they seek and give information related to their problems and the investigation process. How different patients interpret their own body, clues related to the interplay between themselves and staff, and clues related to external conditions also need further investigation. A better understanding of how different patients experience and express existential concerns related to their world views, traditions, and religious faiths in the diagnostic phase would improve quality in following up these patients. How respite can be found and used to strengthen patients using different patterns of "Balancing" can also be explored further.

PWT was generated from patients admitted to a gastroenterological ward. To sample and compare data from patients going through the diagnostic phase at diverse wards, as well as those following an out-patient procedure, would move the substantive theory towards a more formal grounded theory.

Our study focused on patients' experience of going through the diagnostic phase. To investigate and compare health care professionals' evaluation of patients' situation and how they see their own responsibility and role could be interesting.

Future studies could also look at how next of kin experience having a family member going through medical investigations at a hospital, and compare their main concern and handling of the situation with PWT.

7.0 CONCLUSIONS

The two aims of this study (chapter 2.0) have been presented and discussed in the four papers and in this thesis, and they give novel in-depth knowledge about how patients admitted to a gastroenterological ward experience and handle going through the diagnostic phase.

The substantive grounded theory we have developed, called PWT, explains how patients work to prepare themselves for the conclusion of the investigation process and life afterwards. The core category of the theory was titled "Preparative waiting" and the theoretical code, which integrates PWT, was identified as "Balancing between hope and despair". The theoretical code had four patterns named; controlling pain, rational awaiting, denial, and accepting. These four patterns can explain how different patients prepare themselves differently for the concluding interview and life after. The main categories of the theory were generated as "Seeking and giving information", "Interpreting clues", "Handling existential threat", and "Seeking respite". These concepts are analytic and sensitive and PWT thus offers a model that could be used in development of the role of nurses and physicians for patients in the diagnostic phase.

Going through diagnostic workups in hospital was a distressing experience for patients caused by waiting and uncertainty. Interpretation of their situation and coping of it was intertwined in the diagnostic phase, and these processes were conducted in a continuum of levels of levels of awareness. Hope was fundamental in evaluating the meaning of and handling of the situation. Nurses and physicians can hamper or promote the process of "Preparative waiting" for patients in the diagnostic phase.

I have fulfilled the aims of this dr. polit.-project by developing a substantive grounded theory that has fit, works and has relevance for patients going through the diagnostic phase in hospitals and for health care professionals working with them. This research has to be actively applied in order to be conducive to quality care of patients in the diagnostic phase.

REFERENCES

Alligood, M.R. (2006). Introduction to nursing theory: it's history, significance, and analysis. In A.M. Tomey, & M.R. Alligood (Eds.), *Nursing theorists and their work* (pp.3-15). 6th ed. Philadelphia: Mosby Elsevier.

Alvsvåg, H. (2006). Kari Martinsen. Philosophy of caring. In A.M. Tomey, & M.R. Alligood (Eds.), *Nursing theorists and their work* (pp.167-190). 6th ed. Philadelphia: Mosby Elsevier.

Alvsvåg, H., & Gjengedal, E. (2000). *Omsorgstenkning. En innføring i Kari Martinsens forfatterskap.* Bergen: Fagbokforlaget.

Ambler, N., Rumsey, N., Harcourt, D. et al. (1999). Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: comparing "advocacy" with a conventional approach. *Journal of Advanced Nursing*, 29(2), 445-453.

Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, 6(3), 379-393.

Annells, M. (1997). Grounded theory method, part I: within the five moments of qualitative research. *Nursing Inquiry*, 4, 120 – 129.

Artinian, B. (1982). Conceptual mapping: The development of the strategy. *Western Journal of Nursing Research,* 4, 379-393.

Artinian, B.M. (1997). Overview of the Intersystem Model. In B.M Artinian, & M.M. Conger (Eds.), *The Intersystem Model* (pp.1-17). Thousand Oaks: Sage Publication.

Austgard, K. (2006). The aesthetic experience of nursing. *Nursing Philosophy,* 7, 11-19.

Balk, D.E. (1999). Bereavement and spiritual change, *Death Studies*, 23, 485-493.

Benedict, S., Williams, R.D., & Baron, P.L (1994). Recalled anxiety: from discovery to diagnosis of a benign breast mass. *Oncology Nursing Forum*, 21(10), 1723-1727.

Blumer, H. (1969). *Symbolic Interactionism. Perspective and method.* Engelwood Cliffs, New Jersey: Prentice-Hall.

Brilowski, G.A., & Wendler, M.C. (2005). An evolutionary concept analysis of caring. *Journal of Advanced Nursing*, 50(6), 641-650.

Brøbecher, H., & Delmar, C. (2007). Det relasjonelle mode og relasjonskompetence. *Klinisk Sygepleje*, 1, 61-71.

Bury, M. (1997). *Health and illness in a changing society.* London: Routledge.

Charmaz, K. (2000). Grounded Theory. Objectivist and constructivist methods. In N.K. Denzin, & Y.S. Lincoln (Eds.), *Handbook in Qualitative Research* (pp.509-535). 2^(nd) ed. Thousand Oaks: Sage.

Chenitz, C.W. (1986). Getting started: The Research Proposal for a Grounded Theory Study. In C.W Chenitz, & J.M. Swanson (Eds.), *From Practice to Grounded Theory* (pp. 39-47). Menlo Park: Addison-Wesley Publishing Company.

Chenitz, C.W., & Swanson J.M. (1986). Qualitative research using Grounded Theory. In C.W Chenitz, & J.M. Swanson J.M.(Eds.), *From Practice to Grounded Theory* (pp. 3-15). Menlo Park: Addison-Wesley Publishing Company.

Cutcliffe, J.R. (2005). Adapt or adopt: Developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing,* 51(4), 421-428.

Delmar, C. (2006). The phenomenology of life phenomena – in a nursing context. *Nursing Philosophy,* 7, 235-246.

Dietze, E., & Orb, A. (2000). Compassionate care: a moral dimension of nursing. *Nursing Inquiry*, 7, 166-174.

Drageset, S., & Lindstrøm, T.C. (2003). The mental health of women with suspected breast cancer: the relationship between social support, anxiety, coping and defence in maintaining mental health. *Journal of Psychiatric and Mental Health* Nursing, 10, 401-409.

Drageset, S., & Lindstrøm, T.C. (2005). Coping with a possible breast cancer diagnosis: demographic factors and social support. *Journal of Advanced Nursing*, 51(32), 217 - 226.

Edvardsson, J.D, Sandman, P.O., & Rasmussen, B.H. (2005). Sensing an atmosphere of ease: a tentative theory of supportive settings. *Scandinavian Journal of Caring Science*, 19, 344-353.

Fawcett, J. (2000). Analysis and evaluation of contemporary nursing knowledge. Nursing models and theories. Philadelphia; F.A. Davis Company.

Finfgeld-Connett, D. (2006). Meta-synthesis of presence in nursing. *Journal of Advanced Nursing,* 55(6), 708-714.

Finfgeld-Connett, D. (2007). Meta-synthesis of caring in nursing. *Journal of Clinical Nursing,* e-pub, ahead of print.

Fog, J. (2004). *Med samtalen som utgangspunkt. Det kvalitative forskningsinterview.* København: Akademisk Forlag.

68

Folkman, S., & Moskowitz, J.T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774.

Foss, C., & Ellefsen, B. (2004). "De utydelige overtramp? Etiske utfordringer ved kvalitative studier". *Vård i Norden,* 24(3), 30-33.

Fridfinnsdottir, E.B. (1997). Icelandic women's identifications of stressors and social support during the diagnostic phase of breast cancer. *Journal of Advanced Nursing*, 25,526-531.

Giske, T. (1993). *Pasienten si oppleving av meining - sjukepleiaren sitt ansvar?* Bergen: Alma Mater

Giske, T. (1995). Spiritual Care in Nursing Practice. *Christian Nurse International,*11 (4), 4-8.

Giske, T. (2005). Sjukepleiaren som sjelesørgar. Kompetanse, integritet, utfordringar i praksis. *Tidsskrift for fag og tro*, 4, 7 – 12.

Giske, T., & Artinian, B. (2007). Patterns of "Balancing between hope and despair" in the diagnostic phase. A grounded theory study of patients at a gastric ward. *Journal of Advanced Nursing.* Accepted for publication October 2007.

Giske, T., & Artinian, B. (2007). A personal experience of working with classical grounded theory. From beginner to experienced grounded theorist. *International Journal of Qualitative Method.* Resubmitted for publication September 2007.

Giske, T., & Gjengedal, E. (2007). "Preparative waiting" and coping theory with patients going through gastric diagnosis. *Journal of Advanced Nursing,* 57(1), 87-94.

Giske, T., Gjengedal, E., & Artinian, B. (2007). The silent demand in the diagnostic phase. *Scandinavian Journal of Caring Science.* Accepted for publication September 2007.

Glaser, B., & Strauss, A. (1965). Awareness of dying. Chicago: Aldine.

Glaser, B., & Strauss, A. (1967). *The discovery of GT*. Chicago: Aldine.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser, B. (1992). *Basics of grounded theory analysis.* Mill Valley, CA: The Sociology Press.

Glaser, B. (1998). *Doing grounded theory: Issues and discussions.* Mill Valley, CA: The Sociology Press.

Glaser, B. (1999). Keynote address from the fourth annual qualitative health research conference. The future of Grounded Theory. *Qualitative Health Research*, 9(6), 836-845.

Glaser, B. (2001). *The GT perspective: Conceptualization contrasting with description*. Mill Valley, CA: The Sociology Press.

Glaser, B. (2002). *Constructivists Grounded Theory?* Forum: Qualitative Social Research (On-line Journal,) 3(3). http://www.qualitative-research.net/fqs-texte/3-02/3-02glaser-e.htm, Accessed 05 October 2007.

Glaser, B. (2003). *The GT perspective II. Description's remodelling of GT methodology*. Mill Valley, CA: The Sociology Press.

Glaser, B. (2005). *The grounded theory perspective III: Theoretical coding*. Mill Valley, CA: The Sociology Press.

Hartman, J.H. (2001). *Grundad teori. Teorigenerering på empirisk grund*. Lund: Studentlitteratur.

Helsinki Declaration (2004). World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. *World Medical Association.* http://www.wma.net/e/policy/b3.htm, Accessed 05 October 2007.

Heskestad, S., & Tjemsland, L. (1996). Du har kreft. En kvalitativ studie av kvinners akutte reaksjoner ved informasjon om brystkreftdiagnose. *Tidsskrift for den Norske Lægeforening*, 9(116), 1067-1971.

HELTEF (2003). Pasientopplevelser i Helse Vest. Pasienter innlagt i somatiske sykehus. Utredningsrapport nr. 1.

Henderson, V. (1961). *Sykepleiens grunnprinsipper*. Oslo: Norsk sykepleierforbund.

Henderson, V. (1998). *Sykepleiens nature. Refleksjoner etter 25 år.* Oslo: Universitetsforlaget.

Henderson, V. (2006). The concept of nursing. *Journal of Advanced Nursing*, 53(1), 21 – 34.

Holloway, I., & Todres, L. (2006). Grounded theory. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (pp.192-207). Oxford: Blackwell Publishing.

Holm, U. (2005). *Empati. Å forstå menneskers følelser.* Oslo: Gydendal Akademiske.

Hutchinson, S.A., & Wilson, H.S. (2001).Grounded theory. The method. In P.M. Munhall (Ed.), *Nursing research. A qualitative perspective* (pp.209-243). 3rd ed. London: Jones & Bartlett Publisher International.

Hydèn, L.C. (1997). Illness and narrative. *Sociology and Health and Illness,* 19(1), 48-69.

ICN (2006). ICN's definition of nursing. http://www.icn.ch/definition.htm, Accessed 05 October 2007.

Irurita, V.F. (1999). The problem of patient vulnerability. *Collegian (Royal College of Nursing, Australia)*, 6(1), 10-15.

Irving, K.S. (2001). Waiting: Concept analysis. *Nursing Diagnosis*, 12(4), 128-136.

Isaksen, A.S., & Gjengedal, E. (2006). Significance of fellow patients for patients with myocardial infraction. *Scandinavian Journal of Caring Science,* 20(4), 403-411.

Jeon, Y.H. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Science*, 18, 249-256.

Johnson, M., & Long, T. (2006). Research ethics. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (pp.31-42). Oxford: Blackwell Publishing.

Kelly, J. (2004). Spirituality as a coping mechanism. *Dimensions of Critical Care Nursing*, 23(4), 162-168.

Kim, H.S. (2000). *The nature of theoretical thinking in nursing*. 2nd ed. New York: Springer Publishing Company.

Kleinmann, A. (1988). *The illness narratives. Suffering, healing and the human condition. illness.* New York: Basic Books.

Kvale, S. (2001). *Det kvalitative forskningsintervju*. Oslo: Gyldendal Akademiske.

LaRossa, R., & Reitzes, D. (1993). Symbolic Interactionism and Family Studies. In P.G.Boss et. al. (Eds.), *Sourcebook of Family Theories and Methods. A Contextual Approach* (pp.135-163). New York: Plenum Press.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.

Lazarus, R.S. (1999a). *Stress and emotion. A new synthesis.* New York: Springer Publishing Company.

Lazarus, R.S. (1999b). Hope : an emotion and virtual coping resource against despair. *Social Research*, 66(2), 653-678.

Lebel, S., Jakubovits, G., Rosberger, Z. et al. (2003). Waiting for a breast biopsy. Psychosocial consequences and coping strategies. *Journal of Psychosomatic Research*, 55, 437-443.

Leydon, G.M., Bynoe-Sutherland, J., & Coleman, M.P. (2002). The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of Cancer* Care, 12, 317-326.

Logan, J., Hackbusch-Pinto, R., & De Grasse, C.E. (2006). Women undergoing breast diagnostics: The lived experience of spirituality. *Oncological Nursing Forum,* 33(1) 121-126.

Lomborg, K., & Kirkevold, M. (2003). Truth and validity in grounded theory – a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. *Nursing Philosophy* 4, 189-200.

Løgstrup, K.E. (1956). *Den etiske fordring* (The ethical demand). Trondheim: J.W. Cappelens Forlag.

Løgstrup, K.E. (1983). *System og symbol*. Essays. (System and symbol. Essays). Viborg: Nørhaven Bogtrykkeri.

Løgstrup, K.E. (1988). *Udfordringer.* (Challenges). Hadsten: Forlaget Mimer

Løgstrup, K.E. (1997). *The ethical demand*. Notre Dame Indiana: University of Notre Dame Press.

MacDonald, M. (2001). Finding a critical perspective in grounded theory. In R.S. Schreiber, & P.N. Stern (Eds.), *Using Grounded Theory in Nursing* (pp. 113-157). New York: Springer Publishing Company.

MacDonald, M., & Schreiber, R.S. (2001). Constructing and deconstructing: Grounded theory in a postmodern world. In R.S. Schreiber, & P.N. Stern (Eds.), *Using Grounded Theory in Nursing* (pp. 35-53). New York: Springer Publishing Company.

Martinsen, K. (1996). *Fenomenologi og omsorg*. Oslo: Universitetsforlaget.

Martinsen, K. (2006). *Care and vulnerability*. Oslo: Akribe.

Martinsen, K. (2007). Angår du meg? Etiske utfordringer og disiplinert godhet. (Are you of my concern? Ethical demand and disciplined goodness). In H. Alvsvåg & O. Førland (Eds.), *Engasjement og læring - fagkritiske perspektiver på sykepleie* (Commitment and learning - critical perspectives on nursing) (pp. 315-344). Oslo: Akribe.

Mast, M.E. (1995). Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice*, 9(1), 3-29.

Mautner, T. (2000). The Penguin dictionary of philosophy. London: Penguin Books.

McCormick, K.M. (2002). A concept analysis of uncertainty in illness. Journal of Nursing Scholarship, 34(2), 127-131.

McGrath, P., Holewa, H., McGrath, Z. (2006). Nursing advocacy in an Australian multidisciplinary context: findings on medico-centrism. *Scandinavian Journal of Caring Science*, 20, 394-402.

McQueen, A. (2000). Nurse-patient relationship and partnership in hospital care. *Journal of Clinical Nursing*, 9, 723-731.

McSherry, W. (2006). *Making sense of spirituality in nursing and health care practice*. 2nd ed. London: Jessica Kingsley Publisher.

Milligan-Hecox, R.J., England, M., & Artinian, B. (1997). Context of involvement. Situational environment. In B.M Artinian, & M.M. Conger (Eds.), *The Intersystem Model* (pp. 42-63). Thousand Oaks: Sage Publication.

Milliken, P. J., & Schreiber, R.S. (2001). Can you "Do" Grounded Theory without Symbolic Interactionism? In Schreiber R.S. & Stern P.N. (Eds.), *Using Grounded Theory in Nursing* (pp.177-190). New York: Springer Publishing Company.

Miner-Williams, D. (2006). Putting a puzzle together: making spirituality meaningful for nursing using an evolving theoretical framework. *Journal of Clinical Nursing*, 15, 811-821.

Ministry of Education and Research (2005). Rammeplan for sykepleierutdanning. http://www.regjeringen.no/upload/KD/Vedlegg/UH/Rammeplaner/Helse/Rammeplan_for_sykepleierutdanning_05.pdf, Accessed 05 October 2007.

Ministry of Health and Care Services (2006). http://www.regjeringen.no/nb/dokumentarkiv/Regjeringen-Stoltenberg-I/Sosial--og-helsedepartementet/232740/232741/Forskrift-til-lov-om-spesialisthelsetjenesten-mm-pasientansvarlig-lege-mm.html?id=421527, Accessed 05 October 2007.

Ministry of Health and Care Services (2007). National Health plan for Norway 2007 – 2011. http://www.regjeringen.no/Upload/HOD/Vedlegg/Engelsk/National%20Health%20Plan.pdf, Accessed 05. October 2007.

Ministry of Health and Social Affairs (1999). Patients' Rights Act. http://www.ub.uio.no/ujur/ulovdata/lov-19990702-063-eng.pdf, Accessed 05 October 2007.

Mishel, M.H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20(4), 225-232.

Mishel, M.H. (1997). Uncertainty in acute illness. In J. Fitzpatrick, & J. Norbeck (Eds.), *Annual Review of Nursing Research* (15, pp. 57-80). New York: Springer Publisher.

Mishel, M.H., & Braden, C.J. (1988). Finding Meaning: Antecedents of uncertainty in illness. *Nursing Research*, 37(2), 98-103.

Moene, M., Bergbom, I., & Skott C. (2006). Patients' existential situation prior to colorectal surgery. *Journal of Advanced Nursing*, 54(2), 199-207.

Morse, J.M. (2001). Situating grounded theory within qualitative inquiry. In Schreiber R.S. & Stern P.N. (Eds.), *Using Grounded Theory in Nursing* (pp.1-15). New York: Springer Publishing Company.

Neville, K.L. (2003). Uncertainty in illness. An integrative review. *Orthopaedic Nursing*, 22(3), 206-214.

Norheim, A. (2006). Pleiekulturens betydning for en god profesjonell omsorg – et etisk perspektiv. In A.B. da Silva (Ed.), *Etikk og menneskesyn i helsetjeneste og sosialt arbeid* (pp. 228-256). Oslo: Gyldendal Akademiske.

NOU:2 (1997). Pasienten først. http://www.regjeringen.no/nb/dep/hod/dok/NOUer/1997/NOU-1997-2/3.html?id=140692, Accessed 05 October 2007.

NSF (2001). *Ethical guidelines for professional conduct*. http://www.sykepleierforbundet.no/article.php?articleID=10855, Accessed 05 October 2007.

O'Brien, M.E. (1999). *Spirituality in nursing. Standing on holy ground*. Boston: Jones and Bartlett Publishers.

Pursley-Crotteau, S., Bunting, S.NcG., & Brauker C.B. (2001). Grounded theory and Hermeneutics: Contradictory or Complementary Methods in Nursing Research? In R.S. Schreiber, & P.N. Stern (Eds.), *Using Grounded Theory in Nursing* (pp.191-209). New York: Springer Publishing Company.

Peter, E,. & Morgan, K.P. (2001). Exploration of a trust approach for nursing ethics. *Nursing Inquiry*, 8, 3-10.

Playle, J.F., & Mullarkey, K. (1998). Parallel process in clinical supervision: enhancing learning and providing support. *Nurse Education Today*, 18, 558-566.

Poole, K. (1997). The emergence of the "waiting game": a critical examination of the psychosocial issues in diagnosing breast cancer. *Journal of Advanced Nursing*, 25, 273-281.

Poole, K., & Lyne, P.A. (2000). The "cues" to diagnosis: describing the monitoring activities of women undergoing diagnostic investigations for breast disease. *Journal of Advanced Nursing*, 31(4), 752-758.

QSR International (2002). *Using NVivo 2 in Qualitative research*. Doncaster Victoria Australia: QSR International Pty Ltd.

Reed, P.G., & Runquist, J.J. (2007). Reformulation of a methodological concept in grounded theory. *Nursing Science Quarterly*, 20(2), 118-122.

Rhodes, L.A., McPhillips-Tangum, C.A., Markham, C., & Klent, R. (2002). The power of the visible: The meaning of diagnostic tests in chronic pain. In S. Nettleton, & S. Gustafsson (Eds.), *The sociology of health and illness reader* (pp. 35-47). Cambridge: Polity Press.

Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *ournal of Clinical Nursing*, 15, 852-862.

Schantz, M.L. (2007). Compassion: a concept analysis. *Nursing Forum, 42(2), 48-55.*

Schattner, A., Rudin, D., & Jellin, N. (2004). Good physicians from the perspective of their patients. *BMC health Services Research,* 4:26. http://www.biomedcentral.com/content/pdf/1472-6963-4-26.pdf, Accessed 05 October 2007.

Shattell, M. (2004). Nurse-patient interaction: a review of the literature. *Journal of Clinical Nursing*, 13, 714-722.

Scheel, M.E. (2005). *Interaktionel sygeplejepraksis.* 3rd ed. København: Munksgaard.

Selder, F. (1989). Life transition theory: The resolution of uncertainty. *Nursing and Health Care*, *10*(8), 437 – 451.

Sellman, D. (2005). Towards an understanding of nursing as a response to human vulnerability. *Nursing Philosophy*, 6, 2-10.

Sellman, D. (2007). Trusting patients, trusting nurses. *Nursing Philosophy*, 8, 28-36.

Simsen, B.J. (1985). *Spiritual needs and resources in illness and hospitalization.* A thesis submitted to the University of Manchester, Degree of Master of Science in the Faculty of Medicine, Department of Nursing.

Sjöling, M., Ågren, Y., Olofsson, N., Hellzen, O., & Asplund, K. (2005). Waiting for surgery; living on hold – a continuous struggle against a faceless system. *International Journal of Nursing Studies* 42, 539-547.

Starrin, B, Dahlgren, L., Larsson, G, & Styrborn, S. (1997). *Along the path of discovery. Qualitative methods and grounded theory*. Lund: Studentlitteratur.

Stern, P.N., & Covan, E.K. (2001). Early Grounded Theory: Its Process and Products. In R.S. Schreiber, & P.N. Stern (Eds.), *Using Grounded Theory in Nursing* (pp. 17-34). New York: Springer Publishing Company.

Stortingsmelding 26 (1999 – 2000). Om verdiar i den norske helsetenesta. Ministry of Health and Social Affairs.

http://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/19992000/Stmeld-nr-26-1999-2000-.html?id=192850, Accessed 05 October 2007.

Sørlie, V., Torjuul, K., Ross, A., & Kihlgreen, M. (2006). Satisfied patients are also vulnerable patients – narratives from an acute care ward. *Journal of Clinical Nursing*, 15, 1240-1246.

Taylor, E.J. (2002). *Spiritual care. Nursing theory, resech, and practice*. Upper saddle River, NJ: Prentice Hall.

Thorne, S.E., Harris, S.R., Hislop, T.G., & Vestrup, J.A. (1999). The experience of waiting for diagnosis after an abnormal mammogram. *The Breast Journal*, 5(1), 42-51.

Travelbee, J. (1971). Interpersonal aspects of nursing. 2nd ed. Philadelphia: F.A.Davis.

Vike, H, et al. (2002). Maktens samvittighet. Om politikk, styring og dilemmaer I velferdsstaten. Oslo: Gyldendal Akademiske.

Visintainer, M.A. (1996). The nature of knowledge in nursing. In J.W. Kenney (Ed.), *Philosophical and theoretical perspectives for advanced nursing practice* (pp. 32-43). Boston; Jones and Bartlett Publisher

Widerman, E. (2004). Pathways to adult diagnosis of CF: The impact of pre-diagnosis experience on post-diagnosis responses and needs. *Patients Education and Counselling*, 52, 69-77.

Wikipedia (2007). Critical realism. http://en.wikipedia.org/wiki/Critical_realism, Accessed 05 October 2007.

Wilson, H.S., & Hutchinson, S.A. (1996). Methodological mistakes in grounded theory. *Nursing Research*, 45(2), 122-124.

Wilson, V., & McCormack, B. (2006). Critical realism as emancipatory action: the case for realistic evaluation in practice development. *Nursing Philosophy*, 7, 45-57.

Woodward, V., & Webb, C. (2001). Women's anxieties surrounding breast disorders: a systematic review of the literature. *Journal of Advanced Nursing*, 33(1), 29 – 41.