A companionship between strangers
- Patient-patient interaction in oncology wards

PhD dissertation

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Acknowledgement

The last three years of studying have been busy and challenging. This project has never been a ‘onewoman-show’ – it is the result of hard work supported by the people around me. For this, I wish to express my gratitude because I could not have done it without them.

The project was financially supported by The Danish Cancer Society, Trygfonden, Region Midt and VIA University College. You made the project possible and gave me an opportunity to investigate and contribute with knowledge about hospitalised cancer patients experiences with fellow cancer patients. I cannot thank you enough for this opportunity.

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I want to express my appreciation to the healthcare professionals in the two wards included in the study. It was a pleasure to work among you always and thank you for your interest and participation – your approach made me succeed in my doing.

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At last, the people who it was all about – the participating patients with cancer. Without you this project was not possible to conduct. You accepted my presence at a time in your lives with suffering and you made me a part of your lives during hospitalisation. I cannot thank you enough and you will always have my deepest respect.

Thank you all

Lene Søndergård Larsen

Risskov, April 2013
# Table of contents

List of papers .......................................................................................................................... 1
List of tables ............................................................................................................................. 1
Introduction ............................................................................................................................... 2
Background and present research ............................................................................................ 3
  Patient interaction ................................................................................................................... 3
  Sharing information ................................................................................................................ 4
Psycho-social support and care ................................................................................................. 6
Aim ........................................................................................................................................... 7
Design and methods .................................................................................................................. 8
  Qualitative meta-synthesis ..................................................................................................... 8
  Qualitative fieldwork ........................................................................................................... 9
    Setting ............................................................................................................................... 9
    Sampling .......................................................................................................................... 10
    Participant observation .................................................................................................... 10
    Reflection as a tool .......................................................................................................... 11
Qualitative semi-structured interviews ...................................................................................... 12
The conceptual framework for the data analysis ..................................................................... 13
  Inductive thematic analysis ................................................................................................. 13
Structural concepts .................................................................................................................. 15
  Patient-patient interaction and learning ............................................................................. 15
  Patient-patient interaction and the environment ............................................................... 16
  Patient-patient interaction and personal support ............................................................. 16
Trustworthiness ....................................................................................................................... 17
Ethical considerations ............................................................................................................. 18
Findings .................................................................................................................................. 20
  The qualitative meta-synthesis ........................................................................................... 20
  The fellow patient perceived as an enforced companion ................................................ 20
  The fellow patient perceived as an expert on illness and hospital life ............................ 20
The fellow patient perceived as a care provider ......................................................... 21
The fieldwork .................................................................................................................. 21
Learning from shared experiences ............................................................................. 22
Interpretation and discussion ...................................................................................... 25
Environmental challenges to patient-patient interaction ............................................ 32
Interpretation and discussion ...................................................................................... 34
Personal support from fellow patients ....................................................................... 37
Interpretation and discussion ...................................................................................... 39
Summarised discussion ................................................................................................ 43
The complex nature of patient-patient interaction ...................................................... 43
Personal experiences and professional information ................................................... 44
Withholding information ............................................................................................... 45
Gender differences ........................................................................................................ 46
Limitations of the study ............................................................................................... 49
The qualitative meta-synthesis ..................................................................................... 49
The fieldwork ................................................................................................................ 49
Conclusion ..................................................................................................................... 51
Perspectives and implications for practice .................................................................... 53
References .................................................................................................................... 55
Summary ....................................................................................................................... 62
Danish Summary .......................................................................................................... 63
Article 1 ......................................................................................................................... 65
Article 2 ......................................................................................................................... 86
Article 3 ......................................................................................................................... 106
Appendices ................................................................................................................... 126
**List of papers**


**List of tables**

Table 1: Characteristics of patients interviewed
Introduction

The aim of this study is to explore interaction between hospitalised cancer patients. The inspiration came from a study of the culture of hospitalised patients performed by the Norwegian sociologist Dag Album. In Album’s study, a variety of patients were studied – not only cancer patients. However, the hospitalised patients spent approximately 90% of the time during the day in the company of their fellow patients (Album 1996).

Typically, the nurses viewed this time as “empty time”, during which they felt that the patients were occupied with “trivialities”. However, by contrast with the nurses, the patients perceived time spent with fellow patients as qualitative interaction, because it gave them the opportunity to keep abreast of the disease trajectory of their fellow patients and the events taking place in the hospital in general (Album 1996). Ultimately, the nurses and the patients had different perceptions when it came to the importance of patient-patient interaction. In addition, this interaction was partly invisible to the nurses, because it occurred when the nurses were not present in the room.

This “invisible” interaction between patients aroused our curiosity and interest in finding out more about the content as well as the importance of patient-patient interaction. This led us to elaborate on the importance of this interaction: How do patients interact? What is the content of their interaction? What are the environmental conditions in which interaction takes place? And what is the importance of shared experiences for patients?
Background and present research

Patient interaction

Album emphasised in his research that the hospital lay-out and culture caused the patients to be physically close and that this promoted the establishment of relationships with fellow patients (Album 1996). When the connection was established, they helped each other both physically and emotionally through conversation and by being present. According to Album, conversation increased the patients’ opportunity to manage their own disease trajectory because they learned to identify disease patterns which could be related to their own disease (Album 1996). How the learning took place was not elaborated on by Album, but he found connections between what patients learned and the time patients had lived with the disease. He also detected differences in what patients learned, depending on who was the ‘teacher’ and who was the ‘pupil’ (Album 1996).

The impact of learning from the experiences of fellow patients has been investigated among patients in cardiac recovery rehabilitation and in secondary stroke prevention, but it has not been investigated specifically among hospitalised cancer patients (Colella, & King 2004, Gibson & Watkins 2011) In contrast to learning from fellow patients, studies of the learning preferences of cancer patients have concluded that healthcare professionals were perceived as the primary resource from which patients preferred to learn about disease, disease trajectory and treatment (Chelf et al. 2001, Chelf et al. 2002, Piredda et al. 2008).

The results from these studies combined with Album’s research indicate the relevance of a study focusing on learning by experience among hospitalised cancer patients. Interaction between cancer patients has not yet been investigated as a potential learning situation in previous research.

Album’s findings indicated a connection between the hospital lay-out and patient-patient interaction, but the connection was not clarified. With this in mind, the present study sets out to investigate this connection further. In addition, Album sampled patients with a variety of diseases. The sampling in this study is only patients with cancer, with cancer being a life-threatening disease which is assumed to be connected to a specific existential situation. Other than the studies mentioned, a systematic search for literature in international databases provided a sparse selection of studies which had investigated interaction between hospitalised patients. Like Album’s research, these studies describe certain elements of interaction between hospitalised patients. The sampling was similar too (participants with a variety of diseases). Only four of the studies had a specific

It was a surprise to find no more than four studies of interaction between cancer patients. In recent years, researchers have emphasised the need for further research into the importance of patient-patient interaction during hospitalisation (Isaksen & Gjengedal 2000, Forbat, Hubbard & Kearney 2009, Wilson & Luker 2006, McCaughan, Parahoo & Prue 2011). They further emphasise that something goes on in patient-patient interaction, but the knowledge of healthcare professionals is insufficient when it comes to the extent, content and importance of patient-patient interaction.

**Sharing information**

As implied above, the importance of interaction between cancer patients has neither been sufficiently investigated nor acknowledged by nurses and other healthcare professionals. Nevertheless, such interaction does constitute a situation in which patients share information by sharing personal experience (Isaksen & Gjengedal 2000, McCaughan, Parahoo & Prue 2011). Even so, the assumption has been that healthcare professionals know what cancer patients need to know (Luker et al. 1995).

The lack of attention to patient-patient interaction as a situation in which information is shared is reflected in studies that investigate how to improve the supply of information and how to meet the information needs of patients. The information needs of cancer patients have been investigated with the focus on what they need to know, how much they want to know, information-seeking behaviour, and concerns about how to retrieve information (Bennenbroek et al. 2002, Leydon et al. 2000, Walsh et al. 2010).

Studies have found that information is acquired from various sources such as physicians and nurses; but also from brochures, booklets, the internet, and fellow patients (Chelf et al. 2001, Chelf et al. 2002, Maddock et al. 2011). Patients seem to acquire information about their disease and disease trajectory from various sources, but even so it is still a challenge to meet the information needs of patients in the healthcare system (Grønvold et al. 2006, Kidd et al. 2008, Worster & Holmes 2009).

The nurse is supposed to be a key person when it comes to supplying information to patients. This is not entirely in accordance with the experiences of hospitalised patients. The divergence is identified by Album (1996) in his research, but is also clearly stated in the research of Isaksen & Gjengedal (Isaksen & Gjengedal 2000), with the patients verbally stating that their fellow patients
are important sources of information about the trajectory of disease. In Isaksen and Gjengedal’s study (2000), one patient says: “You get to know your own illness through others…most of the information I’ve obtained from fellow patients”.

Similarly, other studies have identified fellow patients as important sources of information in addition to healthcare professionals; but the way in which patients perceive information from healthcare professionals and fellow patients respectively seems to be different (McCaughan, Parahoo & Prue 2011, Kulik, Moore & Mahler 1993).

The studies that investigated patient-patient interaction concluded that patients were an unused resource during hospitalisation. Far from being a resource, patients could also be a stress factor, for example when they had disagreements about when to turn off the television or when to open or close windows. In this way, it is implied that the interaction between patients might entail positive possibilities as well as stress (Isaksen & Gjengedal 2000, Spliid Ludvigsen 2009, Kulik, Shelby & Cooper 2000).

In recent years, the needs of cancer patients for information, communication, counselling, support and care have achieved huge attention in Denmark (Grønvold et al 2006, Sandager et al. 2011, Danish Health and Medicine Authority 2000, 2005, 2010).

This is reflected in the National Cancer Plans, which feature suggestions to strengthen the efforts made for cancer patients. The inclusion of the resources of patients, in what is called ‘patient-centred care and treatment’ is assumed to be an important element in cancer treatment, but it is also regarded as important with regard to the way in which patients perceive the quality of their treatment (Danish Health and Medicine Authority 2010). However, the way in which patient-patient interaction could be harnessed as a contribution to treatment and care as well as to quality development has not yet been identified. It is necessary to provide sufficient knowledge about what goes on among hospitalised patients and the importance of patient-patient interaction according to the patients.

The recommendations of the National Cancer Plans are in accordance with results from the investigation ‘Cancer patients’ world’, which studied Danish cancer patients and their physical and psycho-social needs (Grønvold et al 2006). From the results of this study, it is evident that frequent failures appear when it comes to patients’ needs for communication, psycho-social care and
support. These failures are considered to be of importance to patients’ satisfaction, life quality and health (Grønvold et al 2006).

**Psycho-social support and care**

As mentioned above, Danish studies and plans have identified failures in the accommodation of patients’ information needs, but also in patients’ needs for psycho-social support and care (Grønvold et al 2006, Danish Health and Medicine Authority 2000, 2005, 2010).

Ordinarily, the accommodation of hospitalised patients’ needs is connected to the nurse. According to leading nursing theorists, attending to patients’ needs is a part of the nurses’ daily work – while the importance of patient-patient interaction is not highlighted as important in its own right (Henderson, International Council of Nurses & Dansk Sygeplejeråd 2009, Orem 2001, Martinsen 2003).

However, in the studies found regarding patient-patient interaction, incentives for care and support among patients were present (Album 1996, Isaksen & Gjendedal 2000, Forbat, Hubbard & Kearney 2009, Wilson & Luker 2006, McCAughan, Parahoo & Prue 2011, Spliid Ludvigsen 2009, Isaksen & Gjendedal 2006). In this respect, Album’s research focused attention on the fact that patients calmed and comforted each other in difficult situations, and hence cared for each other (Album 1996).

Like Album, Isaksen & Gjendedal (2000) placed emphasis on the patients’ ability to demonstrate care by taking responsibility for each other. Additionally, it has also been noted that patients sometimes undertake supportive work, develop supportive relationships, and care for each other (Isaksen & Gjendedal 2000, Forbat, Hubbard & Kearney 2009, Wilson & Luker 2006).

Even though these studies had a specific focus on interaction between cancer patients, they did not seek to investigate support and care. No evidence of research into support and care among hospitalised cancer patients has been found in the literature. However, studies of the participation of cancer patients in support groups have included support and care (Bell et al. 2010, Gray et al. 1996, Seale, Ziebland & Charteris-Black 2006). These studies do not state whether the participating patients are hospitalised, which is what makes the present study new because it investigates support among hospitalised cancer patients specifically.
Aim

Our assumption is that interaction between hospitalised patients involves more than patients merely being neighbourly with patients in the same ward as themselves.

*The aim* is to explore interactions between hospitalised patients. Several research questions guided the study:

- What is the importance of patient-patient interaction during hospitalisation?
  - What do patients learn from patient-patient interaction?
  - What is the importance of the hospital environment with regard to patient-patient interaction?
  - How do patients support each other?
Design and methods
The study design is qualitative and exploratory. Fieldwork involving a broad approach was regarded as giving the best opportunity to answer the research questions. The field of ethnography has been used by way of inspiration, leading to the choice of a combination of participant observation and individual semi-structured interviews.

The project was conducted in the following steps:

1) A qualitative meta-synthesis with the aim of providing an overview of knowledge about patients’ importance to fellow patients during hospitalisation, including:
   a. Literature review with assessment and selection of texts
   b. Inductive thematic analysis of findings from included texts as empirical data

2) Qualitative fieldwork with the aim of providing knowledge about patient-patient interaction of importance to hospitalised patients, including:
   a. Participant observation and individual semi-structured interviews with the aim of providing empirical data
   b. Inductive thematic analysis of the empirical data

Qualitative meta-synthesis
The aim of the qualitative meta-synthesis (article 1) was to identify scientific studies that investigated the importance of patient-patient interaction during hospitalisation. The methodological approach employed was based on Sandelowski & Barroso’s guide to qualitative meta-synthesis (Sandelowski & Barroso 2002, Thorne et al. 2004, Sandelowski & Barroso 2007) (Appendix A & B). As a foundation for the following fieldwork, this approach was selected and used as a tool to accumulate knowledge from existing qualitative studies. To synthesise the identified findings, thematic analysis was performed according to Dey’s steps description, classification, and making connections (Dey 1993). This approach is described and elaborated on in the section ‘Inductive thematic analysis’ on page 13.

The results from the qualitative meta-synthesis are presented in article 1 and in the present thesis under the section ‘Findings’. The results are used in ‘Summarised discussion’ as results which represent existing knowledge about interaction between hospitalised patients. To visualise new or
complementary knowledge identified in the fieldwork, the findings from the fieldwork are discussed alongside the findings from the qualitative meta-synthesis.

**Qualitative fieldwork**

Inspired by the methods of ethnographic fieldwork, data was collected with a combination of participant observation and individual qualitative semi-structured interviews (Spradley 1980, Spradley 1979, Hammersley & Atkinson 2007, Kvale & Brinkmann 2009). Ethnography is one of many approaches within social research. It has moved from being a central anthropological methodology to being a multidisciplinary qualitative approach (Hammersley & Atkinson 2007). Over time, ethnography has gained acceptance in nursing research. For example, the Danish researcher Helle Ploug Hansen has investigated relationships between patients and healthcare professionals in hospitals; and the Norwegian researcher Kristin Heggen has produced a doctoral dissertation investigating student nurses who were training to be nurses in hospitals. Both of these researchers used ethnography with the aim of understanding what went on among the actors in the field (Ploug Hansen 1995, Heggen 1995).

Ethnography has been used and influenced by a range of theoretical ideas such as hermeneutics and phenomenology. Although it is difficult to outline a core definition which captures all the meanings of ethnography, the ethnographic method usually involves researcher participation in people’s daily lives for an extended period of time, watching what happens, listening to what is said, asking questions through formal and informal interviews, and collecting any kind of data available to throw light on the issues that are the emerging focus of inquiry (Hammersley & Atkinson 2007).

Ethnography is a tool which offers a way of seeing things through the eyes of others, and it offers a systematic understanding of human cultures from the perspective of those who have learned about them (Spradley 1980, Hammersley & Atkinson 2007). The aim of this study meant that ethnographic fieldwork offered the opportunity to bring forward new and unexpected aspects and dimensions of the phenomenon of patient-patient interaction by participating in the patients’ lives during hospitalisation.

**Setting**

Two hospital wards were selected: one situated in a large Danish university hospital (UH) with 1,150 beds, and one in a smaller Danish regional hospital (RH) with 640 beds.
The UH ward had four separate wards at the oncology department. Each ward had 20 beds, allocated in one-, two- and three-bed rooms. A shared lounge was located between the wards. Meals were served from a trolley in the corridor.

The RH ward had two interconnected corridors with a total of 26 beds in one-, two- and four-bed rooms. The ward had several seating areas in the corridors, and a dining room/lounge where meals were served three times a day.

Both wards had a majority of multiple-bed rooms. The interior of these rooms was similar in the two hospitals, but differed in decor depending on room size.

**Sampling**

Potential participants for observation were identified by the head nurse and given the opportunity to accept or refuse participation. The researcher decided on the final inclusion. The sample size comprised 85 Danish-speaking hospitalised cancer patients with a minimum age of 18 (Appendix C). Twenty-six patients were selected for interviews. Six of these declined to participate due to a lack of energy and personal reasons. Ten men (indicated by “M”) and ten women (indicated by “K”) were interviewed.

The participants were primarily hospitalised because of cancer relapse or complications due to adverse side effects of cancer treatment. Two male and one female patient were bed-bound during hospitalisation and unable to leave the patient room on their own (M17, M36, K27), while the rest of the participants were mobile. For the interviews, a purposive sample was drawn from the observed patients (Patton 1995, 1999). Inclusion criteria were: Men and women with cancer who were able and willing to talk about hospitalisation with fellow patients, Danish speaking, age >18. The participants who were excluded were in-patients with dementia, extensive mental diseases, and physical or mental illnesses that precluded inclusion on ethical grounds.

**Participant observation**

Participant observation was used to observe the everyday lives of the patients in the wards, such as how they spent time, who they talked to, and what they talked about. Spradley’s guidelines for observation were used as a structural tool (Spradley 1980)(Appendix D). The observations were mainly performed through passive participation, but they also included informal interviews between patient and fieldworker (Hammersley & Atkinson 2007).
The oscillation between levels of participation promoted both an ‘inside’ and an ‘outside’ perspective (Spradley 1980). As an ‘outsider’, the fieldworker has an objective view on the field, whereas the ‘insider’ engages in the field and feels some of the emotions that the participants ordinarily feel (Spradley 1980). This oscillation required a balance with the risk of ‘going native’ and surrendering to sympathy or friendship with the participants, or alternatively the risk of keeping too great a distance to the participants and failing to understand their feelings (Spradley 1980, Spradley 1979). This balance was important in the data collection because participation and interest in the patients’ lives gave access to the patients’ daily living during hospitalisation.

Observations ranged from wide lens, grand tour observation involving surveys of place, actors and activities, to individually situated, mini tour observations of patient interaction (Spradley 1980). The features observed were: lay-out, such as different living spaces; artefacts, such as beds and curtains; and daily routines including patients (and healthcare professionals) significant to the ward and interaction between patients and fellow patients – conversation and body language, the patients’ daily events, goals and feelings.

Observations took place in multiple-bed patient rooms, corridors, dining areas (RH), and lounges (UH). Fieldwork was conducted for two-three days a week during selected time spans from 7 a.m. to 10 p.m. over a period of six months in 2010-2011 (Appendix E).

**Reflection as a tool**

Breaks were incorporated throughout the observation period and before and after every interview. During the breaks, notes were elaborated on in immediate continuation of the observations in order to remember observed situations as close to reality as possible and to avoid ethnocentric description (Spradley 1980, Hammersley & Atkinson 2007).

The prior understanding of fieldworkers may constitute a challenge to explicit awareness and openness regarding things which others might take for granted in a similar situation (Spradley 1980). Being able to stay open-minded to everything, even things you did not understand in the situation, was essential with regard to data collection. Staying open-minded is the key to avoiding confirmation of any prior understanding, and is therefore essential in understanding the observed phenomena (Spradley 1980, Hammersley & Atkinson 2007). In order to check for the presence of any prior understanding, reflection was used continuously before and after every observation and interview.
**Qualitative semi-structured interviews**

The main focus of the semi-structured interviews was placed on the experiences of patients regarding interaction with their fellow patients. Using the inspiration of both the formal ethnographic interview and the qualitative interview, the aim was to elaborate on the initial understanding gained from participant observation because the interviews gave the opportunity of asking questions about the patients’ lives as they had been observed (Spradley 1979, Hammersley & Atkinson 2007, Kvale & Brinkmann 2009).

According to Spradley, the best interview is when the fieldworker is able to develop the interview into an ordinary conversation (Spradley 1979). Because of the prior observations, I had already established a relationship of trust with the patients. This trust promoted a relaxed atmosphere between us, so the interviews were like friendly conversations with the participants talking freely about their experiences. As in any other conversation, my approach was forthcoming, friendly, listening, empathic, and open-minded (Kvale & Brinkmann 2009).

The interviews were used to elaborate on observations of patients’ experiences with their fellow patients. An interview guide was used to support me in asking each participant similar questions (Kvale & Brinkmann 2009)(Appendix F). The initial descriptive question was: “Could you please describe how you experience being hospitalised with a fellow patient?” This question led the patients to tell their story about the hospitalisation and the trajectory of their disease, and often they answered questions from the interview guide without being asked.

I tried to encourage the patients to keep talking by asking questions based on what they said (paraphrasing by repeating their words with an open and inquiring approach, thereby encouraging the participants to elaborate further on the subject). Both open and detailed questions were used to ensure the interpretation of statements, for instance “Could you please explain what you mean when you say…” and “Am I to understand this as…”(Spradley 1979). This approach was also used to promote my understanding of the situation and the importance of patient-patient interaction from the patients’ perspective.

The interviews were taped and transcribed verbatim within 24 hours. The characteristics of the interviewed participants are presented in Table 1.
Table 1: Characteristics of patients interviewed

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<th>Characteristic</th>
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<td>Prostate</td>
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<td>Lung</td>
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<td></td>
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<td></td>
<td></td>
<td>Melanoma</td>
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</tbody>
</table>

The conceptual framework for the data analysis

The conceptual framework is a combination of inductive thematic strategies. In accordance with the aim of this thesis, the concepts of interaction in connection with learning, environmental factors and personal support play a structural role in the analysis. The inductive process is employed in both the qualitative meta-synthesis analysis and the fieldwork analysis.

Inductive thematic analysis

The conceptual framework for the inductive thematic analysis is inspired by Dey (1993). Dey presents a pragmatic, pedagogical and guided approach to qualitative data analysis. With this, he attempts to solve the practical problems of conceptualising by focusing on the common core of the multiplicity of qualitative research traditions without focusing on a specific qualitative methodological approach. This approach is chosen because it makes it possible to describe and classify phenomena, and to see how concepts interconnect (Dey 1993). Dialectic interaction between ideas and data gives opportunities to clarify answers to the initial research questions.
According to Dey (1993), a thick description including written observations, transcribed interviews and written and drawn context description constituted the base description for classification. The computer software Nvivo was used as a structural tool in the analysis. Data were managed in files and indexed in maps in Nvivo, and the material was read and annotated to derive initial focus areas from the data. The management of data progressed from initial description to the initial process of breaking down data into bits in the classification (Dey 1993).

Classification can be seen as a form of practical reasoning with data as the foundation for making meaningful comparisons between bits of data (Dey 1993). After several readings, the overall impression revealed aspects of importance to the patients in the situation. A line-by-line coding was performed. The characteristics of the patients’ experiences, statements and observed actions were assigned to categories created according to similarity, for example ‘being strangers’, ‘privacy’, ‘sharing experiences’ and ‘consideration’. The first string of nodes consisted of more than twenty classifications (Appendix G).

The classification occurred without trying to fit the data into pre-existing frames. In doing so, the patients’ experiences with the phenomenon of patient-patient interaction emerged, as they were expressed in the situation (Spradley 1980, Hammersley & Atkinson 2007).

We then compared data bits from one category with those assigned to another to further clarify the categories. This process included ‘splitting’ and ‘splicing’ (Dey 1993). To further detail the classification, ‘splitting’ refined categories by sub-categorisation, for example sub-categorisation of ‘privacy’ into ‘patient room’ and ‘outside patient room’. ‘Splicing’ combined categories to provide fewer categories in the search for greater integration and scope, for instance combining initial categories such as ‘practical help’ and ‘consideration’ into ‘supportive actions’ (Dey).

Classification was an iterative process with a constant movement back and forth. The classification process laid the conceptual foundation upon which interpretation was based (Dey 1993). The process of categorising broke up data into bits, and the sense of how things interacted was lost. To re-capture this information, ‘linking’ and ‘making connections’ of data are important. ‘Linking’ data involves recognising substantive rather than formal relations between categories by identifying the nature of the link between the data bits. Each data bit represents an event in the data.

By ‘linking’ different data bits to each other, patterns of how categories were connected emerged. The ‘linking’ of data was the foundation for an assessment of how categories could be connected.
For example, we linked sharing information to privacy, which resulted in connections to the hospital environment. We also linked sharing information to support, which resulted in connections to patients as care givers. Although we stayed close to the data when creating the themes, the interpretation would not necessarily be recognisable for the participants (Dey 1993).

The process of linking and connection provided themes for further theoretical interpretation. Under ‘Findings’, the empirical themes are presented first and then discussed within a theoretical perspective. Finally, under ‘Summarised discussion’, the findings of this study are discussed in the light of the findings from the qualitative meta-synthesis and additional research within this field.

**Structural concepts**

Several concepts were applied to understand the findings. To understand learning based on patient-patient interaction, the concept of learning from experiences as developed by Jarvis is employed (Jarvis 1992, Jarvis, Holford & Griffin 2003, Jarvis 2009). To understand patients responses to environmental challenges, Altman’s concept of privacy is employed (Altman 1975). To understand personal support, we include the concept of care as an ontological condition in human life (Martinsen 2003, Martinsen 1994, Løgstrup 1975).

**Patient-patient interaction and learning**

Learning is a complex concept which has been studied from a variety of perspectives, but because of the context of this study the informal character of learning and the character of the “teacher” and “student” being fellow patients Jarvis, has been preferred. Jarvis’s approach represents social learning within a cultural context and is concerned with learning as a life-long process during which you learn how to be a person in society (Jarvis 1992, Jarvis, Holford & Griffin 2003, Jarvis 2009). Jarvis’s approach to learning is connected to interaction and provides inspiration in understanding patient-patient interaction. Human lives are interconnected, we interact, and we become persons as a result of living among others (Jarvis 2009). From Jarvis’s theory, concepts such as “life-long learning”, “learning from experience”, “disjuncture”, and “the five learning steps” are employed (Jarvis, Holford & Griffin 2003, Jarvis 2009). The theory is used as a structural framework to understand what happens when patients share experiences, and as a framework to understand how patients learn to live the life of hospitalisation.
The theoretical concepts will be further elaborated when employed in the interpretation and discussion.

Jarvis defines learning as:

“the combination of processes throughout a life time whereby the whole person – body (genetic, physical, biological) and mind (knowledge, skills, attitudes, values, emotions, meaning, beliefs and senses) – experiences social situations, the content of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the individual person’s biography resulting in a continually changing (or more experienced) person” (Jarvis 2009, p. 25).

With this definition as a starting point, this study primarily investigates the practical transformation as experienced in patient-patient interaction. The concepts will be elaborated on in the interpretation and discussion on page 25.

**Patient-patient interaction and the environment**

With inspiration from Altman (Altman 1975, Altman 1973), the concept of privacy regulation in relation to the physical environment was employed. In the 1970s, Altman connected interaction to the environment. The situational context was embedded in his theory and suggests how individuals use the environment to assess personal needs (Altman 1975, Altman 1973). Altman’s theory offers a basis for explaining how people employ environment features to create privacy. From the theories of Altman we employ the concepts of ‘privacy’ and ‘privacy regulation’ (Altman 1975). These concepts will be elaborated on in the interpretation and discussion on page 34.

**Patient-patient interaction and personal support**

Inspired by the work of K.E. Løgstrup, the Norwegian nursing theorist Kari Martinsen has described care as a prerequisite for performing nursing care, but she also describes care as a condition of human existence. Inspired by Løgstrup’s ontological phenomenology, Martinsen points out that human life is relational and that humans are created as fundamentally dependent on human community encounters. Løgstrup maintains that fundamentally humans are created with strong potentials for a community life which includes so-called sovereign life utterances such as trust, sympathy and compassion (Løgstrup 1975).
These sovereign life utterances are expressions of the created ‘human life in it-self’. Life utterances unfold spontaneously and are not results of human consciousness and will. This means that they are more original than their opposites (mistrust, emotional coldness and mercilessness), which Løgstrup sees as secondary phenomena founded in negative ‘cultural human life’.

When Martinsen writes about care, it is often in relation to nursing care. But in this study care refers to patients caring for each other. This is interpreted by employing Martinsen’s ideas, which are inspired by Løgstrup’s phenomenological perspectives on human existence.

From the caring philosophy of Martinsen, the concepts of ‘care’ and ‘generalised reciprocity’ are employed to interpret and discuss care giving among cancer patients (Martinsen 2003, Martinsen 1994). These concepts will be elaborated on in the interpretation and discussion on page 39.

**Trustworthiness**

Four criteria were used in the attempt to ensure trustworthiness: Credibility, transferability, dependability and confirmability (Guba 1981, Lincoln & Guba 1985).

An attempt to ensure credibility (confidence in the ‘truth’ of the findings) was made by triangulation (Patton 1999). Triangulation in methods was performed by a combination of previous research, observations and interviews. The methods complemented each other, especially when it came to comparing statements from participant observation and interviews to ensure understanding from the patients’ perspective. We also used source triangulation by selecting two hospital settings of different size and lay-out, and by including both men and women in the study. In the analysis we triangulated by asking all three authors to check on selective perception and illuminate blind spots, and to include multiple theoretical perspectives to understand and interpret data.

Transferability (showing that the findings have applicability in other contexts). This study does not attempt to form generalisations for all patients with cancer, but the findings may be transferred from one context to another depending upon the degree of ‘fit’ between the contexts concerned.

Dependability (showing that the findings are consistent and could be repeated). This is a qualitative study, so there was no expectation that the findings could be repeated. An attempt was made to ensure consistency by establishing a fieldwork journal, an audit trail, and a thorough methods description. We did not have formalised external auditing; but during data collection the
combination of participant observation and interviews gave us the opportunity to validate data statements.

It was impossible to achieve confirmability (the neutrality of the fieldworker). Instead, systematic reflection on my influence in the field was employed as a research strategy (Spradley 1980, Hammersley & Atkinson 2007). Through critical reflection, an attempt was made to maintain awareness of my impact as a fieldworker.

**Ethical considerations**

Ethnographically inspired fieldwork in a medical setting requires ethical considerations (Hoeyer, Dahlager & Lynoe 2005). In this study we focused on the ethical challenges involved when using participant observation and interviews as methods, and on safeguarding the participants in line with the Helsinki convention (WMA, World Medical Association Inc. 2013).

There is a theory that fieldworkers cannot do fieldwork if they have to have informed consent from all the subjects because it will create disruptions of their social life and make fieldwork impossible to complete (Bosk 2001). In striking contrast, informed consent, confidentiality and anonymisation are the standard approach to protecting informants in medical research (Hoeyer, Dahlager & Lynoe 2005). To protect the individual, this project was registered at the Danish Data Protection Agency 2010-02-10 (Appendix H). Both the Regional Scientific Ethics Committee and the Danish Ministry of Health were informed of the project. Furthermore, permission was granted by the hospital managements, and information sheets as well as an oral presentation were provided (Appendix I).

To get access to the field, the fieldworker often has a “cover story” which is not necessarily the whole truth about the study (Bosk 2001). On the other hand, communicating an understanding of an ethnographic study prior to execution may be difficult (Hoeyer, Dahlager & Lynoe 2005). To accommodate these challenges, the patients were informed of the project by written information sheets and by providing oral individual information in a presentation (Appendix J).

According to Bosk (2001), researchers assume that participants who wish to avoid being observed will find ways to achieve this. In medical studies it is unthinkable to include patients without informed consent (Hoeyer, Dahlager & Lynoe 2005). In this study, permission to observe was achieved by oral consent from the patients, and they had the opportunity to decline participation to the ward nurses or to me. One way of ensuring that patients had the opportunity to decline to participate was by planning the interviews several days in advance. Before carrying out the
interviews, the informed written consent of all the patients taking part in the interviews was obtained (Appendix K).

Ethical considerations also included a respectful, humble and empathic approach to each hospitalised patient with cancer. Patients who were hospitalised for a lengthy period of time and who had consented to take part were assessed daily. If they were perceived to be emotionally fragile or too physically ill, they were excluded from participation until they were considered well enough to participate.

The patients knew that I was a fieldworker with a background in nursing. In my position as a nurse-fieldworker, the patients sometimes asked for advice or for clarification of medical and nursing concepts or results. This dilemma may be connected to the “host group” wanting the fieldworker to participate more actively in the lives of social groups (Anspach & Mizrachi 2007). Primarily, I very delicately declined to answer their questions because I did not wish to be perceived as a member of staff – a role which might have jeopardised the data collection.
Findings

The qualitative meta-synthesis

The overall message that emerged from the qualitative meta-synthesis referred to patients perceiving interaction with fellow patients with ambiguity (article 1). Three core categories emerged: 1) The fellow patient being perceived as an enforced companion; 2) The fellow patient being perceived as an expert on illness and hospital life; and 3) The fellow patient being perceived as a care provider. Interpersonal interaction between hospitalised patients embedded elements of both enforced and volunteered participation.

Typically, interaction was perceived as beneficial and was referred to in positive terms, but the opposite was experienced too. The ambiguity of the relationship clearly emerged in all of the synthesised themes.

The fellow patient perceived as an enforced companion

This theme focuses on the enforced nature of the relationship, and how the patients tried to meet this situation. Being hospitalised was perceived as lengthy, boring and lonely. The company of fellow patients made the time pass and enabled patients to escape from reality for a while. Although interaction was preferred, it was also a cause of distress because it was a burden to be confronted with the illnesses of fellow patients. It was a struggle between closeness and distance to fellow patients. To manage the enforced interaction, patients found strategies that restricted interaction or chose to establish a closer relationship. They also tried to balance accessibility and inaccessibility to control privacy both inside and outside the room.

The fellow patient perceived as an expert on illness and hospital life

This theme focuses on the way in which patients shared information and knowledge during hospitalisation. The primary conversation subject during hospitalisation was the illness. Patients looked at each other to see what was happening as the body revealed signs. They listened to what other patients were informed about, what they talked about, and through conversations they shared information from personal experiences about symptoms, treatments, and life with the illness in general. Patients possessed a specific kind of knowledge derived directly from personal experience. They knew how it felt, and this was highly appreciated by fellow patients. Information was
sometimes a burden and perceived as frightening, depressing and painful too. Some patients withdrew from interaction because of this and others used humour as a tool to manage the situation. Humorous interaction provided some form of mental protection against the unpleasant situation, encouraged important, liberating laughter, and made it easier to endure hospitalisation.

The fellow patient perceived as a care provider
This theme focuses on the way in which patients cared for each other during hospitalisation. The patients’ community was characterised by compassion and care for each other. The experience of being able to support and understand each other made some patients feel that they were esteemed and respected. Interaction with fellow patients gave the opportunity to both give and receive support, and care and caring for others was rewarding. Being met by genuine understanding from fellow patients with similar experiences enabled patients to understand each other. Sometimes support and care was experienced as a burden which was depressing and troublesome. Really understanding and caring for someone was painful, and it hurt to see fellow patients suffer.

The fieldwork
In this section, data from the empirical themes and sub-themes of the fieldwork is presented, interpreted and discussed. The empirical themes represent condensed data with the aim of answering the research questions. The themes are the basis for two articles which are referred to successively. The following sections focus on a large part of the theoretical processing of the fieldwork data.

The empirical themes are presented as they emerged from the patients’ experiences during hospitalisation and interpreted by following relevant theoretical perspectives. In the following presentation, the patients’ uninterpreted statements are used as examples and placed in quotation marks. Although each theme is presented, interpreted and discussed individually, there is a certain amount of overlap between the content of the themes because the themes are intertwined and affect each other. Each presentation of an empirical theme is followed by an interpretation and a discussion. The theoretical concepts are elaborated successively.
Following the presentation, interpretation and discussion of the empirical themes, there is a summarised discussion. This discussion highlights the findings of the fieldwork to be discussed against the findings from the qualitative meta-synthesis and additional relevant research literature.

**Learning from shared experiences**

In this section, the empirical theme concerned with patients sharing experiences is presented. One message from the fieldwork was that hospitalised patients with cancer perceived their fellow patients as resourceful. The patients were perceived as a source of information when it came to the disease, symptoms and hospital life (articles 2 and 3).

**Hospital life**

In general, the patients were kind and forthcoming towards each other, although they were strangers. Some of the patients had not been hospitalised before. Others had been hospitalised before, but were now encountering new strangers. When hospitalised in a multiple-bed room, patients generally met fellow patients who had been admitted previously, patients who may have been hospitalised either for a few days only or even up to several weeks already. But no matter whether patients were ‘newcomers’ (patients with a limited experience of hospitalisation) or ‘experienced’ (patients with experience of several or lengthy periods of hospitalisation), they all needed to learn about the surrounding environment including their fellow patients.

The patients shared their experiences of life during hospitalisation. This included sharing information about how to get around in the hospital; where the bathrooms were located and which bathroom they were allowed to use; which of the cabinets they were allowed to use and which not; when ward rounds were to be expected and which questions to ask the doctor and nurses; when and where meals were served, bedtimes, visiting hours etc.

Both men and women viewed fellow patients as a source of information during hospitalisation, and this emerged in the patients’ expressions during both observations and interviews. Naturally, the patients who had lived some time with the disease had more experience of the disease, treatment and hospitalisation than patients who had just been diagnosed or hospitalised for the first time.

The less experienced patients gained information because they observed what happened, overheard conversations between fellow patients and others, and because they talked about the disease and disease-related subjects with fellow patients. When it came to sharing experiences of hospital life, disease and disease trajectories, the patients regarded the information they received from healthcare
professionals and fellow patients as complementary. The experiences of fellow patients repeated and added clarity to the information received from healthcare professionals: “I think the nurses have told me these things, but it’s as if I didn’t hear what she said. Things are clearer to me now, because my fellow patient has told me about her experiences. I understand it now” (K27). However, the healthcare professionals were not expected to meet the patients’ needs for experience-based information, or regarded as being able to do so. The experiences of fellow patients were an additional source of information.

The primary conversation topic was experiences about life with the disease: “The only thing we have in our head is the disease and what we have to do to get well” (M36). The exchange of experiences was perceived as valuable, not only because these experiences provided understanding of how to live with cancer, but also because they constituted first-hand information. Furthermore, the sharing of experiences encouraged the patients to express a desire to keep on fighting and keep hope for the future. Sometimes, the sharing of experiences also led the patients to surrender to the disease or try to detach themselves from it.

**Women; emotional story-tellers**

The women shared their stories about cancer, and often in detail, from when it appeared and until the present. In the patient community, they learned about the different expressions of the disease: for example symptoms of the disease, and how they could detect it in their body, side effects from treatment, tests and test results, and how the technical equipment worked. For instance, one woman told a fellow patient: “I’ve got this ‘gate’ on my chest. They inject into this instead of into my arms. It’s so much easier and less painful” (K41).

They also shared experiences regarding what to expect from the disease and treatment: how to deal with the emotions related to living with a life-threatening disease; and how to face death. The women’s personal experiences were emotional in terms of content because they often expressed their feelings when sharing experiences. They were very polite listeners and were happy to focus on the details of any topic concerning life with the disease.

The women were observed to copy behaviour and statements that they had experienced in their fellow patients. For example, they used the same sentences and words that they had heard their fellow patients using during rounds or when the nurse was in the room. The women also talked to their fellow patients about which questions to ask the healthcare professionals during rounds.
During rounds, they experimented with different ways of formulating questions. Sometimes they gained the appropriate answer, and sometimes they forgot the question or phrased it differently – resulting in a different answer than that expected.

Afterwards the patients discussed the situation and what they might do differently the next time. In doing so, they acquired information and guidance for the next ward round. Sometimes they succeeded in gaining the appropriate answer, and sometimes they did not. When they failed to ask the question, most fellow patients were very helpful, saying things like “If you forget to ask the question, I’ll remember to ask on your behalf” (K4).

**Men; attentive observers**

The men shared personal experiences primarily derived from overhearing and observation: “We don’t need to talk about the disease all the time, because we can hear everything that’s going on” (M26). Through observation and overhearing they shared the same disease-related topics as the women, but they had fewer disease-related conversations. Their verbal conversations were most often content specific and technical. Here is an example from a conversation between M5 and M9: “I already have my mask for radiation, but…is it like a CT?”(M9), “No, you aren’t locked in like in a CT, but the mask covers your head. Each radiation only takes seven minutes tops, and you get a weekly plan, so you’ll know when to come” (M5).

When the men verbally shared experiences about test results and disease trajectories, they conveyed experiences and information differently from the women. The men did not focus on difficult topics or talk about emotions. Instead, they twisted the conversation with gallows humour and laughed together. They shared their experiences, but it was as if shared information led to a sense of unease which caused them to comment humorously instead of continuing their conversations about the disease.

Like the women, the men were observed to copy the behaviour and statements of their fellow patients. They used the same sentences and words as they had experienced from fellow patients, but they did not discuss what to say or do with fellow patients. Instead they kept their ‘ears and eyes’ open to information. One newly diagnosed patient was very attentive and curious, and listened in on every opportunity: “I’m all ears when they talk. Maybe I’ll get some essential knowledge” (M35).
**Interpretation and discussion**

The empirical data and themes showed that patients shared experiences during hospitalisation. Consequently, you could argue that they participate in a learning community by being together. This learning perspective is the object of interpretation and discussion in the following sections, using Jarvis’s learning theory as an interpretive framework.

**Learning from the experiences of fellow patients**

According to Jarvis, learning represents the process of turning experience into knowledge, skills and attitudes (Jarvis 2003). Every situation in which we interact with others represents an opportunity to learn. When we interact we experience, and through experiences we gain the opportunity to learn and be more knowledgeable (Jarvis 2003, 2009).

According to Jarvis, there are various dimensions of the culture carried by people in social interaction in every new situation. Learning is necessary because we learn ‘how to be’, as well as learning about appropriate behaviour and emotions, learning what is approved and disapproved of, and what is liked and disliked in this exact cultural setting (Jarvis 2009).

The interaction of patients with their fellow patients represents an opportunity to learn what may be expected from living with a life-threatening disease. At the same time, the experiences of patients provided concrete specifications of how to manage the different challenges the disease might involve. With this in mind, the patients learned how to be patients in the company of fellow patients. They learned how to fit in, and adjusted their behaviour accordingly in relation to their fellow patients. The patients valued the experiences of their fellow patients immensely. For ‘newcomers’ they were especially valuable; they looked at and learned from the ‘experienced’ patients, with this interaction helping them to learn ‘how to be’.

According to Jarvis, a great deal of learning in everyday life occurs at the periphery of our conscious awareness, and it is usually unintentionally rather than deliberately embedded within activity, context and culture. In particular, new life situations may promote an adjustment of behaviour (Jarvis 2003, 2009). For instance, when you are hospitalised, this may represent a new life situation in which you need new knowledge to be able to manage life in the hospital environment. The individual might not be aware of the need for new knowledge, but they see and hear what goes on among their fellow patients. What they see and hear represents pre-conscious
learning and may be transformed into knowledge, but not until they find themselves in a situation where they need it. This step from pre-consciousness to consciousness is part of the learning process which is defined by Jarvis (2003, 2009) in five steps:

1) *Remembering*, with a recall of post experiences to relate them to current experiences,

2) *Imitating*, where we copy what we see and what we experience,

3) *Adopting*, where we slightly adjust our behaviour in order to fit into expectations of the life-world

4) *Experimenting*, where you try out likely solutions until one fits, like a trial and error approach

5) *Reinforcing*, which represents a reward before and after action

The data showed that interaction between the patients included observation and listening. The patients *imitated* the words and behaviour of their fellow patients and *adopted* these words and behaviour by *experimenting* with them in a given situation. When the patients did not succeed in *adopting*, they turned to their fellow patients again to share their experiences. When they did succeed in *adopting*, they were *reinforced* and rewarded by the fact that they had achieved their goal.

Once the information had been adopted the patients shared their experiences as their own knowledge with the next patient. In this way, the patients moved from being ‘newcomers’ to being ‘more experienced’ in their interaction with fellow patients.

**Oscillation among responses to potential learning situations**

On the basis of the empirical data, patterns in the responses of patients to shared experiences emerged. These patterns appeared by following Jarvis’s concepts of disjuncture and the learning concepts as presented in the previous section (*Learning from the experiences of fellow patients*).

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1 According to Jarvis (2009), our life-worlds are about practical living in everyday life, so our learning is about action in a pragmatic manner in order to achieve certain goals and behaviours. Most of our everyday learning is action learning.
In the presentation of the patterns, the theoretical concepts are elaborated first and then used successively in the text. The patterns are linked to the characteristics and gender of the patients concerned.

The responses were identified from both interview and observation data. The four responses are:

1) The response of fighting
2) The response of keeping hope
3) The response of non-acceptance
4) The response of capitulation

The sharing of experiences between patients represented a potential learning situation in which the patients seemed to respond to the information according to their conscious level of knowledge about their disease; or as Jarvis would say, according to their individual perception of disjuncture (Jarvis 2009). Their response to a potential learning situation was connected to what they already knew or did not know.

Disjuncture is divided into four levels which occur successively in a potential learning situation: Coincidence, with no conscious experience of a gap; divergence, with a slight gap between expectation and reality; separation, with a larger gap between expectation and reality; and distinction, with a wide gap where we need intensive learning to close the gap, or you have to give up (Jarvis 2009).

The concept of disjuncture offers an explanation of why the patients responded in different ways to a potential learning situation. Differences in the patients’ awareness of their information needs are essential to this understanding. For example, we may experience disjuncture when we enter different cultures and subcultures and lack knowledge about them to manage our daily living. The only way to re-establish a balance in disjuncture is to acquire knowledge, which includes learning from experiences. Re-establishment of the balance in disjuncture is a re-establishment of the individual’s ‘taken-for-granted’ response to situations. Disjuncture represents the gap between the level of consciousness about what information we need to manage any given situation (our expectations), and the reality with which we are actually confronted (Jarvis 2009).
Through interaction with fellow patients, some patients became aware of what they ‘did not know’, while other patients disclaimed information acquired from interaction. For the patients who were conscious of having a need for information, referring to Jarvis, their awareness of disjunction encouraged them to re-establish harmony in disjunction by sharing experiences (Jarvis 2009). For the disclaimers the experience was not conscious, and according to Jarvis they might learn pre-consciously. With this in mind, the constant flow of information among the patients led patients of both sexes to oscillate between four reactions as a response to whatever level of consciousness they possessed about the shared subject.

The constructed responses were identified in both sexes, but they were most evident among the women. The responses were not static, but changed from situation to situation.

**The response of fighting**

“I know I’m ill, but I’m not ready to go yet”. This response indicated that the patients were painfully aware of the severity of their situation. From interaction and from living with the disease, they had learned to be very attentive to body changes. They did not want to surrender to the disease: “I won’t cave in…I’ll fight it again this time” (K43, M30). They recognised symptoms and reactions, they compared the status of their disease with fellow patients, but they already knew that they were very ill.

Experiencing the illnesses of fellow patients and sharing knowledge helped the patients to express that they did not accept that the disease was out of control. From interaction with fellow patients and from living with the disease, they knew that the status of their disease could change rapidly – and that it would not necessarily grow worse. Having learned from their experiences, they chose to believe that fighting was worth it.

Referring to the disjunction concept, these patients were very knowledgeable about the disease; and their response resembled *coincidence* with no conscious experience of learning disjunction – they were the ‘teachers’. They were the ‘experienced patients’ who had lived with the disease for some time, and they were esteemed by fellow patients who acknowledged them as knowledgeable.

In the interaction, the women were very verbal and direct in their statements and expressions, as if they were fighting an enemy – it was an emotional struggle. They argued for fighting by referring to what they already knew from fellow patients and their own experiences. The women were also
story-tellers, and they shared their experiences with less knowledgeable patients in order to help them.

During interaction the men stated that they wanted to fight. This came from an assessment of their situation, like a ‘risk-assessment’. They assessed their situation based on what they had learned from experiences with fellow patients and from themselves. From this assessment, they drew the conclusion that it was worth fighting. The men fought through actions such as finding information about new medication and new treatment, not by talking about it like the women.

The response of keeping hope

“I’m not that ill now, but I might be in the future”. This response indicated an awareness of the situation. From interaction with fellow patients and from living with the disease these patients were insecure about the outcome of the disease, but they remained hopeful: “I’m much better than I was and I still expect to be well again” (M5, K38). When they interacted with fellow patients, they compared their situations. They acknowledged the disease and had learned that it could change rapidly – including changes for the better. Experience from interaction with fellow patients gave hope for better days, and this boosted their hopes for their own recovery. In Jarvis’s terms, they were still learning from the cultural setting (Jarvis 2003, 2009). Their experiences from interaction with fellow patients told them to be realistic in their hopes: to hope for a cure, but still acknowledge the possibility that the disease would grow worse.

Referring to the disjuncture concept, their response resembled both divergence and separation disjuncture. In many cases they knew enough about the disease to respond to different symptoms without a substantial change of knowledge, but sometimes they felt insecure and asked fellow patients about things they had not yet learned. These patients were less knowledgeable than the ‘experts’, but more knowledgeable than the ‘newcomers’. In interaction with fellow patients, they were both ‘teacher’ and ‘student’.

To close the disjuncture gap, the women sometimes asked their fellow patients direct questions. They expressed their hopes verbally and talked about what to do and what to say, and they found solutions together.

The men observed until they acquired the immediate information they needed – otherwise they asked the healthcare professionals. They also expressed their hopes verbally, but it was similar to
the ‘response of fighting’ with the men ‘risk assessing’ and concluding on the basis of their experiences with fellow patients.

The response of non-acceptance

“That has nothing to do with me and my disease”. This response indicated a lack of acknowledgement and awareness of the severity of the situation. In their interaction with fellow patients, these patients kept trying to push the severity of the situation away. These patients did not necessarily feel ill, and they often disclaimed the disease: “No, I’m not like them, I’m not really ill” (M12, K44). They experienced interaction with fellow patients from the spectator’s point of view and felt sorry for them. According to Jarvis’s concept of pre-conscious learning, these patients had not yet learned from interaction with fellow patients; but pre-consciously they gained information that might frighten them.

Referring to the concept of disjuncture, the response of these patients resembled coincidence disjuncture with no conscious experience of a gap (Jarvis 2009). They expressed no conscious need for new knowledge because the experiences of their fellow patients were not related to them. In Jarvis’s terms, they did not know what they needed to know.

The women tried to avoid information about their disease by helping the “unfortunate” patients and by keeping busy, as if they were trying to push reality away. In Jarvis’s terms, they did not know what they did not know (Jarvis 2009). In the situation, they said that they did not want to know.

The men were attentive to information even though they did not necessarily acknowledge the need for it. In Jarvis’s terms, they did not know what they did not know (Jarvis 2009). In the situation they expressed curiosity regarding what the interaction with fellow patients might bring. Referring to the men’s curiosity, it could be concluded that they moved towards divergence.

The response of non-acceptance was different from the other three responses because patients only seemed to learn pre-consciously in the situation. In Jarvis’s terms, shared information might not turn into knowledge until people are aware of the need for it, or until they are ready to accept and understand their situation (Jarvis 2009). In the present study, most of the non-accepting patients were ‘newcomers’ who had just been diagnosed. They tended to find it difficult to accept and understand their new situation.
The response of capitulation

“I give up…there’s nothing I can do”. The response of these patients indicated that they had given up the struggle against the disease, and accepted that the disease had control of their life. This response was observed in two situations: a) as a brief reaction among patients less experienced than themselves, and b) as a brief reaction among more experienced patients.

a) The response appeared when patients had received bad news or following interaction if shared experiences were perceived as overwhelming – but only momentarily – before they shifted to another response (K38, M17). This response was most often observed among less experienced patients.

Referring to the concept of disjuncture, their response resembled a mixture of separation and distinction disjuncture. The reality of the information they received was beyond what they expected and they had a gap in their knowledge. At that moment, their knowledge of the disease from interaction and living was not enough to manage the situation and led to a momentary surrender to the disease.

For both men and women, this was a very brief response which shifted quickly as if they were pushing reality away. The women tried to close the gap by interacting with fellow patients, asking questions, sharing experiences. The men reacted with a momentary withdrawal from the community.

b) The response also appeared among patients who had struggled with the disease for a considerable amount of time and acknowledged that they were dying (K21, M10). These patients knew what to expect, and they had learned from interaction with fellow patients and their own experiences that their symptoms could change rapidly and might easily grow worse. In many cases they oscillated between ‘fighting’ and ‘capitulation’, with capitulation as a momentary response.

Referring to the concept of disjuncture, they were consciously knowledgeable about the disease. Normally, they had no conscious perception of learning disjuncture because they had learned what could be expected from the disease – good and bad. Momentarily, they experienced divergence when they needed a slight adjustment to manage the situation.

The women would express verbally: “I’ve given up”. They dwelt on the thought for a while, sometimes cried, and then they talked to fellow patients about how to handle it. It was an emotional
reaction. The capitulating women were normally the ‘teachers’ and therefore shared their experiences to help other patients. Interaction with fellow patients reminded them of how to manage the situation. According to Jarvis’s concept of pre-conscious learning and learning steps (Jarvis 2009), the women often possessed knowledge from previous experiences, but they required help from fellow patients to remember it.

The men would express verbally: “There was nothing more to be done”. They did not talk to others about their response. Instead they kept it to themselves. According to Jarvis’s concept of pre-conscious learning and learning steps, the men possessed the knowledge from previous experiences and often remembered it without any assistance. Their reasoning was similar to the response of fighting and keeping hope, and involved ‘risk assessing’.

**Environmental challenges to patient-patient interaction**

In this section, the empirical theme regarding the way in which the hospital environment challenged patient-patient interaction is presented. This theme emerged primarily from the empirical data from observations in the hospital context. The predominant environmental factors in hospitals as experienced by the patients were hospital lay-out, hospital routines, healthcare professionals, and fellow patients (article 2).

In contrast to the essentially positive impression of patient-patient interaction presented in the previous sections, a less positive impression is now presented. This impression is connected to the hospital lay-out and to the routines of the hospital, which are controlled by the healthcare professionals. The lay-out and routines challenged the patients’ privacy, and were both perceived by the patients as being beyond their control. The importance of the hospital environment is presented in relation to its impact on patient-patient interaction and how the patients experienced this. Often, hospitalisation was synonymous with new and unknown surroundings, rules and routines. Hospitalisation in multiple-bed rooms meant that the environment forced patients to interact with fellow patients who were strangers to them. Even though the patients were strangers, being hospitalised with fellow patients offered an opportunity for good company and companionship. But it was difficult to withdraw from the attention of fellow patients. The lay-out of the hospital decided where patients could interact, and in multiple-bed rooms it was impossible not to interact with fellow patients. Hospital routines also influenced patient-patient interaction. These routines were
controlled by the healthcare professionals, and for the patients interaction with healthcare professionals had a high priority. Interaction with doctors and nurses was much coveted, but it was also perceived as hard to achieve. In summary, the hospital lay-out and routines were dominant features of the hospital environment that set a framework for patient-patient interaction. In the hospital environment, the patients were temporary visitors who did not make demands that they would make in their everyday lives.

**Withholding information**

The lay-out and hospital routines in multiple-bed rooms forced the patients to share personal information. Most patients did not mind fellow patients overhearing their personal details, but a few patients withheld information from healthcare professionals because their fellow patients were listening. One patient said: “You don’t always get to say all you need during rounds, because you know fellow patients are listening” (K21). The patients accepted this as a part of hospitalisation they could do nothing about.

In a similar way to the empirical data presented in the theme *Learning from shared experiences*, the environment also provided an opportunity to gain information about cancer and hospital life in general which was perceived as positive: “I’m all ears when they talk. Maybe I’ll get essential knowledge” (M35). For the ‘newcomers’, the hospital environment provided information about which they were very attentive and curious. They accepted the hospital conditions without questioning. The ‘more experienced’ patients, who had been hospitalised before or for a longer period, were very aware of the loss of privacy and accepted this as an inevitable condition – although they also objected to it during the interviews.

**Seeking refuge from fellow patients**

Fellow patients were an unavoidable aspect of hospitalisation. Outside the patient room, the lay-out of the two hospitals provided very few opportunities for interaction and refuge fellow patients. One patient said: “I talked to a man in the lounge who had only a few months left. It was tough. I won’t do that again, it’s too hard” (M6). Still, the patient room was the primary refuge, a place where they only had to deal with the fellow patients with whom they were accommodated.

Inside the patient room, the bed was the primary place to seek refuge. The bed belonged to only one patient at a time, and the patient created personal space and privacy by placing artefacts such as the bed curtain, the bed table and chairs around the bed. They also demonstrated their inaccessibility by
focused reading, turning their backs on their fellow patients, or listening to music using earphones. Even so, the patients were extremely dependent on their fellow patients being forthcoming and considerate, because privacy was influenced by the respect of fellow patients for their actions – leading to a physical as well as emotional distance between them.

The lay-out led patients to seek refuge and to physically and mentally remove themselves from fellow patients, but they accepted this as a condition of hospitalisation.

**The room preferences of patients**

Despite the challenges of the hospital environment as presented above, a total of 18 out of the 20 patients interviewed preferred to be hospitalised in a multiple-bed room unless they were too ill to interact. Being hospitalised with fellow patients was experienced positively most of the time. Arguments in favour of multi-bed rooms were: having someone to talk to and spend time with, alleviation from feeling alone, isolated and bored, appreciation of being with like-minded people, sharing knowledge about hospitalisation and disease, and being of use to someone. Two-bed rooms were preferred over three- or four-bed rooms. Additional reasons for this choice were: the ease of interacting with one person at a time, reduced noise level, and more interpersonal interaction.

Arguments against multiple-bed rooms were: loss of privacy and personal control, noise, the enforced company of strangers, withholding of information, and being too ill to interact. Being too ill to interact was the main reason why patients wanted private accommodation. The patients did not want to be a burden on their fellow patients during hospitalisation. They perceived their interaction with fellow patients as challenging at times, but primarily interaction was regarded as positive.

**Interpretation and discussion**

The empirical data shows that the hospital environment offers specific conditions for hospitalisation, and that this environment undoubtedly has an impact on patient-patient interaction. The hospital environment set a framework for how patients could interact and manage hospitalisation and life as a cancer patient. The patients were restricted in their choice of fellow patients because of the multiple-bed room lay-out. The patients did not choose their fellow patients. Instead, the lay-out determined who their neighbours were.
Privacy regulation

The hospital environment made it difficult for the patients to find privacy and refuge from fellow patients. Some patients chose to withhold information because of this. According to Altman (1975), people need different levels of privacy at different times. When people feel crowded during interaction with other people, they try to create personal space by keeping their distance from the others. This distance helps to regulate the desired level of privacy (Altman 1975). And the action involved has a direct influence on interaction because privacy is regulated through interaction.

Privacy regulation involves finding a balance between what you want and what you get when it comes to interaction. According to Altman, people regulate privacy through the regulation of input and output. Input is the impact coming from the surroundings, and output is the impact of the individual on their surroundings. People can regulate this input and output either by deliberately ignoring opportunities for interaction, or by choosing interaction. For both input and output the adequate level of privacy is dependent on reactions from other people and the individual’s ability to regulate their own interaction with the surroundings (Altman 1975).

From the data we found that interaction with healthcare professionals was coveted, and patients often had to wait for it. One way of expressing this is by saying that there was a shortage of this kind of interaction. Altman would say that the level of privacy achieved was less than the level desired due to insufficient input, causing isolation (Altman 1975). Between each interaction with the healthcare professionals, patients waited together and sought the company of fellow patients. In Altman’s terms, by controlling their input they achieved a desired level of privacy by seeking a high level of interaction and being open to it. On the other hand, when the patients needed privacy they used the environment to create personal space or remove themselves from the community. They set up boundaries to achieve adequate input through low interaction. In this way, the hospital routines and the lay-out and artefacts were used by the patients to seek the desired level of privacy.

The patients tried to regulate their interaction with fellow patients by using the artefacts in the rooms, such as chairs, tables, curtains and themselves to provide privacy. They also sought refuge outside the patient room by removing themselves physically from their fellow patients. The patients experienced that they had only little control of the input from the environment. Often, the environmental challenges resulted in a feeling of not being able to create sufficient personal space, with the level of privacy achieved being lower than the desired level.
Acceptance of and resignation to the hospital environment

On the basis of the empirical data, a pattern in patient responses to the hospital environment emerged. The empirical data revealed patterns of how patients accepted the environmental conditions. Three response of acceptance of the hospital environment emerged from the empirical data: uncritical acceptance, acceptance with resignation, and acceptance with silent rebellion. Acceptance is understood as a result of the predominant environmental conditions in which the patients learned how to be patients.

Uncritical acceptance

This response was especially evident when patients were presented with something new, or among ‘newcomers’. Newcomers had little or no experience of hospital conditions, and this resulted in acceptance without questioning because it was perceived as a part of being hospitalised. For example, actions that involved nurses and doctors had top priority among the patients; and patients accepted waiting for them to arrive. The healthcare professionals decided when, the patients had no control over healthcare professionals. In Altman’s terms, the input from healthcare professionals was perceived as insufficient resulting in the achieved level of privacy to be less than the desired level of privacy (Altman 1975). Privacy was not an issue at this point. The hospital architecture, artefacts and routines were regarded as necessary and accepted uncritically.

Acceptance with resignation

This response was especially evident when patients had been hospitalised for some time and had learned about the environmental conditions. At this time, the patients knew from experience that fighting against the predominant conditions was not worth it. They accepted the conditions because trying to do anything about them was perceived as useless: the healthcare professionals controlled the routines, and the hospital lay-out was not changeable. For example, the relinquishment of privacy was accepted as an inevitable result of hospitalisation in a multiple-bed room. Patients expressed their discontent with the loss of privacy; but this was done with silent resignation, and not once during the observations did the patients raise objections verbally. In Altman’s terms, they could not control the level of input from the environment (Altman 1975). Patients accepted the conditions to which they were subjected, and did not express a privacy claim.
Acceptance with silent rebellion

This response was especially evident when patients had been hospitalised for some time or on more than one occasion, and had learned about the environmental conditions. At this time, the patients knew from experience that fighting against the predominant conditions was not worth it, but they rebelled against this thought all the same. For example, patients would remove themselves from the community in protest or withhold information. In addition, they verbally expressed their discontent to me during interviews or to a fellow patient if they knew each other well. They rarely expressed their discontent to the healthcare professionals. In the terms of Altman’s privacy regulation, they could not control the level of input from the environment, but they could control their own output so they did that instead. They silently accepted waiting for healthcare professionals, but rebelled to some extent by turning to their fellow patients for help and support.

According to the patients, an important punch-line is that accepting was an inevitable consequence of being hospitalised, and as time passed they learned how to conform to the predominant hospital conditions. Although the environmental conditions forced patients to interact, the patients rarely said that this enforcement was induced by their fellow patients – it was the hospital environment which forced them to interact with the community.

Personal support from fellow patients

In this section, the theme about support among the patients is presented. This theme emerged from the empirical data. The importance of patient-patient interaction when it came to support and care was expressed through both interviews and observations. Support is presented as expressed by the patients when interacting with each other. They expressed three types of supportive actions: information from shared experience, physical help with daily activities, and emotional support (articles 2 and 3).

Women: emotionally tolerant

The women communicated verbally and observed, equally; and they shared experiences about all facets and emotions related to the disease. For example: “We support each other a lot, we talk, cry, and try to cheer each other up. We talk about everything: how long do you have to suffer before you die, and does it hurt? You never know, do you…we talk about it” (K36). In interaction, the women
provided space for emotional expressions when sharing experiences. By these actions, they defined support.

Emotionally, the expression of both anger and happiness was permitted: they listened to each other and talked about emotionally hard topics such as thoughts about death and dying; they reassured each other through verbally comforting comments; they showed support through physical non-verbal comfort such as a hug, or a gentle touch on the shoulder or hand. They talked about the things that were almost impossible to talk to their relatives about, how to say good-bye to life, and how to cope with the realisation that they only had a limited number of years to live.

Sometimes the patients would help each other by bringing things to each other, such as medicine forgotten in the dining room or drinks from the kitchen. The patient who was most mobile was the one who brought things. It was also the most mobile patient who helped a fellow patient in the middle of the night: “She fell out of the bed. I jumped up to stop her falling on the floor. She might break something, you know, so I helped her to call the nurse” (K44). This patient felt obligated to help because she was perceived as less ill than her fellow patient. It was sometimes hard both physically and emotionally: “It is emotionally hard to look at other very ill people and to hear their stories” (K27).

The women were very aware of, and appreciated, the support of their fellow patients. Each patient was both the provider and the receiver of support, but not necessarily in the same amount. The provision of support encouraged the receiver to share their experiences and emotions. In general, patients who received support subsequently performed additional supportive actions because they wanted to help in the same way as they had just been helped.

The expression of attitudes, concerns and emotions was perceived as a supportive action, but it was also a way to share experiences and learn about life with the disease.

**Men: ‘common decency’**

A discrepancy was identified between the observations and interviews when it came to men being supportive. During observations, the men bonded by talking, laughing, and sharing experiences of their daily lives inside and outside the hospital. The men were very attentive when it came to helping each other with practical issues. One newcomer who did not feel ill said: “I would love to help…they can ask me any day” (M35). As among the women, the most mobile patient was the one who brought things for the others. When asked, the men did not regard their mutual actions to help
each other as support. One patient said: “I wouldn’t call it support or concern, but we sympathise with each other” (M20).

Among the men, sharing experiences and being attentive was regarded as ‘common decency’. They would comment on the progress of their fellow patients because they knew when they were expecting test results, having overheard conversations on the subject. As one patient said: “I ask them (fellow patients) about their progress, and they want to know about me too…we get to know each other” (M26). The men said that ‘common decency’ was related to help with practical issues: “Whenever he leaves the room, he asks if I need anything…extremely positive” (M6). The men did not regard their mutual actions of sharing knowledge, bonding, listening and providing practical help to each other as being supportive.

Emotional outbursts among fellow male patients were rare. When they did occur, the patient in question often withdrew socially, either by leaving the room or by turning his back to the others in his bed. Withdrawal was respected by fellow patients, and fellow patients were often affected by the situation: “It’s so hard for him, I sympathise…he told me that they (the doctors) couldn’t do any more for him…it’s devastating” (M35). The impact of emotional experiences was challenging, and the men used withdrawal and humorous breaks to manage the situation. Humour and laughter were important to the male patients as a way to bond. The men were never observed to be physically supportive like the women.

For both men and women, sharing experiences and being supportive were connected. Sharing experiences created a bond between the patients which led to emotional support. The emotional support bonded the patients even closer and led to more experiences being shared. In this way, the potential of learning through shared experiences had a self-perpetuating effect with emotional support both resulting in and increasing the sharing of experiences and emotions. The process went on until one of the patients left the interaction.

**Interpretation and discussion**

The empirical data showed that cancer patients supported each other during hospitalisation. Support and care are two sides of the same coin, which is why patients may be said to care for each other. The perspective of care is the object of interpretation and discussion in the following section. We employ parts of Martinsen’s philosophy, as inspired by Løgstrup.
The findings showed that the women attached importance to supportive actions such as sharing experiences and emotional support, but with an emphasis on emotional support such as comfort and the opportunity to express emotions.

The men attached importance to supportive actions such as sharing experiences and physical support such as helping with practical issues, but with an emphasis on sharing experience which could provide relevant information for managing the situation. Emotional support was identified in their actions, but they perceived it as ‘common decency’. The men emphasised and talked about supportive actions differently than the women, but this did not mean that the men did not care for each other.

**Giving care**

Interaction and sharing knowledge with fellow patients generated comfort and consideration among the patients. The patients kept their ‘eyes and ears open’, and in doing so they learned about the disease and its trajectory. They were not alone with their disease – they were fellow sufferers, so to speak.

Ordinarily, caring for hospitalised patients is an action which unfolds in the relationship between the nurse and the patient. However, as stated above, care may be viewed as an ontological prerequisite of human existence. According to Martinsen, care is not a ‘function’ belonging to the relationship between the nurse and the patient. Instead, caring is a fundamental human condition. In Martinsen’s terms, this means that human beings are created with a pre-individual and pre-cultural potential for participating in human and caring communities.

Inspired by Løgstrup, Martinsen writes about the sovereign life utterances as fundamental prerequisites for life among human beings. Sovereign life utterances are regarded as sovereign because they are able to spontaneously unfold without conscious control. For example, trust and compassion are not a result of a conscious action, but unfold spontaneously between people in interaction unless their previous experiences preclude their spontaneity.

At the same time, Martinsen emphasises Løgstrup’s thoughts regarding ethical demands. In a phenomenological analysis, Løgstrup suggests that an unspoken utterance appears in relationships between people. This utterance is about meeting each other and taking care of each other. In Løgstrup’s book *The ethical demand* (1975), he emphasises that
“A person never has something to do with another person without also having some degree of control over him or her. It may be a very small matter, involving only a passing mood, a dampening or quickening of spirit, a deepening or removal of some dislike” (p. 25)

It is this phenomenological analysis of the human ontological conditions on which Martinsen builds her caring philosophy (Martinsen 1994). With this in mind, where Martinsen attends to the relationship between the nurse and the patient, it is likely that the relationship between cancer patients encompass care which may be understood by Løgstrup’s phenomenology.

Through interaction, conversation and observation the cancer patients paid attention to and cared for each other. They cared for fellow patients regardless of their perception of them as being stronger or weaker than themselves. In particular, caring was evident among the female cancer patients. They cared for each other altruistically. Among the men, caring actions were also present, though they had a different character than those performed by the women. The empirical data shows that emotional support was perceived as being particularly valuable by the women. The men emphasised sharing experiences and physical help, perceiving this as ‘common decency’.

The fact that the men did not perceive their actions as supportive but instead perceived them as ‘common decency’ does not mean that they did not have a caring relationship with fellow patients. In the terms of Martinsen and Løgstrup, it could be said that sovereign utterances were expressed through compassion, conversation and actions among the men as well as among the women. As mentioned above, the important difference between the men and the women was the way they talked about their actions.

Martinsen (1989) has described care as featuring several actions through which care may be expressed:

1) ‘balanced reciprocity’, where both parties give and take and where the relationship is partly controlled by reciprocity

2) ‘generalised reciprocity’, with primarily one giver who does not expect reciprocity

3) ‘spontaneous caring favours’, which may be more or less random and may be provided for anyone
4) ‘personal favours’, which cannot necessarily be characterised as caring

In Martinsen’s terms, the support among the women as well as the men resembles ‘generalised reciprocity’. Assuming that the men’s support is to be perceived as ‘common decency’, it could be said that this type of care resembles ‘personal favours’. However, the observations left us in no doubt that the men’s supportive actions can be characterised as care and ‘generalised reciprocity’.

On the basis of the above, it could be concluded that the caring actions of cancer patients resemble what would normally be expected from nursing care. In this way, the care among patients significantly complements the care performed by the nurses – in particular because the patients spend far more time together than they spend with the nurses or other healthcare professionals, as mentioned in the introduction.

In addition to this, the expectations of support and care which patients, as well as society, expect in relation to the work of nurses do not apply to the patients. With this in mind, it could be claimed that the unexpected care that the patients provide for each other is (to a higher degree than the care which the nurses are expected to provide) in line with Løgstrup’s phenomenological analysis of the fundamental human conditions with his considerations of sovereign utterances and the spontaneous actions they unfold.
**Summarised discussion**

In this discussion, results from the qualitative meta-synthesis and from relevant research literature are discussed to reveal similarities and differences in relation to the findings of the fieldwork. Through the inductive process, patient-patient interaction turned out to be of a complex nature containing several intertwined aspects which influenced it in various ways. We address the aspects of learning from information, environmental conditions influence on patient-patient interaction and the gender perspective in the following discussion.

**The complex nature of patient-patient interaction**

Patient-patient interaction turned out to be of a complex nature. Complex because it was enforced but because it also promoted learning from experiences, support and care. Complex because patient-patient interaction was challenged by predominant conditions belonging to the hospital environment which caused the patients to both withhold and share information, but also forced the patients to accept the situation. Complex because patients preferred accommodation in multiple-bed rooms despite the challenges of the predominant hospital conditions.

Results from the qualitative meta-synthesis showed that the patients were ambiguous in the perception of their community with fellow patients. Both positive opportunities and stress were emphasised, with the sharing of experiences accentuated as most giving (Isaksen & Gjengedal 2000, McCaughan, Parahoo & Prue 2011). The results from the empirical fieldwork elaborated on these results. The way the patients perceived the ambiguity was much less evident. As in previous research, stress which affected patient interaction was identified. But unlike the results from previous research, patient-patient interaction was primarily perceived as positive, although the hospital lay-out, artefacts and routines were challenging and were perceived as stressful with regard to patient-patient interaction.

Despite the environmental challenges and despite the fact that the cancer patients were ‘forced’ to spend time with strangers at a time of great vulnerability in their lives, the overall picture is that patients perceived interaction with their fellow patients as extremely positive. Fellow patients were resourceful fellow sufferers when it came to information and support during hospitalisation. The research literature in this field contains a great deal of discussion of what is best for patients when it comes to accommodation facilities during hospitalisation: multiple-bed rooms or single-bed rooms (Ulrich & Zimring, C 2004, Frandsen et al. 2009, Florey, Flynn & Isles 2009, Williams & Dawson...
& Kristjanson 2008, Lorenz 2007, Rowlands & Noble 2008). This study contributes to this discussion with findings of the room preferences of hospitalised patients and the reasons for their choice. The empirical data showed that 18 out of the 20 patients in this study preferred accommodation in multiple-bed rooms. This choice provided the patients with access to the experiences of their fellow patients without this being their initial intention.

**Personal experiences and professional information**

The patients acted as informal ‘experts’ from whom fellow patients could learn about life as a cancer patient and life during hospitalisation. Interaction with fellow cancer patients as a means of learning does not seem to have been investigated empirically. However, a few studies have investigated the preferences of cancer patients when it comes to learning about topics related to cancer in an outpatients care setting. According to Chelf et al., 66% of the patients asked preferred to learn about their illness through interactive, interpersonal communication with their favourite physician. Other preferred methods included brochures (33%), discussions with nurses (34%), self-selected print media from information displays (20%), and talking with other patients with cancer (14%) (Chelf et al. 2002). The men and women in our study did not express any learning preferences. Instead, they valued both information from healthcare professionals and information from personal experiences derived from fellow patients. Although the sharing of experience has not been recognised as learning in previous research, it is recognised as a way to acquire information about the disease (McCaughan, Parahoo & Prue 2011, Rotegard, Fagermoen & Ruland 2011). This is in accordance with the findings from the qualitative meta-synthesis.

One important finding was that information provided by the personal experiences of fellow patients summarised and added to the information provided by healthcare professionals. The sharing of ‘expert knowledge’ among patients was perceived as a resource. Isaksen & Gjengedal (2000) have suggested that some patients did not entirely trust information given by the healthcare professionals, leading them to seek verification among fellow patients. The patients in this study never expressed distrust in the information acquired from healthcare professionals. But shared information among the patients elaborated on and explained information acquired from healthcare professionals.

The patients in this study felt that sharing their experiences was a valuable way to gain information. The fact that information derived from patient experiences is perceived as valuable has been indicated in the research literature. According to Maddock’s investigation of online information needs of cancer patients (Maddock et al. 2011), patients wanted information to tell them how the
disease was likely to impact on their everyday lives and the lives of people close to them. The nature of the information in demand, according to Maddock’s study, is similar to the information shared by the patients in our study.

According to reports from the Danish Health and Medicines Authority (2000, 2005, 2010) and research sponsored by the Danish Cancer Society (Grønvold et al. 2006, Sandager et al. 2011), satisfying the information needs of patients is a perennial problem. From a caring point of view in nursing, it is a huge problem if the information needs of cancer patients repeatedly remain unsatisfied. According to the findings of this study, the patients find solutions to their challenges and hereby accommodate their needs in interaction with fellow patients. Sharing experiences has the potential for learning, so learning is a part of patient-patient interaction during hospitalisation among cancer patients.

**Withholding information**

Findings from the qualitative meta-synthesis primarily connected lack of privacy issues to patient-patient interaction. In the fieldwork, the findings connected lack of privacy to the predominant hospital conditions and elaborated on the impact and connection of these conditions with regard to patient-patient interaction.

We found that patients withheld information when they talked to healthcare professionals because they knew fellow patients were listening in on conversations in the patient room. Withholding information may be important because the healthcare professionals depend on information from the patient to plan treatment and care. Furthermore, patients may not gain the information they need if they are reluctant to ask healthcare professionals relevant questions. Several studies have found that if patients’ information needs are unmet, the concomitant uncertainty causes control to decrease (Williams, Dawson & Kristjanson 2008, Maher & de Vries 2011, Andreassen et al. 2006); but no studies including cancer patients withholding information have been found. One study revealed that patients in acute care settings withheld information because fellow patients could overhear their conversations (Barlas et al. 2001). In another study (Malcolm 2005) patients were careful about what they said because they could not prevent their fellow patients from overhearing their conversations, a conclusion which matches the findings of our study.

Also, withholding information was connected to accept of the environment conditions – especially acceptance with rebellion. Acceptance was not addressed in the qualitative meta-synthesis, but a
few studies have found that patients ‘adapt’ to hospitalisation conditions or ‘resign themselves’ to them. However, this issue has not been discussed further (Isaksen & Gjengedal 2000, Wilson & Luker 2006, Rydahl-Hansen 2005, McIlfatrick et al. 2007). If patients withhold information important to treatment and care, there may be consequences in terms of their hospitalisation experience, well-being and information needs because physicians and nurses are highly dependent on information from patients to meet the patients’ needs.

**Gender differences**

In this study, some gender differences in terms of learning and support among cancer patients were identified. Although gender was not a primary focus area of this study, the data revealed findings which could not be ignored. Gender differences have been investigated among patients with cancer from different angles. In a study of patients with colon cancer, gender differences were identified in patients’ religious coping strategies (Murken et al. 2010). Another study investigated gender differences in young men and women’s accounts of chemotherapy-induced alopecia (Hilton et al. 2008). A number of studies have performed gender-specific investigations of women’s experiences with cancer as well as men’s experiences with cancer (Vaartio, Kiviniemi & Suominen 2003, Warren 2010, Denieffe & Gooney 2011, Morrell et al. 2011). Also, gender-specific investigations of support in support groups have been identified (Oster et al. 2012, Fitch et al. 2008). We found no similar studies of patient-patient interaction that elaborated on gender differences, and the findings of the qualitative meta-synthesis did not reveal any such differences either.

**Gender differences in learning**

When patients learned from experiences, some gender differences were identified. The women learned from the emotional stories of fellow patients. Although they shared experiences through observation and overhearing, they largely learned through verbal conversations. They also oscillated between different responses to learning, and their reactions were most often complemented by their feelings. In contrast, the men largely learned from observation and overhearing and less through verbal conversation. The men were also oriented towards the technical information and details of treatment and symptoms, and their responses to learning were often accompanied by a ‘risk assessment’.
Jarvis’s theory of learning does not specifically include gender differences in learning, but he suggests that gender (as well as social class, ethnic background and age) influences the way we perceive and respond to learning situations (Jarvis 2003). In the research literature, we found no studies which investigated gender differences in experiential learning among hospitalised cancer patients. However, gender differences in learning have been identified in studies of experiential learning styles in education (Kulturel-Konak, D’Allegro & Dickinson 2011, Heffler 2001). Heffler (2001) found that women had a concrete learning approach: they preferred an experienced-based approach with hands-on experiences to learn; and they made feeling-based judgements, were people oriented, and felt comfortable with ambiguity. Conversely, the men had an abstract learning approach: they had an analytic approach to learning with logical and rational orientation, and they respected authority. Comparing our findings with the Heffler’s findings they seem similar for both men and women. At the same time, our findings differ from the studies mentioned here because they provide concrete examples of what cancer patients learn from each other and the importance of interaction when learning.

Gender differences in personal support

When patients supported each other, some gender differences were identified. The women were emotionally tolerant and supported each other through conversation and physical touch. They paid attention to emotional support and were both the receiver and the giver of support, but without demanding any kind of reciprocity. The men regarded support as shared information and help with daily trivialities. They also supported each other emotionally through bonding and conversation, but they perceived this as ‘common decency’ and not as support. The actions of both men and women resembled care.

As stated at the start of this section, studies of cancer patients and support groups have performed gender-specific investigations of both men and women, but only a few studies have identified gender-related comparisons (Gray et al. 1996, Seale, Ziebland & Charteris-Black 2006). Seale et al. (2006) compared men and women by looking at how they talked in online support groups. Among the women, they found a use of words such as “help” and “supportive”; and found that women were explicit about their feelings. Among the men, no keywords were found related to the notion of support, and they found that men limited the expression of feelings to “concerned” or “embarrassed” (Seale, Ziebland & Charteris-Black 2006). Comparing our findings with the findings presented from support groups, they seem similar for both men and women. However, our findings
elaborate on and complement the vast selection of comparative gender studies by contrasting gender differences among patients with cancer. Additionally, the findings provide an understanding of how the patients experience support from fellow patients, as well as highlighting the importance of support from fellow patients during hospitalisation.
Limitations of the study
This section presents a few reflections regarding the rigour and limitations of the study with regard to the qualitative meta-synthesis and fieldwork.

The qualitative meta-synthesis
A valid, scientific qualitative method was required for the inclusion of studies. We used the guidelines of Sandelowski & Barosso, which have been widely used by researchers in health sciences. The suitability of studies was determined on the basis of the relevance of the findings, and studies were not excluded because they used incomparable methods (Sandelowski 2004). The variable different qualitative methods in the selected studies might not be comparable, but the findings seemed to be.

One weakness of this meta-synthesis may be the rather small number (n = 7) of studies included. Scientists do not agree on the exact number of studies required for adequate elaboration. Bondas & Hall (Bondas, Hall 2007a, Bondas, Hall 2007b) recommend the inclusion of 10-12 studies, while Sandelowski et al. (Sandelowski, Docherty & Emden 1997) argue against using excessively large sample sizes. An excessive sample size may impede deep analysis, and threaten the interpretive validity of the findings (Sandelowski, Docherty & Emden 1997). We included seven studies, which may be enough to elaborate on important and general themes.

The inclusion and exclusion criteria for the literature review could have been different, thereby providing a different result. The inclusion of the perspective of nurses regarding the significance of patient-patient interaction might have added extra detail to the results. A few studies were excluded even though they examined patient-patient interaction during hospitalisation. This was because they used a quantitative method approach – which might of course have contributed supplementary or amplifying knowledge.

The fieldwork
Reflections on purposeful sampling: Reflection was performed during observation in order to decide which patients would be ‘information-rich’ and hence included for interviews. Inclusion criteria were: Men and women with cancer who were able and willing to talk about hospitalisation with fellow patients, Danish speaking, age >18. Patients perceived as ‘information-rich’ during observation did not necessarily turn out to be so in the interviews. Nor was the converse true.
Reflections on data saturation: Ahead of the fieldwork, it was impossible to decide how many interviews to perform before achieving data saturation. After six to eight interviews, patterns began to emerge and several themes seemed to be consistent. Bearing the time perspective for the study in mind, the fieldwork ended after 20 interviews with an equal grouping of men and women. As a qualitative study, the number of participants was adequate (Kvale & Brinkmann 2009). It could be argued that more interviews would generate more knowledge. However, Kvale & Brinkmann argue that beyond a certain number of respondents you achieve no new relevant data (Kvale & Brinkmann 2009). In this study, less and less new knowledge appeared in the latter phases of data collection. We estimated that data saturation was achieved.
Conclusion

The aim of this project was to explore the interaction of hospitalised patients with their fellow patients.

The qualitative meta-synthesis showed that interaction between hospitalised patients was perceived ambiguously. Fellow patients were perceived as enforced companions, but also as experts on illness and hospital life, and as care providers. Social interaction among hospitalised patients embedded elements of both enforced and volunteered participation. Typically, social interaction was experienced as giving and was referred to in positive terms, but this was not always the case.

Findings from the fieldwork supplemented findings from the qualitative meta-synthesis and provided new knowledge about interaction between cancer patients. The company of fellow patients was preferred, and patients perceived interaction as valuable and regarded their fellow patients as a resource to turn to for information and support. Interaction with their fellow patients helped people to learn about life with cancer based on the personal experiences of others. Learning from experiences led patients of both sexes to oscillate between four general responses to potential learning situations: fighting, keeping hope, non-acceptance, and capitulation.

Learning from experiences and being supportive were interconnected. Sharing personal experiences provided information and promoted support among the patients, and supportive actions promoted more sharing of experiences. In this way learning and support were self-perpetuating. Gender differences were identified, with men being oriented towards supportive actions including factual information and help with daily activities. The women were more oriented towards emotional support. Through supportive actions the patients cared for each other.

The predominant conditions of the hospital environment appeared to be of importance to patient-patient interaction. The hospital environment imposed conditions that caused loss of privacy. Refuge from fellow patients was hard to achieve, and the fact that personal conversations were overheard by fellow patients caused some patients to withhold information from healthcare professionals. Nevertheless, patients accepted the conditions imposed by the hospital environment.

The environmental conditions had a negative impact on patient-patient interaction, but even so they did not matter much to the patients. Or perhaps they regarded the benefits of interaction with their fellow patients as more important than the negative impact of the hospital environment. This was
reflected in the patients’ room preferences, with 18 out of 20 preferring accommodation with fellow patients in a multiple-bed room.
Perspectives and implications for practice

The findings of this study elaborate on and contribute new knowledge about interaction between hospitalised cancer patients. The findings constitute research-based knowledge which could be applied to the everyday work of nurses in clinical practice, and in the training of nurses. Until now patient-patient interaction has not been acknowledged as a specific focus area in need of attention during the training of nurses in Denmark. Increased awareness of the importance of patient-patient interaction when training nurses might result in increased awareness of the significance of patient-patient interaction in nursing practice.

The idea that patients can be care givers may be something of a challenge to nurses in nursing practice, especially as nurses in general are perceived as primary care givers. The fact that the patients engage in interaction as care givers should be regarded as an extra resource in nursing. The care provided by patients does not replace the care provided by nurses, but it does mean that the concept of care could be expanded to accommodate this particular phenomenon. Patients share their personal experiences whenever they are together, and they learn from each other even when they have already been informed by the healthcare professionals. Learning from the experience of fellow sufferers is a way to acquire complementary information, and this is important to patients. Nurses need to address the differences in the information provided by healthcare professionals and fellow patients, and to acknowledge patients as resourceful information givers.

The gender differences might challenge the healthcare professionals’ ability to individualise information and support. The awareness of such differences is only one step towards meeting the patients’ needs. It is essential to improve knowledge and skill in order to meet the male patients’ needs as well as the female patients’ needs. More research focusing directly on gender-specific and gender-related comparison in interaction between hospitalised patients is needed.

Modern nursing focuses a good deal on protecting the privacy of patients, and single-bed rooms are regarded as essential with a view to achieving this end. However, the patients’ needs have been proven to be of a more complex nature in our study. Ideally, a hospital design with flexible rooms might be the best solution in the future. We may build evidence-based physical environments to promote well-being and healing in hospitals, but beneficial interaction among hospitalised patients is a vital aspect of any healing hospital design. Referring to our findings, 18 out of 20 cancer patients preferred accommodation in multiple-bed rooms in the company of fellow patients. This
finding is a challenge to the planning and building of new hospitals in Denmark, where new hospitals are designed to incorporate a majority of single-bed rooms. We may need further investigation of patients’ wishes and needs during hospitalisation in this field.

The fact that patients sometimes withhold information from healthcare professionals constitutes an urgent problem because the withholding of information may have consequences for care and treatment, and ultimately for the patients’ well-being and experience of hospitalisation. Hopefully, our findings will contribute to an increased awareness of the complexity of patients’ experiences during hospitalisation.
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Summary
The study presented here sets out to investigate the importance of patient-patient interaction between cancer patients in a hospital setting. When patients are hospitalised in a two-bed or multiple-bed room, they spend a significant amount of time together. Only a few studies have investigated the importance of interaction between hospitalised patients with cancer.

Methods: A qualitative design was applied. Firstly, by doing a qualitative meta-synthesis we accumulated previous knowledge. Secondly, qualitative fieldwork was performed with participant observation and semi-structured individual interviews inspired by ethnography. Data were collected from patients hospitalised in two oncology wards in two Danish hospitals. A total of 85 participants were observed, with ten men and ten women participating in interviews. Inductive thematic analysis strategies were applied.

Findings: The qualitative meta-synthesis showed that interaction between hospitalised patients was characterised by ambiguity. Fellow patients were perceived as enforced companions – but also as experts on illness and hospital life, and as care providers.

The fieldwork showed that hospitalisation with fellow patients promoted the potential for learning by sharing experiences with fellow patients. Learning from the exchange of experiences with fellow patients provided an understanding of the disease because information provided by the personal experiences of fellow patients complemented and expanded on information given by healthcare professionals. Sharing their experiences meant that patients of both sexes oscillated between various responses to learning situations. Sharing experiences also promoted support among the patients. Gender differences were identified in both learning and support.

The predominant conditions of the hospital environment caused strain but also offered the possibility of good company and support from fellow patients. Refuge from fellow patients was hard to achieve, and the fact that personal conversations were overheard by fellow patients caused some patients to withhold information from healthcare professionals. Nevertheless, patients accepted the hospital environment.

Conclusion: Findings from the fieldwork provided new knowledge about interaction between hospitalised cancer patients. Patients regarded interaction with fellow patients as positive and as a source of information, help and emotional support. In spite of the strain imposed by the hospital environment, 18 out of 20 patients preferred multiple-bed rooms with the company of fellow patients.
Danish Summary

Formålet med dette studie var at undersøge betydningen af kræftpatienters samspil med medpatienter under indlæggelse. Når patienter er indlagt på en flersengsstue, bruger de det meste af deres tid i samspil. Der har indtil videre kun været få studier, som har undersøgt betydningen af dette samspil.


Hospitalsmiljøts indretning og rutiner var forudbestemte, og resulterede til tider i en emotionel belastning for patienterne, men miljøet tilbød også mulighed for godt selskab og støtte fra medpatienter. Det var svært at flygte fra medpatienternes selskab, og da patienterne vidste, at medpatienterne kunne høre alt hvad der foregik, valgte nogle at tilbageholde information i samtaler med sundhedspersonalet. Alligevel accepterede patienterne hospitalets vilkår som uundgåelige.

Konklusion: Fund fra det empiriske feltarbejde udvidede vidensgrundlaget om kræftpatienters sampil under indlæggelse. Hospitaliserede patienter med kræft oplevede overvejende samspillet med medpatienter som positivt og som en ressource til information, fysisk hjælp og emotionel
støtte. På trods af belastninger påført af hospitalsmiljøet, foretrak 18 ud af 20 adspurgte at være indlagt på en flersengsstue i selskab med medpatienter.
Article 1

Title: An ambiguous relationship – a qualitative meta-synthesis of hospitalized somatic patients’ experience of interaction with fellow patients

Aim: The aim of this study was to provide a clear view of existing knowledge regarding patients’ significance to fellow patients during hospitalization.

Method: Sandelowski & Barroso’s approach to qualitative meta-synthesis was selected and systematically used for collecting and assessing findings from qualitative studies. Data consisted of seven qualitative studies published as one book, four scientific articles and two doctoral thesis’ from Scotland, UK, Norway and Denmark. The analysis and synthesis was conducted with inspiration from both Sandelowski & Barroso and Ian Dey’s approach to qualitative data analysis.

Results: The qualitative meta-synthesis resulted in the heading An Ambiguous Relationship under which three core categories illustrate the hospitalized patients’ different interaction roles. The core categories were: 1) The fellow patient experienced as an enforced companion, 2) The fellow patient experienced as an expert on illness and hospital life and 3) The fellow patient experienced as a care provider. Each core category was elaborated through several sub-categories. Social interaction among hospitalized patients embedded elements of both enforced and volunteered participation. Typically, the social interaction was experienced as giving and was referred to in positive terms but recurrently, the opposite was experienced too. The ambiguity of the relationship clearly emerged in all of the synthesized themes presented in this article.

Implications for practice: Hospitalized patients experienced interaction with fellow patients to be of great significance. We suggest that knowledge of patients’ interaction is to be included in the nursing education; and that nurses reflect on how this knowledge may be implemented as a part of caring in nursing.

Keywords: Fellow patients, patients experiences, qualitative meta-synthesis, social support, patients’ interaction, peer-support, caring, self-care, social comparison
INTRODUCTION

The significance of social interaction is commonly discussed and intensively studied as a substantial concept in the nursing profession. Interaction is inherent to nursing care and acknowledged as such (1,2). The earliest empirical studies on interaction in nursing were published in the 1950’s and 1960’s. The studies focused specifically on the nurse’s behavior in the nurse-patient interaction both in psychiatric and somatic wards (1,3-6). In recent years, research studies have expanded to examine interaction between nurses, patients and doctors (7,8), parents (9), children (10), and relatives(11,12). Also, study designs have moved from the nurses’ to the patients’ perspective (13-15)

The patient-patient relationship have been studied in psychiatric settings since the early 1960’s(16-18); but interestingly, social research conducted in hospital settings has prioritised to examine interaction between patients and doctors, patients and nurses, and patients and relatives over patient-patient interaction (19). ‘Interesting’ as Album (14) stated that patients spent approximately 90 % of their time in company with fellow patients during hospitalization. Conclusively, only 10 % of the patients’ time was spent with health care professionals.

Several studies have investigated patients’ social interaction in somatic contexts between discharged patients and fellow discharged patients, and health care professionals in support groups(6,20,21).Van Hastregt et al (22) documented that patients with a chronic disease, and severely ill patients in particular, benefitted from participation in self-help groups, talking to people with similar illnesses. In contrast, a similar study indicated that patients undergoing diagnostics did not discuss their illnesses, and experienced no social support from fellow patients, although they participated in the process of understanding and handling their situation by talking with each other (23).

Studies investigating patients’ experience with illnesses included sporadic elements of patients’ interaction in hospitals in their findings. Interaction with fellow patients was experienced as both positive and negative (24). Patients and fellow patients shared information and experiences about the illness (25-27), they talked and spent time together (28), and they showed charity to fellow patients who were experienced more in need than themselves (29).
Studies investigating social comparison between patients with similar illnesses during hospitalization and in support groups concluded that patients compared state of health both upwards - comparison to a fellow patient in a better state than oneself - and downwards - comparison to a fellow patient in a worse state than oneself (30-32). Upwards comparison could lead to patients feeling sad and depressed, whereas downwards comparison could contribute to well-being in patients’ suffering from serious diseases (30). Patients compared experiences related to prognosis, treatment, and coping with the disease. Though, some patients preferred to avoid contact with fellow patients with the same disease to promote downward comparison (32). In opposition, Legg et al (31) suggested that peer support programs could help patients, who felt threatened by their diagnosis, by maximizing exposure to potential upward comparison targets. Fellow patients better off than one-self became role-models.

Investigating surgical patients, fellow patients’ effect on pre- and post-operative anxiety and recovery, studies indicated less post-operative anxiety and shorter post-operative stays for pre-operative patients, who shared occupancy with postoperative roommates (33-35).

Similar for all of the reviewed articles above are the lack of attention towards patients’ lived experience of interaction with, or relationship to, fellow patients during hospitalization. Existing research is primarily performed with patients with cancer but patients with other diagnosis seem to have similar interaction patterns. Exploration of patients’ dyads during hospitalization from the patient’s perspective is rare.

The aim of this qualitative meta-synthesis is to provide an overview, from selected publications, of knowledge about patients’ significance to fellow patients during hospitalization.

METHOD

Meta-synthesis is a systematic approach used for collecting, analyzing and synthesizing findings from qualitative studies (36). Numerous scientists have contributed to a variety of methodological approaches used in meta-synthesis which have resulted in a profound toolbox of guidelines for approaching and performing meta-synthesis (37-39). The attention to qualitative meta-synthesis has
promoted ongoing discussions of methodological models and diversities among scientists, and elucidated multiple issues related to performing qualitative meta-synthesis (40-42).

In 1997, Sandalowski claimed that researchers conducting qualitative studies did not accumulate knowledge gained from their studies (43). Nor were the findings systematically processed in order to be accessible for clinical nursing practice (40,44,45). However, in recent years, the number of published meta-synthesis has increased, and the method stands out in the pursuit of condensing knowledge from qualitative studies (46-48). Meta-synthesis is perceived equivalent to the quantitative systematic review or meta-analysis; but instead of quantifying data the meta-synthesis aims to provide useful research-based knowledge by facilitating accessibility for clinicians, researchers and policy makers (37,49,50).

The methodological approach employed in this study is based on Sandelowski & Barroso’s (36,51,52) approach defining meta-synthesis as “a process and product of scientific inquiry aimed at systematically reviewing and formally integrating the findings in reports of completed qualitative studies” (36), p. 17).

Data collection

A systematic literature search was performed in the online databases; Bibliotek.dk, CINAHL, PubMed (Medline), CSA (ProQuest). The search time period was from 1950 to 2011. The key search term was fellow patients. Because fellow was widely used in studies which examined eye diseases, for example fellow eye, several complementary search terms were applied, such as roommate, camaraderie, patient-patient, interaction, peer-groups, support groups and social comparison. The initial search comprised 10267 texts. When the search terms exceeded more than 1000 hits, they were combined with delimiting search terms such as qualitative study OR patients experience, adults>18, and abstract included. This reduced the initial number of text to 5979. In the attempt to catch relevant literature, the search was very broad as the audit trail shows (Table 1).

Firstly, a selection was performed by reviewing report headlines. When unable to decide inclusion or exclusion on headlines alone, abstracts were read searching for key terms. This step delimited the number of texts dramatically to 50. Secondly, by reading abstracts and key words, the 50 texts were
delimited to 21. Thirdly, “berry picking” was performed on the 21 texts by examining cited citations and references. As in the first step, when unable to decide to include or exclude on headlines alone, abstracts were read. This resulted in additionally five texts to a total of 26 texts. Fourthly, the 26 texts were read in full text and assessed according to the inclusion and exclusion criteria.

Inclusion criteria were: studies using qualitative methods; studies with the patients’ perspective of hospitalization with fellow patients; studies published as books or book chapters, as unpublished theses or as scientific peer-reviewed articles including abstracts. Publication languages: Danish, Swedish, Norwegian, English and German.

Exclusion criteria were: quantitative studies; studies with children or adolescents <18 years, studies in psychiatric settings and studies with findings of mainly personal descriptive and narrative nature. This step excluded nineteen texts.

Seven texts were included; four scientific articles, two doctoral thesis and one book chapter (Table 2). Finally, all seven texts were assessed using elements of Sandelowski & Barrosos’ (36) reading guide to appraise research rapports. The guide provided a systematic approach to identify what could be found in the texts, no matter where it was located, and how it was presented (36,51) . In particular, focus was on locating text findings because these were essential for the meta-synthesis’s contribution to knowledge. Also sampling strategies, data management, discussion, and implications and techniques for maximizing validity were essential for quality assessment, and ultimately for inclusion. The research group participated equally in the discussion, selection and evaluation of the steps presented. An audit trail documented and explicated procedural moves and decisions. Refworks was used to manage references.

Data analysis
The findings were categorized using Ian Deys’ (53) method for qualitative data analysis. To achieve both a wide and deep understanding of hospitalized patients’ experience of interaction, the findings were conceptualized by constantly comparing fragments of text to identify themes both within and across the findings with a focus on similarities and differences. To secure validity according to the original understanding, a constant movement between fragment and original text was embedded.
Furthermore, preliminary themes were organized into more elevated interpreted themes which synthesized a new understanding of the original data.

The qualitative data analysis computer software, NVivo9, was used to organize findings. The software allows users to classify, sort and arrange information and examine relationships in the data (54). Analysis of findings resulted in several themes focusing on the patients different interaction roles during hospitalization. These are an interpretation of meanings beyond the individual findings of the included studies.

FINDINGS - AN AMBIGUOUS RELATIONSHIP

The analysis resulted in three categories: The fellow patient experienced as: 1) an enforced companion, 2) an expert on illness and hospital life and 3) a care provider, all illustrating significant interaction roles of fellow patients.

Social interaction among hospitalized patients embedded elements of both enforced and volunteered participation. The patients had no influence on the wards’ patient composition in the patients’ room. They could not avoid meeting other patients and they were enforced to interact with whomever they were placed with (55). Hence, the initial interaction was experienced ambiguously with both positive and negative emotions (14,15). Interaction was experienced as a meeting between strangers in a hospital context which might be unfamiliar to the patients. Furthermore, they were ill and uncertain of how the disease would influence their life and future. Despite the enforcement of the arrangement and the uncertainty of the situation the patients interacted continuously. Findings indicated that most patients interacted willingly; but also because they felt awkward not to interact with persons they had to spend so much time with; also they believed it to be rude not to interact (14,15). Typically, the social interaction was experienced as giving and was referred to in positive terms but recurrently, the opposite was experienced too. The ambiguity of the relationship clearly emerged in all of the synthesized themes presented in this article.
The fellow patient experienced as an enforced companion

This theme represents issues regarding the enforcement of the relationship, and how they tried to meet this situation. The theme is divided in two subthemes: Distance and closeness and Balancing accessibility and inaccessibility.

**Distance and closeness**

Patients usually thought of interaction with fellow patients positively (14,15,56,57). The patients experienced themselves as comparable equals, and initially, they wanted to interact with each other (14,15,55-57). The hospital stay was filled with a large quantity of inactivity and latency (15). This was experienced as lengthy, boringly, and lonely. Spending time with fellow patients was a good diversion which dissipated the boredom and loneliness (14,15,56,57). The fact that latency was enforced during hospitalization apparently promoted patients to interact. They needed to make time pass anyway. In the company of fellow patients, patients could tone down the feeling of being ill (14,15,56). The close interaction provided an opportunity to flee from reality for a while. Interacting with like-minded in the smoking room created a sort of silent revolt against the illness. Some patients bonded in ”common fronts” against patients who were seen as too demanding or different from themselves (15).

The feeling of comfort which companionship gave, and the sense of humor developed during hospitalization, made the stay easier to endure (57). But although interaction with fellow patients was a good experience for some patients, it was a cause to distress, sadness and hopelessness for others. It was a burden to witness other people being ill, and too much contact and involvement impeded recovery and detracted focus from coping with own situation (14,15,55,56,58). The closeness was experienced so intense and so demanding that patients shut off mentally or withdrew physically for periods (56). The fellow patients might be perceived as burdens, if they were too noisy, had too many guests, snored, smelled, or if they had disputes about how to live in the room, such as the sound level of the television (14,56). However, disputes and bad experiences were burdens patients tried to avoid by keeping a deliberate distance (56,59).
Balancing accessibility and inaccessibility

The company of fellow patients added feelings of fellowship and recovery (15,56,57). However, privacy was very hard to achieve. Fellow patients were there always (14,55,55,56). In the patients’ room you could hear, see and smell almost everything. No conversation went overheard, no body odor unsmelled, and it was nearly impossible to withdraw from the fellow patients’ vision (14,15,56,57). In the patients’ room intimacy was enforced, a situation which in everyday life was usually unheard of in the company of strangers. Exposing the most private or intimate details, generated unpleasant feelings of being naked or imprisoned (14,15). For example, personal questions from fellow patients could be perceived as intrusive (59).

Patients found strategies that restricted their interactions with fellow patients, or they chose to expand them by establishing a closer relationship (15). In the pursuit of privacy from fellow patients, placement of artifacts, and of one self, in and outside the room, was essential. The bed was every patient’s refuge, but being in the bed patients were not necessarily perceived unapproachable by fellow patients (15). To create a sense of privacy, and to show inaccessibility, patients would use screens or curtains around the bed, or they would place chairs and bed tables between their own bed and that of the fellow patient (14). Additionally, patients would symbolize inaccessibility by reading or lying in bed with the back to the others, or with closed eyes (14,15).

A higher degree of freedom regarding patient-patient interaction was possible outside the patient room. Control of accessibility and inaccessibility was easier (14,15). Patients made themselves accessible or inaccessible to other patients by choosing different locations, such as the corridor, the smoking room, and the living room (14,15,55-59). Unfortunately, volunteer choosing of location was not an option for patients unable to get out of bed. They experienced loneliness when they had to dine in their room when fellow patients dined in the dining room (14,59).

The fellow patient experienced as an expert on illness and hospital life

This theme represents issues of how patients share information and knowledge during hospitalization. The theme is divided in two subthemes: Look, listen, and learn – knowing what to expect and Too much information was frightening.
Look, listen and learn - knowing what to expect

Most patients shared their knowledge from present and previous hospitalization with each other generously, for example information concerning the daily living as a patient, such as who to talk to, what to say, and what to do (14,15). Information encouraged patients to make greater demands on the staff, become braver, not to put up with things, and do more themselves to make things happen (57).

The primary conversation subject during hospitalization was the illness. Patients looked at each other to see what was happening as the body revealed signs. They listened to what other patients were informed about, what they talked about, and through conversations they shared information and knowledge about symptoms, treatments and life with the illness in general (14,15,55-59). On these issues, patients experienced information given by health care professionals to be quite different from that of fellow patients (56). Patients possessed a specific kind of knowledge derived directly from personal experience. They knew how it felt, and this was highly appreciated by fellow patients (14,15,55-59).

Too much information was frightening

Unfortunately, information meant to be helpful, might be experienced as frightening, depressing and painful (14,57). Listening to fellow patients’ illness stories and seeing them being ill was a burden which might rock patients’ confidence and hope for their own recovery (56). Some patients withdrew from interaction because of this (59).

One way of managing the knowledge and information related to their illness was by using humor. Humor was often used in conversations to express something sad or tragic (14). Patients used gallows humor when they talked about life threatening issues, or raised questions which were perceived as being difficult (14). Humor advanced a mental protection against the unpleasant situation, and the illness, and humor united patients. They felt solidarity (15). Humorous interaction stimulated important liberating laughs which cheered up everyone. Also, it generated feelings of comfort which made it easier to endure the hospitalization (56,57). Fooling around, making fun, and joking mediated feelings of fellowship between patients and with the use of humor they built up a shield against the illness (15).
The fellow patient experienced as a care provider

This theme represents issues of how patients cared for each other during hospitalization. The theme is divided in two subthemes: Helping fellow patients was helping oneself, and Caring was rewarding and troublesome.

Helping fellow patients was helping oneself

Helping others with practical issues was a way to “break the ice”, and show accessibility towards fellow patients (14,15). The patients’ community was characterized by compassion. Most patients had at one time either received care from, or given care to, a fellow patient (55,57,59). Patients were very attentive towards each other. They had the time to listen, and addressed negative emotions such as anxiety, pain, worry, fear, and low mood in fellow patients (14,56-59). The patients tended to say just as much about the support, they gave as about that which they received (57,58). The experience of being able to support and understand each other made some patients feel that they were esteemed and respected (57). When patients helped fellow patients they helped themselves (56).

The patients often found it easier and more acceptable to show their real feelings to a fellow patient than to family and friends. The experience of having the same disease provided a unique self-insight, and enabled patients to understand others in similar situations (55,56,58). Being met by genuine understanding was regarded as a major support. Patients experienced that only a fellow patient understood you better; this was comforting to know (14,57,58).

Caring was rewarding and troublesome

Interacting with and supporting fellow patients were mainly experienced as rewarding but sometimes it was depressing and troublesome too. Really understanding and caring for someone was painful and it hurt to see fellow patients suffer (14,15,55-57). Most importantly, patients had to care for themselves and their illness but for some patients caring for others was rewarding as well. Being with a fellow patient who was similar to you presented opportunity to both give and take and
patients strengthened their own self-esteem by helping others or bringing them some relief. It meant a lot to them to be there for someone (56,57).

Patients expressed obligations to be attentive to, and take care of, fellow patients but at the same time they might have weakened surplus. Balancing between the obligation to care and their weakened surplus made caring troublesome. Not only was it troublesome to care for fellow patients but it could also be experienced as troublesome to receive help from others (15). Patients spent time helping, supporting and caring for fellow patients to a degree that likened a part time job, but the patients thought it was important to have something to do during hospitalization (56,59).

DISCUSSION

Rigor of the study
A valid, scientific qualitative method was required for inclusion of studies but not necessarily the same method for all. Suitability of studies was not selected because of identical methods but because of findings’ relevancy (52). A weakness of this meta-synthesis may be the rather small number (n = 7) of studies included. Scientists do not agree on the exact number of studies which may elaborate adequately. Bondas & Hall (42,60) recommend inclusion of 10–12 studies, while Sandelowski et al. (43) warned against using too large sample sizes. This may impede deep analysis, and threaten the interpretive validity of the findings. Seven studies may not be enough to generalize worldwide but certainly elaborate on important and general themes.

The inclusion and exclusion criteria for the literature review could have been different, and hence, provided a different result. Inclusion of nurses’ perspective of the significance of fellow patients’ interaction may have nuanced the results. A few studies were excluded although they examined patients’ interaction during hospitalization (33-35). They were excluded because of a quantitative method approach and might have contributed with supplementary or amplifying knowledge.
The synthesized themes

The aim of this study was to synthesize research knowledge from a patients’ perspective about hospitalized patients’ experience of interaction with fellow patients. The following findings will be discussed: The enforced ambiguous interaction and coping, and the patients as care providers - contribution and coping. The interactions’ ambiguity and enforcement stand out as recurring themes in the findings. The themes are interconnected and may affect patients’ interaction. Also, patients as care providers, was a significant finding. It caught our attention because caring during hospitalization ordinarily is described as an action between nurses and patients.

The enforced ambiguous interaction during hospitalization

The findings comprised the patients’ interaction to be ambiguous. As a research topic, ambiguity among hospitalized patients interacting has not been explored, hence this finding is difficult to discuss. Ambiguity does emerge randomly in studies including patients’ interaction. Studies from Kulik (35) and Isaksen, Thuen & Hanestad (12) investigating patients and fellow patients showed that positive experiences with fellow patients were significantly more common than negative experiences. Also, Williams & Irurita (7) studied therapeutic and non-therapeutic interactions and showed a variety of situations in which interaction with fellow patients might induce feelings of security and validation, but also feelings of insecurity and devaluation. The ambiguity of the relationship presented in these studies is in agreement with our findings. Interestingly, our findings also showed that negative experiences were interconnected to the positive experiences continuously. It is likely, that the ambiguity of the interaction is connected to the patients’ surplus. Because the surplus may differentiate from day to day, patients’ positive or negative experiences with fellow patients are dependent upon the surplus of the day. This connection needs further investigation.

The findings comprised that being hospitalized entailed fellow patients as enforced companions. We found that even though patients could not voluntarily choose their roommates, they generally wanted to interact with the fellow patient they were assigned to. The challenge of the enforcement was to balance between closeness and distance to fellow patients. Vaartio (24), who studied men’s experience with cancer, mentioned the enforced togetherness, and found that some patients were interested in talking to fellow patients, and others wished to be left alone, or wanted to decide for themselves, who they talked to. The latter is problematic if patients lack the surplus needed or the
ability to withdraw from interaction with fellow patients with whom they are forced to share a room. This might influence the patients experience with fellow patients as well as the hospital stay in a negative way.

Interaction with fellow patients could be used as a volatile distraction from the reality of the situation. Distraction through humoristic interaction was frequently used as a coping strategy. Humor was a way of expressing dangerous and unmanageable issues in a way that protected the patients’ mental health. Interacting humorously was a way of keeping distance to the illness or venting frustrations, anger, fear or sorrow related to the illness, fellow patients, the hospital or the health care professionals. Humor is a well-known coping strategy and the effect of humor for patients, have been studied from different angles (61). Olson et al (62) found that laughter as a result of humor was identified as being able to create closeness or distance between individuals. Humor could be used not only as a distraction but also as a way to handle the enforcement of the fellow patient.

**The care providers during hospitalization**

The findings comprised that patients were perceived as experts on illness and hospital life. Patients retrieved information and knowledge about their illness from both health personnel and fellow patients. Information from health personnel often addressed specific issues such as treatment or test answers, whereas information from fellow patient concerned knowledge derived from lived experience. This is in agreement with other studies but none of the studies have investigated why and how patients function as experts (25,26,29). Our findings illustrated that purposes for retrieving information were different but interconnected. Both the health care professionals, and the fellow patients were seen as experts, but they conveyed different information. Combining the two types of information was of great importance to explain and understand the illness’ expressions and to know what to expect from the illness. Isaksen, Thuen & Hanestad (12) showed that patients who gained much knowledge and support from fellow patients were more satisfied with the information from the public health services, than the patients who gained less. Our findings may have provided an understanding of why this is. When patients’ share expert knowledge, they establish coherence between health care professionals’ information and fellow patients lived experience. Patients process information from health care professionals, using information from fellow patients in coping with their illness.
The patients as care providers are an unusual understanding of hospitalized patients’ role, and no current studies have been found with this focus. Typically, the health care professionals possess the position of care providing and especially the nurse is perceived as one of the primary caregivers in the hospital (7,63). It is striking, that patients have the strength to care for fellow patients when they themselves are very ill. Being ill does not necessarily remove the urge to care for others who are in a similar position. Herman (64) found that caring for others was a spiritual need among dying patients. To Martinsen (65), caring is fundamental to mans’ existence and is expressed in our interaction with fellow human beings. Caring is to help and to take care of by acting towards fellow men in the same way, as you want them to act towards you. According to Martinsen, humans are connected through reciprocal dependence where you can both give and take care, but you can never expect reciprocity. Because care is fundamental to any human being, an ontologically basic condition, so to speak, we want to care for people who need it. This may explain patients caring for fellow patients.

Our findings illustrated that attention from fellow patients was primarily experienced as supportive, comforting and compassionate. Patients had confidence in fellow patients and together they cared for each other by trying to make sense of why this happened to them and tried to understand what it meant emotionally and existentially. Other studies agreed in these findings (8,26) and stated that patients appreciated the emotional support from fellow patients (35). It is likely, that the patients’ community survives when the stronger patient acts as substitute caregiver for the weaker fellow patient (66).

We found that caring for fellow patients was rewarding as patients were recognized for their help and understanding. Caring for others, the patients felt useable and satisfied to help someone, who was just as ill, or more ill, than themselves. Also, when caring for fellow patients, they helped their own feelings of coping, as caring could be a way to redirect attention from their own disease and feel empowered in the role of caregiver. Samael et al (21) studied social cancer support groups and found that by engaging with others in similar difficulty, patients might develop better coping and adaptive mechanisms to the sequel of the illness and its treatment. It is likely that the same mechanism applies for patients’ interaction during hospitalization as the peer support may be comparable even though the setting is different.
Implications for nursing practice

The aim of this study was to synthesize findings from qualitative studies to provide an understanding of patients’ significance to fellow patients during hospitalization. The synthesis established new relationships between already analyzed concepts and arrived at a new understanding of significant social roles embedded in hospitalized patients’ interaction. So far, hospitalized patients interaction has not been acknowledged as a specific focus area in need of attention in nursing in Denmark. In nursing education, we demand an implementation of knowledge through inclusion of scientific articles as a part of the demand of scientific knowledge (67). An acknowledgement of interaction in nursing of being more than interaction between the patient and health care professionals or relatives is needed. We suggest both nursing educators and student nurses discuss our findings to strengthen the student nurses’ knowledge and hereby, their ability to facilitate actions to accommodate patients’ needs. Also, an increased attention in the nursing education may provide an increased attention on patients’ interaction when practicing nursing.

In the practice field, the health care professionals need sufficient knowledge about the quantity and quality of hospitalized patients’ interaction to accommodate the patients’ needs. We agree with Album (14) that there is a lack in nurses’ knowledge or a diversity of opinion when it comes to the significance of hospitalized patients’ interaction. We suggest dialogue between caregivers on the subject of patients’ interaction, and on how the patients’ different roles may contribute to patients’ experience of hospitalization. Also a debate of how to implement the knowledge as a part of the daily work would be recommendable.

The patient as a caregiver may cause some curiosity among nurses especially as nurses in general are perceived as primary caregivers. We may ask ourselves if patients feel too much responsibility for fellow patients, and if this is connected to a lack of nurse care? Maybe we need to discuss a change of attitude and change our traditional way of thinking about this? The fact that the patients engage in interaction as a caregiver should be regarded as an extra resource in nursing which adds care to the caring by nurses. The patients caring do not replace the nurse care but it expands the possibilities of care to accommodate the patients’ needs. Also, we suggest attention to the patient as a provider of information and knowledge. We agree with Isaksen & Gjengedal (56) when they suggest that care providers may tend to regard themselves as key persons when it comes to information and that it is striking to see how little attention they pay to information shared between
patients in the hospital. We need to address the differences between information and knowledge and discuss how we are able to accommodate both of these patients’ needs sufficiently.

Additionally more research with direct attention to hospitalized patients is needed. We agree with the included studies, in the fact that the significance of patients’ interaction needs visibility to be accepted and acknowledge as an important research area. Another very good reason for expanding this research area is that the patients pay this interaction a huge amount of attention and it is important to them.

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Article 2

Title. A companionship between strangers - the hospital environment as a challenge to patient-patient interaction in oncology wards

Aim. To present an identification and discussion of the impact of the hospital environment on interaction among cancer patients.

Background. In recent years, researchers have focused on identifying and describing features of the hospital environment which promote healing, recovery and well-being. It has been discovered that architectural features affect hospitalised patients both positively and negatively. But the research has failed to include fellow patients as part of the hospital environment.

Method. A qualitative approach inspired by ethnography with participant observation and individual qualitative interviews was used to collect data. From a total of 85 observed cancer patients, ten men and ten women were interviewed. Data were analysed using inductive thematic analysis.

Findings. Patients had ambiguous views regarding their fellow patients and the hospital environment. The hospital environment imposed conditions that caused stress factors such as the loss of personal privacy and control; but it also offered the possibility of good company and support from fellow patients. Refuge from fellow patients was hard to achieve, and the fact that personal conversations might be overheard by fellow patients caused patients to withhold important information from healthcare professionals. Nevertheless, patients accepted the hospital environment uncritically, with resignation or with silent rebellion. Despite the challenges, 18 out of 20 patients preferred multiple-bed rooms with the company of fellow patients.

Conclusion. The influence of the hospital environment on hospitalised cancer patients and their interpersonal interaction needs to be acknowledged by healthcare professionals. In addition, evidence-based hospital design must include research into patient preferences and arguments. Further investigation is needed.

Keywords: Patient-patient interaction, hospital environment, healing environment, privacy, loss of control, patient room preferences, acceptance, nursing, interpersonal interaction.
SUMMARY STATEMENT

What is already known about this topic

The hospital environment has an impact on patient outcome, well-being and infection rates.

The hospital environment has an impact on patients’ sense of personal control.

Evidence in favour of single-bed rooms as a standard is controversial.

What this paper adds

Patients accept the hospital environment uncritically, with resignation or with silent rebellion.

Patients withhold information from healthcare professionals because their fellow patients may overhear their conversations.

If they are well enough to interact with their fellow patients, 18 out of 20 hospitalised cancer patients prefer multiple-bed accommodation.

Implications for practice and/or policy

Nurses need to be aware of how the environment influences patients and patient interaction if they are to provide effective care.

Nurses need to acknowledge the significance of interaction between hospitalised patients.

Evidence-based hospital design must include research into patient preferences and arguments.
INTRODUCTION

In recent years, researchers have focused on identifying features of the hospital environment which promote healing, well-being, and health recovery (Lorenz 2007). It has been discovered that architectural features such as light, noise, art, colours, and room size affect hospitalised patients both positively and negatively (Frandsen et al. 2009, Ulrich & Zimring 2004, Ulrich et al. 2008). The significance of therapeutic, psychologically supportive and healing environments in hospitals has been proved to enhance patient safety and well-being (Lorenz 2007, Frandsen et al. 2009, Dijkstra, Pieterse & Pruyn 2006) and systematic reviews have revealed a strong connection between healthcare environments and patient outcomes in terms of patient safety, distress, and fatigue (Ulrich & Zimring 2004, Ulrich et al. 2008, Arneill & Devlin 2003).

In studies exploring hospitalised cancer patient-patient interaction, the hospital environment implied both positive and negative experiences (Isaksen & Gjengedal 2000, McCaughan, Parahoo & Prue 2011, Wilson & Luker 2006). A connection between features of the hospital environment, information needs and personal privacy has been discussed briefly. However, interaction between patients has not been included in these studies. The studies lack a more comprehensive understanding of the patient in the hospital environment including the significance of hospital architecture, artefacts, and routines.

Background

Positive and negative contributors in the hospital environment

Fellow patients are inevitably part of the hospital environment, especially in multiple-bed rooms. Research has already revealed that the hospital environment is a major negative contributor with regard to privacy, personal control, and noise. These factors increased the levels of stress experienced by patients and affect their well-being (Arneill & Devlin 2003, Ulrich 1991, Ulrich 1992). On the positive side, personal supportive environments, social support, and distractions improve patient healing, recovery and comfort, as well as reducing stress (Lorenz 2007, Dijkstra, Pieterse & Pruyn 2006, Arneill & Devlin 2003). Douglas & Douglas (2004) explored patients’ perception of hospital environments in the UK. Patients’ perception of the hospital environment was associated with whether they felt that hospitals were homely spaces. In another study, patients’ experience of personal control was connected to environmental factors such as accessibility to
healthcare professionals, relevant information, and dependence upon others for help (Williams, Dawson & Kristjanson 2008)


**Single-bed or multiple-bed rooms**

Various studies indicate that patients experience more privacy in single-bed rooms than in multiple-bed rooms (Pattison & Robertson 1996), but conclusions regarding the impact of single-bed rooms and multiple-bed rooms vary. One review has concluded that single-bed rooms are essential to reduce noise and infection rates, and to improve the confidentiality of information (Ulrich et al. 2008). In a US study, Easter (2003) concluded that family-focused, private rooms should be mandatory for cancer patients. A literature review of the benefits of single-bed rooms revealed conflicting results in terms of infection rates, noise reduction, and privacy (van de Glind, de Roode & Goossensen 2007). Two studies (Florey, Flynn & Isles 2009, Pease & Finlay 2002) concluded that from the patient’s point of view the arguments in favour of single-bed rooms were not overwhelming. In a study of the life quality of cancer patients, the majority of patients preferred multiple-bed rooms providing that they were well enough to interact with their fellow patients (Rowlands & Noble 2008). Lack of space and choice in multiple-bed rooms affected the balance between being involved and finding privacy (Edvardsson, Sandman & Rasmussen 2006). Privacy was hard to achieve, and for some patients noise and perpetual disturbance was hard to endure (Isaksen & Gjengedal 2000). On the plus side, patients in multiple-bed rooms built up relationships and shared knowledge (Forbat, Hubbard & Kearney 2009).

In conclusion, knowledge about the connection between the hospital environment and interaction between hospitalised cancer patients is insufficient and even contradictory, and makes further investigation necessary.
THE STUDY

Aim

The aim of this study was to explore the significance of patient-patient interaction during hospitalisation. The findings in this first article present an identification and discussion of the impact of the hospital environment on interaction among cancer patients.

Design

The study methodology was qualitative and inspired by ethnography (Spradley 1979, Spradley 1980). Ethnographic fieldwork involves the study of what the world is like for the people living in it. The objective is to understand another way of life from the point of view of the indigenous population. The essential core of ethnography is the meaning of actions and events to the people we seek to understand. To understand we observe what people do, what people make and use, and we listen to what people say. Inspired by Spradley, participant observation and semi-structured interviews were chosen to explore patients’ experiences with fellow patients during hospitalisation with the phenomenon of interaction as a focal point. Triangulation was employed in both the fieldwork and the analysis (Patton 1999).

Participants

Potential participants for observation were identified by the head nurse and given the opportunity to accept or refuse participation. The researcher decided on the final inclusion. The sample size comprised 85 Danish-speaking hospitalised cancer patients with a minimum age of 18 (Table 1). Twenty-six patients were selected for interviews. Six of these declined to participate due to a lack of energy and personal reasons. Ten men (indicated by “M” below) and ten women (indicated with “K” below) were interviewed. The participants were primarily hospitalised because of cancer relapse or complications due to adverse side effects of cancer treatment. Two male and one female patient were bed-bound at the time of the interview (M17, M36, K27), the rest of the participants were mobile. For the interviews, a purposive sample was drawn from the observed patients (Patton 1995). Inclusion criteria were: Men and women with cancer who were able and willing to talk about hospitalisation with fellow patients, Danish speaking, age >18. The participants who were excluded were in-patients with dementia or serious mental or physical illness that precluded inclusion on ethical grounds.
Table 1: Interviewed patients’ characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Characteristic</th>
<th>Number</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td><strong>Type of cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>Head and neck</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>Sarcoma</td>
<td>2</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>Colon</td>
<td>1</td>
</tr>
<tr>
<td>40-49</td>
<td>2</td>
<td>Breast</td>
<td>4</td>
</tr>
<tr>
<td>50-59</td>
<td>7</td>
<td>Abdominal</td>
<td>1</td>
</tr>
<tr>
<td>60-69</td>
<td>8</td>
<td>Prostate</td>
<td>2</td>
</tr>
<tr>
<td>70-79</td>
<td>3</td>
<td>Leukemia</td>
<td>2</td>
</tr>
<tr>
<td>Room type</td>
<td></td>
<td>Cervical</td>
<td>1</td>
</tr>
<tr>
<td>Single-bed room</td>
<td>0</td>
<td>Lung</td>
<td>1</td>
</tr>
<tr>
<td>2-bed room</td>
<td>11</td>
<td>Bladder</td>
<td>1</td>
</tr>
<tr>
<td>3-bed room</td>
<td>2</td>
<td>Liver</td>
<td>1</td>
</tr>
<tr>
<td>4-bed room</td>
<td>7</td>
<td>Multiple myeloma</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Melanoma</td>
<td>1</td>
</tr>
</tbody>
</table>

Setting

Two hospital wards were selected: one situated in a large Danish university hospital (UH) with 1,150 beds, and one in a smaller Danish regional hospital (RH) with 640 beds.

The UH ward is one of four separate wards at the oncology department. Each ward has 20 beds, allocated in one-, two- and three-bed rooms. A shared lounge is located between the wards. Meals are served from a trolley in the corridor.

The RH ward has two interconnected corridors with a total of 26 beds in one-, two- and four-bed rooms. The ward has several seating areas in the corridors, and a dining room/lounge where meals were served three times a day.

The interior of the patients’ rooms is similar in the two hospitals, but differs in decor depending on room size.
Data collection

Data were collected over a six-month period in 2010-2011 using participant observation and individual semi-structured interviews.

Participant observation was used to observe the everyday lives of the patients in the wards, such as how they spent time, who they talked to, and what they talked about. Emphasis was placed on features of the hospital environment: architecture, such as different living spaces; artefacts, such as beds and curtains; daily routines significant to the ward; and healthcare professionals and fellow patients. Observations took place in the patients’ rooms, corridors, dining areas (RH) and lounges (UH). Observations ranged from wide lens observation with surveys of the space, actors, and activities, to individually situated observations of patient interaction, acts, objects, and events. Notes were written during observation, and reflection breaks were incorporated throughout the observation period. Insight from reflection breaks was clarified through more focused observations. Concurrently, a fieldwork journal was produced to reflect and elaborate on thoughts and ideas (Spradley 1980). The researcher was present two-three days a week during selected time spans from 7 a.m. to 10 p.m.

The interviews were used to elaborate on observations of patients’ experiences with fellow patients. Afterwards, a descriptive question was asked: “Could you please describe how you experience being hospitalised with a fellow patient?” Both open and detailed questions were used to ensure the correct interpretation of statements, for instance: “Could you please explain what you mean when you say…” and “Am I to understand this as…” (Spradley 1979). The interviews were taped and transcribed verbatim within 24 hours.

Ethics

The project was registered at the Danish Data Protection Agency 10.02.2010. Both the Regional Scientific Ethics Committee and the Danish Ministry of Health were informed of the project. Furthermore, permission was granted by the managements of both hospitals. All the patients were informed of the project on posters and by providing oral information. Informed written consent was obtained from the patients participating in interviews.
Data analysis

Inductive thematic analysis strategies were used. The conceptual framework was inspired by Dey (1993). He identified three stages of thematic analysis: description, classification, and making connections. A thick description including observations, interviews, context description, and the fieldwork journal constituted the base description for classification. The inductive process of classification occurred without trying to fit the data into pre-existing frames. Instead, the characteristics of the patients’ experiences, statements, and observed actions were assigned to categories according to similarity, for example ‘being strangers’ and ‘privacy’. When comparing across the data, connections were made, and one theme concurrently influenced the patients’ experiences of interacting with fellow patients: ‘conditions specific to the hospital environment’. The explanation of themes was inspired by the concepts of healing environments ((Frandsen et al. 2009, Ulrich & Zimring 2004) and of interpersonal interaction and the environment (Altman 1973, Altman 1975).

Rigour

Trustworthiness was sought through four criteria: Credibility, transferability, dependability, and confirmability (Guba 1981, Lincoln & Guba 1985). Participant observation and interviews complemented each other when it came to comparing statements to ensure understanding of the situation. Source triangulation was employed by selecting two hospital settings of different size and architecture, and by including both men and women in the study. In the analysis we triangulated by including three authors with a view to checking on selective perception, illuminating blind spots, and employing multiple theoretical perspectives to understand and interpret data. Additionally, a constant movement between fragments and original texts was performed to secure the connection to the patients’ experiences (Dey 1993).

FINDINGS

Struggling with the hospital environment

Several significant themes arose from the analysis, which showed that patients struggled with various features of the hospital environment. The themes are: Healing and non-healing accommodation, Withholding information due to enforced public privacy, Seeking refuge from
fellow patients, Single-bed room or multiple-bed room, and Acceptance of and resignation to the hospital environment.

Healing and non-healing accommodation

Being hospitalised with a stranger was perceived with ambiguousness. The patients perceived their initial meeting with fellow patients as a meeting between strangers, but strangers with something very important in common (their illness). Patients would say: “It’s strange, we don’t know each other, but because we are ill we start talking about important issues very fast” (K7) and “…you throw your reservations overboard, and then you talk. It’s good to talk to a fellow sufferer” (K36). Patients conversed although they were strangers and they perceived the interaction positively. As one of the patients said: “It’s unnatural not to talk to the person you are this close to physically” (K7). The willingness and ability to partake in conversations with fellow patients was imperative to the interpersonal interaction between patients and the atmosphere in the room. The design of the multiple-bed room made it possible for the patients to see each other at all times, and this promoted interaction. On the other hand, it was difficult to withdraw from the attention of fellow patients. For some patients, the accommodation involved uncertainty and stress: “It’s really hard to be forced to relate to a stranger when you’re ill” (K43). One patient sharing a room with a disengaged fellow patient said: “I’m surrounded by her negativity 24 hours a day and I just have to put up with it” (K25). It was distressing to share a room with a fellow patient who had no wish to interact. The patients understood that hospitalisation was necessary owing to their illness and they hoped to get better during hospitalisation. Unfortunately, they often regarded the hospital environment as stressful and non-healing. The patients both appreciated and disliked interaction with fellow patients, with the dislike being connected to the architecture in multiple-bed rooms, which made it almost impossible to create privacy or find refuge from fellow patients. One patient said: “You don’t recover in this environment” (M17), and another said “My fellow patients all knew they were dying this time. It’s devastating for me to listen to” (K7).

Withholding information due to enforced public privacy

Patients sharing rooms were enforced to relinquish demands of privacy which under normal circumstances were regarded as imperative. All the patients interviewed experienced situations in which they were forced to share information with their fellow patients. One patient said: “During
rounds, you hear everything… social security number…everything” (K21). The information overheard included social security numbers, state of illness, examinations and test answers.

When it came to overhearing conversations in rooms, two scenarios were dominant: fellow patients hearing your conversations, and you hearing their conversations.

Most patients did not mind fellow patients overhearing their personal details, but a few patients withheld information from healthcare professionals because their fellow patients were listening. Patients said: “You don’t always get to say all you need during rounds, because you know fellow patients are listening” (K21), and “I just won’t say things which I don’t want to hear from others later on” (K36).

All the patients interviewed had overheard conversations between fellow patients and healthcare professionals: “It’s not because you want to listen, you just can’t avoid it” (M20, K43). The patients tried not to listen; but as most of them said: “You can’t help hearing things”. Patients regarded this enforced listening as distressing, but the environment also provided an opportunity to gain information about cancer and hospital life in general which was experienced positively.

Patients new to hospitalisation were less concerned with privacy than those who had been hospitalised before. The “new” patients were very attentive and curious, and listened in on every opportunity. One patient hospitalised for the first time said: “I’m all ears when they talk. Maybe I’ll get some essential knowledge” (M35). By contrast, patients who had been hospitalised before were very aware of the loss of privacy and objected to this during the interviews. One of them said: “I’m included in something I really don’t want to know” (M30). Others said: “It’s hard being forced to listen to others who are ill” (M36, K40).

**Seeking refuge from fellow patients**

The ward architecture affected patient interaction. The architecture of the two hospitals provided only few, but different, opportunities for interaction with and refuge from fellow patients.

Our data revealed a strong connection between the physical environment and patients’ actions and interactions. Patients tried to regulate their ideal level of interaction and privacy by using the different rooms in the hospital. In the RH men found refuge outside their rooms, whereas men primarily stayed in their rooms in the UH. When patients went outside their rooms they gained
some privacy but also met other patients, and being confronted with severe illness in this way was regarded as difficult.

Although the UH encompassed a lounge, corridors, mainly two-bed rooms, and a garden area, this was not enough to find refuge from fellow sufferers. In the lounge one patient “…talked to a man who had only a few months left…it was tough… not anymore, it’s too hard” (M6). The lounge was used as a waiting facility for other cancer patients and their relatives; healthcare professionals had illness-related conversations with patients there; and you could hear what went on not only in this lounge, but also in the lounge upstairs (these two lounges have an open-plan layout). The patients rarely used the lounge when they were alone, but frequently had visitors in there. When patients had visitors, their fellow patients did not approach them. Outside their rooms patients experienced no refuge, unless they were in the company of relatives or friends. Their rooms were their only refuge, and they were extremely dependent on fellow patients being forthcoming. By contrast, accommodation in the RH often implied sharing your room with three or four fellow patients, causing male patients in particular to seek refuge outside their rooms. The patients in the RH interacted in the dining room before, during, and after meals. As the patients did not visit each other in their rooms, the dining area offered a welcome possibility to interact without obligation. The dining room was especially useful for patients who knew each other but did not share a room. One patient said: “I know the patients in room x, but you don’t go in there…we meet to talk in the dining room” (M26). Although both men and women attended the dining area during meals, only men used the room for interpersonal interaction later on. In both situations the patients experienced a loss of privacy and personal control, and were exposed to distress due to the architectural environment.

**Single-bed room or multiple-bed room**

Interaction with fellow patients was regarded as inevitable in multiple-bed rooms. Despite the challenges of enforced public privacy and the hospital environment in general, a total of 18 out of the 20 patients interviewed preferred to be hospitalised in a multiple-bed room unless they were too ill to interact. Being hospitalised with fellow patients was experienced positively most of the time. Arguments in favour of multi-bed rooms were: having someone to talk to and spend time with, alleviation from feeling alone, isolated and bored, appreciation of being with like-minded people, sharing knowledge about hospitalisation and disease, and being of use to someone. Two-bed rooms were preferred over three- or four-bed rooms. Additional reasons for this choice were: the ease of
interacting with one person at a time, reduced noise level, and more personal interpersonal interaction. Arguments against multiple-bed rooms were: loss of privacy and personal control, noise, the enforced company of strangers, withholding of information, and being too ill to interact.

The patients in the RH seemed to struggle more with the lack of privacy than patients in the UH. This might be due to their accommodation in four-bed rooms, whereas the patients in the UH were accommodated in two- and three-bed rooms. In addition, at the RH there was often an extra bed in the room, which was regarded as an additional stress factor. It was somewhat easier for the UH patients to withdraw from one fellow patient in a two-bed room than to withdraw from three or four fellow patients as in the RH patient rooms. The bed and bedside table were private territory and were only used by the patient to whom they had been assigned. Patients sought privacy by placing their bedside tables between themselves and the next bed, by using headphones, by turning their backs on their fellow patients, and by drawing the curtain between themselves and the next bed – but only halfway because they did not want to be rude!

Acceptance of and resignation to the hospital environment

Three types of acceptance of the hospital environment were identified from the data: uncritical acceptance, acceptance with resignation, and acceptance with silent rebellion. Patients expressed acceptance and resignation when it came to emotional stress caused by fellow patients, and the physical environment in general. The hospital environment was controlled by the healthcare professionals, and patients were temporary visitors who did not make demands that they would make in their everyday lives.

Actions that involved nurses and doctors had top priority among the patients. When nothing was happening patients waited together. One patient said: “During 24 hours, action occurs within one hour only. The rest of the time we just wait…it’s most annoying” (M17). Time was experienced as lengthy and boring. They waited for minutes or hours, and sometimes for days when examinations were cancelled. Patients waited for the doctor to come, for the nurse to bring clothes, towels or medicine, for test answers, for examinations, and so on. These hospital routines were regarded as necessary. They were beyond the patients’ control and silently accepted as such.

Patients were very patient and understanding when it came to waiting for healthcare professionals, and rarely expressed any annoyance in this connection. They were simply resigned to the situation. When the wait was longer than expected, patients expressed their concern about the delay to fellow
patients, especially when they were waiting for specific answers from tests. The longer they waited, the more anxious they became that the answer would be disadvantageous. And patients rarely asked the nurses about delays. Instead they asked fellow patients about their experiences and debated options. They silently accepted the wait, but rebelled to some extent by turning to fellow patients for help and support.

This relinquishment of privacy was accepted reluctantly, as an inevitable result of hospitalisation in a multiple-bed room, although most of the time it was not a problem to be hospitalised with a fellow patient. Patients expressed their discontent with the loss of privacy; but this was done with silent resignation, and not once during the observations did the patients raise objections verbally. Patients accepted the conditions to which they were subjected, and did not express a privacy claim. One male patient in a four-bed room said: “It’s impossible to get any rest with five beds in the room… I walk around and stay in the lounge as much as I can” (M20). He rebelled silently by leaving his room. When a third bed was placed in her two-bed room, one female patient said: “Now, it’s very cramped in here. She is very ill and we can’t talk… we just lie here” (K34). It was stressful to be ill, but the stress of being with fellow patients could be almost unbearable. Even so, the patients rarely complained to the healthcare professionals and rarely confronted their fellow patients. The patients followed the social norms and rules implied by the hospital environment and used the artefacts and rooms provided by the architecture. During the interviews all the patients said that there was nothing they could do about the conditions enforced by the environment. Accepting was an inevitable consequence of being hospitalised. Uncritical acceptance and acceptance with resignation decreased patients’ experience of personal control. Acceptance with silent rebellion led patients to find solutions on their own or with fellow patients.

DISCUSSION

Limitations of the study

As a qualitative study, the number of participants was adequate (Kvale & Brinkmann 2009). However, the inclusion of only twenty patients did not provide an adequate basis for generalisations about patient preferences regarding multiple-bed or single-bed rooms. It could be argued that more interviews would generate more knowledge. However, Kvale and Brinkmann argue that beyond a certain number of respondents you gain less new knowledge, and you achieve data saturation
(Kvale & Brinkmann 2009). In this study, less and less new knowledge appeared in the latter phases of data collection. We estimate that data saturation was achieved.

A more nuanced understanding of the findings might have been gained by including patients accommodated in single-bed rooms. Unfortunately, this was not an option because of the selection of wards. Both wards had a limited number of single-bed rooms; and these rooms were always reserved for very ill or terminal patients. For ethical reasons, these patients were excluded from participation.

**Findings and previous research**

The patients did not regard the hospital environment as a healing environment. The environment gave no room for privacy, which caused the patients to withhold information and seek refuge. Hospitalisation was perceived as a necessity and patients had to accept the conditions of hospitalisation.

Despite the loss of privacy and personal control, a total of 18 out of 20 interviewed patients preferred a multiple-bed environment. This preference is of great interest, because new hospitals are already being built or planned with a significant increase of single-bed rooms in several countries in Europe (Danske Regioner 2012, Dean 2010, Helsebygg Midt-Norge 2012, Moore 2011). In hospitals worldwide, evidence-based design is created to provide a caring, safe, and effective patient-centred environment (Frandsen et al. 2009, Ulrich & Zimring 2004). An important healing element is access to single-bed rooms. Findings related to this subject are inconsistent From a healthcare perspective, single-bed rooms are essential in order to minimise infections and promote well-being and health recovery (Lorenz 2007, Ulrich & Zimring 2004); but when you ask the patients, they prefer the company of fellow patients in multiple-bed rooms (Florey, Flynn & Isles 2009). Other studies imply that accommodation preferences are dependent on the individual patient, diagnosis, and treatment (Frandsen et al. 2009). Our findings are consistent with other qualitative findings from the patients’ perspective, but they also elaborate on reasons for the patients’ choice of multiple-bed room accommodation. The company of fellow patients provided both essential support and information for the patients.

However, features of the hospital environment clearly led to privacy problems, causing some patients to withhold information from healthcare professionals. This is a very disturbing finding, because patients may withhold information which is important to treatment and care. For example,
patients may not be gaining the information they need because they are reluctant to ask healthcare professionals personal relevant questions. Several studies have found that if patients’ information needs are unmet, the concomitant uncertainty causes personal control to decrease (Williams, Dawson & Kristjanson 2008, Maher & de Vries 2011, Andreassen et al. 2006); but no studies including cancer patients withholding information have been identified. One study revealed that patients in acute care settings withheld information because fellow patients could overhear their conversations (Barlas et al. 2001). In another study (Malcolm 2005), patients were careful about what they said because they could not prevent their fellow patients from overhearing their conversations. These findings match the findings of our study and underline the need for further investigation among patients with cancer.

Another disturbing finding related to the struggle for privacy was the fact that it was very difficult to find refuge from fellow patients during hospitalisation both inside and outside patient rooms. We have not identified any studies which have investigated cancer patients’ need for seeking refuge during hospitalisation. However, a study investigating patient experiences in a radiotherapy unit found connections between the environment and the possibilities for withdrawal from fellow patients. An undersized environment lacking freedom of choice could bring about an invasion of private space, and associated experiences of being involuntarily exposed to – and unable to protect oneself from – the pain and suffering of other people and of strangers (Edvardsson, Sandman & Rasmussen 2006). The influence of the hospital environment on patients’ lack of privacy, seeking refuge, and withholding information during hospitalisation clearly represents an argument in favour of a hospital design with a majority of single-bed rooms and multiple recreation spaces. However, it is a paradox that the patients’ arguments are in favour of multiple-bed rooms in the present study.

All the patients expressed uncritical acceptance, acceptance with rebellion, or silent resignation. The fact that the architecture led to enforced interpersonal interaction among the patients was accepted as a condition but not necessarily a bad condition. We have found no similar studies that specifically investigated this behaviour among hospitalised cancer patients in relation to the hospital environment. Studies have stated that patients adapt to hospitalisation conditions (McIlfatrick et al. 2007, Rydahl-Hansen 2005), or resign themselves to them (Isaksen & Gjengedal 2000, Wilson & Luker 2006). The fact that three categories of acceptance among patients were registered in this study seems to be new knowledge and needs further investigation, as it may have implications for both patients and practice.
From the patients’ perspective, the acceptance of environmental conditions was connected to their experience of loss of control. Previous studies have stated that cancer patients’ loss of control was associated with loss of personal autonomy in decision making (Denieffe & Gooney 2011), ability to cope with environmental features (Vaartio, Kiviniemi & Suominen 2003), and inability to influence one’s own situation (Saarnio, Arman & Ekstrand 2012). These consequences are undeniably important for both patients and healthcare professionals, and need further investigation.

CONCLUSION

In order to promote a healing environment for the patients, we need to pay attention to the connection between the hospital environment and the patients’ experience of control with a view to helping nurses to meet the patients’ needs for privacy and information. The patients accept the conditions of hospitalisation because they regard these conditions as beyond their control. This leads to a discussion about who the hospital is for – the patients or the healthcare professionals? We need to discuss and implement these findings both in nursing degree programmes and in clinical practice to promote an awareness of the situation from the patients’ perspective.

Modern nursing focuses a good deal on protecting the privacy of patients, and single-bed rooms are regarded as essential with a view to achieving this end. However, the patients’ needs have been proven to be of a more complex nature. Ideally, a hospital design with flexible rooms might be the most sufficient solution in the future. We may build evidence-based designed physical environments to promote well-being and healing in hospitals, but beneficial interaction among hospitalised patients is a vital aspect of any healing hospital design. Patients withholding information from healthcare professionals constitutes an urgent problem because the withholding of information has consequences for care and treatment, and ultimately for the patients’ well-being and experience of hospitalisation. Hopefully, our findings will contribute to an increased awareness of the complexity of patients’ experiences during hospitalisation.

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Article 3

Title. A companionship between strangers – learning from fellow cancer patients in oncology wards

Aim. An identification and discussion of learning from experience among hospitalised cancer patients.

Background. Much literature focuses on information needs related to disease and treatment as an act between healthcare professionals and patients. Lesser attention is given to information from personal experiences. Sharing of personal experiences withholds learning opportunities. Patient-patient interaction as a learning situation has not been identified in current research.

Method. A qualitative approach with participant observation and qualitative interviews was used. From a total of 85 observed cancer patients, ten men and ten women were interviewed. Data was analysed using qualitative data analysis inspired by Ian Dey and structured using NVivo9.

Findings. The hospitalised patients learned about life with cancer from information and personal experiences of fellow patients. Sharing personal experiences promoted support and care among the patients. Gender differences were identified with men being oriented towards supportive information and women towards emotional support. Sharing personal experiences promoted patients of both sexes to oscillate among four general response stages; the stage of fighting, the stage of keeping hope, the stage of non-acceptance and the stage of capitulation.

Conclusion. Learning from exchange of experiences with fellow patients provided a better understanding about the disease. Gender differences need attention of healthcare professionals when planning information and support services. Patients personal experiences with disease is an under used resource in nursing.

Keywords: Patient-patient interaction, learning from experiences, social support, care
SUMMARY STATEMENT

What is already known about this topic

Hospitalised patients with cancer have a substantial need for information about their disease.

The healthcare professionals are perceived as the primary information and care givers of disease related information.

Fellow patients withhold personal experiences about how to be a patient with cancer.

What this paper adds

Hospitalised patients with cancer learned from fellow patients experiences with the disease.

Gender differences was identified when it came to how cancer patients shared experiences and how they experienced support

Sharing experiences promoted patients´ oscillation among four learning stages: fighting, hope, non-acceptance and capitulation

Implications for practice and/or policy

Nurses need to acknowledge that patients´ need both information from healthcare professionals and from fellow patients.

Nurses need to acknowledge the significance of support among hospitalised patients.

Gender differences are to be taken into account when planning information and support references.
INTRODUCTION

Hospitalised patients with cancer have a substantial need for information about their disease (Fitch et al 2008, Grønvold 2006, Sandager et al 2011). The healthcare professionals are perceived as the primary information givers from whom patients learn about their disease, disease trajectories and treatment (Chelf et al. 2001, Chelf et al. 2002, Piredda et al. 2008). As a supplement to information from healthcare professionals, hospitalised patients turn to the personal experiences of their fellow patients (Isaksen & Gjengedal 2000, Wilson & Luker 2006, Album 1996). A number of studies have investigated information shared between healthcare professionals and patients, whereas information provided by the personal experiences of patients has received less attention. From a learning perspective, situations in which people share personal experiences do involve learning (Jarvis, Holford & Griffin 2003, Jarvis 2009), but patient-patient interaction as a learning situation has not been identified in previous nursing research.

BACKGROUND

When cancer patients are hospitalised, the nature of the hospital environment means that they are inevitably brought into contact with fellow cancer patients. Being hospitalised in multiple-bed rooms, information was shared both willingly and unwillingly (Isaksen & Gjengedal 2000, Larsen, Larsen & Birkelund 2012, McCaughan, Parahoo & Prue 2011). In studies of the experiences of hospitalised cancer patients, information needs that were not met were frequently associated with anxiety, lack of personal control (McIlfatrick et al. 2007, Williams, Dawson & Kristjanson 2008) uncertainty (Maher & de Vries 2011, Warren 2010), and vulnerability (Worster & Holmes 2009). According to these studies, information was a key component when it came to relieving suffering related to these aspects.

Information needs

The assumption has been that healthcare professionals know what patients with cancer need to know (Luker et al. 1995). However, some patients regard the information provided by healthcare professionals as a limited resource because of the limited duration of their interaction with them (Bennenbroek et al. 2002). The information needs of cancer patients have been investigated with the focus on what they need to know, how much they want to know, information-seeking behaviour, and concerns about how to retrieve information (Bennenbroek et al. 2002, Leydon et al. 2000, Walsh et al. 2010). Patients acquire information from various sources including fellow patients.
(Chelf et al. 2001, Chelf et al. 2002, Maddock et al. 2011). According to Maddock’s (2011) investigation of the online information needs of cancer patients, patients wanted information to tell them how the disease was likely to impact on their everyday lives and the lives of people close to them.

Learning from experience

The impact of learning from the experiences of fellow patients has been investigated among patients in cardiac recovery (Colella & King 2004), rehabilitation (Kenen et al. 2007, Kingsnorth et al. 2011) and in secondary stroke prevention (Gibson & Watkins 2011), but has not been investigated among hospitalised cancer patients. However, in studies of cancer support groups, sharing personal experiences was highly valued by both men and women (Bell et al. 2010, Gray et al. 1996, Seale, Ziebland & Charteris-Black 2006).

The fact that people learn informally from experience is acknowledged by the OECD, which refers to it as “a simple fact of existing with constant exposure to learning situations” (OECD). Jarvis describes learning as a lifelong social process from which we learn from experiences in all human settings. Just by being exposed to other people, we learn. Learning in everyday life may occur at the periphery of our conscious awareness (Jarvis 2009).

To summarise, patient-patient interaction during hospitalisation as a source of retrieving information has been generally overlooked in studies of the information needs of cancer patients. No similar studies of patient-patient interaction have investigated learning among hospitalised patients. It seems that learning from information shared in patient-patient interaction by hospitalised patients has not yet been recognised as a substantial research area. What is needed is further study of what patients learn from each other, and how they learn it.

THE STUDY

Aim

The aim of this study was to explore the significance of patient-patient interaction during hospitalisation. The findings in this second article present an identification and discussion of learning from experience among hospitalised cancer patients.
Design

The study methodology was qualitative and inspired by ethnography (Spradley 1979, Spradley 1980, Hammersley & Atkinson 2007). The objective of ethnography is to understand another way of life from the point of view of the people concerned. To understand their lives we observe what people do and what they make and use, and we listen to what people say. Participant observation and individual semi-structured interviews were chosen to explore the experiences of hospitalised patients with their fellow patients, with the phenomenon of interaction as a focal point.

Participants

Potential participants for observation were identified by the head nurse and given the opportunity to refuse participation. The researcher decided on the final inclusion. The sample size comprised 85 Danish-speaking hospitalised cancer patients with a minimum age of 18 (Table 1). Ten men (indicated by “M”) and ten women (indicated with “K”) were interviewed. The participants were primarily hospitalised because of cancer relapse or complications due to adverse side effects of cancer treatment. Two male and one female patient were bed-bound at the time of the interview (M17, M36, K27), and the rest of the participants were mobile. For the interviews, a purposive sample was drawn from the observed patients (Patton 1999). The participants who were excluded were in-patients with dementia, extensive mental diseases, and physical or mental illnesses that precluded inclusion on ethical grounds.

Table 1: Interviewed patients’ characteristics
### Setting

Two hospital wards with cancer patients were selected: one situated in a large Danish university hospital (UH) with 1,150 beds, and one in a smaller Danish regional hospital (RH) with 640 beds.

### Data collection

Data were collected over a six-month period in 2010-2011 using participant observation and individual semi-structured interviews.

Participant observation was used to observe the everyday lives of the patients in the wards, such as how they spent time, who they talked to, and what they talked about. Emphasis was placed on the nature of patients’ shared experiences, how they shared experiences and how they experienced sharing experiences. Observations took place in the patients’ rooms, corridors, dining areas (RH) and lounges (UH). Observations ranged from wide lens observation with surveys of the space, actors and activities, to individually situated observations of patient interaction, acts, objects and events. Notes were written during observation, and reflection breaks were incorporated throughout the observation period. Insight from reflection breaks was clarified through more focused observations. Concurrently, a fieldwork journal was produced to reflect and elaborate on thoughts and ideas (Spradley 1980, Hammersley & Atkinson 2007). The researcher was present two-three days a week during selected time spans from 7 a.m. to 10 p.m.
Individual interviews were selected to elaborate on observations and the experiences of patients with their fellow patients (Spradley 1979, Kvale & Brinkmann 2009). Every interview started out with characteristic questions to be used in the analysis for comparison of experiences with regard to age, gender and length of stay. Afterwards, a descriptive question was asked: “Could you please describe...”. Both open and detailed questions were used to ensure the correct interpretation of statements (Spradley 1979). The interviews were taped and transcribed verbatim within 24 hours.

Ethics

The project was registered at the Danish Data Protection Agency 2010-02-10. Both the Regional Scientific Ethics Committee and the Danish Ministry of Health were informed of the project. Furthermore, permission was granted by the managements of both hospitals. All the patients were informed of the project on posters and by providing oral information. Informed written consent was obtained from the patients participating in interviews.

Data analysis

Inductive thematic analysis strategies were used. Dey (1993) identifies three stages of thematic synthesis: description, classification, and making connections. A thick description including observations, interviews, context description and the fieldwork journal was the base description for classification. The inductive process of classification occurred without trying to fit the data into pre-existing frames. Instead, attending in detail to the characteristics of the patients’ experiences, statements and observations were assigned to categories according to similarity and accumulated into empirical themes such as ‘sharing knowledge’ and ‘support among patients’.

The interpretation and discussion of connections within the empirical themes was inspired by Jarvis’s theory of learning in society (2003, 2009). In particular, two concepts were used: The five steps of learning (remembering, imitating, adapting, experimenting and reinforcing); and disjuncture (in other words the gap between what we expect to perceive and the reality with which we are actually confronted). The five steps of learning were used to identify learning behaviour among the patients, and disjuncture was used to identify the patients’ consciousness of their information needs. Disjuncture was identified through four levels: coincidence, with no conscious experience of a gap; divergence, with a slight gap between expectation and reality; separation, with a larger gap between expectation and reality; and distinction, with a wide gap where we need intensive learning or give up (Jarvis 2009).
Rigour

Trustworthiness was sought through four criteria: credibility, transferability, dependability and confirmability (Guba 1981, Lincoln & Guba 1985). Participant observation and interviews complemented each other when it came to ensuring understanding of the situation. Source triangulation was done by selecting two hospitals of different sizes and architectural designs, and by including both men and women. Triangulation in the analysis was employed by the participation of all three authors to check on selective perception, to illuminate blind spots, and to include multiple theoretical perspectives to understand and interpret data.

RESULTS

The core messages derived from the inductive process was that hospitalised cancer patients learned from and supported each other. **Learning from fellow patients – a complementary learning experience**

The primary conversation topic was experiences about life with the disease: “The only thing they (fellow patients) have in their head is their disease, and what we have to do to get well” (M36).

*The women* shared stories about cancer verbally, and often in detail from when it appeared and until the present. In the community, they learned about the different effects of the disease; what to expect from the disease and treatment; how to deal with the effects; how to live with a life-threatening disease, and facing death. They shared experiences about a variety of subjects: symptoms of the disease, and how they could detect it in their bodies, side effects from treatment, tests and test results, and how the technical equipment worked. For instance, one woman told a fellow patient: “I have this ‘gate’ on my chest. They inject into this instead of into my arms. It’s so much easier and less painful” (K41). In addition, personal experiences served to repeat and clarify information that had already been given by healthcare professionals: “I think the nurses have told me these things, but it’s as if I didn’t hear what she said…things are clearer to me now, because my fellow patient has told me about her experiences…I understand it now” (K27). In terms of their content, the women’s personal experiences were primarily emotional. They talked about their experiences, they shared information about symptoms, treatment, what to expect, and what it meant to them both
physically and emotionally. They were very polite listeners and were happy to spend time discussing any topics chosen concerning life with the disease.

The women learned from the behaviour of their fellow patients. They copied the behaviour they observed and used the same sentences and words as their fellow patients. Sometimes they succeeded in experimenting with new information and sometimes they did not. For example, they would talk to fellow patients about which questions to ask the healthcare professionals during rounds. In the situation, they experimented with formulating the question. Sometimes they got the appropriate answer and sometimes their lack of adaptation to the situation led them to forget the question or place it differently. Afterwards they discussed the situation with fellow patients so they could remember better the next time.

*The men* most commonly acquired information from personal experiences, through observation and overhearing: “We don’t need to talk about the disease all the time, because we can hear everything that is going on” (M26). They shared the same disease-related topics as the women, but they were less verbal in their expressions. Verbal explanations were related to a topic and were often of a technical nature. Here is an example from a conversation between M5 and M9: “I already have my mask for radiation, but…is it like a CT?” (M9), “No, you’re not locked in as in a CT, but the mask covers your head. Each radiation only takes seven minutes tops, and you get a weekly plan, so you’ll know when to come” (M5).

In terms of content, the men’s personal experiences were specific and technical when they verbally shared information about symptoms, treatment, and what to expect. However, they conveyed experiences differently from the women: they asked a question, they got an answer, they responded, and then the conversation often stopped. They continued to talk about something else, such as life outside the hospital, or, often, they twisted the conversation with gallows humour and laughter. Sometimes they resumed the conversation after having laughed, but at other times the conversation simply stopped. They shared experiences, but it was as if the information led to unease which caused them to comment humorously instead.

The men learned from the behaviour of their fellow patients. They copied the behaviour they observed similarly to the women. However, the men never talked to fellow patients about which questions to ask, instead they observed what was said and tried again.
Learning from the exchange of experiences with fellow patients was valuable and provided an understanding of cancer and life with cancer based on personal experiences. They regarded the information acquired from healthcare professionals as different from that acquired from fellow patients. Even so, healthcare professionals were not expected to meet the patients’ needs for this type of information, nor regarded as being able to do so. Personal experiences constituted a complementary source of information in addition to the information acquired from healthcare professionals.

**Support and self-perpetuating learning**

The companionship among fellow patients generated comfort and consideration. They bonded as fellow sufferers. Sharing experience entailed information and this was perceived as a supportive action as well as emotional support and practical help. The shared experience bonded the patients and promoted emotional and practical support. The supportive actions had a self-perpetuating effect.

*The women* attached importance to information and emotional support, but with the emphasis on emotional support. They regarded interaction with fellow patients as emotionally comforting. They were allowed to express anger as well as happiness: “We support each other a lot…we talk, cry, and try to cheer each other up” (K36). When fellow patients were sad they showed consideration through physical non-verbal comfort such as a hug, or a gentle touch on the shoulder. They also reassured each other through verbally comforting comments such as: “You’ll get through this”. The women supported each other emotionally by listening to and talking about emotionally hard topics such as thoughts about death and dying: “How long do you have to suffer before you die, and does it hurt? You never know, do you…we talk about it” (K36). They talked about the things that were almost impossible to talk to their relatives about, how to say good-bye to life, and how to cope with the realisation that they only had a limited number of years to live. It was reassuring to talk to a fellow patient: “They understand your emotions and your thoughts” (K36). They were allowed to be emotional, and this led fellow patients to be supportive.

*The men* attached importance to information and practical help, but with the emphasis on information. However, they were reserved when it came to acknowledging the term ‘support’. One patient said: “I wouldn’t call it support or concern, but we sympathise with each other” (M20). The data revealed that the male patients helped with practical daily living, for example they would open
windows or get water. It was perceived as a duty and common decency to help others. The men did not acknowledge or understand their mutual actions to help each other as support, even though they performed a number of supportive actions.

Emotional outbursts among fellow male patients were rare. When they did occur, they were due to disturbing news related to the disease. The patient involved often withdrew socially, either by leaving the room or turning his back on the others in his bed. Withdrawal was respected by fellow patients, and they were often personally affected by the situation: “It’s so hard for him, I sympathise…he told me that they (the doctors) couldn’t do any more for him…it’s devastating” (M35). Apart from withdrawal, the men would comment humorously and ease the tension in the situation. Situations like these gave the opportunity to learn about accepted behaviour, responses and what to expect. The men were never observed to be physically supportive like the women.

**Oscillation among four responses to learning**

During the interpretation of connections between the empirical themes, patterns emerged when patients shared experiences. These patterns are interpreted and discussed within a learning perspective as described in the ‘Method’ section and linked to characteristics and gender (Jarvis, Holford & Griffin 2003, Jarvis 2009). Their response to a potential learning situation was connected to what they already knew or did not know.

*The response of fighting*

“I know I’m ill, but I’m not ready to go yet”. This response indicated that the patients were painfully aware of the severity of their situation. From interaction and from living with the disease, they had learned to be very attentive to body changes. They did not want to surrender to the disease: “I won’t cave in…I’ll fight it again this time” (K43, M30). Having learned from experiences, they knew that the status of the disease could change rapidly – and that it would not necessarily grow worse. They chose to believe that fighting was worth it.

Referring to the disjuncture concept, these patients were very knowledgeable about the disease; and their response resembled *coincidence* with no conscious experience of learning disjuncture – they were the ‘teachers’. They were the ‘experienced patients’ who had lived with the disease for some time; and they were esteemed by fellow patients, who acknowledged them as knowledgeable.
The women were verbal and direct in their statements and expressions, as if they were fighting an enemy – it was an emotional struggle. They argued for fighting by referring to what they already knew from fellow patients and their own experiences.

The men assessed their situation, like a ‘risk assessment’, by employing what they had learned from experience and drawing a conclusion. They fought through actions such as locating information about new medication and new treatment.

*The response of keeping hope*

“I’m not that ill now, but I might be in the future”. This kind of response indicated that the patients in question were aware of the situation and insecure about the outcome of the disease, but that they remained hopeful: ”I’m much better off and I still expect to be well again” (M5, K38). They acknowledged the disease and had learned that it could change rapidly – including changes for the better. Their experiences from interaction with fellow patients told them to be realistic in their hopes; to hope for a cure, but still to acknowledge the possibility that the disease would grow worse.

Referring to the disjuncture concept, their response resembled both *divergence* and *separation* disjuncture. Often, they knew enough about the disease to respond to different symptoms without a substantial change of knowledge; but sometimes they felt insecure and asked fellow patients about things they had not yet learned. These patients were less knowledgeable than the ‘experts’, but more knowledgeable than the ‘newcomers’. In interaction with fellow patients, they were both ‘teacher’ and ‘student’.

To close the disjuncture gap, the women sometimes asked their fellow patients direct questions. They expressed their hopes verbally and talked about what to do and what to say, and found solutions together.

The men observed until they acquired the information that they needed at present, or they would ask the healthcare professionals. Similar to the response of fighting, the men ‘risk assessed’.

*The response of non-acceptance*

“That has nothing to do with me and my disease”. This response indicated a lack of acknowledgement and awareness of the severity of the situation. In the interaction, these patients
kept trying to push the severity of the situation away. They did not necessarily feel ill, and they often disclaimed the disease: “No, I’m not like them, I’m not really ill” (M12, K44). They experienced interaction with fellow patients from the spectator’s point of view and felt sorry for them. According to Jarvis’s concept of pre-conscious learning, these patients had not yet learned from interaction with fellow patients; but pre-consciously, they gained information that might frighten them.

Referring to the concept of disjuncture, the patients’ response resembled coincidence disjuncture with no conscious experience of a gap (Jarvis 2009). They expressed no conscious need for new knowledge because the experiences of their fellow patients were not related to them. As Jarvis suggests, they did not know what they needed to know.

The women tried to avoid information about their disease by helping the “unfortunate” patients and by keeping busy, as if they were trying to push reality away. In Jarvis’s terms, they did not know what they did not know (Jarvis 2009). In the situation, they said that they did not want to know.

The men were attentive to information even though they did not necessarily acknowledge the need for it. In Jarvis’s terms, they did not know what they did not know (Jarvis 2009). In the situation they expressed curiosity about what interaction with fellow patients might bring. Because of their curiosity it could be assumed that they moved towards divergence.

The response of capitulation

“I give up…there’s nothing I can do”. These patients’ response indicated that they had given up the struggle against the disease, and accepted that the disease had control of their life. This response was identified with reference to two situations: a) as a brief reaction among patients less experienced than themselves, and b) as a brief reaction among more experienced patients.

With regard to a): if shared experience was perceived as overwhelming (K38, M17). These patients would oscillate between ‘keeping hope’ and ‘capitulation’.

Referring to the concept of disjuncture, their response resembled a mixture of separation and distinction disjuncture. The reality of the information they received was beyond what they expected and they had a gap in their knowledge. At that moment, their knowledge of the disease from interaction was not enough to manage the situation and led to a momentary surrender to the disease.
The women tried to close the gap by interacting with fellow patients, asking questions, sharing experiences. The men reacted with a momentary withdrawal from the community.

With regard to b): when patients had struggled with the disease for a considerable amount of time (K21, M10). These patients knew what to expect, and they had learned from interaction with fellow patients and their own experiences that their symptoms could change rapidly, and might easily grow worse. In many cases they oscillated between ‘fighting’ and ‘capitulation’.

Referring to the concept of disjuncture, in most cases they had no conscious perception of learning disjuncture because they had learned what could be expected from the disease – good and bad. Momentarily, they experienced divergence where they needed a slight adjustment to manage the situation.

The women would express verbally: “I’ve given up”. They sometimes cried, and then they talked to fellow patients about how to handle it – it was an emotional action. The capitulating women were normally the ‘teachers’. Interaction with fellow patients reminded them of how to manage the situation. According to Jarvis’s concept of pre-conscious learning and the learning steps, the women often possessed the knowledge from previous experiences but they acquired help from fellow patients to remember it.

The men would express verbally: “There was nothing more to be done”. They did not talk to others about their response. According to Jarvis’s concept of pre-conscious learning and the learning steps, the men possessed the knowledge from previous experiences and most often remembered it by themselves. As mentioned before, the men ‘risk assessed’.

DISCUSSION

Limitations of the study

As a qualitative study, the number of participants was adequate (Kvale & Brinkmann 2009). It could be argued that more interviews would generate more knowledge. However, Kvale & Brinkmann (2009) argues that beyond a certain number of respondents you gain a minimum of new knowledge. In this study, less and less new knowledge appeared in the latter phases of data collection, probably because of the combination of participant observation and interviews. The two
methods for data collection complemented each other, and lead us to estimate that data saturation was achieved.

**Findings and previous research**

The patients acted as informal ‘experts’ from whom other patients could learn how to live life with cancer. Learning from fellow patients has not been identified as a research area in the reviewed studies. The sharing of experience has not been recognised as learning in the research literature, but it is recognised as a way to acquire information about the disease (McCaughan, Parahoo & Prue 2011, Rotegard, Fagermoen & Ruland 2011). Both men and women valued information from healthcare professionals as well as information from personal experiences derived from fellow patients. Shared experience complemented and elaborated information acquired from healthcare professionals.

**Gender differences**

In this study, gender differences in learning and support among cancer patients were identified. Although gender was not a primary focus area of this study, the data revealed findings which could not be ignored. Gender differences have been investigated among patients with cancer from various angles such as patients’ experiences of cancer (Fitch et al. 2008, Warren 2010, Vaartio, Kiviniemi & Suominen 2003, Denieffe & Gooney 2011). We found no similar studies of patients’ interaction that elaborated on gender differences.

**Gender and learning**

When patients learned from experiences some gender differences were identified, with the women learning from the emotional stories of fellow patients. Although they shared experiences through observation and overhearing, they largely learned through verbal conversations. They also oscillated between different responses to learning, and their reactions were most often complemented with their feelings. In contrast, the men largely learned from observation and overhearing and less through verbal conversation. The men were also more interested in technical information and details of treatment and symptoms, and their responses to learning were often accompanied by a ‘risk assessment’.

Jarvis’s theory of learning does not specifically include gender differences in learning, but he suggest that gender, as well as social class, ethnic background and age influence the way we
perceive and respond to learning situations (Jarvis 2003). In the research literature, we found no studies which investigated gender differences in experiential learning among hospitalised cancer patients. However, gender differences in learning have been identified in studies of experiential learning styles in education (Boyatzis, Kolb & Mainemelis 2002, Heffler 2001, Kulturel-Konak, D'Allegro & Dickinson 2011). Heffler (2001) described that women had a concrete learning approach: they preferred an experienced-based approach with hands-on experiences to learn; and they made feeling-based judgements, were people oriented and felt comfortable with ambiguity. Conversely, the men had an abstract learning approach: they had an analytic approach to learning with logical and rational orientation. Comparing our findings with Heffler’s findings, they seem similar for both men and women. At the same time, our findings differ from the presented studies by providing concrete examples of what cancer patients learn from each other and the importance of interaction when learning.

**Gender and personal support**

When patients supported each other, certain gender differences were identified. The women were emotionally tolerant and supported each other through conversation and physical touch. The men also supported each other emotionally through bonding and conversation, but they perceived this as ‘common decency’ and not as support.

As stated at the beginning of this section, studies of cancer patients and support groups have carried out gender-specific investigations of both men and women, but only a few studies have made gender-related comparisons (Gray et al. 1996, Seale, Ziebland & Charteris-Black 2006)). Seale (2006) compared men and women by looking at how they talked in online support groups. Among the women, they found a use of words such as “help” and “supportive”; and they found that women were explicit about their feelings. Among the men, no keywords were found related to the notion of support, and they found that men limited the expression of feelings to “concerned” or “embarrassed” (Seale, Ziebland & Charteris-Black 2006). Comparing our findings with the findings presented from support groups, they seem similar. However, our findings both elaborate on and supplement the small number of comparative studies by contrasting gender differences among patients with cancer. Our findings also offer an understanding of how patients experience support and the importance of support in relation to disease trajectories during hospitalisation.
CONCLUSION

Learning from the experience of fellow sufferers as a way to acquire complementary information is important to patients, and so is the support among them. We suggest that nurses should acknowledge that patient experiences constitute a valuable source of information and that patients are resourceful experts on living a life with disease – also when the disease is life threatening. A debate on how to implement this knowledge into everyday nursing care is recommended.

The gender differences might make it difficult for healthcare professionals to tailor the information and support they provide to suit the needs of individuals. An awareness of such differences is only one step towards meeting the patients’ needs. In order to meet the different needs of men and women, healthcare professionals must be prepared to acquire the knowledge and skills required. As a result, more studies of interaction between hospitalised patients are needed.

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Appendices

Appendix A: Assessment tool

Appendix B: Audit trail

Appendix C: Participants’ characteristics

Appendix D: Observation guide

Appendix E: Timeline for data collection

Appendix F: Interview guide

Appendix G: Screenshot from Nvivo

Appendix H: Registration The Danish Data Protection Agency

Appendix I: Information to the healthcare professionals in the ward

Appendix J: Information to the participants

Appendix K: Informed consent sheet

Appendix L: Co-author declarations
Appendix A: Assessment tool

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Appendix D: Observation guide

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Inspiration from James Spradley (1980).
Appendix E: Timeline for data collection

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Data production in the hospital paused for weeks 10, 11, 12, and 13

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Legend:
- **Observationstid, timer**
- **Interview, enhed**
- **Afslag interview, enhed**
- **Afslag observation, enhed**
Appendix F: Interview guide

Hvor længe har du været indlagt? Er dette første gang du er indlagt? Hvilken type kræft har du og hvorfor er du indlagt?

Til belysning af undersøgelsesspørgsmålet: Hvilken betydning kræftpatienternes indbyrdes relation har i forhold til at begå sig som patient under indlæggelse?
- Kan du fortælle om hvordan du oplevede at blive indlagt på afdelingen?
  o Hvad skete der?
  o Hvad gjorde du?
  o Hvad følte du?
  o Hvad tænkte du?
  o Hvem var der?
- Hvordan opleves det at blive indlagt på en stue sammen med en helt fremmed person?
  o Hvad skete der?
  o Hvad gjorde du?
  o Hvad følte du?
  o Hvad tænkte du?
  o Hvad talte i om?
- Hvordan begår man sig på afdelingen?
  o Hvordan fandt du ud af at begå dig i afdelingen?
  o Hvem hjalp dig?
  o Er der regler for hvornår man skal hvad?
  o Hvordan skal man opføre sig?

Til belysning af undersøgelsesspørgsmålet: Hvilken betydning kræftpatienternes indbyrdes relation har i forhold til information om sygdom og sygdomsforløb under indlæggelse?
- Kan du fortælle om hvad I taler om som patienter på patientstuen når sygeplejersken/lægen er gået?

- Kan du fortælle om en specifik oplevelse?
  o Hvad talte i om?
  o Hvordan oplevede du det og hvad følte du?
  o Hvad tænkte du?
  o Hvad vidste du i forvejen og hvorfra kom denne information?

Til belysning af undersøgelsesspørgsmålet: Hvilken betydning kræftpatienternes indbyrdes relation har i forhold til psykosocial støtte under indlæggelse?
- Kan du fortælle om hvordan I hjælper hinanden på patientstuen?
  o Hjælper i hinanden fysisk/psykisk?
  o Hvad hjælper I hinanden med?

- Kan du fortælle om en specifik oplevelse?
  o Hvordan hjælper I hinanden?
  o Hvordan oplevede du det og hvad følte du?
  o Hvilken betydning har det for dig?
Appendix G: Screenshot from Nvivo
Adjunkt. Ph.d. studerende Leæe Søndergård Larsen  
Sygeplejerskuddannelsen  
Toldbodgade 12  
8800 Viborg

Sendt til: lela@vianc.dk

19. februar 2010
Datatilsynet  
Borgergade 28, 5.  
1300 København K
CVR-nr. 11-88-37-29
Telefon 3319 3200  
Fax 3319 3218
E-post d@datatilsynet.dk  
www.datatilsynet.dk
J.nr. 2010-41-4312

Sagbehandler  
Anne Mette Riis Steinsen  
Direkte 3319 3217

Vedrørende anmeldelse af: Patient-patient-relationer. Hvilken betydning har medpatienter for kræftpatienters sygdomsophattelse, indlæggelsesforløb og oplevelse af at være kræftpatient?

Ovennævnte projekt er den 28. januar 2010 anmeldt til Datatilsynet efter persondatalovens § 48, stk. 1. Der er samtidigt søgt om Datatilsynets tilladelse.


Oplysningerne vil blive behandlet på følgende adresser: CSF – Center for Sygeplejeforskning, Heibergs Allé 2, 8000 Viborg samt Julsovej 242, 8240 Risskov.

TILLADELSE

Datatilsynet meddeler hermed tilladelse til projektets gennemførelse, jf. persondatalovens § 50, stk. 1, nr. 1. Datatilsynet fastsætter i den forbindelse nedenstående vilkår:

Med venlig hilsen

Anne Mette Riis Steinsen

1 Lov nr. 420 af 31. maj 2000 om behandling af personoplysninger med senere ændringer.
Appendix I: Information to the healthcare professionals in the ward

Til personalet.

Mit navn er Lene Søndergård Larsen og jeg er i øjeblikket i gang med et forskningsprojekt i forbindelse med et Ph.d. forløb ved Institut for Folkesundhed, Århus Universitet. Jeg har fået lov til at bevæge mig rundt på afdelingen for at indsamle data til projektet, hvorfor jeg vil være synlig i afdelingen i en periode på ca. 3 mdr. fra november 2010 til januar 2011.


Metoden til dataindsamlingen er feltmetode. Jeg være deltagende observatør i afdelingen hos patienterne og udvælge patienter til interviews i forbindelse med observationsarbejdet.

Eftersom fokus ligger på patient-patient-relationen, vil min omgang primært være med patienterne og der hvor patienterne befinder sig, men jeg vil selvfølgelig være synlig i afdelingen for jer også. Jeg vil dog bestræbe mig på, at være til mindst mulig gene og respektere afdelings daglige arbejde.

Hvis I har spørgsmål, står jeg til rådighed.

Med venlig hilsen

Lene Søndergård Larsen
Ph.d. studerende, cand.cur., sygeplejerske
Kære Patient

Når man er indlagt på hospitallet, er der mange mennesker, man skal forholde sig til. En af dem er medpatienten, ikke mindst fordi, der tilbringes rigtig meget tid sammen med ham/hende i løbet af indlæggelsen. At være så meget sammen med et andet menneske, som man måtte møde før første gang, kan være forbunden med såvel positive som negative oplevelser og følelser. For at få viden om dette, vil jeg hedre dig om at deltage i denne videnskabelige undersøgelse.

Formål med projektet:
Formålet med denne undersøgelse er at bidrage med viden om hvilken betydning medpatienter har, for kæmpatienters sygdomsmønstre, indlæggelsesforløb og oplevelse af at være kæmpatient. Dette kan du være med til, ved at dele ud af dine erfaringer og oplevelser med medpatienter under indlæggelse.

Fremsætningsmåde:
Jeg vil foretage observationer, ved at gå rundt i afdelingen og sidde på patientstuen eller dagligstuen, hvor patienter er sammen under indlæggelsesforløbet. Det som interesserer mig er, hvad du oplever og tenker i forbindelse med din indlæggelse, hvad du taler med medpatienterne om og hvilken betydning, deres samtaler kan have for dig. Derfor vil jeg endvidere interviere nogle af deltagerne i projektet til et personligt og mere uddybende interview. Interviewet varer ca. en halv time og jeg har brug for din tilladelse til, at optage vores samtale på lyd, så jeg efterfølgende ved nødvendigt, hvad du har sagt. Vores samtale vil sammen med andre patienters fortællinger indgå som data i forskningsprojektet.

Anonymitet:

Du er velkommen til tage sig betænkningstid før du accepterer og hvis du har brug for mere information vedrørende projektet før du tager din beslutning, er du velkommen til at kontakte mig.

Projektet er finansieret af Regionshospital Viborgs Forskningsfond, RegionMidtjylland, VIA University College, TrygFonden og Kærefonden, men jeg varetager ikke bestemte interesser direkte af disse.

Med venlig hilsen

Lene Søndergaard Larsen
Ph.D. stud., cand.curs. sygeplejerske
Det Sundhedsvidenskabelige Fakultet
Afdeling for Sygeplejedoktor, Bygn. 633
Højeh-Gulbergsgade 6A
8000 Århus C
Tlf. 20303626
Email: lene.sondergaard@sygeplejedk.au.dk

Om mig:
Jeg er studerende på Ph.d studiet ved Afdeling for Sygeplejedosent, Århus Universitet. Jeg er uddannet sygeplejerske og arbejder i nødhelikopter med en undersøgelse af, hvordan patienter under indlæggelse på hospitallet, oplever forholdet til medpatienter.
Appendix K: Informed consent sheet

Ifølge Datatilsynet og lov om behandling af personoplysninger er der fastsat vilkår for undersøgelser til beskyttelse af private og personlige forhold for deltagere:

Efter persondataloven (lov nr. 429 af 31. maj 2000) har registrerede personer følgende rettigheder:
• Ret til at bede om indsigt i de oplysninger der behandles
• Ret til at gøre indsigelse mod at oplysningerne behandles
• Ret til at kræve berigtigelse, sletning eller blokering af oplysninger der er urigtige, vildledende eller på anden måde er behandlet i strid med lovgivningen

- du skal være informeret såvel skriftligt som mundtligt når du giver oplysninger om dig selv til forskningsformål
- du skal være informeret om hvad undersøgelsen går ud på
- du skal vide at alle dine oplysninger bevares anonyme så din identitet ikke kan genkendes i den færdige afhandling

Du deltager på frivillig basis og jeg har som interviewer informeret dig om dine rettigheder i forhold til dette.
Nedenstående slip er en bekræftelse på, at du er indforstået og gerne vil deltage som informant i undersøgelsen.

__________________________
den underskrift

__________________________
Appendix L: Co-authorship declarations