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PhD Thesis

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Communication practice in an oncology outpatient clinic

Perspectives from patients with cancer and health care professionals and observations of communication practices during oncological treatment

This thesis has been submitted to the Graduate School of Health and Medical Sciences, University of Copenhagen, 7 July 2020

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List of original papers

Paper I

Prip A, Møller KA, Nielsen DL, Jarden M, Olsen MH, Danielsen AK. **The patient-healthcare professional relationship and communication in the oncology outpatient setting: A systematic review**. *Cancer Nursing* 2018;41(5):E11-E22. doi:10.1097/NCC.0000000000000533

Paper II

Prip A, Pii KH, Møller KA, Nielsen DL, Thorne SE, Jarden M. **Observations of the communication practices between nurses and patients in an oncology outpatient clinic**. *European Journal of Oncology Nursing*. 2019;40:120-125. doi:10.1016/j.ejon.2019.03.004

Paper III

Prip A, Pii KH, Nielsen DL, Jarden M. **Patients' experience of communication during their course of treatment in an oncology outpatient clinic: A qualitative study**. (Accepted *Cancer Nursing*, 28 June 2020)

Abbreviations

AP: Anne Prip
HCP: Healthcare professional
ID: Interpretive description
IV: Intravenous
KAM: Kirsten Alling Møller
KHP: Kathrine Hoffmann Pii
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Introduction

My background in oncology nursing and personal experiences of collaboration with patients undergoing cancer treatment has been a central motivation for developing this PhD project. Specifically, I have been curious to understand the implications of the changes made in the organisation of cancer treatment - from inpatient to outpatient treatment. This has increased my interest in how patients experience being treated in the outpatient setting and whether the changed conditions have an impact on the support they receive from healthcare professionals (HCP). Communication in a cancer context is multifaceted and complex (1). Thorough and understandable information about treatment and side effects are essential as patients need to be able to adequately care for themselves at home (2–4). Furthermore, the many physical, emotional, existential and psycho-social consequences that patients experience when living with cancer (2,5–7) require a heightened focus on communication. This thesis contributes to the discussion of the communication practice between HCP and patients during treatment in oncological outpatient settings.

Background

Global developments in cancer care and treatment

Cancer is the second leading cause of death worldwide (8), and the leading cause of death in Denmark (9). The incidence of cancer increases with age, which means that as the population ages the number of people with a cancer diagnoses is rapidly growing globally (10,11). Estimates predict that new cancer cases worldwide will grow from 18.1 million in 2018 to 29.5 million by 2040 (12). Consequently, more and more people will need treatment for cancer. Cancer care and treatment are currently primarily undertaken in outpatient settings (13,14). Thus, in light of demographic trends (8), the availability of better and more treatment modalities (15,16) and the growth of novel treatment methods (e.g. immunotherapy) (17), the number of patients undergoing outpatient cancer treatment will grow.

Oncology clinical setting in Denmark

In recent years an overall national health strategy in Denmark has been to organise patient care so that patients are only hospitalised if no relevant outpatient care is available (14,18). From 2007 to 2014 the number of outpatient visits in Denmark for people with cancer has grown by over 40% (14), with a simultaneous increase in cases for most cancers occurring during the same period (14). This development puts a significant demand on healthcare services, creating new terms and conditions for encounters between patients and healthcare professionals (HCP), as this interaction if often brief (19–21). Furthermore, another health strategy has been the implementation of fast-track cancer referral programmes designed to organise treatment pathways that avoid unnecessary waiting time to improve the prognosis and quality of life of patients, which further increases pressure on the health service (19). A 2012 report assessing implementation of fast-track cancer referral programmes emphasised that the fast pace places high demands on HCP communication with patients (20).

Research shows that when HCP have limited time to communicate and to get to know the individual patient, it can hinder them from identifying the patient's needs (22–24). A report on care services of the future in the Danish healthcare system predicted in 2010 that a prerequisite for converting successfully from inpatient to outpatient care is an increased focus on the communicative and relational skills of HCP in that the shorter amount of time available in outpatient clinics requires more intensive communication and qualified patient involvement if the healthcare challenges of the future are to be met (21).

Support needs of patients with cancer

Research shows that patients with cancer experience a range of care needs during treatment and in their management of the cancer disease (6,25,26). These care needs relate to physical side effects such as fatigue, pain, nausea and/or vomiting (3,25); emotional needs such as dealing with anxiety (5,25) and depression (5,26); social needs related to, e.g. their work life (27), family life (28) and financial support (29); existential needs due to the potentially life-threatening aspect of the disease (1,30,31); and, finally, sexual needs (26,32–34). Although it is well known that these supportive care needs vary depending on the individual cancer trajectory (2,6,7,31), systematic reviews show that patients with cancer experience having many unmet needs during and after the treatment pathway (5,6,35). Recent systematic reviews indicated that patients with cancer have both unmet psychological and physical needs (5,6). For instance, Wang et al. found that the most frequent unmet needs were related to emotional support and being informed about treatment side effects (5).

Significance of communication between patients and healthcare professionals

Communication between patients and HCP is fundamental in cancer care due to the many physical, emotional, existential, psycho-social and practical challenges, that many patients with cancer experience. Communication is crucial for many reasons, for example receiving a cancer diagnosis is perceived as one of the experiences people fear most in their lives (36) due to its potentially life-threating nature, which means that support in handling the emotional impact of the disease is required (37,38). Furthermore, treatment is often complex, presenting many challenges for patients in terms of understanding and remembering comprehensive and complex information (2,38,39). A systematic review found that patients with cancer are often unable to describe their own information needs, which is why HCP play an important role in supporting the deliberation processes required to define their needs (40). Although communication is essential in meeting the care needs of patients with cancer, studies have shown that their needs are generally not being addressed fully in their communication with HCP in oncology (40) and outpatient settings (41–44). Research shows that communication with HCP is critical for patients and influences their satisfaction with care and health outcomes (45,46). For instance, a review found that when the topic of life expectancy is broached and HCP communicate empathetically in a way that supports hope, the anxiety of patients is reduced (47). Another review showed that patient complaints are often due to poor communication (48,49), while a survey from the United States found that 30–50% of cancer survivors experienced unsatisfactory patient centred communication with their HCP, particularly regarding support in managing uncertainty and HCP poor response to their emotional concerns (45).

In summary, research shows that communication between patients with cancer and HCP is essential, and that patients' communication needs with the HCP is not adequately addressed. Only a few studies, have examined patients' experience of communication with HCP when undergoing outpatient treatment (24,50–52), though research indicates that the brief amount of time available during treatment makes it difficult to identify patients' needs (24,53,54).

Despite the multiple systematic reviews available on various aspects of cancer communication (1), none of them, based on our assessment, covered the outpatient setting viewed from the patient perspective, except for the systematic review conducted in this thesis (50). Recent systematic reviews focus particularly on two approaches to improve the quality of communication for patients with cancer: 1) using structured communication tools (55–57) and 2) communication skills training (58,59). However, it is not possible on the basis of these reviews to identify specific characteristics of the communicative practice in an outpatient clinic, either because the setting is not reported (55,59), or because of unspecified treatment type (e.g. treatment and follow-up) or different treatment and care context (56–58).

Moreover, research indicates that communication is often not as patient-centred as recommended (36,40,60–62), failing to embrace an awareness of and response to individual patient preferences, needs and values (36,63,64). More specifically, the U.S. National Cancer Institute states that patient-centred communication in cancer care must: (1) foster healing relationships, (2) exchange information, (3) respond to emotions, (4) manage uncertainty, (5) involve decision-making and (6) enable patient self-management (38). While this definition describes the six functions that patient-centred communication should include, it does not define *what* communication is and *how* it is practiced. Communication can be defined in multiple ways, and this thesis embraces Blumer's (1969) symbolic interactionist perspective and Albrecht et al.'s (65) definition of clinical communication. From a symbolic interactionist perspective, all communication is symbolic and based on interaction and meaning (66). When individuals interact with each other they communicate meaning. Communication is an ongoing use of language and gestures, where individuals interpret social situations and respond to them based on that interpretation (66). (See also "Theoretical underpinnings", p. 20).

Albrecht et al. (65, p. 49), who echo central aspects of Blumer's understanding of communication, offer this more clinically oriented definition:

[A] dynamic, interpersonal process in which patients and healthcare professionals 'exchange information that mutually influence attitudes, behaviors, and relationships' regarding treatment and care, where healthcare professionals and patients 'interpret one another's verbal and nonverbal, explicit and implicit, obvious and subtle interactional behavior'.

This thesis investigates communication in its multiple forms between patients and HCP as it is practiced verbally and nonverbally in responsive and adaptive interactions in order to understand the consequences of the actual communication practice on how patients' needs for support are met in an outpatient setting.

Knowledge gaps

Despite the well-established significance of communication between patients and HCP, there is still a gap in the literature regarding communication practices between HCP and patients during treatment in outpatient clinics (50,51,67). We also lack knowledge on the role and perspectives of patients on this communication both in general (49,53,68), and especially when the encounters take place in an oncology outpatient setting (42,51,69). According to D'Agostino et al. (59) the majority of research in health communication generally focuses on HCP perspectives. It is important to gain insight into how patients with cancer are supported in this setting as the shift from hospitalisation to outpatient care and treatment requires that patients are capable of managing their condition at home to a greater extent (2,3,70) and that they take a more active role (4,71). Hence, this thesis addresses these knowledge gaps in an effort to understand patient-HCP communication in an outpatient context from the patient perspective to gain insights into how patients are supported in this setting, helping to pinpoint potential areas for improvement.

Aims

This thesis is based on the assumption that communication and the relationship between the HCP and patients with cancer have an impact on the patient's ability to manage the physical, emotional, existential and psycho-social consequences that many patients experience when living with cancer.

The overall purpose of this thesis is to provide knowledge about communication practices between HCP and patients with cancer undergoing treatment in an outpatient clinic to gain insight into how patients are supported in this setting. This thesis is based on three papers and supplemental data from a focus group interview with HCP with the following specific aims:

- To summarise the literature from the perspective of the patient on experiences of and the need for relationships and communication with HCP during chemotherapy in outpatient settings (Paper I).

- To explore communication between nurses and patients undergoing chemotherapy in an outpatient clinic to gain insight into how patients are supported in this setting (Paper II).

- To explore how patients experience communication with HCP during their course of treatment in an oncology outpatient clinic in order to illuminate how their needs for support are met (Paper III).

- To explore the perspective of HCP on their communication with patients during the patients' course of treatment in an oncology outpatient clinic (Thesis).

Concept clarification

As the overall purpose of this thesis is to provide knowledge about patient-HCP communication practices and how patients experience the communication when treated in an outpatient clinic, both their communication with nurses and physicians is examined. HCP thus refer to nurses and physicians, unless otherwise indicated. Th**e** reason for including both perspectives is that cancer care is provided in teams and because patients with cancer receive support from both nurses and physicians during treatment (40,72). For instance, when nurses and physicians present information on treatment and side effects they often communicate complementary, which is why it may be difficult for patients to distinguish who communicated what. In Paper I, we were interested in examining the existing evidence in the research literature about patients' experiences of their communication and relationships with HCP when they receive outpatient treatment. In Paper II we investigated the communication in the actual treatment encounter, which concerns only nurse-patient communication, since the treatment is provided by nurses. Paper III focused on the patients' experiences of the communication when receiving outpatient treatment, which regarded communication with nurses as well as physicians. Finally, supplementary data from a focus group interview with HCP is included in the thesis and present the perspectives of both the nurses and the physicians on their communication with patients.

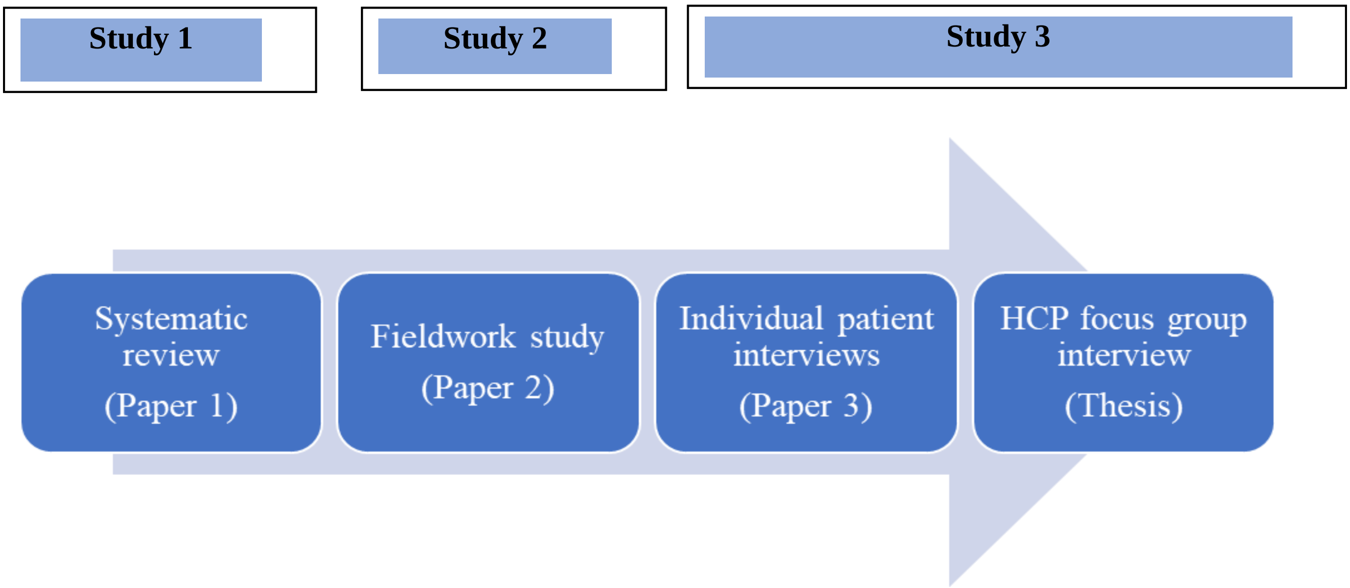
Methods and methodology

The purpose of this section is to clarify the methods and methodological foundation and present the theoretical underpinnings of the thesis. The section describes the study design and presents the methods and methodology applied in the thesis.

Study design

This thesis comprises three studies. The first study (Paper I) was a systematic review conducted to summarise the literature on HCP-patient communication and relationships in outpatient settings during chemotherapy treatment. The two subsequent studies employed a qualitative design, with the second study (Paper II) generating data through participant observation of the communication practices between patients and nurses during administration of treatment (70 hours) and via supplementary ad hoc interviews conducted with nurses in an oncology outpatient clinic. The third and last study (Paper III) comprised individual semi-structured interviews (n=18) with patients undergoing chemotherapy or immunotherapy in an outpatient clinic and a focus group interview with HCP (nurses (n=3) and physicians (n=3) from the outpatient clinic conducted to supplement the data generated from patient interviews and to gain insight into the perspectives of HCP on communication during cancer treatment. Figure 1 provides a visual overview of the three studies and papers.

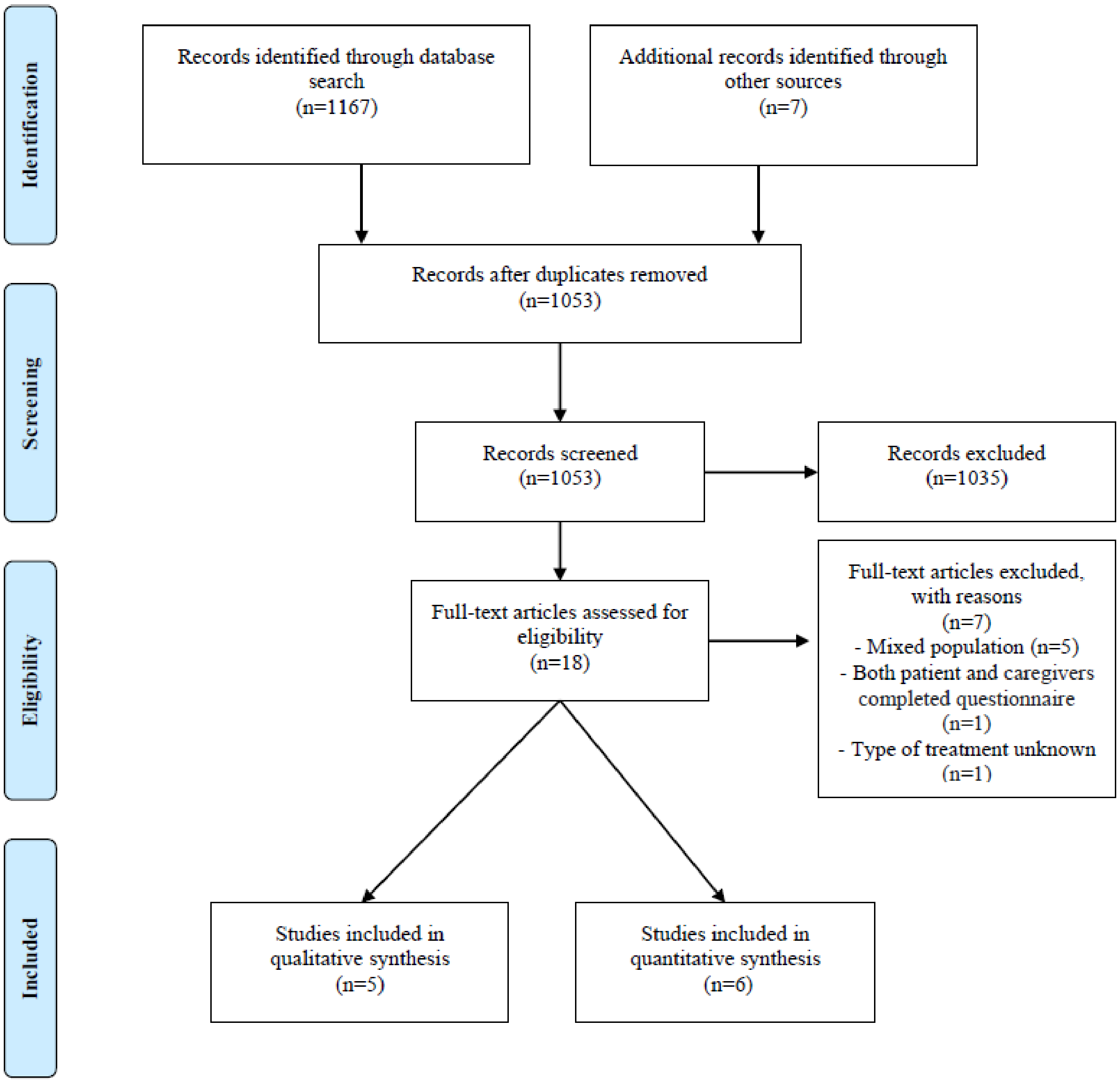
Figure 1. Study design



Methods behind systematic review (Study I)

The systematic review included qualitative and quantitative studies to avoid excluding important scientific knowledge solely based on the method (73). The review was planned and carried out according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (74) to provide transparency during the identification, screening, eligibility and inclusion process. In accordance with the PRISMA checklist, what is known as the PICO (Patient, Intervention, Control, Outcome) framework was used to structure, concretise and refine the literature search (74). The systematic search was carried out in Medline, CINAHL, The Cochrane Library and Joanna Briggs Institute Evidence-Based Practice Database. Even though Paper I only included original studies, we searched for systematic reviews to ensure that a similar study had not previously been carried out and to allow a manual search of the references. A research librarian assisted in conducting the search strategy, e.g. in choosing the correct search terms. No time limits were placed on the search as an initial literature search revealed that few studies existed on the subject. The literature search was last updated 6–7 June 2016. Figure 2 illustrates the steps taken in the literature search.

Figure 2. Flowchart of literature retrieval and selection process



Methodological quality assessments were carried out using Joanna Briggs Institute's study-appropriate assessment tools (75), which provided a structured evaluation of the studies. The overall methodological quality of the qualitative and quantitative studies ranged from medium to high. Data from the qualitative and quantitative studies were extracted, assessed and summarised in parallel processes. Subsequently, main findings across the included studies were extracted based on the study aim of Paper I, which was to summarise the literature from the perspective of the patient on experiences of and the need for relationships and communication with HCP during chemotherapy in outpatient settings. Even though we conducted a broad literature search and included qualitative and quantitative studies, only nine studies were eligible for inclusion. Due to the limited number of studies, the small sample sizes and the heterogeneity of the included studies, the knowledge extracted from this review was limited. However, the review confirms the existence of a knowledge gap and the need to produce research-based knowledge on the subject. The systematic review provided some insights on the significance of the relationship and communication between patients with cancer and HCP and on how the relationship and communication affected the patients in managing the disease and their satisfaction with care in an outpatient setting. Furthermore, the review helped to specify which aspects of the communication are central in the patient–HCP interaction from the patient perspective, which was also helpful in planning the subsequent studies.

Methodology (Study II and Study III)

Interpretive description

Interpretive description (ID) was the methodology chosen to guide this thesis (76). The methodology was conceptualised by Canadian nurse researcher Sally Thorne in the 1990s to develop a research method better suited for developing knowledge that directly can inform practice rather than developing grand theories. The approach was chosen for four reasons. First, ID focuses on the exploration of clinical problems and phenomena (76,77) and seeks knowledge development based on empirical integrity and disciplinary utility (76). Thus, ID aligns with a constructivist and naturalistic orientation toward inquiry (78,79) that acknowledges the *constructed* and *contextual* nature of human experience (79). ID seeks understanding by exploring action in natural settings (76,80), where realities are seen as local and as socially and experientially generated (78). ID strives to go beyond mere descriptions by engaging in the “so what” questions that drive all applied disciplines (76), i.e. by providing answers of practical relevance to specific disciplinary fields. The underlying ideas for this thesis originated in the clinical field. Hence, the thesis is aimed at developing a clinical understanding of communication practices in the oncology outpatient clinic and at understanding how the changes made in the organization of cancer treatment impact the support patients receive from HCP.

The second reason is that ID employs a methodologically inductive approach (76), which is suitable for exploring the phenomena under investigation, such as patients’ experience of communication when undergoing treatment in outpatient clinics. Third, since ID studies are data driven and sensitive to context, they allow flexible designs. The initial focus of the research project was modified in the research process, moving from an emphasis on relationships between patients and HCP in outpatient treatment to a more specified focus on their communication practices in the outpatient setting. These adjustments occurred based on the knowledge gained from the systematic review and during the participant observations in study 2. Finally, the fourth reason is that ID allows the researcher to draw on different combinations of established qualitative methods to fit the specific study instead of trying to align the research question with the methods (76). ID draws on established qualitative research traditions and techniques such as phenomenology, grounded theory and ethnography (81) but differs in that it applies a pragmatic approach, which, according to Thorne, is what research questions in applied health disciplines often require. The overall purpose of ID studies is to inform practice, not to generate theory, which is the case with grounded theory, for example.

This thesis embraces four methodological features that generally characterise ID studies. First, *scaffolding study*, which means it is located in existing knowledge to allow reflection on what is already known and what is not (76). This was achieved through an initial systematic review summarising existing knowledge on the subject. Next, *framing and strategising the study,* which in an ID approach often implies the use of multiple data sources to provide rich data on the study aim and to be flexible in the research process by, e.g. expanding the data collection, if needed, to ensure that there are both commonalities and variations in the data (76,77). I combined data from observations and individual and focus group interviews to explore the communication practice. In accordance with Thorne (76), the data generation and analysis took place concurrently, e.g. during the observation period the three first authors involved in Paper II met several times to review methodological aspects, such as observation strategy, field note generation and discussing initial analyses, patterns and variations in the data. Third, *entering the field*, which includes reflecting on and documenting one's own subjectivity (76). To achieve this, before starting each study, I was either interviewed by a colleague about my ideas and/or I wrote down my preconceptions. I also kept an analysis log to record personal reflections during the analytical process, which especially made me aware of my preconceptions formed in my earlier work as a nurse in an oncology department. Finally, *constructing and working with data,* which implies an inductive approach and broad coding of data (76), which was conducted after each study.

Theoretical underpinnings

The understanding of communication in the thesis is based on a symbolic interactionist perspective (66). The thesis focuses on the characteristics of patient-HCP communication in their interactions and the implications of the symbolic meaning of this communication. According to Blumer (66, p.2) symbolic interactionism is based on three premises:

> *Human beings act towards things on the basis of the meaning that things have for them.* [...] *The meaning of such thing is derived from, or arises out of, the social interaction that one has with one's fellows.* [...] *these meanings are handled in, and modified though, an interpretative process used by the person in dealing with these things he encounters.*

Symbolic interactionism and ID, which share the same epistemological foundations (82), also in terms of pragmatism, focus on contextualised action (76,80). The former has guided many ID studies because it is well suited for exploring the interactions of human beings on a micro level (76,80,82). In the thesis, symbolic interactionism was not chosen from the outset because the idea was to use an inductive approach in the primarily data-driven analysis. Symbolic interactionism was added later during the analysis to attain a deeper understanding of the communicative practices we explored through observations and interview studies. Adding a suitable theoretical perspective after data generation is according to Thorne and Kirkham (79) a more suitable approach than generating data with an priori theoretical perspective, as such an approach cannot encompass the multiple realities that applied research studies are likely to encounter. Symbolic interactionism helped create a deeper understanding of the observations providing a vocabulary to understand the mutual processes of communication and construction of lines of expectations in communicative interactions (66). Symbolic interactionism I thus provides a valuable perspective for exploring communication between patients and HCP in an outpatient clinic as it can broaden understanding of the complex processes that occur when individuals communicate with each other (66,83).

Methods (Study II and Study lII)

Data generation

Data were generated through different methods and perspectives to gain deeper insight into the communication practice. As the systematic review found, there is limited knowledge on patient-HCP communication during chemotherapy (Paper I). Exploring and describing how communication was practiced between patients and nurses in their encounters during treatment was thus a central interest to investigate further (Paper II). Participant observation was a strategy used to observe communication practices during outpatient cancer treatment. The method is suitable for observing communication in action (76,84,85), also because there may be a discrepancy between what people say they do and what they actually do (85). We paid close attention to, for instance what people spoke about and how, who took the initiative to speak, what was left unarticulated and the duration of the conversation, in addition to the behaviours and activities that took place and the setting of their conversations; see Appendix A: Observations strategy. Observations were supplemented with ad hoc interviews with the nurses to gain insight into their reflections about their actions and the observed situations (Paper II). Fieldnotes were taken during observations, conversations between patients and nurses and the ad hoc interviews with nurses were noted. These handwritten fieldnotes were subsequently digitally transcribed the same day.

To explore how patients experienced their communication with the HCP during their treatment trajectory, individual semi-structured interviews were conducted to gather rich and multifaceted subjective perspectives on the communication practice (76,86) (Paper III). Our approach also gave us the opportunity to inquire about the actions and social interactions we observed (Paper III), see Appendix B: Interview guide cancer patients. Furthermore, a focus group interview with HCP generated secondary data, allowing us to gain insight into their perspectives on communication during cancer treatment (see “Findings from the focus group interview”, p. 34-37 for more detail). The aim of the focus group interview was to support the clinical relevance of our findings as Thorne recommends applying a “practice test” to data which allows clinicians to catch clinical patterns and perspectives that may be invisible to the researcher and that can enrich study findings (76), see Appendix C: Focus group interview guide with HCP. The individual and focus group interviews were audio recorded and transcribed verbatim, but the latter was also video recorded to better enable identification of who was speaking.

To support a systematic and transparent analysis NVivo^{TM} (87) was used to organise and manage the data from the participant observation study (Paper II) and the individual interviews (Paper III). Data from the focus group interview were coded and managed manually (Thesis, p 34).

Table 1 presents a summary of the data generation process.

Table 1. Data generation process

Data sources	Reported	Data generation (month, year)
Participant observations of nurse-patient interactions and ad hoc interviews with nurses 70 hours	Paper II	October and November 2014
Individual semi-structured interviews with patients with cancer (n=18)	Paper III	March and April 2016
Focus group interview with healthcare professionals (n=1); 6 participants (nurses: n=3; physicians: n=3)	Included in thesis as secondary data	June 2016

Study setting

The study setting was an oncology outpatient clinic at Herlev and Gentofte Hospital, which is a public university hospital with about 6,300 employees distributed across two locations in the Capital Region of Denmark. The hospital where the study was carried out has one oncology inpatient clinic and four outpatient clinics. Patients visit the outpatient clinics for follow-up and to receive treatment for their disease. This study was conducted in an outpatient clinic receiving patients with mixed cancer diagnoses, including gynaecological, melanoma, renal, bladder and prostate cancer. More specifically the study included patients undergoing intravenous systemic therapy; chemotherapy or immunotherapy. The clinic provides medical cancer treatment for approximately 24 patients daily. In addition to carrying out other nursing tasks (e.g. blood transfusions and taking blood samples from Port-a-Cath), the nurses provide treatment for 4–5 patients daily, with treatments lasting from 30 minutes to six hours, see Appendix D: Ambulatory setting.

Sampling and recruitment

The purpose of this PhD was to provide knowledge about the communicative practices taking place when patients with cancer receive treatment in an outpatient clinic– regardless of specific conditions, such as sex, age or tumour site. According to Thorne (76) sampling patients with different diagnoses can be a useful method when the aim is to describe a general phenomenon. The participants in the participant study comprised patients undergoing intravenous systemic therapy in the outpatient clinic described above and the nurses who treated them (Paper II). Data were generated by two researchers, Anne Prip (AP) and Kirsten Alling Møller (KAM), to broaden the perspectives on the observed communication (see "The researcher's role", p. 24-25). We discovered that the best way to gain access to nurse-patient communication was to follow the nurses' daily routines as their interactions were brief and occurred multiple times (at the beginning, middle and end of the treatment). This strategy gave insight into the many encounters and communicative interactions that took place, providing the opportunity to conduct short ad hoc interviews with the nurses. For ethical reasons, we did not conduct ad hoc interviews with patients because other patients were able to hear what was being said. Our observations included a diverse group of patients in terms of, e.g. sex, age, education and treatment experience. The observed nurses had clinical oncology experience that varied from less than one year to over 10 years.

To gain a broader perspective, we observed other interactions that patients experience in the outpatient clinic i.e. consultations with the physician. This approach provided additional information about communication before and after the treatment encounter. We ended the observations after 70 hours as we identified both commonalities and variations in the generated data (76,84).

The patients and HCP who participated in the individual interviews (Study 3) were purposively sampled by AP and an oncology nurse from the outpatient clinic to achieve variation in data (76) (see "Participant characteristics" in Paper III). Inclusion criteria were >18 years, recipient of at least two series of chemotherapy or immunotherapy, conversant in the Danish language and willing to share their experiences. All 18 participants, comprising nine females with a mean age of 55 and nine males with a mean age of 66, were ethnic Danes. We mainly included patients receiving chemotherapy, but to embrace all patients receiving oncological treatment at the outpatient clinic, a few patients receiving immunotherapy were included (Papers II and III).

Participants in the focus group interview (Study 3) were multidisciplinary HCP, including (n=6) nurses (n=3) and physicians (n=3) who had daily contact with the patients during treatment in the outpatient clinic. Their clinical oncology experience varied from three to over 15 years and all of them had a minimum of one year's experience in working in the oncology outpatient clinic. The focus group interview was carried out in an undisturbed conference room at the hospital and lasted 90 minutes. Kathrine Hoffmann Pii (KHP), assisted as co-researcher and facilitated the interview according to the interview guide, while AP observed the interaction between participants and made notes.

The researcher's role

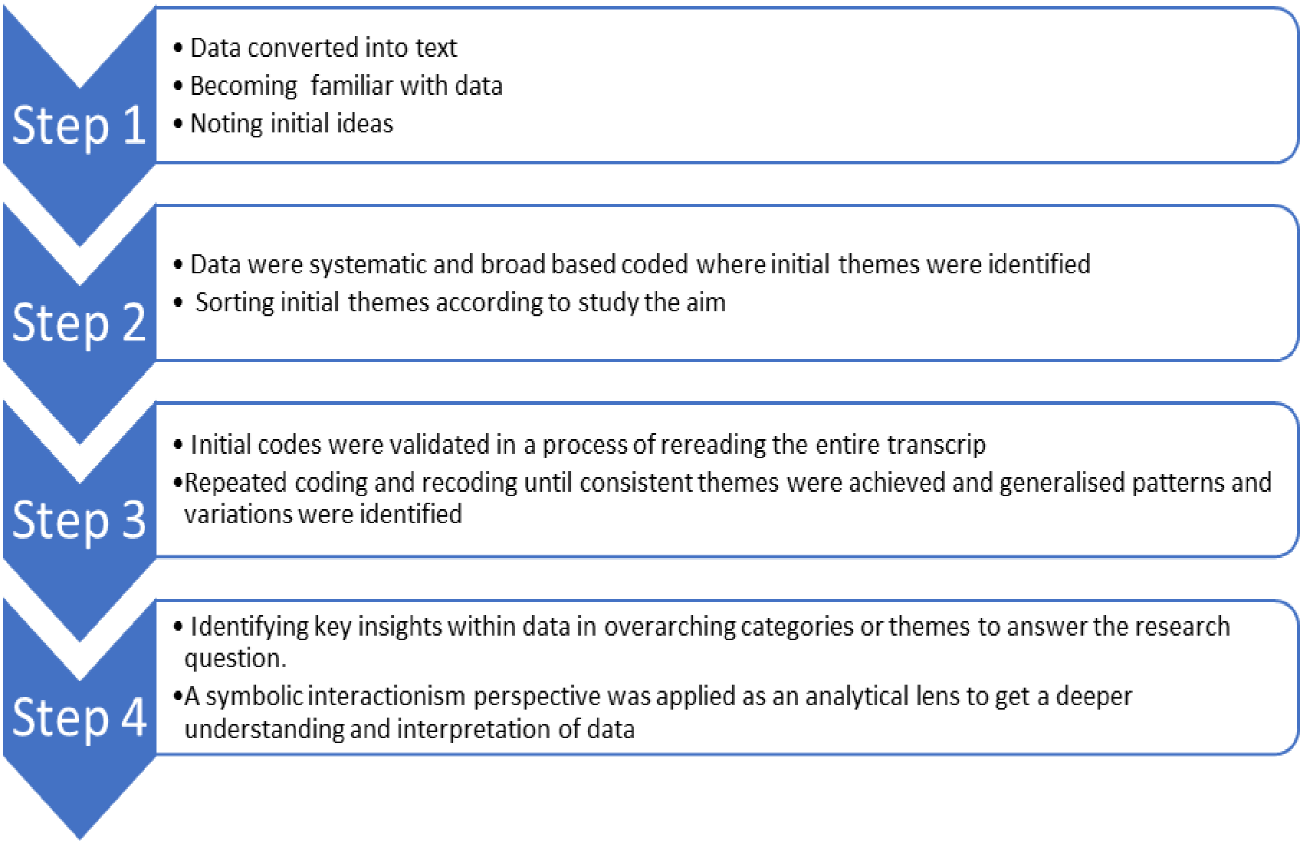
According to Thorne (76) nurses with knowledge and experience in the field of study have a valuable starting point in applied research as they are able to frame clinical relevant research questions (76,78). However, their disciplinary perspective influences how the particular issues are framed and interpreted (78,88). Throughout the entire project, it has been particularly important to reflect on how I generated and interpreted the data. To do so, I have attempted a transparent, reflective approach to the knowledge generated, by engaging in methodological and analytical discussions with various co-researchers throughout the research process to help me to confront my blind spots. Prior to each study, I also undertook an explication of my preunderstanding either by having a colleague interview me or by writing it down. My preunderstanding was formed by my clinical experiences, which included previous work as an oncology nurse in both in- and outpatient settings, experience as a volunteer cancer counsellor, and by the exposure of research on the subject. On the one hand, having worked as an oncology nurse was an advantage because I had easy access to the field and was familiar with treatment procedures and routines, just as I found that my clinical experience meant that both patients and HCP were highly accepting and willing to collaborate and share their thoughts, experiences and opinions with me. There was the risk, on the other hand, of not adequately researching some of the obvious issues I observed. As a result, I chose to carry out the project at a hospital that I had not previously worked in, which meant I was unfamiliar with the practices, routines and organisation of the particular outpatient clinic and did not know the HCP. Furthermore, during study 2, I chose to observe with a co-researcher with a nursing background but who had never worked in oncology. While generating data I also discussed the data with my multidisciplinary supervisor team, including an anthropologist without HCP background (Paper II); see Appendix A: Observation strategy. Researcher triangulation was conducted to ensure study credibility and methodological reflection during the data generation step, and my supervisors provided assistance with methodological reflections during every stage of the project (76,86,89). Finally, I also kept an analysis log to record and document my reflections, questions and ideas during the empirical studies to support an inductive analytical process (76).

Data analysis

In accordance with ID methodology the data was inductively analysed in four steps (76). Step 1 involved becoming familiar with the data by repeatedly reading the transcripts and the fieldnotes (Paper II), by both reading and listening to the interviews (Paper III) and by jotting down initial ideas. Data were then broadly coded in step 2, which involved identifying initial codes. In study 3 the interviews were coded separately for each interview and then across interviews (Paper III). In step 3 these initial codes were validated in a process that involved rereading the entire transcript according to these initial codes, where a repeated coding and recoding took place until consistent themes were determined, and generalised patterns and variations were identified. In step 4 the key insights were refined into three overarching themes (Paper II), or overarching categories and underlying themes (Paper III) addressing each of the research questions. To understand nurse-patient communication (Paper II) and patient experiences and reflections on that communication (Paper III), an symbolic interactionist (66) perspective was applied as an analytical lens in step 4 to further develop an understanding and interpretation of the data. Thus, SI, which was an approach that I did not initially choose when I began the research, but was later included to provide a perspective based on the desire to achieve a deeper analysis, understanding and interpretation of the data (76). Figure 3 provides an overview of the data analysis process in Paper I and Paper II.

Data from the focus group interview were broadly coded based on the study aim and the findings from the previous studies (Papers I, II and III). The findings from the focus group interview are presented and disseminated as a thematic summary (76). Thus, the purpose of the focus group interview was to catch clinical patterns from the HCP perspective to gain a broader perspective on the communication practices in the outpatient clinic as well as to support clinical relevance.

Figure 3. Overview of data analysis in Paper I and Paper II



Step 1

- Data converted into text
- Becoming familiar with data
- Noting initial ideas

Step 2

- Data were systematic and broad based coded where initial themes were identified
- Sorting initial themes according to study the aim

Step 3

- Initial codes were validated in a process of rereading the entire transcrip
- Repeated coding and recoding until consistent themes were achieved and generalised patterns and variations were identified

Step 4

- Identifying key insights within data in overarching categories or themes to answer the research question.
- A symbolic interactionism perspective was applied as an analytical lens to get a deeper understanding and interpretation of data

Themes and findings were discussed with my supervisors and an international researcher during the analysis to avoid defining themes too quickly or superficially. In addition, my supervisors represent a variety of professional backgrounds and scientific traditions, bolstering my research due to the diverse perspectives and critical or penetrating questions they always asked. Another strength was that one of my supervisors is an oncology clinician, allowing her to ensure the clinical foundation and relevance of my research (76,90).

Ethical considerations

This thesis was carried out in accordance with the Helsinki Declaration (91) and approved by the Research Ethics Committee of the Capital Region of Denmark (no. H-4-2014-FSP) and the Danish Data Protection Agency (no. 2018-521-0054).

Initially all HCP at the outpatient clinic were invited to attend a meeting describing the project, giving them the opportunity to ask in-depth questions about the project. To inform patients about the participant observations (Paper II), informational posters were displayed in the outpatient clinic's reception area, hallways and treatment rooms that described the project and the participating researchers. Furthermore, when possible, researchers provided patients with information during the observations on the principles of voluntary participation and anonymity and gave them the opportunity to decline participation. The HCP who were observed in study 2 (Paper II) were also informed about the study, including the principles of voluntary participation and anonymity. For ethical reasons, we only conducted ad hoc interviews with nurses and not patients because it was not possible to interview the patients without other patients or nurses overhearing what was said. We also wanted to avoid disturbing patients with interviews during their treatment.

AP contacted potential patients in the outpatient clinic for the individual interviews (Paper III). They were provided with oral and written information on the purpose of the study, anonymity and the voluntary nature of participation. Furthermore, it was stressed that participation or non-participation would not influence the care and treatment they received in the clinic. Some patients suggested that they be interviewed the same day they were contacted, but I chose to do the interviews at a later visit in the outpatient clinic to give them time to better consider participation. Three patients declined participation due to a lack of energy. For both the individual interviews and the focus group interview written informed consent was obtained from all study participants.

Findings

This section presents the key findings of Papers I, II and III, and the unpublished findings from the focus group interview (study 3) are presented with selected quotations.

Paper I

Title: "The patient-healthcare professional relationship and communication in the oncology outpatient setting: A systematic review"

AIM	DATA	FINDINGS
To summarise the literature from the perspective of the patient, on experiences of and the need for relationships and communication with HCP during chemotherapy in an outpatient setting	Nine original studies (n=9), five qualitative (n=5) and four quantitative (n=4)	Three themes: • The relationship between the patient and HCP is important for the patients' ability to cope and has an impact on satisfaction with care • Hope and positivity are a need and strategy for patients with cancer and are facilitated by HCP • Outpatient clinic visits frame and influence communication and relationships

The relationship between the patient and HCP is important for the patients' ability to cope and has an impact on satisfaction with care

The review showed that the relationship with HCP was significant for patients during the course of chemotherapy and affected their satisfaction with care in the outpatient clinic. Patients emphasised that the relational aspect of communication was pivotal for the quality of their relationship with the HCP. The review found that relational aspects of patient-HCP communication were related primarily to the HCP interpersonal skills, such as the HCP being a good listener, being trustworthy and having a caring approach. Furthermore, patients valued being recognised (e.g. by being called by their first names), having their individual needs met and being followed by the same HCP during their course of treatment. The review also pointed to aspects of the communication that the patient valued, such as the HCP basing their communication on dialogue, eye contact and the ability to convey information in understandable language. The nurses were highlighted as being particularly central as a psychosocial caregiver and in communicating information about treatment and its side effects. The review found that the patient-HCP relationship and communication had an impact on how the patients were supported, e.g. by reducing anxiety and helping them cope with the treatment and gain control.

Hope and positivity are a need and strategy for patients with cancer and are facilitated by HCP
The review showed that striving to find hope and positivity during treatment was a strategy that patients used to cope with the cancer disease and treatment. Patients tried to live by this strategy and wanted to be met with this approach in their communication with HCP. The patients associated hope and positivity with better outcomes, whereas they believed that a negative attitude would adversely affect their treatment.

Outpatient clinic visits frame and influence communication and relationships
The review found that the communication between patients and HCP was framed by the setting that it took place in. Some patients experienced the environment negatively. For example, in one of the papers included in the review, a patient compared the setting to visiting a fast food restaurant due to the HCP focus on the treatment, instead of viewing the patient as a whole person (69). The review demonstrated that an outpatient setting has advantages and disadvantages in terms of patient experiences. On the one hand, it can make it easier for patients to maintain a sense of normalcy and remove some of the feelings related to disease. On the other hand, some patients felt isolated and alone with the disease and experienced a lack of professional support. One of the surveys included in the study found that a lack of communication with the HCP was related to not receiving enough information on how to manage side effects at home (92).

In conclusion, this review underscored the significance of the relationship between patients with cancer and HCP, specifying the aspects of communication that are central in the patient-HCP interaction from the patient perspective. Furthermore, it indicated the significance of the patient-HCP relationship and communication as important factors in supporting and facilitating the patient’s ability to cope with cancer in everyday life.

Paper II

Title: "Observations of the communication practices between nurses and patients in an oncology outpatient clinic"

AIM	DATA	FINDINGS
To explore communication between nurses and patients undergoing chemotherapy in an outpatient clinic to gain insight into how patients are supported in this setting	Fieldnotes from 70 hours of participant observations of nurse-patient interactions Notes from ad hoc interviews with nurses	Three themes: • Communication content (treatment-centred communication) • Communication form (efficient communication) • Communication setting (spatially bound communication)

The nurse-patient communication was characterised in terms of its content, form and the setting it took place in.

Communication content: treatment-centred communication

Nurse-patient communication primarily centred on aspects of treatment, which is reflected in the focus of their verbal exchanges and in their actions, e.g. when they focus on setting up the intravenous (IV) catheter and starting treatment. The patients learned this communication practice during treatment, apparently accepting and replicating it. The observations revealed that the nurses focused on practical issues and rarely explored patient concerns, especially in terms of existential issues like death.

Communication form: efficient communication

Nurse-patient communication was brief, and the time was used efficiently, e.g. once the patient was called from the waiting room and on the way to the treatment room, the nurse asked about how the patient had managed since their last treatment. The nurses often multitasked, informing the patient about side effects while moving around or engaging in other tasks, such as inserting the IV catheter. Furthermore, messages were often communicated in an implied manner, through few words or nonverbally, for instance an outstretched arm indicating that the patient was ready to have the IV catheter inserted.

Communication setting: spatially bound communication

The outpatient clinic had a high level of activity with a steady flow of patients arriving, exchanging treatment chairs and departing. The setting influenced how the nurse-patient communication took place and its content. For example, we observed that communication differed depending on the size of the two treatment rooms. The large treatment room, where most patients were treated, offered poor conditions for sensitive conversations, which may be one reason why existential, psychosocial and sexual issues were rarely brought up during treatment. Another reason may be the limited amount of time available to communicate. This shows that the setup of the outpatient clinic can affect what is talked about and hence the type of support the patient is given.

In conclusion, the study showed that communication was characterised in terms of its content (a focus on topics related to treatment and side effects), its efficiency (brief, implied messages and prevalence of multitasking) and that the outpatient clinic setting affected the content, form and quality of nurse-patient communication. To improve communication, there should be a greater awareness of nonverbal communication to ensure that a broader range of supportive care needs are addressed and managed when patients are treated in oncology outpatient clinics.

Paper III

Title: “Patients’ experience of communication during their course of treatment in an oncology outpatient clinic: A qualitative study”

AIM	DATA	FINDINGS
To explore how patients experience communication with HCP during their course of treatment in an oncology outpatient clinic in order to illuminate how their needs for support are met	Interview transcripts from 18 semi-structured individual interviews	Three overarching communication categories: • Verbal practices ○ Informative communication ○ Cheerful banter and superficial chatting ○ Issues absent from conversations • Nonverbal practices ○ Routines ○ Instrumental focus • Relational aspects ○ Continuity in relationships with HCP

Three overarching communication categories illustrate how patients experienced their communication with HCP during the course of their treatment: verbal practices, nonverbal practices and relational aspects, with underlying themes describing distinct characteristics of the communication and its quality and capturing the complexity within each of the categories. Although people simultaneously communicate verbally and nonverbally, separating verbal and nonverbal communication is an analytical distinction that serves to illustrate when communication is primarily verbal or primarily nonverbal.

Verbal practices

Informative communication

Communication mainly comprised a large volume of information provided by the HCP with detailed explanations about treatment and its side effects. This was particularly the case when patients received chemotherapy or immunotherapy for the first time. Being well-informed created a sense of security for the patients, helping them to cope with the treatment and its consequences at home. Even though informative communication was experienced as supportive, some patients felt it could become impersonal due to its general nature.

Cheerful banter and superficial chatting

Being met by HCP with a positive, cheerful and energetic attitude was a communication style that the patients valued in their encounters as it instilled hope. Even though patients requested this style of communication and HCP met this demand, it was sometimes experienced as superficial and hindering discussions about more serious issues.

Issues absent from conversations

Existential issues such as death were absent in communication with the HCP, and rarely addressed, despite the fact that almost every patient had thoughts about issues like this. However, only a few patients considered sharing these concerns with the HCP.

Nonverbal practices

Routines

The patients experienced that the repetitive, similar nature of what the nurses did during treatment gave them a feeling of security as it was interpreted as professional and correct. Various patients emphasised that the routine nature and continuity of the nurses' nonverbal actions was even more important than relational continuity.

Instrumental focus

Verbal communication centred on treatment but so did nonverbal communication, the latter was evident in the instrumental and clinical task focus of interactions with the nurses when patients received treatment. Despite the reassuring nature of the continuity of these clinical routines, some patients described them as being automatic, even dehumanising.

Relational aspects

Continuity in relationships with HCP

The continuity of relationships with HCP affected how patients experienced communicating with them. Patients felt that the continuity of their contact was an important aspect of supportive communication as it created a sense of togetherness, confidentiality and continuity in their conversations. In addition to positively influencing the topics, content and depth of the conversations that took place, it supported communication based on the individual patient's needs and preferences. Many patients however, expressed the opposite, stating that this relationship was not of great importance.

In conclusion, the communication practice in the oncology outpatient clinic supported patients in managing their treatment and side effects. However, patients existential and psychosocial concerns were rarely addressed, requiring the patient to self-manage these issues in everyday life while living with cancer. Patients are socialised by verbal and nonverbal communication practices in the outpatient clinic, which influences their expectations of what to talk about during their treatment.

Findings from the focus group interview

An overview of the aims, data and findings in the focus group interview (study 3).

AIM	DATA	FINDINGS
To explore the perspective of HCP on their communication with patients during their course of treatment in an oncology outpatient clinic	One focus group interview with HCP (n=6): nurses (n=3) and physicians (n=3)	Three thematic summaries: • The outpatient clinic setting framed the communication • The significance of continuity in relationships and its influence on communication • Challenges in meeting patients' individual needs

Three thematic summaries illustrate the perspective of HCP on the communicative practices in the outpatient clinic. HCP expressed that both the outpatient clinical setting and the continuity in relationships with patients influenced the quality of the communication and how patients' individual care needs were met.

Thematic summary

The outpatient clinic setting framed the communication

A limited amount of time available and the setting were two common themes that arose during the focus group interview. The HCP experienced limitations in terms of communication, for example because the amount of time available for the individual patient was brief and the room where conversations took place was unsuited for private conversations, as the following statements by nurses indicate:

> *The setting we work in poses certain restrictions communication-wise, certainly when it comes to the treatment, [...] it's a large room and it's difficult to create privacy [...] and there's a risk of broaching something that you just don't have time for or can't do anything about [...] that's the hardest part in my view [...] I have to say that time-wise, I mean if I have a new patient who arrives in 15 minutes ... the reality is a bit harsh.* (Tove, nurse)

> *The brief meetings we have are characterised by trying to pack everything you can into the limited time available.* (Bodil, nurse)

The limited nature of the setting (time and space) for conversations meant that HCP tried to use their time as efficiently as possible. This, however, also led to them prioritising the treatment and being familiar with the patient's treatment history as opposed to the patient's personal story and preferences. The outpatient clinic setting established certain conditions for what type of communication unfolded and was possible between patients and HCP.

The significance of continuity in relationships and its influence on communication

All of the HCP in the focus group interview said that it was important to know the patient not only for the patient's sake but for their own, as illustrated by the following quotes:

> *So, you can start a [consultation] right where you left off last* […] *and then continue to build on that.* (Malene, physician)

> *Continuity also means something to us, that we know the patients, that we don't have to start over from the beginning [...], so you achieve mutual collaboration.* (Marianne, physician)

> *The possibility to go into a bit more detail, sometimes, when you already know the person and their family.* (Tove, nurse)

Thus, continuity of care gave the HCP a stronger basis for their communication, positively impacting it by making the conversation more mutual. In addition, the HCP also found that meeting the patients' individual needs was easier if a relationship had already been established, as the following statements show:

When you know them [the patient] you can quickly, or more quickly deciphering how they are feeling. (Tove, nurse)

[When] you have seen a patient several times and you have something to build on, you can ask things like, "How did it go in Legoland with your grandchildren?" You know things that give them the feeling that you know them, [...] you have a better idea of how you can communicate something, [...], what you say is more individualised because you know how they will react [...] if you don't know them, it takes a bit of time to get to know ... who the person sitting opposite you is. (Malene, physician)

The focus group interview participants also believed that continuity provided a high level of security for patients. As one nurse explained:

It gives them a sense of security; they feel that you know them. That's better than if they were just a number (Sille, nurse).

Our findings showed that HCP believed that continuity played a role in determining whether the communication was reciprocal or not. They also found decoding the individual needs of patients was easier if the brief time available was used efficiently, which also created a greater sense of security for patients.

Challenges in meeting patients' individual needs

As described above, time, the setting and continuity were aspects that mattered in terms of whether the patients' needs were identified and met. The HCP also identified the patients' needs by reading their nonverbal cues, which they said was easier to do if they already knew the patient, as indicated by the following statements:

It's also easier to start up communication [...] and it takes five seconds to work out; you can tell by looking at patients if they're someone you know. (Birgitte, physician)

It's also about discerning exactly what they need in the brief encounter you have that day. (Tove, nurse)

However, the HCP did not always find that it was possible to respond to the patients' nonverbal cues due to a lack of time and the physical setting. On the one hand, they found that it was difficult because it was, "*hard to see them go out the door when you think that there might be some issues that you should have picked up on"* (Sille, nurse), while on the other, they explained their actions by saying that it was not possible to meet all of the patient's needs: "*I don't feel that, well within the available frame, that it is possible to manage everything*" (Malene, physician). The HCP explained that it was not always possible to provide patient-centred care, where the communication focused on all of the patient's needs. This meant that the HCP prioritised what they felt was the most important to discuss in the brief time available. As one nurse declared: "*There are always side effects [...] that's the important part of it at any rate* (Bodil, nurse). In other words, treatment-related communication is essential but if the patients have needs that go beyond this, they can only be accommodated if enough time and the setting permit.

A couple of the physicians also mentioned that identifying the needs of patients can be difficult if the patients do not bring them up by themselves during consultations:

> *People ask questions and you answer, I mean if you find out what they need because they ask or because they start crying or whatever, although I don't think you'd find out with someone like him [referring to a patient statement that was read aloud] so you'd have to ask very specifically.* (Birgitte, physician)

This quote illustrates that taking responsibility for what is discussed is not necessarily considered a professional task, but one that is passed on to patients, giving patients the responsibility to bring up, e.g. issues of an existential nature.

In conclusion, the focus group interview provided insight into the perspective of HCP on communication practices in the clinic. Lack of time and the constraints in the setting were the primary explanation HCP gave for what was possible to communicate and thus also what needs they were able to meet. HCP pointed out that a greater degree of continuity of care would serve to improve the quality of the communication by providing a better foundation for understanding the patient's needs and preferences. Relational continuity would also mean that communication did not have to start from the beginning each time, making it possible to utilise the brief time available more efficient.

Discussion

Findings

The aim of this thesis was to provide knowledge about communication practices between HCP and patients with cancer undergoing treatment in an outpatient clinic to gain insight into how patients are supported in this setting. While the findings of each paper are discussed within their specific aim, in this section, I will discuss the findings across the studies and relate them to a more general conceptual frame regarding the ideal of patient-centred communication and more specifically the criteria defined by the U.S. National Cancer Institute regarding patient-centred communication in cancer care, which was presented in the background section. This frame constitutes a range of quality criteria for describing the communication practices and its function within cancer care in relation to the ideal of patient-centered communication. This is relevant for discussing how the communication practices in the oncology outpatient clinic supports patients during their course of treatment and thus achieving the aim of the thesis. Although these quality criteria were not used as analytical orientations during the research process, they are well suited for discussing the findings across the studies and pointing at possible areas for development in clinical practice. The specific criteria include: (1) foster healing relationships, (2) exchange information, (3) respond to emotions, (4) manage uncertainty, (5) involve decision-making and (6) enable patient self-management (38).

Foster healing relationships

There is strong evidence that the quality of the relationship to the HCP is essential for patients' management of living with a cancer disease and their quality of life during treatment (38,40,68,93,94). Hjorleifsdottir et al. found that the patient-HCP relationship was the main factor impacting patient satisfaction during treatment in an oncology outpatient setting (24). According to the U.S. National Cancer Institute's, such healing relationships are composed of many dimensions including caring attitude from HCP, being known as a "whole person", trust in HCP instrumental skills, and mutual understanding of roles and responsibilities (38,40). These qualities were also found in the systematic review as central for patients' positive experience of their communication and relationships with HCP. In terms of the caring attitude, patients expressed that HCP and especially the nurses administering the treatment were positive and friendly. However, the treatment-centred focus in the communication, which this thesis identified, and the absence of psychosocial and existential issues in communication question whether the patients were cared for as a "whole person" and thereby also question the extent of the caring attitude.

Both patients and HCP saw continuity in relationship as significant for the quality of communication (e.g. by ensuring that the content of the communication was relevant to the individual patient) and for their collaboration. In the focus group interview, HCP expressed that following the same patient had a positive impact on the communication as it became more mutual and made it easier to identify and meet patients' individual needs and preferences, and thus ensuring patient-centred communication. While some patients confirmed this in the interview study, they also talked positively about other types of continuity which they experienced as reassuring, namely the continuity of nurses' routines and the recognizability of their practices. Observing that nurses handled treatment in the same way made the patients feel safe. Trust in the HCP technical skills, competence and knowledge is a central aspect in fostering healing relationships (38,40). This is in line with an umbrella review which revealed that patients value the instrumental and technical competence of the nurses as it made them feel that they can trust the relationship (93). This review found that patients valued the instrumental, technical caring more than nurses did (93). This means that the quality of the relationship is not necessarily tied to the individual HCP or relational continuity with a specific HCP, but that the patients also feel reassured by the practices tied to the nurse role and responsibility. However, research demonstrated that HCP must balance the caring aspect of nursing with technical care and should be given together (69,93,95).

Exchange information

The exchange of information requires a mutual process between patients and HCP (38,40). Information is a broad term, however the empirical studies (Paper II and III) showed that the communication practice in the outpatient clinic was characterised by a primarily treatment-centred focus, which regarded information about how the treatment is working and possible side effects. The information exchange was somewhat unbalanced, tending towards an information distribution from the nurse to the patient. This corresponds with other studies in oncology outpatient settings, which have found that much of the patient-HCP communication was characterised by being one-way communication (61,62). Patients were primarily invited to share information about how they were coping with the treatment and the side effects. This was part of the standard inquiry on the walk from the waiting room to the treatment room. The treatment centred focus was also expressed through the nurses' nonverbal communication, where their actions predominantly concerned practical or instrumental aspects of treatment, this, in a symbolic interactionist perspective, also serves as information in the communication practice and thus confirms the dominance of treatment-centred communication observed in the verbal information given by the nurses (66). There is growing evidence that communication during outpatient chemotherapy mainly revolves around the treatment itself (61,69,96). The empirical studies demonstrated that patients are supported by the current communication practice in terms of receiving adequate information about treatment and side effects. This confirms that this type of information is highly valued by patients as it supports them in managing the disease and treatment in their everyday lives (2,69). Information about the existential and psychosocial dimensions of undergoing cancer treatment was on the other hand rarely exchanged or addressed during treatment, despite the fact that these issues are found to be important to most patients during cancer treatment (5,30,48,97,98). Other studies point to a risk that a predominant treatment-centred and task related focus in communication may be at the expense of addressing other needs patients might experience when undergoing treatment (53,61,69). When probed about existential and psychosocial needs during treatment (Paper III), most patients expressed that they had worries and concerns e.g. about their life expectancy, how much their quality of life would be influenced by side effects, how the end of life would be, and how the family would cope emotionally and economically if or when they died. Only a few had however, considered to share these concerns with the HCP, as this was not perceived as relevant information to exchange.

This thesis found that existential and psychosocial needs were not supported adequately and were absent from the current communication practices. The different data sources provide a variety of explanations for this and draw attention to several barriers to meeting patient needs. The focus group interview with HCP pointed at different explanations for why existential and psychosocial issues are absent from the communication and information exchange in the outpatient clinic. Nurses pointed at lack of time and the unsuitable physical setting for that kind of conversation. This is in line with findings from the observational study, which indicated that the outpatient setting was an influential factor that determines the type and content of communication. Corresponding with other studies, limited time and structural factors such as high patient flow, busy atmosphere, workload and lack of privacy have been found (13,53) to hinder the exchange of patients existential and psychosocial concerns (61,99). Another explanation brought forward by a physician in the focus group interview addressed the issue of responsibility in terms of who should initiate conversations about existential and psychosocial needs. The physician explained that it was the patients' own responsibility to broach these types of issues during the consultation if they felt the need to talk about them. However, if the exchange of relevant information is a mutual process between the HCP and patient, it can also be argued on the basis of convincing evidence, that most patients undergoing cancer treatment are in need of existential and psychosocial support (1,5,6,26,30) and that the exchange of such information should be part of standard clinical communication practice (38,40,46,100). These explanations stated in the focus group interview reveal different types of local barriers that could be addressed in the local clinical practice so that the support of patient needs regarding these issues can be accommodated.

Respond to emotions

Emotions and the response to them are especially central as a part of communication in a cancer care context as the cancer diagnosis and treatment can cause a variety of emotions in patients such as sadness, fear, anxiety and depression (5,26,38). In this thesis responding to emotions were identified in different ways across the studies. The systematic review emphasized that patients valued when HCP responded to their emotions with a caring approach and highlighted the nurses as being central psychosocial caregivers. During the observation study, different emotions and reactions were observed in one of the described situations, where the nurse responded to the patients’ sad emotions by trying to create a shielding space with her body and create some privacy for the patient to talk with the patient about his feelings and thus attempting to overcome some of the spatial barriers in the outpatient clinic. Another situation described how the nurse responded to a patient’s worried emotions about death by changing the subject to practical matters regarding the next treatment and thereby discouraging further exploration of the patient’s emotions. During the focus group interview, some of the nurses expressed that they were not always able to respond to patients’ emotions, due to limited time or the physical setting was unsuitable for talking about sensitive issues. Some of the physicians also mentioned that it was sometimes difficult to identify patients’ concerns if they did not bring them up openly themselves during consultations and thus difficult to respond to.

Nurses’ cheerful approach was observed and commented on by patients, who saw this as a response to the gravity of the treatment context. This was by some patients seen as an acceptable and encouraging response, while others interpreted it as a superficial response that excluded more grave emotions. This is in agreement with the study by McCreaddie et al. who argue that positivity can be constructed as a norm in patient-HCP communication, which may hamper the response to emotions and lead to failure in identifying patients’ individual needs (102). Another barrier for responding to patients’ emotions was observed in terms of nurses’ often multitasked communication practice, where conversations were conducted while setting up treatment and focusing on other clinical tasks, which could hinder nurses’ observation of patients’ emotional cues. Furthermore, the multitasked communication can also prevent patients from sharing their concerns and asking questions, as a recent study from an oncology setting argued (53). From a symbolic interactionist perspective, this illustrates how patients learn about the symbolic meaning of communication through interpretive processes by observing and participating in the communication practices in the outpatient clinic. As others suggest, patients learn which emotions are suitable to express by observing how emotions are responded to and thereby adapt their emotional responses to the social roles that they assume, and the implicit expectations of those roles in the situation (66,103). In other words, the patients' scope of action is framed by the situational expectations and options that arise in their interaction with the nurses. Thus, the patients are formed by the communicative practice in the outpatient clinic at the same time as they reproduce this practice. A risk of this communication practice is that patients become somewhat passive in defining the content of communication and that they withhold emotions, which they need support to manage. These results should be taken into account when considering how to support patients in taking a more active role in communication. Likewise, the results indicate the importance of HCP becoming aware of not only their verbal communication, but also their nonverbal behavior. Thus, there are many explanations for why HCP do not respond to patients' emotions and why patients do not raise their concerns in the conversation themselves.

Manage uncertainty

Patients living with cancer often experience prognostic uncertainty, (24,30,104) and during cancer treatment there is uncertainty about the outcome of the treatment and how to handle the many side effects (40). Managing this uncertainty should be addressed in the communication between HCP and patients (24,38). Although, one way of managing uncertainty is through communication, the interview study pointed at, in line with literature, that it is most likely not possible to remove all uncertainty patients may experience when living with a life-threating disease as cancer (24,105,106). However, this thesis found that some of the uncertainty related to the treatment situations was reduced by the consistency of nurses' clinical routines and that the recognisable practices during treatment made them feel safe. In fact, the continuity in the nurses' nonverbal actions and consistency in the information the nurses provided during treatment was emphasised by patients as being more important than relational continuity. According to Reid et al. (107,108) continuity of care can be approached based on various forms of continuity: management, relational and informational continuity. Management continuity refers to the coordination of health care adapted to the patient's changing needs throughout the treatment trajectory (107,109–111). Relational continuity refers to personal continuity, i.e. seeing the same HCP, whereas informational continuity refers to the provision of consistent medical information from different HCP and that HCP use their familiarity with the patient from previous encounters, including the patient's values and preferences (107–109). This nuanced understanding of continuity may point at different ways to manage uncertainty during treatment. The focus group interview showed that HCP had a strong desire to attain a greater degree of relational continuity in their care as it provides a better foundation for understanding and supporting the patient's individual needs and preferences because the conversation did not have to start from the beginning each time. HCP described relational continuity as valuable in terms of supporting a patient-centred approach and more mutual communication. One possible reason for the patient's opposing statements on the significance of relationships identified in the data may be that the current communication practice primarily consists of information about treatment and side effects in general terms, which could suggest that relational continuity is less important. The literature states that the continuity in care influences the quality of the communication and is strongly connected to patient experiences of health-related quality of life (101,111) and increase patients' capacity for emotional management (111), which arguably relates to the management of uncertainty. On the other side, lack of relational continuity prevents patients from discussing psychological and existential issues with HCP and can thus have an impact how they manage the uncertainty when living with a cancer disease (26). Lack of relational continuity can also be an explanation for why patients do not share their psychological and existential concerns with HCP. Although patients down-play the value of relational continuity, other findings in the thesis confirm the literature in that the relational continuity of care has a positive impact on the quality of the communication. When communication is patient centred, it enables HCP to build conversations on their previous knowledge of the patient which may in turn support the patient in managing uncertainty (109,111).

Involve decision-making

Decision-making is a central aspect of clinical practice and essential in cancer care due to the many decisions that are made throughout the treatment trajectory (38). The research in this thesis has not addressed treatment decisions made between HCP and patients as such, but the systematic review found that being involved in decision-making regarding treatment was important to patients with cancer (92,113). However, only a few studies reported investigating patients'experiences of being involved in decision-making (92,113). It is notable though, that Kleeberg et al. found that almost half of the 4615 surveyed patients did not experience personal involvement in decisions regarding their treatment. This points to a relevant area for development in clinical practice. As mentioned, decision-making was not an explicit focus in the thesis, however decisions were part of the communication practice observed, nonetheless in a more subtle and implicit way. Where to sit, which hand to use for the IV catheter, and which issues to talk about are considerations and decisions made during the treatment encounter. Especially "what to talk about", is a crucial decision. Such a decision can open or close conversation about issues that patients need support on. Observations and patient interviews show that existential and psychosocial needs are absent issues from conversations. The decision to exclude such issues may not be deliberate, but implicitly made by both HCP and patients. HCP express that the physical environment is not suitable for talking about such issues, or that there is not enough time, or that it is the patients' responsibility to bring up relevant issues in the conversation. These explanations reveal an implicit decision not to ask certain questions or bring up certain issues. Organisational factors such as limited time, high workflow, lack of continuity of care and physical environment are found to be barriers for involving patients in decision-making (114). Patients, who observe and learn from the interactions in the outpatient clinic make an implicit decision not to bring up issues that seem meaningless in the specific situation and context, and this in itself can be a barrier to open dialogue with the HCP. This is in line with a meta-synthesis that found the role patients are socialised into during their interaction with HCP can present a barrier to shared decision-making as they adopt a passive role based on past experiences (115) and thus many decisions are left to the nurses e.g. where to sit in the outpatient clinic and which issues to discuss. However, according to the Danish Health Act, patients have a right to be involved in discussions and decision about treatment and care and an important political health goal is to increase patient involvement in decision-making (116,117). Although the studied communication practice in this thesis did not involve explicit decision making, it is important to draw attention to the implicit decisions made and the ground for these decisions as well as the dynamics of how decisions are made as they influence the support that patients receive during their treatment.

Enable patient self-management

Enablement of patients' self-management refers to the support patients receive in order to be capable of managing life with the disease, the treatments and its side effects (38). This is particularly important when being treated in an outpatient setting as patients need to acquire the ability to manage independently at home (2–4). Research shows that the main reason for unplanned hospitalisations for patients receiving chemotherapy in outpatient clinics are related to not being capable to self-manage side effects at home (3). The literature demonstrates that patients with cancer experience a range of support needs during treatment as described in the background section (page 9). Adequate information and understanding of treatment and side effects is central for patients' reactions and management of symptoms and even vital in terms of their reactions to critical symptoms (2–4). As in other studies, our systematic review found that information about treatment and side effects enabled patients in their self-management (24,69,118), e.g. by reducing anxiety and helping them gain control in their everyday lives (69). Although we observed that the nurse-patient communication was mainly about treatment and side effects, other studies demonstrate, in line with the systematic review, that patients have unmet informational needs regarding side effects during treatment in outpatient settings (3,99), which underscores the value of and a continual need to promote treatment related communication to enable patients self-management. Likewise, the observations and interviews showed that the current communication practice supported this part of patients' self-management. However, if self-management also includes the more existential and psychosocial aspects of living with a potentially life-threatening disease, as research suggests (4,5,24,30), the current communication practice is less enabling. This thesis demonstrated that patients have a need for support in managing their existential and psychosocial needs during the course of treatment.

According to the U.S. National Cancer Institute's criteria for patient-centred communication, the findings in the thesis draw special attention to central aspects of communication between HCP and patients that play a key role in achieving patient centred care. The thesis contributes to knowledge on *how* communication is practiced which highlights further development of the clinical practice to ensure that the individual patients' needs are recognised and well supported in oncology outpatient settings.

Methodological considerations

In the following I will discuss the strengths and weakness of the chosen methodologies and methods applied in the thesis, and how these choices might have affected the credibility of the findings.

Study 1: Systematic review

To assess the methodological quality of the included studies, the Joanna Briggs Institute's assessment tools for the qualitative and quantitative studies (75) was chosen, which provided a uniform and structured evaluation of the studies. (Paper I). The initial literature search indicated that knowledge on the subject under study is sparse, which is why we chose not to apply a specific time period and to include both qualitative and quantitative studies to avoid excluding important scientific knowledge solely based on the method (73). The decision not to restrict the time period resulted in the inclusion of a quantitative study from 2008 (92) and one from 1998 (119). Admittedly, since publication of these two studies, the conditions for relationships and communication between HCP and patients with cancer have changed significantly. Despite this, we chose to include all available evidence, regardless of the date of publication, as few studies met the eligibility criteria for inclusion (74). Including both qualitative and quantitative studies resulted in a high level of heterogeneity, which is why it was particularly important to extract and assess data in parallel processes (73,120). It was also not possible to carry out a meta-analysis (73,89). Although a protocol was prepared prior to the systematic review, in accordance with PRISMA guidelines, the protocol was not registered, decreasing the transparency of the study (74).

The systematic review contributed to specify the focus and development of the subsequent studies. As our search terms show (Paper I), we focused on short-term relationships, i.e. on relationships in an outpatient clinic. However, due to the findings of our review we decided to shift the focus from short-term relationships to communication in an outpatient setting in the subsequent studies. This was because we recognised that distinguishing between relationships and communication is difficult and because we wished to exploratively and openly describe the nurse-patient encounter during treatment (Paper II), and how patients experienced it (Paper III), rather than pre-determining that the encounter is brief. However, communication was included as a search term, which is why we also included studies on communication between HCP and patient during treatment

The inclusion and exclusion process contain crucial steps that aid identification of the knowledge that exists in the field (74). Even though we conducted a broad literature search only nine studies met the inclusion criteria. One of the reasons for the limited volume of literature is that our requirement was for patients to be actively undergoing chemotherapy, and we excluded studies with samples that included patients who were cancer survivors, unless the patient groups were analysed separately. Existing literature on communication in outpatient regimes is mostly about physician consultations rather than the treatment encounter. In our screening of studies we discovered a number of grey areas, especially in terms of the phenomenon of interest (74), which meant that particularly the first, second and last author in our study met multiple times during the process to discuss the extent to which a study could be included, which helped to increase the internal validity of the review (89). Even though several researchers screened the studies, a thorough assessment was performed and repeated our search four times, we discovered an additional study that ought to have been incorporated into our review (2). The study was not found originally because it was indexed using terms not in our search protocol: chemotherapy, symptoms, qualitative research, self-management and grounded theory. Knowledge from this study is nonetheless included in Paper II, Paper III and the thesis.
A limitation of this review is that we did not search PsycInfo®, which may have been relevant due to the focus of the review on relationships and communication; however, we did search in four different databases. Despite the limitations, this review provided a knowledge base for developing the subsequent studies.

Study 2 and Study 3: Empirical studies

In the following I will comment on the strengths and weakness of study 2 and study 3 by applying ID evaluation criteria: epistemological integrity, representative credibility, analytic logic and interpretive authority (76). This section will demonstrate my reflexivity in the research process in terms of how my research role unfolded, the choices I made and how this influenced the findings and conclusions (121).

Epistemological integrity refers to consistency between the epistemological standpoint and the research question, the applied methods and generated findings (76). The epistemological integrity of this project is thus reflected in the research process and the methodological decisions made underway. I apply ID's epistemological foundation by acknowledging the contextual and social impact on the generation of knowledge (76,78,79). Objective knowledge cannot be captured through empirical analysis as '*reality' involves multiple constructed realities […]* (76, p.82). Furthermore, ID acknowledges "*an inseparable interaction between the knower and the known, such that the inquirer and the 'object' of that inquiry influence one another in the production of the research outcome"* (76, p.82). For instance, the knowledge generated in the individual interviews was influenced by the interaction with patients, my background and the context in which the interview took place. Knowing that I was an oncology nurse may have influenced what the patients shared of experiences with me. This was particularly evident in the first interview, where I was spoken to as if I were one of the nurses from the outpatient clinic. To prevent them from seeing me as an insider (76), I then chose to further clarify that my purpose was to study their perspectives and not to evaluate the HCP. Furthermore, the fact that the interview took place at the outpatient clinic, and not in their own homes, influenced my data. The context in which conversations are situated and thus socially constructed influences what patients talk about and how (76,84). Since the patients are socialised to the communicative practice in the outpatient clinic and were interviewed in precisely that context, I am aware that their statements and the meaning they ascribed to different experiences were influenced within that institutional setting.

Thorne argues that in applied practice research, the disciplinary orientation is the epistemological positioning (76). In my research, I kept my disciplinary orientation in focus in a variety of ways. First, the project was developed in collaboration with clinicians in order to support its relevance.

Second, one of my supervisors and co-researchers supported the clinical gaze throughout the research process and during the writing up of the findings. Third, the findings from the studies were discussed in a focus group interview with HCP, which verified the relevance of the findings from the observation study and interviews with patients and helped to identify scope for development. Finally, based on the studies' findings, clinical implications and recommendations supporting the quality of care and treatment for patients with cancer who receive outpatient treatment were identified. The results from the studies were interpreted into the clinical context, which is pivotal in ID studies, since descriptions alone are not satisfactory, owing to the fundamental desire to resolve clinical problems (76,122).

Representative credibility refers to whether the findings of this study are consistent with the methods selected to generate data to explore the overall research question (76).
As our systematic review (Paper I) confirmed that few studies have examined the communication between HCP and patients during outpatient medical treatment, it was important to initially study and describe how communication unfolded in this encounter. An explorative and open approach was therefore essential, which is why the inductive approach and flexible design of ID methodology was beneficial (76). The credibility of the thesis is strengthened by the triangulation of data sources and data generation methods that support the trustworthiness of the findings (78,89). Our participant observations became important in that the study showed that the communication practice we observed was often implied and much was communicated nonverbally, which represents knowledge that we could not have attained by solely interviewing the patients (76,84). Moreover, this knowledge subsequently helped to understand and interpret the patients' experiences and explanations, providing deeper insight into the communicative practice than would have been possible without them (Paper II).

The credibility of the findings is also strengthened by continuous reflexivity achieved through researcher triangulation (89), for example two researchers did the observations and the data was discussed with an anthropologist on an ongoing basis as the data was generated (Appendix A and Paper II). Even though the research team made a joint decision to discontinue observations once patterns and correlations were identified in the data after 70 h of observations (76), the relatively short duration of the observations can be subject to criticism. Single cases and small studies are often mentioned as a limitation in fieldwork, but according to Hammersley et al. they can have "*intrinsic interest, so that generalization is not the primary concern"* when exploring "*characteristics of the particular situations*" (84, p. 32).

Participatory observation, the main method used in anthropological fieldwork, is heralded by ID and symbolic interactionism as an optimal approach for gaining insight into a field as it allows experiencing the social life as it unfolds. This implies an interplay between the positions of participation and observation (84). However, the opportunity to actually participate in practices in the outpatient clinic was limited as, e.g. administration of chemotherapy requires specialised training. While participant observation is an ideal method for fieldwork, it has been argued that the specialised skills required to participate in the clinical field mean that the term *negotiated interactive observation* is more suitable**.** This concept refers to gaining access to the field and to engage in the roles and actions that are both possible and made available for the observer to take part in (123).

Conducting the study in several outpatient clinics at more hospitals may have strengthened the credibility of study 2 and study 3 in that contextual differences affect the knowledge generated. Therefore, just as contexts change over time, findings will only be true within the time and context they are generated (76). Participant observation, however, provided the opportunity to reflect upon the verbal (e.g. what was talked about and what was not talked about) and nonverbal communication (e.g. behaviour and mutual interactions) in a specific context played out in its natural setting (76,84). Thorne emphasises the contextual significance of results by stressing that researchers must strive to create meaning rather than truths (76, p 238). Nevertheless, it can also be argued that analytical generalization of the findings from local context is possible when compared with related empirical research from other contexts. In the thesis, I have thus continuously compared my empirical findings with the empirical research generated in other local contexts.

Analytic logic refers to the researcher's ability to demonstrate the use of analytic logic throughout the research process, from preparing the study design to the conclusion of the study (76). Effort was made to comply with this in several ways. First, I clearly stated and documented my preconceptions both in the introduction and after each individual study (86). Second, I carried out the analysis as transparent as possible by keeping an audit trail (76) , where I documented reflections, initial interpretations and choices of method during the course of the project. Third, the methodological reflections during the data generation were supported by researcher triangulation at every stage of the project (89). Fourth, the findings of the studies are documented in published papers, verifying the connection between quotations, the interpretation and the conclusion. Finally, symbolic interactionism contributed an analytical perspective after the data generation, demonstrating that I have been true to the inductive and explorative approach (see “Contribution of symbolic interactionism to this thesis”, p. 51-53).

Interpretive authority addresses the trustworthiness of the findings in the thesis, which is central as knowledge is perspectivist (76). It has been particularly important for me to boost credibility through a high level of reflection throughout the research process because, as a nurse previously working in the field of oncology, I am already familiar with the field and at risk of interpreting data through that particular clinical lens (76). Thus, in the second study I maintained an open and descriptive approach to what I was observing and to question the nurses’ actions – even when my curiosity was not particularly aroused (84,124). The psychologist Ernesto Spinelli’s method of the phenomenological conversation, described by psychologist Bo Jacobsen, particularly inspired me to adopt an inductive and open approach to my observations and interviews (124). This approach involves reining in preconceptions and prejudices and the urge to hastily analyse and interpret the situation (124). It has guided me to remain curious and open-minded and to stay focused on what I saw and heard rather than on what I believed. The fact that there were two of us carrying out observations also helped increase awareness of blind angles (125).

On the other hand, my clinical experience was an advantage as it made it easier to access the field and engage in dialogue with both patients and HCP because it created a sense of confidence about the relationship. Another advantage was that being familiar with clinical routines and administration of chemotherapy gave me insight into when it was an appropriate time to observe.

Contribution of symbolic interactionism

The symbolic interactionism framework did not serve as the starting point for this thesis due to the initial inductive approach. Thorne believes that it is important to be highly wary of involving theoretical frameworks in one’s research, as doing so can prevent findings from being inductively based and rooted in data, instead leading them to be shaped by theoretical concepts

(76,77). Thorne is critical about the fact that theoretical frameworks from other disciplines are often used to justify a nursing enquiry, which is sometimes at the expense of the clinical orientation of the study design (77). However, this thesis used a symbolic interactionist perspective in the analysis to interpret what was observed (Paper 1) and how the patients experienced communication in the clinic (Paper 2). We asked ourselves questions such as: Why are certain issues not talked about even though the patients say that they are important to them, and why do they accept or tolerate this?

The symbolic interactionist perspective was thus used to qualify the analysis and not to legitimise the study. I found that symbolic interactionism helped to understand the complexity of how patients construct meaning through their interactions with e.g. the nurses and the symbolic meaning within certain situations (e.g. when receiving chemotherapy) (66,126). I found that symbolic interactionism aided in seeing how the patient's behaviour (e.g. what they did and did not talk about) was shaped by their interaction with the HCP and the social context in which the interaction took place. The reason for a lack of communication on certain issues must be due to more than just patients not feeling the need to talk about them; it is also an expression of the fact that patients respond and act based on what they have learned through their communication with the HCP and thus the communicative practice they are socialised in to in the outpatient clinic. Precisely because much of the communication between patient and nurse in the treatment situations was non-verbal, symbolic interactionism was particularly valuable due to its focus on interactions, behaviour and actions, thus contributing to central findings in this thesis that provide useful insights into improving practice.

Symbolic interactionism has been criticised for not paying enough attention to macro aspects of society when explaining interactions and social behaviour, i.e. how people act based on social structures (127,128). Blumer, however, argues that society's structures are a product of social behaviour, which means that structures do not determine social behaviour: *"It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life*"(66, p. 19). Although I was interested in exploring patient-HCP communication and relationships at a micro level, it would have also been relevant to examine, how structural factors affect the interactions, particularly since political decisions such as staffing (macro level) and the concrete physical settings in which the communication takes place (meso level) also create the conditions in which the communication can unfold.

Overall validity of the thesis

This PhD thesis provides new insights that fill in some of the gaps regarding communication practices when patients with cancer undergo treatment in the outpatient clinic. However, it also has some limitations beyond those elaborated upon above, which may affect the project's validity. One of the aims was to gain knowledge on the communicative practices taking place when patients receive treatment on an outpatient basis – regardless of specific conditions, such as sex, age, cancer diagnoses or prognosis. As a result, we deliberately focused on nurse-patient communication in study 2, regardless of these aspects. The knowledge we have gained offers insight into the communicative practice on an outpatient basis, which also provided knowledge on how patients are supported in the outpatient clinic. The patients in the study had many commonalities, for example, they all lived with a severe cancer diagnosis and they all received treatment (chemotherapy or immunotherapy). The knowledge we generated revealed some general aspects of the communicative practice in the treatment encounters in the particular context (i.e. outpatient clinic) and is thus valid under these conditions (76,89). These findings may be transferrable to similar settings and contexts with similar conditions (external validity) (89). However, we know from the literature that patients' needs vary in terms of sex (44,129), age (5,43,129), prognoses (130,131) and cancer trajectory (2,6,7,35,132). Thus, it was surprising that we did not observe (Paper II) or hear (Paper III) any significant differences in the communication, which limits the transferability (extern validity) (76,89). The contribution of new perspectives by an international research in study 2, however, strengthened the validity of this study, which may improve the transferability of the findings as the triangulation of perspective most likely enhances that the findings will be meaningful in a broader context (90).

Focusing on solely nurse-patient communication (instead of patient-HCP communication) may have made the knowledge generated in this PhD thesis more distinctive, but this path was not chosen due to the understanding of the difficulties patients can have in distinguishing between their communication with nurses and physicians. Cancer care is provided by teams, and the overall communication is what helps patients manage their disease and treatment (72). In study 1 knowledge about the patient-HCP communication was generated, while study 2 contributed with knowledge on nurse-patient communication in the treatment encounter. Although study 3 explored patient perspectives on their communication with both the nurses and the physicians, the patients predominantly described their communication with the nurses. As a result, this PhD thesis primarily generated knowledge on nurse-patient communication.

A focus group interview with nurses and physicians from the clinic was conducted to explore their perspectives on the communication practice (76). While data from the focus group discussion was not included in the scientific article the insights from the focus group have shed light on the project's findings by providing their perspective for instance on why existential matters are seldom brought up during conversations and consultations. In this way, the focus group interview supports contextual awareness, which the researcher may not have been aware of and point to potential areas for clinical development and improvement (76,133). However, the dependability and the trustworthiness (76) of the focus group interview are limited as only one was conducted, which means its results must be interpreted with caution and the data generated must be seen as supplemental. This approach is not without its merits as, according to Brown, "*a sole focus group can be used as a form of member checking or as a means to supplement the findings*" (134, p. 118).

Conclusion

Communication is central for supporting patients undergoing cancer treatment. The outpatient clinical setting poses specific conditions that challenge this communication and the results from the studies show that there are areas for development to achieve patient-centred communication.

The treatment-centred communication practice in the outpatient clinic supports to some degree patients' needs as it provides thorough information about treatment and side effects. Patients' needs for support in handling the psychosocial and existential dimensions of undergoing cancer treatment are however not met sufficiently.

The thesis points out well-known barriers for communication in the outpatient clinical setting, as lack of time and unsuitable physical conditions, as inhibiting structural conditions. The analytical symbolic interactionist perspective provided additional explanations, by unfolding the dynamic processes of the communication practices between HCP and patients and arguing that patients are socialised into the existing communication practices of the clinic and thereby learn not to expect that psychosocial and existential issues are a relevant and meaningful part of the communication with HCP.

Based on the discussion of the findings in relation to the ideals of patient-centred communication, the thesis point at a range of implication for clinical development and future research areas, that are recommended to strengthen the communication practice in the outpatient clinic in order to improve the support of patients' multiple needs when undergoing cancer treatment.

Perspectives

In the following, the clinical implications of the thesis are presented. This section will also point to future research avenues that can further contribute to the knowledge regarding the communicative practice in the oncology outpatient clinical setting in order to ensure that patients' needs are met.

Implications for practice

- This thesis identified barriers to delivering patient-centred communication in an outpatient setting. Findings from this thesis could be used to develop and implement initiatives to overcome some of the identified barriers such as adjusting the organisation and environment to facilitate the opportunity for patients to express their needs and for HCP to respond to them e.g. by devoting time and ensuring a more conducive physical setting to enable patient-centred communication. This is supported by the recent recommendation from Danish Health Authorities regarding rehabilitation conversations (117). Outpatient clinics should consider facilitating and integrating initiatives that highlight patient-centred communication during administration of oncological treatment in the everyday outpatient practice.

- A prerequisite for achieving patient-centred communication in cancer care is highlighting the central role of the HCP in being open to dialogue with patients regarding their emotional needs and responding accordingly to support patients in managing the uncertainty they may have while living with cancer (38). There is a need to bridge this gap between the current practice and the clinical evidence as patient needs (135) otherwise remain unmet regarding their existential and emotional needs. PRO and PROM, as means to identify patient's needs, may represent possible communication tools for supporting patient-centred care (55–57,136–139).

- This thesis demonstrates that multifold aspects and dynamic processes impact on the communication practice in the oncology outpatient clinic. Dynamic processes point at the importance of reciprocity during patient-HCP communication as a means of encouraging patient involvement. Patient centred care and patient involvement implies that patients are invited to share their needs, values, preferences and experiences as a part of the communication practice (140). Therefore, in order for patients to take an active role in communication, it is important for the HCP to be aware of their clinical role and responsibility in reciprocal processes. Additionally, the communication form identified in the outpatient clinic points to educational implications that will prepare HCP to communicate with and meet the needs of patients during the treatment encounter.

Implications for research

- Future effort should be made to study the feasibility and effect of pragmatic interventions that promote person-centred communication in outpatient settings based on the specific conditions (possibilities and limitation) of the outpatient setting, to support existential, psychosocial and emotional aspects of care

- Further research is needed to establish how HCP can facilitate and support patients in learning and applying strategies to self-manage existential, psychological and emotional challenges while living with a potentially life-threatening disease.

- Future research on patient-HCP communication should design a communication course for HCP that integrates nonverbal communication skills to establish how it affects mutual communication and the patients' experience of the quality of care in an outpatient context.

A greater awareness of the issues outlined above can contribute to the development of communication in clinical practice, further qualifying it to the benefit of patients.

English summary

Communication between patients and healthcare professionals (HCP) is essential in cancer care due to the many physical, emotional, existential and psychosocial challenges that many patients with cancer experience. Today, communication between patients and healthcare professionals becomes increasingly important as patients with cancer are primarily treated in outpatient settings, where the time to communicate is often brief. At the same time, the annual number of patients requiring treatment on an outpatient basis will grow substantially worldwide in the coming decades due to an increase in the annual number of cancer cases. Consequently, the demands on healthcare services in outpatient settings and on patient-HCP communication will increase in the effort to ensure that patients' need for support are met.

The overall purpose of this thesis is to provide knowledge about communication practices between HCP and patients with cancer undergoing treatment in an outpatient clinic and to gain insight into how patients are supported in this setting. Three studies were conducted: The first study (Paper I) was a systematic review conducted to summarise the literature on HCP-patient communication and relationships in outpatient settings during treatment. The two subsequent studies had a qualitative design, with the second study (Paper II) generating data through participant observation of the communication practices between patients and nurses during treatment, with supplementary ad hoc interviews with nurses. The third study (Paper III) comprised individual semi-structured interviews with patients undergoing treatment in an oncology clinic and a focus group interview with HCP conducted to supplement the data generated from patient interviews and to gain insight into the perspectives of HCP on communication practices (documented in this thesis). The methodology was guided by Interpretive Description and Symbolic Interactionism inspired the analytical approach of the empirical studies.

The systematic review (Paper I) highlighted the significance of the relationship between the patients with cancer and HCP, specifying the aspects patients valued in their communication with HCP. These included continuity in terms of being followed by the same HCP as well as specific HCP skills, such as being a good listener, being trustworthy and having a caring approach. Furthermore, they valued when communication was based on dialogue and they emphasised the nurses' role as a central psychosocial caregiver. The review identified a

knowledge gap in the literature on what characterises patient-HCP communication during outpatient treatment and could not specify adequately how patients were supported in this setting. The results from the review constituted the background for my empirical studies, which explored patient-HCP communication practices.

The observation study (Paper II) found that communication between HCP and patients in the outpatient clinic was characterised by its treatment-centred content with emphasis on information about the treatment and its side effects. Furthermore, by being efficient in that it was brief, often implied and took place while nurses performed other tasks. Finally, it was found that the outpatient setting, with its physical limitations and high patient flow, affected the content of communication in such a way that information about treatment and side effects was prioritised, while more sensitive and emotional issues were not discussed.

The interview study (Paper III) showed that patients experienced the communication practice with HCP during treatment as informative, routinsed, encouraging and marked by being focused on clinical task, which they found to be supportive to some extent, but also impersonal and mechanical at times. Furthermore, it was found that existential and psychosocial issues were absent in the communication and that neither HCP nor patients brought up sensitive issues despite a need among some patients for support in handling them.

The focus group interview (page 32) provided insight into the perspectives of HCP, informing our understanding of the communication practices identified in the observations and patient interviews. The HCP indicated that lack of time and the physical surroundings were barriers in identifying needs of patients in the outpatient clinic. HCP pointed out that a greater degree of relational continuity of care would improve the quality of the communication by providing them with a better foundation for understanding patient needs and preferences.

The overall conclusion of this thesis is that communication between HCP and patients in the oncology outpatient clinic supported patients in managing their treatment and its side effects, however existential and psychosocial needs were not supported adequately and were in fact often absent from current communication practices. Additionally, the thesis points to other communicative, physical and organisation barriers hampering patient-centred communication in an outpatient setting. The analytical symbolic interactionist perspective provided additional explanations, by unfolding the dynamic processes of the communication practices between HCP and patients and arguing that patients are socialised into the existing communication practices of the clinic and thereby learn that only certain issues are relevant and meaningful in communication with HCP.

Dansk resumé

Kommunikationen mellem sundhedsprofessionelle (SP) og mennesker med kræft er fundamental på grund af de mange fysiske, følelsesmæssige, eksistentielle og psykosociale udfordringer, som mange kræftpatienter oplever som følge af sygdom og behandling. Idet mennesker med kræft i dag primært behandles ambulant, hvor tiden til at kommunikere ofte er kort, bliver kommunikationen af stadig større betydning. Andelen af mennesker der kræver ambulant behandling vil stige markant inden for de næste årtier på grund af den demografiske udvikling med flere og flere ældre samt stadig flere og nye behandlingsmetoder. Hvis patienternes behov skal imødekommes i ambulant regi, stiller dette krav til de sundhedsprofesionelle kommunikative kompetencer.

Afhandlingens overordnede formål er at generere viden om den kommunikative praksis mellem SP og patienter med kræft, når de modtager ambulant behandling, for at få indsigt, i hvordan de støttes i denne kontekst. Afhandlingen består af tre delstudier: indledningsvis blev der gennemført et systematisk litteraturstudie (Artikel I) for at opsummere den forskningsbaserede viden på området. De to efterfølgende empiriske studier havde et kvalitativt studiedesign. Studie 2 var et observationsstudie af den kommunikation, der udspillede sig mellem sygeplejersker og patienterne under behandling, og blev suppleret med ad-hoc interviews af sygeplejersker (Artikel II). Det tredje studie omfattede individuelle semistrukturerede interviews med patienter, der gennemgik behandling i et onkologisk ambulatorium (Artikel III), og et fokusgruppeinterview med SP. Fokusgruppeinterviewet blev gennemført for at få indsigt i SP's perspektiver på den kommunikative praksis. Metodologien i afhandlingen er Interpretive Description, og Symbolsk Interaktionisme har inspireret den analytiske tilgang til afhandlingens empiriske studier.

Den systematiske litteraturgennemgang (Artikel I) fremhævede relationens betydning og specificerede hvilke aspekter patienterne værdsatte i kommunikationen med SP. Dette indbefattede at blive fulgt af den samme SP (relationel kontinuitet), specifikke færdigheder hos SP som f.eks. at de var gode til at lytte, var troværdige, samt udviste en omsorgsfuld tilgang. Derudover fremhævede patienterne, at kommunikationen var baseret på dialog, og anså sygeplejerskerne som værende en central psykosocial omsorgsgiver. Undersøgelsen identificerede et videnshul i litteraturen, og kunne ikke tilstrækkeligt specificere, hvilken hjælp

og støtte patienterne får, når de modtager ambulant behandling. Resultaterne fra studiet blev anvendt til at informere de kommende empiriske undersøgelser.

Observationsstudiet (Paper II) viste, at kommunikation mellem patienterne og SP var karakteriseret ved at have et behandlingsorienteret indhold, der primært indeholdt informationer omkring behandling og bivirkninger. Herudover var den karakteriseret ved at være kortvarig, ofte indforstået, og foregik ofte mens sygeplejerskerne udførte andre kliniske opgaver. Studiet pegede på, at ambulatoriets fysiske begrænsninger og høje patientflow påvirkede kommunikationens indhold på en sådan måde, at information om behandling og bivirkninger blev prioriteret, mens mere følsomme og eksistentielle emner ikke blev italesat.

Interviewundersøgelsen (Artikel III) viste, at patienter oplevede at kommunikationen med SP var kendetegnet ved at være informativ, rutineret, opmuntrende og centrerede omkring instrumentelle opgaver i forbindelse med behandlingen, hvilket mange oplevede som støttende, men kunne også tippe over og blive upersonlig og mekanisk. Patienternes eksistentielle og psykosociale tanker var fraværende i kommunikationen, som SP ikke adresserede i samtalen, ligesom patienter ikke selv bragte det op, på trods af at mange har behov for at blive støtte i håndtering af disse bekymringer.

Fokusgruppeinterviewet (side 32) gav indsigt i SP perspektiver på den identificerede kommunikationspraksis fra tidligere studier. Ifølge SP var mangel på tid og de fysiske omgivelser de største barrierer for at kunne identificere patienternes behov i ambulant regi. SP pegede på, at en større grad af relationel kontinuitet i pleje og behandling kunne øge kvaliteten af kommunikationen ved at give dem et bedre grundlag for at kende den individuelle patients præferencer og behov for støtte.

Afhandlingens overordnede konklusion er, at patienterne gennem deres kommunikation med SP støttes i deres håndtering af behandling og dens bivirkninger, hvorimod de ikke blev støttet tilstrækkeligt i at håndtere de psykosociale og eksistentielle problematikker, fordi det var fraværende i den kommunikative praksis. Herudover peger afhandlingen på andre kommunikative, fysiske og organisatoriske barrierer, der kan hæmme patientcentreret kommunikation i ambulant regi. Det analytiske, symbolske, interaktionistiske perspektiv bidrog med yderligere forklaringer ved at udfolde de dynamiske processer der udspillede sig mellem SP og patienterne i deres gensidige kommunikation. Afhandlingen peger på, at idet patienterne socialiseres ind ambulatoriets eksisterende kommunikationspraksis, gennem kommunikationen med SP, lærer de herigennem hvad der er relevant og meningsfuldt at bringe op i kommunikation med SP, og hvad der ikke efterspørges.

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PAPER I

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OPEN

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The Patient–Healthcare Professional Relationship and Communication in the Oncology Outpatient Setting

A Systematic Review

KEY WORDS
Ambulatory chemotherapy
Communication
Coping
Healthcare professional–patient relation
Nurse-patient relation
Outpatient care
Patient perspective
Professional-patient interactions
Systematic review

Background: Today, cancer care and treatment primarily take place in an outpatient setting where encounters between patients and healthcare professionals are often brief. **Objective:** The aim of this study was to summarize the literature of adult patients' experiences of and need for relationships and communication with healthcare professionals during chemotherapy in the oncology outpatient setting. **Methods:** The systematic literature review was carried out according to PRISMA guidelines and the PICO framework, and a systematic search was conducted in MEDLINE, CINAHL, The Cochrane Library, and Joanna Briggs Institute Evidence Based Practice Database. **Results:** Nine studies were included, qualitative (n = 5) and quantitative (n = 4). The studies identified that the relationship between patients and healthcare professionals was important for the patients' ability to cope with cancer and has an impact on satisfaction of care, that hope and positivity are both a need and a strategy for patients with cancer and were facilitated by healthcare professionals, and that outpatient clinic visits framed and influenced communication and relationships. **Conclusions:** The relationship and communication between patients and healthcare professionals in the outpatient setting were important for the patients' ability to cope with cancer. **Implications for Practice:** Healthcare

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professionals need to pay special attention to the relational aspects of communication in an outpatient clinic because encounters are often brief. More research is needed to investigate the type of interaction and intervention that would be the most effective in supporting adult patients' coping during chemotherapy in an outpatient clinic.

In recent years, cancer care and treatment have shifted toward ambulatory services, fewer hospital admissions, and shorter hospital stays.[1,2] Today, oncology treatments are primarily provided in outpatient settings.[3–5] In general, international data on this development are not available. However, in Denmark, the overall number of outpatient treatments in public hospitals between 2006 and 2011 increased by 19%, and the number of hospitalization days during the same period decreased by 12%.[6] For the past years, the goal of the national health policy in Denmark has been to reorganize the healthcare system so that patients are hospitalized only when there is no appropriate outpatient treatment available.[7,8] This development continues internationally as the global cancer burden is growing significantly because of an increase in the world's elderly population and the overall adoption of cancer-causing behaviors.[9] Furthermore, the number of patients with cancer who require ambulatory chemotherapy is increasing.[10,11] Although outpatient treatment leads to better cost control,[7] efficiency can change the way care is given and overlook the key role the relationship with the healthcare professional (HCP) has for patients' coping.[12] At the same time, studies have suggested a possible risk of not identifying patients' needs because of the limited time allotted.[13,14] Research has clarified that the relationship between patients with diabetes and HCPs was central for patients' ability to cope with their disease.[15,16] In particular, patients with cancer need supportive and caring relationships with the HCP[17,18] because cancer treatment often affects patients' quality of life, even years after the diagnosis.[19] A systematic review pointed out that patients with cancer often associated the term *good nursing* with their relationship to the nurse, and this was perceived as being important for the feeling of confidence and well-being.[20] A qualitative study exploring nurses' experiences of providing nursing care in a day hospital for patients with cancer identified barriers to establishing relationships.[21] In particular, focus on administration of chemotherapy was experienced as a central barrier for a well-functioning nurse-patient relationship. In addition, the authors reported that research focusing on the needs of patients with cancer has mainly been carried out during hospitalization.[21]

Because of a growing trend in outpatient cancer management, focus on the encounters between patients and HCPs during oncology treatment has become increasingly important. Healthcare professional communication skills have been found to be increasingly vital in meeting the challenges within the healthcare system.[22,23] Clinical guidelines are necessary for the development of evidence-based practice; however, current recommendations are primarily based on the HCPs' perspective and, to a lesser extent, on the patients' perspective, and they do not take into account the treatment setting and context, that is, outpatient.[24] Patient experiences can help identify areas for improvement in cancer care,[25,26] leading to gains in clinical quality[27] and efficiency.[28] Furthermore, the patients' experience is a key factor in patient-centered care.[28,29]

Objective

To understand the meaning and impact of the encounter between the patient and the HCP in an oncology outpatient setting, this systematic review aimed to summarize the literature from the perspective of the patient on the experiences of and need for relationships and communication with the HCP during chemotherapy treatment in an outpatient setting.

■ Methods

Search Strategy

The literature review was planned and conducted according to the PRISMA guidelines[30] and the PICO framework[30,31] and based on a protocol. The systematic search was carried out in MEDLINE, CINAHL, The Cochrane Library, and Joanna Briggs Institute Evidence Based Practice Database. The last search was performed on June 6 to 7, 2016. The search included MESH terms and keywords, and each keyword was combined with Boolean operators (and, or, not); truncation was used to expand the number of hits. Moreover, the reference lists of the included articles were hand searched,[32] and no gray literature was included. The following is an example of a search string applied in PubMed: ((((neoplasms OR cancer)) AND (((“nurse patient relations” OR “professional patient relations” OR “psychosocial support” OR communication OR “supportive care” OR “nursing interaction”)) OR oncologic nursing)) AND (((outpatients OR “outpatient clinics” OR “day care” OR “ambulatory care” OR ambulatory OR “time factors” OR “time management” OR “short term stay” OR ”short encounters”)) OR ((“length of stay”) AND short))) AND (coping OR empowerment OR “sense of coherence” OR “quality of life” OR “sense of control” OR “patient satisfaction” OR “patient participation” OR “patients experience*” OR “patients expectation*”).

The inclusion criteria were studies that included adult patients with cancer (≥18 years old) undergoing cancer treatment (curative or palliative), receiving primarily intravenous chemotherapy in an oncology outpatient setting; we applied no time limitation. Studies that captured the patients' experiences and needs and evaluation of “patient-HCP” interactions by individual interview, focus group interview, or patient-reported outcomes were included. Studies published in English, Swedish, Norwegian, and Danish were included. Excluded were studies taking place in the in-hospital setting, intervention trials, and questionnaire validation studies.

Data Collection

After eliminating duplicates, the first and second authors (A.P. and K.A.M.) screened the titles and abstracts for inclusion, and full-text copies were obtained when necessary. A.P. and K.A.M. independently assessed the identified studies for inclusion, and disagreements were resolved by discussion with the last author (A.K.D.). All studies meeting the inclusion criteria were subsequently read in full text and assessed for inclusion, and disagreements were settled among the entire author group.

Critical Appraisal of the Selected Studies

All included studies were critically appraised according to the Joanna Briggs Reviewer Manual[31] using the critical appraisal tools: Qualitative Assessment and Review Instrument for the qualitative studies (Table 1) and Meta Analysis of Statistics Assessment and Review Instrument for the quantitative studies (Table 2).

Data Extraction

Data were extracted and assessed by 2 authors (A.P. and K.A.M.). Data from the qualitative and quantitative studies were extracted and assessed in parallel processes. Subsequently, we conducted an integrative synthesis summarizing data from the qualitative studies followed by the quantitative studies.[41] Hereafter, we identified main findings across the included studies, and these results were presented as narrative summaries[31,41] (Tables 3 and 4). The findings were extracted based on our aim, and only findings that elucidated our aim were reported.

■ Results

Identification of Relevant Studies

In all, 1174 studies were identified by literature search (n = 1167) and reference search (n = 7) (Figure). Once duplicates were removed, the remaining studies (n = 1053) were screened for inclusion. Furthermore, 1035 studies were excluded by title and abstract reading because of not fulfilling the inclusion criteria, and the remaining studies (n = 18) were read in full. Nine studies were excluded after full-text reading because they did not meet the population inclusion criteria. Of these, 5 studies included control and/or surgical patients not undergoing chemotherapy; 2 studies were intervention studies; in 1 study, both patients and caregivers had completed questionnaires; and, in 1 study, it was not clear which treatment the patients had received. Finally, 9 studies, 5 qualitative (Table 3) and 4 quantitative (Table 4), were included.

Characteristics of Included Studies

A total of 5050 patients were included in this review, 86 patients from the 5 qualitative studies and 4964 patients from the 4 quantitative studies. Both genders were represented, female (n = 2888) and male (n = 2024); 138 patients did not report their gender. The participants had mixed cancer diagnosis predominantly treated with chemotherapy. Eight of the studies were conducted in

Table 1 • Assessment of the Qualitative Studies: Qualitative Assessment and Review Instrument

Appraisal Criteria	Cameron and Waterworth,[4] 2014	Ekwall et al,[33] 2011	Hargie et al,[34] 2009	Hjörleifsdóttir et al,[35] 2008	Mcilfatrick et al,[36] 2007
Congruity between the stated philosophical perspective and the research methodology	Unclear	Unclear	Yes	Unclear	Yes
Congruity between the research methodology and the research question or objectives	Yes	Yes	Yes	Yes	Yes
Congruity between the research methodology and the methods used to collect data	Yes	Yes	Yes	Yes	Yes
Congruity between the research methodology and representation and the analyses of data	Yes	Yes	Yes	Yes	Yes
Congruity between the research methodology and the interpretation of results	Yes	Yes	Yes	Yes	Yes
Statement locating the researcher culturally or theoretically	Unclear	Yes	Yes	No	No
The influence of the researcher on the research and vice versa is addressed	Yes	Yes	No	Yes	No
Participants and their voices are adequately represented	Yes	Yes	Yes	Yes	Yes
The research is ethical according to current criteria and so on	Yes	Yes	Yes	Yes	Yes
Conclusions drawn in the research report do seem to flow from the analysis, or interpretation, of the data	Yes	Yes	No	Yes	Yes

Table 2 • Assessment of the Descriptive Studies: Meta-analysis of Statistics Assessment and Review Instrument

Appraisal Criteria	Arraras et al,[37] 2013	Kleeberg et al,[38] 2007	Pinto et al,[39] 2014	Sitzia and Wood,[40] 1998
Was study based on a random or pseudorandom sample?	No	No	No	No
Were the criteria for inclusion in the sample clearly defined?	Yes	Yes	Yes	No
Were confounding factors identified and strategies to deal with them stated?	Yes	Unclear	Unclear	Unclear
Were outcomes assessed using objective criteria?	Yes	Yes	Yes	Yes
If comparisons are being made, were there sufficient descriptions of the groups?	n/a	n/a	n/a	n/a
Was follow-up carried out for a sufficient time?	n/a	n/a	n/a	n/a
Were the outcomes of people who withdrew described and included in the analysis?	No	No	No	Yes
Were outcomes measured in a reliable way?	Yes	Yes	Yes	Yes
Was appropriate statistical analysis used?	Yes	Yes	Yes	Yes

Abbreviation: n/a, not applicable.

Europe—Belgium (n = 1),[39] Germany (n = 1),[38] Iceland (n = 1),[35] Ireland (n = 2),[34,36] Spain (n = 1),[37] Sweden (n = 1),[33] and United Kingdom (n = 1)[40]—and 1 study was conducted in New Zealand (n = 1).[4]

Data from the qualitative studies were collected by semi-structured in-depth individual interviews[4,33–36] (Table 3). Three quantitative studies[37,39,40] used a cross-sectional observational study design with different measurement tools, and 1 study[38] used a prospective survey (Table 4).

Assessment of the Methodological Quality

The assessment of the methodological quality was performed independently by A.P., K.A.M., M.J., and A.K.D. using Joanna

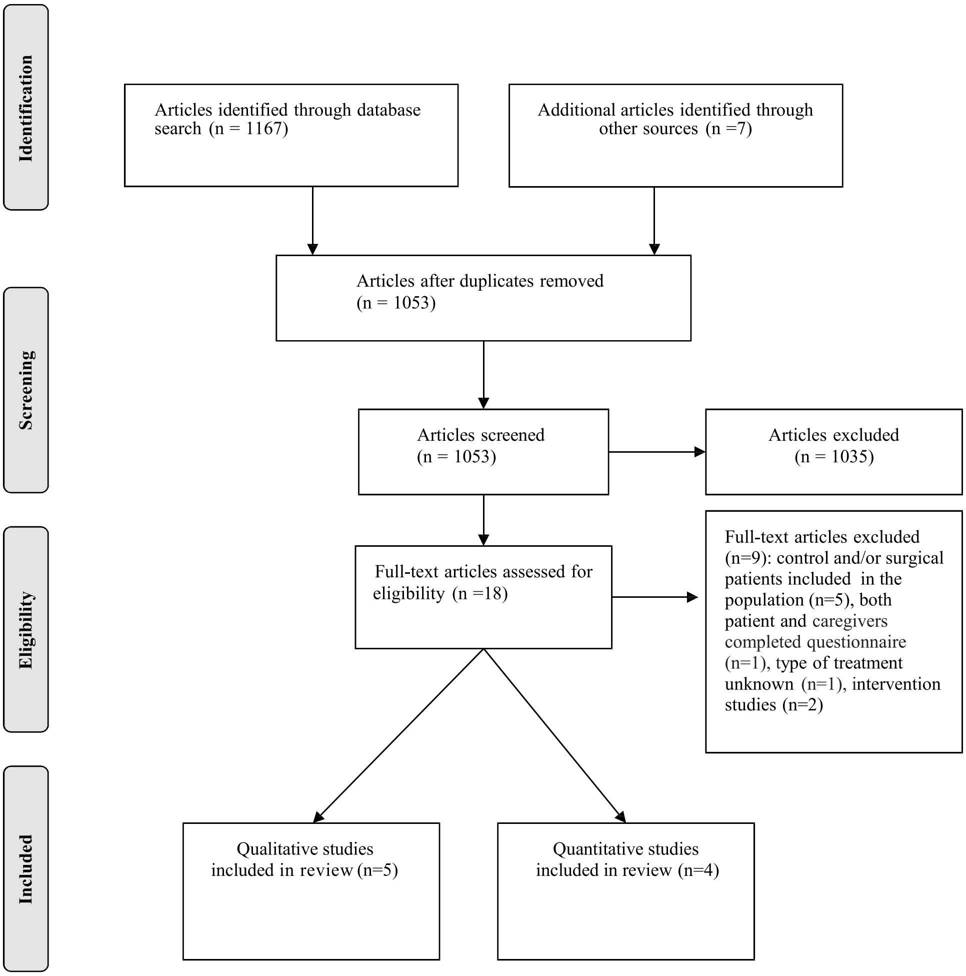

Figure ■ Flowchart of the study retrieved and selection process.

Table 3 • Characteristics of the Qualitative Studies

Author(s), Year, and Country	Aim of Study	Population	Method	Main Findings
Cameron and Waterworth,[4] 2014, New Zealand	To explore patients' experiences of being treated with palliative chemotherapy for metastatic colorectal cancer	n = 10 Colorectal cancer, female (n = 6) and male (n = 4) Age > 50 y Chemotherapy (n = 10)	Semistructured interviews	Patients experienced: • The relationships with the nurses were important and had a positive impact on how they experienced the atmosphere of the unit and their treatment • Patients needed to be referred to by their first name and having their preferences respected, which made them felt known • Patients expressed a need for being met with "positivity" by the HCPs and experienced this as an important coping strategy, which was also associated with a risk of overlooking patients' concerns and needs
Ekwall et al,[33] 2011, Sweden	To investigate what women with recurrent ovarian cancer perceived as essential in their communication with the HCPs	n = 12 Mean age, 57.5 y Chemotherapy for the first recurrence of ovarian cancer (n = 12)	Semistructured interviews	Patients experienced: • A need of becoming familiar with the disease based on: ○ being seen as a unique person who depended on a good interpersonal relationship with the HCP ○ a need to have meaningful explanations about the disease and treatment • A need to be involved and the possibility to share responsibility as competent and resourceful partners • A need to be able to prepare oneself before treatment
Hargie et al,[34] 2009, Ireland	To investigate how patients interpreted initial consultations with oncologic nurses in terms of how they perceived the role of the nurse	n = 9, female (n = 4) and male (n = 5) Mean age, 59 y *Campylobacter coli* (n = 3), prostate cancer (n = 2), breast cancer (n = 1), lung cancer (n = 2), and endocrine organs (n = 1) Medical treatment (n = 8), primarily chemotherapy; no treatment (n = 1)	Semistructured interviews	Patients experienced: • Nurses playing an important role as information givers and psychosocial supportive caregivers • That they valued that nurses used a language that was understandable and that nurses had enough time and encouraged patients to talk about important personal issues and seeing the same nurse were important
Hjörleifsdóttir et al,[35] 2008, Iceland	To explore oncology outpatient experiences of having cancer, to illuminate coping strategies, and to explore perceptions of care and service provided while being treated for cancer	n = 25, women (n = 16) and men (n = 9) Mean age, 55 y Cancer diagnoses: breast (n = 11), prostate (n = 3), ovarian (n = 2), colon (n = 2) and others (n = 7) Chemotherapy (n = 15) or chemo-radiotherapy (n = 10)	Semistructured interviews	Patients experienced: • Positive relationships between the patients and the HCPs enhance satisfaction and well-being • Coping with cancer was seen as balancing life as it was before against current to achieve normality and to believe in the treatment and maintaining hope • The waiting room and the waiting time affected patients' satisfaction negatively

(continues)

Table 3 • Characteristics of the Qualitative Studies, Continued

Author(s), Year, and Country	Aim of Study	Population	Method	Main Findings
McIlfatrick et al,[36] 2007, Ireland	To explore patients' experiences of having chemotherapy in a day hospital setting	n = 30, female (n = 19) and male (n = 11) Age range, 21–77 y Ovarian (n = 15), breast (n = 1), testicular (n = 6), lung (n = 2), esophageal (n = 3), non-Hodgkin's lymphoma (n = 1), melanoma (n = 1), unreported (n = 1); all received chemotherapy	In-depth qualitative interviews	• Patients need to be met with a caring human attitude by the HCPs. • The patients emphasized the importance of good interpersonal skills by the HCP. • Patients expressed a need to remain positive. • Patients experienced the day hospital setting both positively—keeping a sense of normality and an absence of sick role—and negatively, feeling isolated and unprepared for going home.

Abbreviation: HCPs, healthcare professionals.

Briggs critical appraisal tools,[31] hereafter compared for consistency, and discussed until agreement was reached between the 3 authors and afterward in the entire author group.

The overall methodological quality of the qualitative studies was generally high in all 5 studies[4,33–36] because they had congruity between the research question and methods for collecting, analyzing, and interpreting data. Two studies scored 9 of 10,[33,34] and 3 studies scored 8 of 10[4,35,36] (Table 1).

The methodological quality of the quantitative studies was rated slightly lower, although two of the appraisal criteria were not applicable and therefore not included in the overall assessment. One study scored 5 of 7 points,[37] and 3 studies scored 4 of 7 points.[38–40] No random or pseudorandom sampling strategy was applied in any of the included quantitative studies.[37–40] Hence, Arraras et al[37] recruited the first 3 eligible patients who were to receive chemotherapy on a given day, Kleeberg et al[38] included patients consecutively, Sitzia and Wood[40] included patients during a given period, and Pinto et al[39] included 1 of 3 eligible. Nevertheless, they did not describe how the patients were selected. All studies had inclusion criteria, although the criteria presented by Kleeberg et al[38] were interpreted through their presentation of exclusion criteria. All the quantitative studies applied appropriate and reliable statistical analysis including relevant correlation analyses.[37–40] All studies that met the inclusion criteria were included in the review regardless of methodological quality.

Findings Emerging From the Studies

Across the 9 included studies, 3 main findings emerged that elucidated our aim: (1) the relationship between the patients and HCPs is important for the patients' ability to cope and has an impact on satisfaction of care, (2) hope and positivity are a need and a strategy for patients with cancer and are facilitated by HCPs, and (3) outpatient clinic visits frame and influence communication and relationships.

The Relationship Between the Patients and HCPs Is Important for the Patients' Ability to Cope With Cancer and Has an Impact on Satisfaction of Care

All studies found that patients reported that their interactions and relationships with the HCPs were associated with satisfaction with care.[4,33–40] The qualitative studies[4,34] and quantitative studies[37,38] showed that nurses in particular played an important role for patients' satisfaction with care.[4,35] The patients' encounters with the HCP were closely related to the treatment situation. A patient supported this: "It is undisputed that the behavior, caring encounters and encouragement of the doctors and nurses can influence the treatment, it is simple, I feel better and therefore it is easier for my body to do its job,[…]. I am certain, that these caring attitudes matter most, and I think the medical treatment comes next."[37(p520)]

Central elements in forming the relationship between the HCP and the patient were highlighted including the importance of the HCP having good interpersonal skills,[33,34] which

Table 4 • Characteristics of the Quantitative Studies

Author(s), Year, and Country	Aim of the Study	Population	Method	Outcomes Measured	Main Findings
Arraras et al,[37] 2013, Spain	To evaluate SC and identify SC determinants and to compare SC and quality of life	n = 176, female (n = 80) and male (n = 96) Mean age, 60.8 y Disease location: respiratory (n = 30), gastrointestinal (n = 60), genitourinary (n = 9), gynecological (n = 9), head and neck (n = 3), breast (n = 47), brain (n = 3), others (n = 15) Chemotherapy (n = 176)	Cross-sectional observational study	EORTC QLQ-C30 (version 3.0) and OUT-PATSAT35 CT	• Patients experienced overall high SC (MS > 70). • All scales in the nurses' domain achieved the highest scores and dominated in overall satisfaction, eg, "interpersonal skills" (MS, 89.4). • Less satisfaction was found in the domains "doctor availability" (MS, 69.3) and "environment" (MS, 59.4) ($P < .01$).
Kleeberg et al,[38] 2008, Germany	To investigate how patients evaluate their cancer care and in which degree HCPs meet their expectations	n = 4615, female (57%), male (40%), not defined (3%) Mean age, 63.5 y Breast (25%), colorectal (20.6%), blood (11.6%), lymphoma (11.1%), lung (6.1%), others (23.6%), not defined (2.0%) Chemotherapy (92.2%)	Prospective survey	The 2004 PASQOC questionnaire. For statistical analysis, PF was calculated for each item in the questionnaire.	• Patients experienced highest satisfaction within the dimensions "further support in everyday life" (PF, 3%), "nursing staff and other practice assistants" (PF, 5%), and "patient-physician relationship" (PF, 8%). • Patients experienced lowest satisfaction within the dimensions "handling of side effects" (PF, 39%), "co-management and shared decision-making" (PF, 30%), and "side effects" (PF, 30%).
Pinto et al,[39] 2014, Belgium	To evaluate self-reported information and compare with the patients' demographic and clinical characteristics	n = 101, female (n = 79) and male (n = 22) Mean age, 56.9 y Breast (n = 59), gastrointestinal (n = 20), urogenital (n = 6), gynecological (n = 5), lung (n = 5), melanoma (n = 3), head and neck (n = 2), sarcoma (n = 1) Chemotherapy (n = 101)	Cross-sectional observational study	The EORTC QLQ-C30 questionnaire (version 3.0) and its information module EORTC QLQ-INFO25	• Patients experienced satisfaction with the overall information level. • Higher information levels were associated with a higher QoL ($P = .06$). • Patients expressed unmet information needs about their treatment ($P < .001$).

(continues)

Table 4 • Characteristics of the Quantitative Studies, Continued

Author(s), Year, and Country	Aim of the Study	Population	Method	Outcomes Measured	Main Findings
Sitzia and Wood,[40] 1998, United Kingdom	To identify areas of significant satisfaction or dissatisfaction with chemotherapy care among patients, to examine the correlation between patient characteristics and their satisfaction with care, and to determine which components correlate most with overall satisfaction	n = 173, female (n = 120) and male (n = 53) Mean age, 56.2 y Solid tumor (n = 117), hematological (n = 56); the diagnoses are not further specified. Chemotherapy (n = 173)	Cross-sectional observational study combined with qualitative comments	WCSQ	• Patients experienced an overall high satisfaction: 83% very happy and 14% fairly happy. • Of the 6 "interpersonal nursing care" topics, "reassurance and support" had the highest MS (76.2%), and "concern for your privacy when talking about your personal details" had the lowest (57.0%). • Patients evaluated nurses' "technical skills in giving chemotherapy" high (MS, 78.3%), and a lower satisfaction level was found with the nurses' "awareness of side effects" (MS, 70.6%). • 25% of text units concerned ward environment, and 20% of these expressed dissatisfaction.

Abbreviations: EORTC QLQ, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; HCP, healthcare professional; MS, mean score; PASQOC, Patient Satisfaction and Quality in Oncological Care Questionnaire; PF, problem frequency; QoL, quality of life; SC, satisfaction with care; WCSQ, Worthing Chemotherapy Satisfaction Questionnaire.

included being a good listener,[35] being trustful,[35] having a compassionate attitude,[36] and using a caring approach.[35] In addition, patients valued being addressed by their first name, which made them feel recognized,[4] and they appreciated the continuity of meeting the same HCP at each outpatient visit.[33,35]

Patients with cancer expressed a special need for good communication with the HCP in the outpatient clinic.[33–35,38] Patients valued communication that was facilitated in a personal and meaningful way,[33] for example, using eye contact[33,36] and based on dialogue.[33,36] Patients expressed a need for the HCP to have certain communication skills such as having a compassionate attitude along with the ability to convey information in an understandable language.[4,33,34,36] Being treated with chemotherapy required information regarding treatment and adverse effects, and 4 studies[34,36,37,39] found that patients regarded nurses as having a key role in communicating information about treatment and adverse effects. Three of the quantitative studies reported that patients receiving treatment in an outpatient clinic expressed an immense need for information from the HCP.[37–39] This finding was also supported by 3 qualitative studies, as information was connected to the ability to cope with the disease, treatment, and daily life[34–36] by reducing anxiety and helping patients gain control.[36] Although communication and information from the HCP were experienced as essential to the patient, three of the quantitative studies found that patients had unmet information needs.[38–40] Information about handling adverse effects had a problem frequency of 49% in Kleeberg et al,[38] where 27% of the patients answered that they wanted more information on adverse effects. This study also found that patients who reported adverse effects (eg, pain or gastrointestinal discomforts) were less satisfied with their HCP.[38]

Patients experienced the nurse as a psychosocial caregiver encouraging patients to talk about issues perceived as important to them.[4,34] Furthermore, patients appreciated when nurses gave the impression of having time for them[34]: "Even though she maybe had other things to do, she didn't make me feel that she had anything else to do…so I felt free to talk about it."[34(p75)] A qualitative study also emphasized that patients with cancer wanted to be involved in treatment and to be seen as competent partners.[33] In one of the included studies, 48% of the 4615 surveyed patients reported that they were not involved in decisions regarding their treatment.[38]

Hope and Positivity Are a Need and a Strategy for Patients With Cancer and Are Facilitated by HCPs

Three of the 5 qualitative studies found that the attribute of maintaining hope and positivity was both a need and an important strategy for coping with the cancer disease.[4,35,36] Positivity is composed of remaining with a positive attitude:[4,36] "I just try to think positive that everything's going to be alright and I try not to worry about it. Well, if you let yourself get down, then it is harder for you to keep yourself motivated and going."[36(p269)] Being positive was thus turned into a coping strategy, which was associated with better outcome, whereas being negative meant working against the treatment.[35] Some patients also expressed a need for the HCP to enhance hope in their interactions with them.[35]

Positivity was in many cases facilitated by the HCP: "The doctors said you have to be positive; if you are not positive, you won't beat the disease. You must be positive."[36(p269)] Although patients expressed a need for and had an expectation that the HCP should facilitate hope and positivity, it could conversely lead to underreporting of adverse effects or toxicities. This could lead to overlooking patient concerns and needs in the encounters with HCPs during chemotherapy.[36]

Outpatient Clinic Visits Frame and Influence Communication and Relationships

The studies reported both possibilities and restrictions for patients in establishing a relationship with the HCP when the encounters took place in an oncology outpatient clinic. McIlfatrick et al[36] identified advantages and disadvantages of attending an oncology outpatient clinic. The study found that the outpatient location made it easier for patients to maintain a sense of normality and security associated with home, removing some of the feelings related to illness. Furthermore, attending an outpatient clinic was experienced positively because it became a part of their daily routine.[4] In contrast, some patients felt isolated and alone with the disease and experienced a lack of professional support: "When I went home, I was feeling quite low and nauseous, and I was really worried about how I would get on[…]. I felt isolated and quite left alone."[36(p268)] Kleeberg et al[38] found that lack of communication with the HCP could hamper the patients' ability to cope with the disease in their daily life; for example, "not receiving enough information on dealing with pain at home" had a problem frequency of 47%, and "was not told how to effectively manage side effects" had a problem frequency of 38%.

Four studies concluded the outpatient environment for administrating chemotherapy was a negative experience for some patients.[35–37,40] The treatment in an outpatient clinic was compared with visiting a fast-food restaurant:[36] "it is a bit factory-like. You're getting the treatment[…]. I would like to see a bit more attention paid to your life as well as, or incorporated with, the treatment.[…] to discuss about yourself as a mother or a wife, or as a girlfriend or a retired person and your everyday life."[36(p268)] Some patients experienced the treatment environment as dehumanizing, which was described by McIlfatrick et al[36] as a central finding in their study. The environment in the outpatient clinic thus had an influence on patients' experiences of their communication and relationship with the HCP.

Cameron and Waterworth[4] found the patients' experience of the atmosphere in the outpatient clinic to be influenced by how they experienced the relationship with the nurses. For instance, caring behaviors improved satisfaction with care and well-being.[35] Moreover, waiting time in the outpatient clinic was experienced negatively by the patients.[35–37,40] When examining other factors affecting satisfaction, patients rated the environment low (mean score, 59.4), for example, the waiting room, waiting time, and access to parking.[37] However, the environment seemed to have the least influence on satisfaction with care.[37]

Discussion

The aim of this systematic review was to summarize the literature from the perspective of the patient on the experiences of and need for relationships and communication with HCPs during chemotherapy in an outpatient setting. On the basis of 9 studies included in this review, evidence showed that the relationship and communication with HCPs were experienced as essential for patients during chemotherapy in an outpatient clinic. In particular, the relationship with the nurses was highlighted as playing an important role for coping with the disease and influenced overall satisfaction. These findings correlate well with other studies where the relationship between the patient and the HCP was the most important factor influencing patient satisfaction,[17,42,43] where the experience of being acknowledged as a person with individual needs was also emphasized.[44]

The relational aspect of communication was stressed by the patients, as well as the importance of the HCP relating to the individual needs of patients with cancer. This finding is in line with Skea et al,[45] who examined what patients with urological cancer valued in their interaction with the HCP. However, this raises the question of whether there is sufficient time to identify the individual needs of patients when encounters are brief,[21] and as previously described, studies have found a risk of overlooking patients' needs when time is limited for each patient.[13,14] Nevertheless, only a few studies mentioned time as an issue. Hargie et al[34] found that patients valued that nurses gave an impression of having enough time for them. Sitzia and Wood[40] found that the outpatient clinic could be experienced as too busy, but lack of time was only mentioned by less than 3% of those who expressed dissatisfaction. A qualitative study exploring key issues associated with providing effective psychosocial care for hospitalized patients with cancer showed that lack of time prevented the identification of healthcare needs.[14] Another qualitative study examining the nurse-patient interaction in an acute care environment revealed that some of these interactions focused on routines rather than an individualized approach to the patient.[46] McIlfatrick et al[21] explored nurses' experiences of giving chemotherapy in an outpatient clinic compared with their experiences of working in an inpatient setting and found that nurses experienced a lack of ability to develop the nurse-patient relationship and insufficient time to provide psychosocial care. The study emphasized that nursing in an outpatient setting required a balance between administering chemotherapy and maintaining the centrality in the nurse-patient relationship.[21] The current literature indicates that relationship-based care can decrease task-oriented care,[47] and a relationship-based model can support a patient-centered environment and patient satisfaction.[48]

Continuity of care and meeting the same HCP were viewed as important central aspects by the patients treated in the outpatient clinic.[33–35] This was in line with research evaluating satisfaction with care among patients receiving chemotherapy and radiotherapy in an oncology outpatient clinic.[5] This finding might not be surprising, but perhaps, continuity of care is particularly important in an outpatient clinic where visits can be frequent and encounters with the HCP can be brief. Manthey[49] has contributed to the development of the concept of primary nursing in an inpatient setting, which has been found to improve patient satisfaction in an oncology outpatient clinic.[50] However, as our review revealed, the topic "continuity of care" is sparsely investigated in the oncology outpatient setting.

This review confirmed the importance of the HCP having competence in interpersonal and communication skills. The National Cancer Institute has pointed out that communication between patients and the HCP is essential for patients' experience of quality in cancer care.[17] In general, cancer treatment requires a great deal of information about treatment and adverse effects, and as identified in this review, some patients experienced unfulfilled information needs, especially related to information about the handling of adverse effects. This might be explained by the lack of time to inform patients adequately. Patient involvement in decision-making regarding treatment was important to patients with cancer.[33,38] Conversely, only a few studies reported whether they investigated patients' experiences of being involved in decision-making.[33,38] Nevertheless it is notable that Kleeberg et al[38] found that almost half of the 4615 surveyed patients did not experience personal involvement in decisions regarding their treatment. A systematic review concluded that most patients wanted a collaborative and active patient role but also showed that more research would be needed before clear recommendations can be made.[51]

Patients expressed a need for hope and positivity during cancer treatment and used these as a strategy to cope with the disease in their everyday life. The HCP was found to play a central role in enhancing hope and positivity for the patient in their interactions. Research supported that hope and positivity can lead to better coping[52] and suggested that absence of hope in a patient-doctor interaction can have a negative influence on the patients' well-being.[53] Conversely, positivity was found to increase risk of the HCP overseeing patient concerns and needs and was also linked to patients downgrading some of their concerns in their encounters with the HCP. This finding was in line with McCreaddie et al[54] who found that positivity can be constructed as a norm in HCP-patient encounters, which may lead to failure in identifying patients' individual needs.[4]

McIlfatrick et al[36] stressed the advantages of receiving chemotherapy in an outpatient clinic because it facilitated patients' feelings of normality but also revealed that there was a risk of the patients feeling alone with their disease. Research indicated that effective psychosocial support might improve patient outcomes in relation to, for example, pain, anxiety, and depression during chemotherapy in an outpatient clinic.[55,56] Benor et al[57] found a significant effect on patients treated with chemotherapy in an outpatient clinic on their psychosocial symptoms when combined with home visits by nurses with a follow-up of 3 months. Nursing interventions including guidance, education, and support significantly improved symptom management in the intervention group in 15 of the 16 symptoms, for example, anxiety, pain, fluid intake, and sexuality. The largest reduction was found in psychosocial symptoms, especially on level of anxiety, body image, and sensuality.[57] The results might imply that the time used to establish a relationship with the patient was an important factor in patients' coping with the disease and treatment.

The environment in the outpatient clinic was the issue that was evaluated most negatively by patients and was even compared with a fast-food restaurant in 1 qualitative study.[36] Similar findings were reported in a survey on satisfaction in an oncology outpatient clinic where patients were treated with radiotherapy or chemotherapy, whereas service and care organization, for example, environment of the buildings and access to parking,[5] and physical environment, for example, comfort,[58] were reported as least satisfying. A systematic review indicated that the physical healthcare environment affected the well-being of patients[59]; for example, sunlight and windows had positive effects. However, the review also revealed limited evidence due to a scarcity of research in this field.[59]

Review Strengths and Limitations

We conducted a broad literature search and applied strict systematic methods throughout this review. We also chose to include both qualitative and quantitative studies, which may have provided a more multifaceted result. Despite a comprehensive search strategy, only 9 studies were eligible for inclusion. Because of the limited number of studies, the small sample sizes, and the heterogeneity of the included studies, the results must therefore be interpreted with caution.

Methodological quality assessments were carried out using Joanna Briggs study-appropriate assessment tools, which provided a uniform and structured evaluation of the studies. The overall methodological quality of the qualitative and quantitative studies ranged between medium to high.

The review focused on the relationship between the HCP and the patient with cancer—regardless of the cancer diagnosis—but certain diagnosis groups were more represented than others. Therefore, results may not be representative of the wider population of patients with cancer. Furthermore, we initially aimed to include studies where patients were undergoing chemotherapy; however, because there were only a limited number of studies found, we also included studies where a minor part of the population received radiotherapy instead (see Tables 3 and 4). Although this review focused on the multidisciplinary HCP group, we mainly generated knowledge about the patient-nurse relationship because the HCPs included in the studies were predominantly nurses. Reasons for predominance of the nursing perspective may be explained by nurses being the ones primarily administering chemotherapy in outpatient clinics. Historically, there has also been more focus on the patient-nurse relationship in a clinical context with further development of relationship-based practice care models.[12,15,16,49,60]

Despite the limitations, this review provided insight regarding the significance of the relationship and communication between patients with cancer and the HCP and how it affected the patients coping with the disease and satisfaction of care in an outpatient setting. Furthermore, it helped to specify which elements of the communication are central in the patient-HCP interaction from the patients' perspective.

■ Conclusions

This review revealed the importance of the patient-HCP relationship and communication as important factors in supporting and facilitating the patients' ability to cope with cancer in everyday life. Furthermore, our review showed that the patient-HCP relationship can affect patients' experiences of satisfaction of care in the outpatient clinic. This review also emphasized the relational aspect of communication and the importance of HCPs relating to patients' individual needs. Patients with cancer wished to be involved in decisions regarding their treatment and to be viewed as competent partners. Finally, the limited number of studies included in our review proved the point that patients' experiences in an oncology outpatient context have been sparsely investigated. Therefore, we suggest that more research is conducted in this area studying which type of interaction and intervention would be most effective in supporting patients in their coping with the disease while undergoing treatment in an outpatient clinic, that is, exploring whether a relationship-based care model[12,60] can support patients when treated in an oncology outpatient setting.

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PAPER II

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Observations of the communication practices between nurses and patients in an oncology outpatient clinic

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ABSTRACT

Purpose: Effective communication in cancer care and treatment is linked to better health outcomes, improved treatment adherence, and improved quality of life for cancer patients. While the characteristics of effective communication have been identified, there is sparse knowledge about the current conditions for providing effective communication especially within the outpatient clinical context, where the majority of cancer patients are currently being treated. This study aimed to explore communication practices between nurses and patients undergoing chemotherapy in an outpatient clinic to gain insight into how patients are supported in this setting.
Methods: Data were collected through 70 h of participant observations of nurse-patient interactions supplemented with ad hoc interviews with nurses in an oncology outpatient clinic. The methodology and data analysis are guided by interpretive description, thematic analysis and symbolic interactionism.
Results: Three themes were generated that characterised communication in the outpatient clinic: Treatment-centred communication, efficient communication and spatially-bound communication. While there was good opportunity for patients to learn about treatment and side effects during cancer treatment, psychosocial concerns were rarely addressed.
Conclusions: The outpatient setting influences the type and quality of communication between nurses and patients. Improvement of communication should include not only verbal and written information, but focus on the importance of nonverbal communication in the oncology outpatient clinic. Furthermore, there is a need to make environmental adjustments that can facilitate the opportunity for patients to express their needs and for nurses to respond to them.

1. Introduction

Today, patients with cancer are increasingly and primarily treated in outpatient settings (Bonacchi et al., 2016). This development will continue as the annual number of cancer cases worldwide is expected to increase from 14 million in 2012 to 22 million within the next 20 years (WHO, 2018). Benefits associated with outpatient treatment include better cost control (Bonacchi et al., 2016) and a positive impact on patients' ability to maintain normalcy in everyday life (Hjorleifsdottir et al., 2008; McIlfatrick et al., 2007). However, some patients feel left alone when treated in an outpatient clinic and experience that they do not receive adequate professional support to help them cope with cancer and treatment (McIlfatrick et al., 2007).

The quality of communication between health care professionals (HCPs) and patients influences the quality of cancer care and thereby patients' ability to live with the disease (Epstein and Street Jr., 2007; Prip et al., 2018; Skea et al., 2014; Thorne et al., 2013). Effective communication has been linked to better health outcomes (Epstein and Street Jr., 2007; Street et al., 2009), and improved cancer treatment adherence (Roberts et al., 2005). While effective communication informs, supports and guides patients with cancer (Coolbrandt et al., 2016; McKenzie et al., 2011; Thorne et al., 2013), ineffective communication results in confusion and distress (Thorne et al., 2013). HCPs communication skills are central to the support of cancer patients in

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their efforts to cope with a potentially life-threatening disease (Botti et al., 2006; Thorne et al., 2013) and maintain hope (Prip et al., 2018; Thorne et al., 2008) while becoming familiar with the disease and treatment (Ekwall et al., 2011).

Cancer treatment in an outpatient clinic requires patients to have a good understanding of the side effects of chemotherapy in order to manage symptoms more independently (Coolbrandt et al., 2016; McKenzie et al., 2011). Research shows, however, that patients receiving chemotherapy in outpatient clinics often have unmet needs related to the management of side effects and that these symptoms are the main reason for unplanned hospitalizations (McKenzie et al., 2011). Furthermore, studies find that cancer patients experience concerns and unmet needs related to psycho-emotional issues when treated in an outpatient setting (Bonacchi et al., 2016; Prip et al., 2018). Limited time for communication and brief encounters between patients and HCPs has been identified as a barrier for effective communication in cancer treatment (Banerjee et al., 2016; Hjorleifsdottir et al., 2008).

Although most cancer patients undergo chemotherapy in outpatient clinics, there is little research on communication in this context (Brédart et al., 2015; Hendershot et al., 2005; McIlfatrick et al., 2007; Prip et al., 2018) and how this treatment environment effects communication.

2. Objective

The aim of the study is to explore communication between nurses and patients undergoing chemotherapy in an outpatient clinic to gain insight into how patients are supported in this setting.

3. Methods

3.1. Study design and methodology

This study is based on participant observations of interactions between nurses and patients in an oncology outpatient clinic supplemented with ad hoc interviews with nurses. Interpretive description (ID), a qualitative inductive approach developed to explore clinical problems and phenomena, guided the study (Thorne, 2016; Thorne et al., 2016). ID draws upon established qualitative research traditions and techniques such as phenomenology, grounded theory and ethnography but rejects the “tyranny of method” by encouraging a pragmatic use of methods to suit the specific context of study (Hunt, 2009; Thorne, 2016). ID seeks understanding by exploring natural settings where realities are seen as local and socially experientially generated (Hunt, 2009; Thorne, 2016). As individuals and context are inseparable, it is necessary to observe nurse-patient interactions in the environment in which they take place (Thorne, 2016). In this study, we explored the communicative practice in the clinic including not only verbal communication and the explicit content of their conversations, but also by observing the nonverbal communication of the nurse and patient interactions, their behaviour, activities, and their responses to each other. Symbolic interactionism (SI) guided our understanding of the inherent meaning of the observed communication (Blumer, 1969). SI is a well-established theoretical framework in ID studies and shares the same epistemological foundations (Oliver, 2012), given ID's background in pragmatism and focus on contextualised action (Handberg, 2016; Thorne, 2016). The SI approach rests on three premises: 1) human beings act based on the meanings the phenomena have for them; 2) the meaning of a phenomenon is derived from social interactions with others; and 3) these meanings are handled in, and modified through, an interpretative process (Blumer, 1969). This means that individual actions are both formed by and influence the actions of others (Blumer, 1969). When people interact with each other, they communicate meaning through words and gestures (Blumer, 1969).

3.2. Setting and participants

The study was carried out in an oncology outpatient clinic at a public university hospital in Copenhagen, Denmark in October and November 2014. The participants were patients over 18 years of age with mixed cancer diagnoses: gynaecological cancer, melanoma or cancer in the kidney, bladder or prostate. Sampling patients with different diagnoses can be a useful method when the aim is to describe the general phenomenon regardless of specific conditions, such as gender or tumour site in isolation (Thorne et al., 2016). The nurses involved in the observations performed the same clinical tasks regardless of their clinical oncology experience (varying between < 1 year and > 10 years). These include, besides administering chemotherapy, other nursing tasks such as providing information, changing bandages and collecting blood samples. Each nurse treats approximately five patients depending on the length of treatment. Although the duration of patients' treatment varied from 30 min to 6 h, the interactions between the nurses and patients were predominantly brief, often consisting of 4–7 encounters, each lasting only a few minutes after initiation of treatment. The study was primarily carried out in the 40-m^2 treatment room where most patients received chemotherapy at the outpatient clinic.

3.3. Data generation

Approximately 70 h of participant observation was conducted over a period of two months. Five hours of observation were conducted a day including observations of the nurse-patient interactions, talking with patients and nurses, and participating in practical non-clinical tasks.

We followed the nurses' daily routines, which provided insight into the many encounters and communicative interactions that took place and gave opportunity for short ad hoc interviews (lasting between 2 and 10 min) with the nurses during the day. Questions related to the observations and explored the nurses' reflections about their actions and the observed situations. Approximately six hoc interviews were conducted daily.

Fieldnotes were taken during observations, just as transcripts from conversations between nurses and patients and ad hoc interviews with nurses were documented. Subsequently, the handwritten fieldnotes were transcribed electronically on the same day as the observations according to recommendations of writing ethnographic fieldnotes (Hammersley and Atkinson, 2007).

Anne Prip (AP) and Kirsten Alling Møller (KAM), both registered nurses, collected the data individually. AP has extensive oncology experience and Kirsten Alling Møller (KAM), who had no prior clinical oncology experience has broad experience with ethnographic fieldwork. Their different clinical experiences enabled a variety of perspectives on the data generation and analyses. AP, KAM and Kathrine Hoffmann Pii (KHP), a trained anthropologist, collaboratively developed the fieldwork strategy and methods. All the observations were carried out individually on different days and discussed among AP, KAM and KHP three times during the observation period to review methodological aspects and identify patterns and variations in the data. For example, the three researchers met after two days of observations to develop an observation strategy which included selection of specific activities to follow (Hammersley and Atkinson, 2007). Investigator triangulation was conducted to ensure study credibility and methodological reflection (Malterud, 2001).

3.4. Data analysis

Data analysis was inductively driven and carried out as a thematic analysis (Braun and Clarke, 2006) involving the author group at different stages to ensure credibility (Malterud, 2001). NVivo 10™ software (Edhlund and McDougall, 2012) was used to organise and manage the data. The first step was to become familiar with the data through repeated readings of the transcripts and by noting initial ideas (AP, KAM). The data were then coded, and the transcripts re-read according to the initial codes, after which the data were repeatedly coded and recoded. Next, patterns and variations in the data were identified and discussed as potential themes (AP, KAM, MJ, KHP). The final coding and analysis were discussed in the entire author group. SI inspired the analysis of the observed communication by drawing attention to the nonverbal communication in interactions and the inherent symbolic meaning of nurses and patients' actions.

3.5. Ethics statement

The study was carried out in accordance to the Helsinki Declaration (WMA, 1974) and approved by the Danish Data Protection Agency (no. 2018-521-0054) and Research Ethics Committee of the Capital Region of Denmark (no. H-4-2014-FSP).

HCPs at the outpatient clinic were informed about the study, including principles of voluntary participation and anonymity. Information posters about the project and the involved researchers were placed in the reception area, hallways and treatment rooms. Researchers introduced themselves when possible during the observations to give patients the opportunity to decline participation, and inform them about the principles of voluntary participation and anonymity. No patients or nurses declined participation.

4. Results

The analytical process led to the identification of three main themes that characterised the communication in the outpatient clinic in terms of its content, form and setting: treatment-centred communication, efficient communication and spatially-bound communication. Although presented separately, the themes are interrelated and mutually influence each other, as illustrated in Fig. 1.

4.1. Communication content: treatment-centred communication

Communication between nurses and patients primarily focused on aspects of treatment. Often, communication was initiated by the nurse, who explained the physiological effects of chemotherapy and the side effects that the patient needed to be aware of, e.g. how chemotherapy affects the bone marrow, stomach and intestines. Patients responded by listening or asking questions, accepting that the nurses set the agenda for the conservation. A treatment appointment typically started with the nurse accompanying the patient from the waiting room to the treatment room. To start treatment promptly, the nurse had prepared the patient's chemotherapy in advance and inserted the intravenous catheter (IV catheter) as soon as the patient was seated. When the patient asked questions during this procedure, the nurse sometimes answered and other times she waited until the IV catheter was in place, signaling through her actions that treatment had to be started before engaging in conversation. Thereby, the nurse communicated verbally and nonverbally a priority order, i.e. that treatment took precedence over dialogue. We observed that the patients responded to this symbolic action (insertion of the IV catheter as the initial action) by either waiting to ask questions until the nurse was ready to converse or by asking questions directly related to the treatment or side effects. In this regard, nurses initiated a line of activity and shaped patients communication in terms of how they responded and which types of questions they asked.

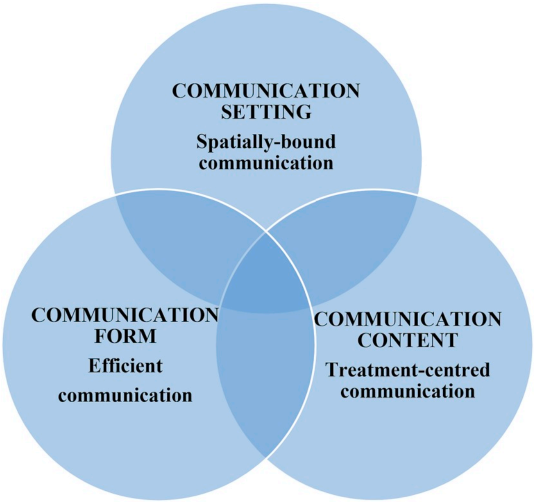

Fig. 1. Themes characterising communication in the outpatient clinic.

Patients' actions were also a reflection of the priority of treatment in the clinic, especially those patients who were familiar with the clinical routines of chemotherapy. Often they initiated communication with the nurse by asking the nurse *which hand she would like [for the IV catheter]* (Observation day 9), indicating that the patients had been socialized to the treatment-practice and had learned the clinic's priorities, i.e. that treatment was the primary focus in their interaction. The following field notes present an example of the situation:

> *After the initial greeting, the patient gets comfortable in the chair. It doesn't seem as if the patient and nurse know one another, but the patient seems familiar with the procedure. The nurse inspects the patient's veins on both arms right away and asks while she inspects: “Are you feeling well?” The patient answers that he has stomach problems. The nurse moves away from the patient, fetches the IV equipment, pulls out a chair and sits down in front of the patient. The IV catheter is inserted on the first try. No words are spoken, but the patient looks on with curiosity.*
>
> *The nurse inspects the IV chemotherapy connected to the patient, and says after reading from the flowchart: “I can see that the dose has been lowered slightly since the last time."Patient: “Has it … ?"*
>
> *Once the treatment begins the nurse sits down, looks at the patient and asks about his stomach problems* (Observation day 5, large treatment room).

For the most part, the nurse returned to the patient's questions after the chemotherapy had been started. However, at times supportive needs were unmet as questions were left hovering in the air unanswered.

Although treatment was pivotal for their interaction, we also observed variations where patients sometimes shared their concerns. The following nurse-patient interaction lasted no longer than 2 min while the nurse was removing the IV catheter:

> *The patient is reading a magazine but puts it away as the nurse enters.*
> *Nurse: “You're sighing?”*
> *Patient: “Yes, you get sad when you read this.”*
> *Nurse: “Yeah, we're being blitzed at the moment [a particular TV channel has been focusing on cancer all week]… but you could turn it off.”*
> *Patient: “I have children and grandchildren … I imagined that I would live to be 90 … but then again, I won't.”*
> *Nurse: “No, you probably won't … but let's see how the treatment works for you.”*
> *Patient: “Yeah, but then again, I'd like to feel good … otherwise there wouldn't be much to it … ”*
> *Nurse: (short silence) “Did you get your new appointment?”*
> (Observation, day 5).

In this situation, the nurse noticed and responded to the patient's initiation of communication (the sigh). The dialogue illustrates that it is possible to engage in conversations about existential issues even in a very short period of time. However, it underpins our general observations, that the nurses rarely explored patients' concerns, especially existential issues as death. As the fieldnotes illustrate, the nurses could either open or close the dialogue with the patient by pursuing or avoiding questions that the patient posed, for instance, by changing the subject, and in this case, by asking about the patient's next appointment.

4.2. Communication form: efficient communication

We observed that the interactions between the nurses and the patients were brief and used efficiently. The nurses' actions were often multitasked, informing the patient about side effects while moving around or engaging in other tasks such as placing the IV catheter and checking the progress of the chemotherapy.

An example of efficient communication was observed when nurses accompanied the patient from the waiting room to the treatment room. During this short walk, the nurse often asked how they had been since the last treatment. By making this enquiry already before arriving to the treatment room, the nurse communicated that time was brief and needed to be used efficiently. This was also confirmed in an ad hoc interview with a nurse about her reflections on the depth of the conversations in the outpatient clinic. She said: *"The patients know that there's only a limited amount of time, so they need to get to the point quickly"* (Informal interview with a nurse, day 3).

Aside from the communication form being brief, much of the meaning was implied. This inherent meaning nevertheless appeared to be understood by the patients who were familiar with the outpatient clinic. These patients used either more direct communication and fewer words to make themselves understood or communicated nonverbally e.g. by extending an arm for the IV catheter.

Although the nurse-patient interactions were brief, we also observed variations where the nurses spent more time with patients who were at risk of developing an allergic reaction during treatment. The nurses also provided more detailed information about the treatment and side effects to patients receiving treatment for the first time. We also observed situations where nurses broke the rapid work pace and took time for a longer dialogue with the patient, e.g. to make sure that a patient understood the information or if a patient showed signs of emotional distress. In certain situations, the nurses thus compensated for the restricted amount of time available in the clinic and created a new line of activity in the busy clinic.

4.3. Communication setting: spatially-bound communication

The clinical setting influenced the interactions between the patient and nurses in terms of how they communicated and the content of the communication. The outpatient clinic had a steady flow of patients arriving, exchanging treatment chairs and departing. This flow created a constant high activity level among the nurses as they prepared for new patients.

The physical environment influenced the content of the verbal communication. We observed a difference in the content of the conversations depending on whether the patients were treated in the large or small treatment room. Especially the large treatment room where most patients were treated, offered poor conditions for sensitive conversations. Patients chose the small rooms when it was an option and sometimes requested one.

As described earlier, existential, psychosocial and sexual issues were rarely brought up in conversations during treatment. One reason for the absence of these issues could, besides from the restricted time to communicate, be related to the lack of privacy in the outpatient clinic making it difficult to have confidential conversations. This challenge was also discussed among the nurses:

> *At the nurses' office, one of the nurses tells another nurse about a newly diagnosed patient with malignant myeloma that she treated the day before. The nurse had never met the patient before and had asked him to sit in the small treatment room. When she asked how he was doing, he broke down in tears. She reflects that he was in crisis and says: "I'm not sure whether I have the skills to care for patients with a newly diagnosed malignant melanoma." […]. The other nurse replies [addressing her answer to me as well]: "Of course we're equipped – a crisis is a crisis. We're professionals, but the question is whether we have the proper conditions to handle the crisis."* (Observation, conversation between two nurses in their office, day 9).

The nurse who shared her experience interpreted the situation as her own lack of professional skills, whereas the other nurse interpreted that the physical conditions in the clinic reduced the possibility of adequately supporting patients. This understanding of the spatial limitations for conversation and support was especially observed in the large treatment room, where nurses sometimes used their bodies to create a confidential space between themselves and the patients, e.g. moving closer to the patient, lowering their voices, and widening their backs as a shield. The nurses thus used their bodies as a medium to compensate for the lack of privacy by creating space for a more private dialogue.

In summary, the analysis found that communication in the outpatient clinic focused on issues related to treatment, which is the main objective of the outpatient clinic visit. Most communication was about the practical or instrumental aspects of chemotherapy, which was delivered efficiently while nurses simultaneously provided information about side effects. Furthermore, communication was characterized by its briefness, reflecting that patients were socialized into the specific communicative practices in the clinical context. Nurses experienced that the lack of privacy, lack of communication skills and restricted time to communicate made it difficult to communicate about sensitive existential, psychosocial and sexual issues.

The themes identified should be understood dynamically as they can influence and mutually reinforce one another, i.e. the setting in which the communication took place with time limitations created a form of communication characterised by efficiency that required prioritization of the content of conversation, resulting in treatment-centered communication. At the same time, the spatial conditions in the clinic made it difficult to have conversations about psychosocial issues, which was further challenged by the brief communication form.

5. Discussion

The study showed that communication was characterised in terms of its content (focusing on topics related to treatment and side effects), its efficient form (brief, implied and multitasked) and that the setting of the outpatient clinic affected both the content, form and quality of communication between the nurses and patients. In the following, we discuss the communication practice observed and the implications it may have for the support patients are offered during chemotherapeutic treatment.

The study revealed that the nurse-patient communication in the clinic predominantly focused on information and aspects of treatment and its side effects. This focus was also expressed in nonverbal communication as the observed actions centered around the technical aspects of treatment. These findings are in line with McIlfatrick et al. who found that the primary focus on treatment in an oncological outpatient clinic was criticized by nurses who expressed that they spent most of their time administering chemotherapy at the expense of their caring role, which they described as "nursing the clinic" as opposed to "nursing the patient" (McIlfatrick et al., 2006). The study argued, that the dominant focus on treatment-related issues in the communication reduced the attention given to other needs that patients have during cancer treatment (McIlfatrick et al., 2006). Our study found that treatment-centered communication provides patients with the opportunity to learn about and discuss the medical and physiological aspects of their treatment. This type of support is highly valued by patients according to a systematic review synthesizing knowledge on patient-HCP relationship and communication in oncology outpatient settings (Prip et al., 2018). The review found that patients request information about treatment and side effects to help them manage the disease and treatment by, e.g. reducing anxiety and helping them gain control in their everyday lives (Prip et al., 2018). Although we observed that the nurse-patient communication was mainly about treatment and side effects, other studies demonstrate that patients have unmet informational needs regarding side effects (Bonacchi et al., 2016; McKenzie et al., 2011; Prip et al., 2018) which underscores the value of and a continual need to promote communication about treatment. Despite its importance, the treatment-centred content of communication cannot stand alone in nurse-patient communication in an oncological treatment setting. Existential, psychosocial and sexual issues are important to address in cancer care (Bonacchi et al., 2016; Fitch et al., 2013; Maguire et al., 2013) and studies show that patients with cancer have unmet needs regarding such psycho-emotional issues (Bonacchi et al., 2016; Prip et al., 2018). In our observations, these issues were rarely part of the content of the communication. The absence of these issues can be explained in different ways. Limited time is a common explanation expressed both by the nurses in our study and by HCP in the literature (Banerjee et al., 2016; Chan et al., 2013). We observed that nurses had limited time to communicate with the patients in the outpatient clinic, which may explain why nurses prioritized talking about treatment and side effects rather than psychosocial aspects of the disease. Also patients express that limited time may have a negative impact on communication (Chan et al., 2018; Coolbrandt et al., 2016; Finset et al., 2013) and influence which topics patients choose to communicate (Chan et al., 2018). Poorly-designed outpatient settings may also fail to provide an adequate environment for good communication and supportive care (McIlfatrick et al., 2006; von Plessen and Aslaksen, 2005) and may hinder confidential conversations about sensitive issues as some of the nurses in our study expressed. Another explanation may be that patients do not experience a need to discuss psychosocial issues. This was found by Dilworth et al. in a study of patients' support needs in an oncology clinic (Dilworth et al., 2014). The study however also found that patients were not aware of the psychosocial support services available to them (Dilworth et al., 2014), which is a possible reason why patients do not request support regarding these issues. Patients' supportive needs and desire to communicate about their needs are person-specific, and vary depending on the individual cancer trajectory (Botti et al., 2006; Coolbrandt et al., 2016; Thorne et al., 2013). Therefore, communication during treatment needs to be adapted to the individual's specific and changing needs. Although there may be patients who do not experience a need to address the psychosocial issues of cancer and treatment, our study suggests a need to improve the conditions for communicating about and addressing psychosocial needs. If the conditions are not improved, patients must find other ways of dealing with such needs outside the context of the hospital (McKenzie et al., 2011). Moreover, this is an important opportunity for HCP to apply their highly specialized knowledge to help and support patients with psychosocial needs.

The verbal and nonverbal communication in the clinic was also characterised by its efficient form in which the nurses tried to optimize the time available with the patient. This efficiency and level of activity made the clinic appear busy, but nevertheless, patients appeared unfazed as they quickly learned the clinics' routines. However, Chan et al. found patients' experiences of nurses' busyness and multitasked communication to be counterproductive to good communication (Chan et al., 2018). In fact, some patients have even described receiving outpatient chemotherapy as de-humanizing, and even compared it to visiting a fast-food restaurant (McIlfatrick et al., 2007). Although our study did not inquire into patients' experience of the communication practice, these findings indicate the potential drawbacks of efficiency of the outpatient clinic. The observed communication was also characterized by its briefness and implied meaning. This may have consequences for the patients' ability to cope as it can lead to misunderstandings and hamper the flow of information that patients need. Although communication was predominantly brief, we also observed variations where nurses took time for longer conversations, as during the patients ‘first chemotherapy session or when patients showed signs of distress. In these situations, the nurse responded to patients’ reactions and attempted to overcome some of the barriers created by the spatially bound challenges in the outpatient clinic. This indicates that nurses adjusted their communication to the individual patient and situation, which is important to meet the needs of patients and to ensure effective care (Coolbrandt et al., 2016). The brief and implied communication may indicate that the nurses delivered effective care by utilising time efficiently and communicating complex information in a brief manner to convey as much meaning as possible in the constrained setting.

This study found that the outpatient setting influenced the content and form of the communication. Lack of privacy can hamper conversations about existential, psychosocial and sexual issues, an issue that has been found in other oncology outpatient clinics (Coolbrandt et al., 2016). Furthermore, another study found that patients hospitalized in a single room asked more questions compared to patients in four-bedded rooms, arguing that smaller rooms create a positive impact on HCP-patient communication (van de Glind et al., 2008).

Outpatient clinics are a cost-effective way of organizing treatment, often enabling patients to maintain a normal everyday life. However, our study showed that outpatient treatment poses certain communicative challenges that may hinder the support of patients' care needs, especially needs regarding the psychosocial, existential and sexual dimensions of cancer and treatment. Furthermore, our study emphasised the relevance of attending to HCPs nonverbal communication and the symbolic meaning communicated to patients. This communication may support or discourage patients’ willingness to share certain concerns and thus influence the support they have access to in the clinic. It is central that improvements of communication in oncological outpatient clinical settings not only include verbal and written information, but also attend to the nonverbal communication.

5.1. Methodological considerations

As this study focused on the communication between nurses and patients during chemotherapy, we do not know whether the patients had discussed psychosocial needs with the HCPs in other encounters or if patients in fact, have unmet needs based on observations alone. Yet, our observations provided insight into nurse-patient communication and the supportive practices in the outpatient setting in general regardless of, e.g. gender, tumour site, treatment and duration of treatment. Our findings correspond with other studies focusing on oncology outpatient clinics, but also developed new insight into what characterises the communication practice within this context. The SI perspective emphasised the importance of being aware of how HCPs communicate through their non-verbal actions as this influences which subjects the patients bring up in their conversation with the nurses and thus influence the support the patients are offered in the clinic.

Researcher triangulation at several stages (data generation, analysis and writing process) amplified the validity of the study. However, transferability would have been strengthened if we had conducted the study at multiple outpatient sites and included adhoc interviews with patients during the observations.

6. Conclusion

The findings in this study show that communication in an outpatient oncology clinic is characterized by its treatment-centred content and effective form. Other important aspects of cancer care, such as the patients' existential, psychosocial and sexual concerns are rarely explored and expressed in the communication between patients and nurses in this setting. Our study demonstrated both the general communicative challenges in the outpatient clinic and how nurses work creatively within the constraints of the setting to address patients' individual needs. Nevertheless, there is still a need to make environmental adjustments that can facilitate the opportunity for patients to express their needs and for nurses to respond to them. Moreover, there is a need to find methods to identify the patients' supportive care needs in an outpatient setting so that these needs can be met either in the clinic or in alternative settings, such as community services, general practitioner, or cancer rehabilitation centers. This will ensure that a broader range of supportive care needs are addressed and managed when patients are treated in oncology outpatient clinics.

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PAPER III

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Patients' Experience of Communication During Their Course of Treatment in an Oncology Outpatient Clinic

Qualitative Study

KEYWORDS
Ambulatory care
Cancer care
Communication
Interpretive description
Outpatient clinic
Patient–healthcare professional interaction
Patient-nurse interaction
Symbolic interactionism

Background: Communication between patients and healthcare professionals becomes increasingly important as patients with cancer are primarily treated in outpatient settings, where the time to communicate is brief. There is a need to understand patients' experiences of communication to ensure person-centered communication during treatment. **Objective:** The aim of this study was to explore how patients experience communication with healthcare professionals during their course of treatment in an oncology outpatient clinic to elucidate how their needs for support are met. **Methods:** Data were generated through semistructured qualitative interviews in patients with cancer who received treatment in an oncology outpatient clinic (n = 18). Interpretive description methodology and symbolic interactionism inspired the analytical approach. **Results:** Three overarching communication categories were generated, namely, verbal practices, relational practices, and nonverbal practices, which reflect distinct characteristics and the quality of the communication. Communication was characterized as being informative, cheerful, and routinized, which the patients found supportive and, contrarily, superficial, task focused, lacking continuity in care, and missing existential dimensions. **Conclusion:** The communication practice in the oncology outpatient clinic especially supported patients in managing their treatment and side effects. However, psychological, social, and existential concerns were rarely addressed, requiring the patient to self-manage these issues in everyday life while living with cancer. **Implications for Practice:** Patients are socialized by verbal and nonverbal

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communication practices in the outpatient clinic, which influences their expectations of what to talk about during their treatment. Methods are needed to support person-centered communication in outpatient settings, so patient care needs are met more broadly.

Communication between patients and healthcare professionals (HCPs) becomes increasingly important as adult patients with cancer are primarily treated in outpatient settings,[1] where the amount of time available to communicate is often brief.[2–4] Brief encounters and time constraints are barriers to supportive communication in cancer care, just as a lack of time challenges HCPs in communicating empathically.[5] In addition, patients indicate that a shortage of time hinders them in sharing their concerns with HCPs.[2,6] Communication is supportive when it informs, guides, and helps patients to live with the disease and manage the treatment.[7–9] The quality of communication affects clinical outcomes[10–12] and has an impact on the quality of life of patients with cancer,[11] reduces anxiety,[10] and helps patients to feel confident about their treatment.[13] Furthermore, communication plays an important role in supporting how patients manage psychosocial and existential concerns that are common due to the possibly life-threatening nature of cancer.[14] Although it is well established that supportive communication is crucial to support the needs of patients with cancer, studies show that patients have unmet needs, for example, management of side effects[15] and psychosocial and existential concerns.[1,16]

Communication in a clinical context has been defined as a dynamic, interpersonal process in which patients and HCPs "exchange information that mutually influences attitudes, behaviors, and relationships" regarding treatment and care, where HCPs and patients "interpret one another's verbal and nonverbal, explicit and implicit, obvious and subtle interactional behavior."[17(p49)] Although clinical communication is defined as a mutual process, the role of the patient in communication has been explored to a lesser extent.[6,18–20] There is a lack of research on patient perspectives on communication in general[18] and in outpatient clinics,[19] which are central to identifying the topics they prefer to discuss[21] to allow the provision of person-centered communication.

Despite the well-established significance of communication between patients and HCPs, studies show that improvements are still needed[22] to ensure person-centered care and adequate time to support patient concerns when undergoing cancer treatment.[3] From the patient perspective, there is a lack of knowledge on communication when encounters take place in an oncology outpatient setting.[19,22] Patient perspectives are important in identifying the central and complex needs of patients with cancer[3,23] to point to potential areas for improvement. The aim of this study was to explore how patients experience communication with HCPs during their course of treatment in an oncology outpatient clinic to elucidate how their needs for support were met.

■ Methods

Study Design and Methodology

This qualitative study used individual semistructured interviews to explore patient perspectives in depth. The study methodology was guided by interpretive description, a qualitative inductive approach that draws upon established qualitative research techniques and that was developed to explore clinical problems arising from practice disciplines and to generate knowledge in the applied practice context.[24]

Setting and Participants

This study was carried out at a public university hospital in Copenhagen, Denmark. The Danish healthcare system is tax-funded and based upon free and equal access to public healthcare.[25] In total, 40 796 new cancer cases were registered in Denmark in 2018.[26] The oncological unit at the hospital comprised an inpatient ward and 4 outpatient clinics. Patients visit the outpatient clinics for follow-up with a physician and to receive oncology treatment administered by nurses. Individual interviews (n = 18) were carried out in March and April 2016 at one of the oncology outpatient clinics, which provides medical cancer treatment for approximately 24 patients daily. Nurses administer treatment to 4 to 5 patients daily that lasts 30 minutes to 6 hours, and they also perform other nursing duties, for example, blood transfusions. In accordance with the study aim, patient-HCP communication was the primary focus, well knowing that caregivers also play a key communicative role in patients managing their disease. The outpatient clinic treats adult patients older than 18 years with various cancer diagnoses: gynecological cancer, melanoma, and kidney, bladder, or prostate cancer treated with intravenous chemotherapy or immunotherapy (Table 1). Purposive sampling was carried out by the primary investigator, A.P., who has a background as an oncology nurse, and a nurse who had in-depth clinical knowledge from the outpatient clinic who helped maximize sample variation.[24] We sought to gain insight into patients' experience across diagnostic groups, age, and sex to capture a diversity of perspectives.[24] This resulted in a balanced sample in terms of diagnosis and sex, ensuring that the various types of patients treated at the clinic were represented in the study. Inclusion criteria were as follows: (1) recipient of a minimum of 2 cycles of chemotherapy or immunotherapy, (2) conversant in the Danish language, and (3) willing to share their experiences. All 18 participants, comprising 8 women with a mean age of 55 years and 8 men with a mean age of 66 years, were ethnic Danes. Three patients declined participation because of a lack of energy.

As the purpose of this study was to provide knowledge about communication practices in an outpatient clinic and how patients experienced this, patients experience of their communication with both nurses and physicians was examined. Unless otherwise indicated, HCP refers to nurses and physicians. Cancer care was provided by teams, and patients with cancer received support from nurses and physicians during treatment. Furthermore, the communication was often complementary,[27] making it difficult for patients to distinguish between who communicated

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Table 1 • Characteristics of Participants

Participants	Sex	Age Group (1–5)	Cancer Diagnosis	Treatment
Ellen	Female	1	Gynecological	Chemotherapy
Rie	Female	1	Gynecological	Chemotherapy
Charlotte	Female	2	Gynecological	Chemotherapy
Heidi	Female	3	Gynecological	Chemotherapy
Pernille	Female	3	Gynecological	Chemotherapy
Susanne	Female	4	Gynecological	Chemotherapy
Vibeke	Female	4	Melanoma	Immunotherapy
Ingelise	Female	5	Bladder	Chemotherapy
Grethe	Female	5	Melanoma	Immunotherapy
Rene	Male	2	Melanoma	Immunotherapy
Henning	Male	4	Prostate	Chemotherapy
Michael	Male	4	Prostate	Chemotherapy
Bjarne	Male	4	Bladder	Chemotherapy
Klaus	Male	4	Bladder	Chemotherapy
Lars	Male	4	Bladder	Chemotherapy
Mogens	Male	4	Melanoma	Immunotherapy
Jens	Male	5	Melanoma	Immunotherapy
Børge	Male	5	Prostate	Chemotherapy

Age groups 1–5: 1, 30–39 years; 2, 40–49 years; 3, 50–59 years; 4, 60–69 years; 5, 70–80 years.

what. However, patients most often talked about the communication they had with nurses during treatment. There were male and female HCPs, aged 39 to 62 years and with less than 1 to 20 years of oncology experience, working in the outpatient clinic, although all the nurses were women.

Recruitment and Data Generation Procedures

Patients were contacted by A.P. in the outpatient clinic and provided with oral and written information on the purpose of the study, anonymity, and the voluntary nature of participation. Furthermore, it was stressed that participation/nonparticipation would not influence the care and treatment they received in the clinic. Written informed consent was obtained from each study participant.

A semistructured interview guide was developed jointly by A.P., K.H.P., and M.J. based on the study aim, the literature,[19] and a previous observational study of the communication practice between nurses and patients during treatment in an outpatient setting.[2] The interview guide focused on exploring patient experiences and expectations toward communication with the HCPs (eg, "Can you please give me some examples of what you typically talk to the physicians and nurses about?") as well as their support needs and how they managed the physical, psychosocial, and existential consequences of the cancer disease and treatment (eg, "Can you please describe how you manage daily life, your illness and treatment?"), in addition to how they experienced being treated in an outpatient setting (eg, "How do you experience receiving your treatment here at the outpatient clinic?").

Patients were individually interviewed in the outpatient clinic and typically during their next outpatient visit to give them time to consider participating after receiving the information about the study. For the patient's convenience, the interviews took place in a private room near the outpatient clinic. Three patients chose to have a relative present during the interview. Inclusion of patients stopped after 18 interviews because we had identified both patterns and variations in data.[24] A.P. conducted the interviews, which lasted 46 minutes (29-67 minutes) on average. The interviews were audio recorded and transcribed verbatim. A professional translator translated all quotes in collaboration with the native Danish and English-speaking author. Finally, the study was carried out in accordance with the Helsinki Declaration[28] and approved by the Research Ethics Committee of the Capital Region of Denmark (no. H-4-2014-FSP) and the Danish Data Protection Agency (no. 2018-521-0054).

Data Analysis

In accordance with interpretive description methodology, the data analysis was inductively driven.[24] NVivo qualitative data analysis software was used to organize and manage the data to support a systematic, transparent analysis. The first step was to become familiar with the data by listening to the interviews and repeatedly reading the transcripts. Data were broad-based coded and based on the study aim, with initial codes identified for each interview and then across interviews. These initial codes were then validated in a process of rereading the entire transcript according to the initial codes, a repeated coding and recoding taking place until consistent themes were achieved, and generalized patterns and variations identified. Finally, the key insights were divided into overarching categories and underlying themes addressing the research question. Symbolic interactionism inspired the analysis of patient experiences of communication, including the symbolic meaning of both verbal and nonverbal aspects of communication, such as behaviors, activities, and mutual interactions.[29] All of the study's authors contributed to the analysis at different stages to ensure credibility.[24] A.P., K.H.P., and M.J. contributed to each stage of the analysis, and D.L.N. provided clinical perspective on the data, which ensured clinical foundation and relevance.

■ Results

Patient perspectives on communication in the oncology outpatient clinic during treatment were divided into 3 overarching communication categories, namely, verbal, relational, and nonverbal practices, with underlying themes. The themes reflect distinct characteristics and the quality of the communication (Table 2) and capture the complexity within each of the 3 categories. Although people simultaneously communicate verbally and nonverbally, separating verbal and nonverbal communication is an analytical distinction that serves to illustrate when communication is primarily verbal (category 1) or primarily nonverbal (category 3).

Category 1: Verbal Practices

This category, which reflects the topics that patients experienced as predominant in the conversations and topics that they felt were left out during conversations, is divided into the 3 themes presented next.

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THEME: INFORMATIVE COMMUNICATION

The patients' primary associations with communication regarded information about treatment and side effects, aspects that were part of every encounter with the nurses in the clinic. Being well-informed about side effects created a sense of security for the patients:

> […] The first time the nurse definitely helped to reassure me. […] she [nurse] went through everything in detail. And she listed a whole load of possible side effects, which sounded worrying, but the way she did it was very good […] It was especially important the first time because I was feeling very uneasy about the whole situation. (Klaus)

Extensive information and detailed explanations about treatment and side effects reduced feelings of uncertainty. Patients mentioned that they had a greater need for information about treatment and side effects when they began treatment and

Table 2 • Communication Categories and Themes

Communication Categories	Themes	Additional Patient Quotes
Verbal practices	• Informative communication	“As I say, they [nurses] are good at letting me know about my medicine. Which medicine I should take and all that, right?” (Heidi) “We do not just sit around talking about the weather for ages. We just focus on what’s relevant to my treatment, and they ask how you are doing that day. And they check that my blood count and other things are okay and, uh, then I'm ready to get my chemo. Then they bring out the cart and everything goes from there.” (Lars)
	• Cheerful banter and superficial chatting	“Yeah, but they [nurses] can take a joke and send one right back at you, you know? […] Sometimes they come in occasionally and we have a little chat about what the weather was like yesterday, right?” (Bjarne) “Well, there's a positive atmosphere, also despite the fact that they are busy sometimes, so I think that they are incredibly pleasant and smile a lot.” (Charlotte) “In that way, what you talk to them about is limited. There's the chat you have while you are waiting, I'd say. […] How are you feeling? And then you just have your blood count, blood pressure and other stuff done.” (Vibeke)
	• Issues absent from conversations	“I've mostly been preoccupied about, well about, the uncertainty […] about how the disease is expected to develop. […] But, you cannot say anything with certainty, but, that's actually what adds to the sense of uncertainty.” (Klaus) “I compartmentalize it [the cancer disease], hide it, and ignore it.” (Grethe) “Both the doctor and I are aware of why we are talking, you see. And it's not because the doctor is dying, but because it is my turn, right?” (Bjarne)
Relational practices	• Continuity in relationships with health professionals	“It's really nice [when the same nurse] has done it before. Not because, they probably cannot remember, but I remember, you know? And you might have something you did not finish talking about.” (Susanne) “I do not mind outpatient treatments, but you do not make any ties with anyone because you see a new physician or nurse every time. It's not, uh, not a relationship with any continuity, there's no one who knows your idiosyncrasies, or what you do in your free time, or who can look at you and tell whether you are having a really bad day.” (Pernille) “But it actually means something, so it would be good if it was the same physician and the same nurse.” A.P.: How are your conversations different? “Well, there's a sense of intimacy. Kind of like you have with friends. The more you see them, the more you trust them. But when you get the impression that you are just a number [...] Then how much you are willing to open up is limited.” (Mogens)
Nonverbal practices	• Routine	“And the treatments run the same way every time. I get a needle inserted and then I just wait, you know?” (Bjarne) “I think that they are very competent and that they, uh, for the most part, all do things in the same way. And this makes you think that it's the right way; there's nothing that sticks out.” (Ellen) “They [nurses] do it [administer the treatment] according to the same procedure.” (Charlotte)
	• Instrumental focus	“They [nurses] come in with a bunch of paraphernalia plus chemo, plus salt water, plus all those tubes, and I do not know what else. So, what actually happens is that the nurse rigs all this up. And while that happens, you also have the opportunity to have a talk. […] the last time [I received me treatment], maybe it illustrates it a bit, and maybe there was actually more weight put on connecting the tubes and so on, than the conversation she was focusing on, you see?” (Klaus) “That's obviously why it feels a bit mechanical when you are sitting out there [in the treatment room].” (Mogens)

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emphasized that their information needs changed during treatment. Although informative communication was primarily perceived as supportive, patients also said that the information could be perceived as impersonal because of its general nature, instead of being based on the individual patients' situation.

THEME: CHEERFUL BANTER AND SUPERFICIAL CHATTING

The patients explained that the HCPs met them with a positive, friendly, and energetic attitude, which they experienced as reassuring and instilling hope. While receiving treatment, this type of communication was particularly reflected in their interactions with the nurses: "They [the nurses] are quite cheery [...] of course, it's a serious illness. But you just have to live with it and make the best of it" (Susanne). The patients valued the nurses' positive attitude during the treatment because it helped them maintain hope about managing their life-threatening disease.

The patients said that the HCPs created a positive atmosphere in the clinic, for example, by talking in a light-hearted, cheerful tone while carrying out their clinical work. Although the patients valued this type of communication, some patients experienced it as superficial: "[In the treatment situation the nurses] actually mostly come up with some things that you need to know when you are on your way out the door" (Vibeke). Mogens explained: "Generally, I would say they [nurses and physicians] keep up a cheerful banter. It tends to be superficial chatting, but I can understand that. I mean, they have to get through each day too. [...] I mean, both the nurses and the doctors experience most of, or many of, their patients dying." This last quote also illustrates how patients show an understanding of what the HCPs experience by justifying the superficial communication.

In summary, the communication style was thus experienced by the patients as encouraging, inspiring hope, and raising spirits but also, to a certain degree, superficial and camouflaging the seriousness of the situation.

THEME: ISSUES ABSENT FROM CONVERSATIONS

Some patients felt that conversations with the HCP rarely addressed existential issues such as survival, loneliness, and uncertainty about how the disease would develop over time and about death. This meant that their need to talk about difficult issues that they also found hard to discuss with relatives and friends was unmet.

> When you are sitting opposite your doctor and you have a life-threatening disease, you want to ask them: When do you expect that I'll die? Because I have a family to look after, who'll carry on living after I'm gone. There's a whole load of financial stuff. And what about the time up to when I die? You know, those kinds of questions [...] they are racing round your head. You cannot help it. What about my kids? [...] Who can I talk to? There is not really anyone I can talk to. When I start to talk to people [others around him], I notice them shifting the conversation to another topic, and I understand that [...] ultimately, when all's said and done, you are on your own when you die. Those are the kind of things you start to think about when you get the diagnosis. You never have thoughts like that otherwise. When I die, I'll be completely on my own. (Mogens)

> Michael explained that "the bottom line is of course whether the chemo will help. It's on your mind [...] and the uncertainty about how things will develop... life expectancy with this is presumably limited. So, it takes over your thoughts," adding that, when asked, he had not considered sharing these thoughts with the HCP.

> Most patients mentioned that they had thoughts about death and other existential issues but that these concerns were rarely part of their conversations with the HCPs, although some patients wished to share these concerns with the HCPs. One of the patients said that he had learned which kinds of questions to raise and which ones to suppress or leave out—Henning: "[...] I think they are good at explaining, and I've also got better at knowing what to ask [Henning laughs]. Okay, you are not supposed to ask how long do I have, because no-one can answer that, right?"

Through interactions with the HCPs, patients learned what the typical communication practice in the clinic entailed, for example, the commonly acceptable content of communication and which issues to avoid.

Category 2: Relational Practices

This category, which reflects how patients experienced the quality of the relationships with HCPs and how it influenced communication, contains 1 theme:

THEME: CONTINUITY IN RELATIONSHIPS WITH HCPS

In general, patients expressed that continuity in their contact with the HCPs was an important aspect of supportive communication. Being treated by the same nurse or seeing the same physician created a sense of togetherness, confidentiality, and continuity in conversations:

> [...] I'd feel more reassured; it would feel more personal [...] Because it's like you have to start all over again every time you need to talk [to a new HCP]. Ideally you would have the same person [HCP] [...]. I think, I would open up more. You know, also talk about other things, sometimes it's all about the illness and nothing else. (Pernille)

The continuity of care that arises when encountering the same HCP positively influenced the topics, content, and depth of the conversations in the outpatient clinic. Furthermore, it gave the patients a sense of being met as individuals. A lack of continuity, in contrast, was described as "feeling like just another number" (Charlotte).

Overall, the patients described their relationships with the HCPs as professional and kind. Some patients experienced their contact as superficial if the HCPs only had limited knowledge about them as individuals. In addition, time constraints hindered the exchange of personal stories:

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> "Well, it's not like, you know, we are sitting there and having a friendly chat and a good laugh. There's no time for that, and it's not like we know each other well. [...] They [nurses] know your name and that's about it" (Lars).

Several patients expressed a need for support that was related not only to the cancer treatment but also to how the disease affected their daily lives. These patients expressed a wish for more personal conversations and the opportunity to discuss individual issues. In addition, encounters with many different HCPs meant that conversations "had to start from scratch" (Klaus) and lacked follow-up and continuity, which made the communication ineffective.

Category 3: Nonverbal Practices

This category, which reflects what patients experienced concerning nonverbal practices in the outpatient clinic, contains 2 themes that reflect patient interpretations of the communication practices, that is, what the practices convey to the patients. It also describes how patients thought the nonverbal practices affected communication.

THEME: ROUTINES

The patients said that the clinical routines they experienced during treatment gave them a sense of continuity and promoted a feeling of security:

> Henning: [...] It feels reassuring when it looks like things are being done properly each time. That matters to me more than some of the other things.
>
> A.P.: It does not matter if it's the same person [nurse]?
>
> Henning: No, because they all do the same thing. I can see that. It's the same procedure; it's been pre-arranged. That's why I'm saying I can see that everyone's getting treatment in the same way. The same is true for me.

Continuity in the nurses' nonverbal actions was emphasized as even more important than relational continuity. The similarity of the nurses' actions was interpreted as professional and correct, which gave the patients a sense of security: "It feels very much like there's a lot of continuity in the way they work [the nurses] [...] you get the impression it's right; nothing sticks out as different. It seems very professional" (Ellen).

Patients gradually became familiar with the clinical routines and found reassurance in the continuity that was created. These clinical routines were also learned by observing how fellow patients received treatment: "They are professional [the nurses]. They know exactly what they are doing. And you can see that in the way they are with other patients, you know? [...] It's the same, the same pattern, right?" (Børge).

THEME: INSTRUMENTAL FOCUS

Although patients found the clinical routines reassuring, they were also critical toward the nurses' primary focus on clinical tasks, such as inserting intravenous catheters or administering chemotherapy. Some of the patients described the routines as mechanical—"Here's your arm, let us stick this in [IV catheter]" (Mogens), or Klaus explained: "It's really just about sitting there and getting fuelled up."

Patients expected the treatment situation to serve as an opportunity to have a conversation with the nurse, but because of the limited amount of time available, patients experienced that their need to talk was secondary to starting up the treatment. The patients said that the content of the communication during treatment was basically the same each time. This standardized communication was experienced not only as both professional and reassuring but also as distancing and mechanical. The experience of "getting fuelled up" illustrates that patients see themselves as a receptacle, a passive participant in the communication practice. However, most patients did not question or express dissatisfaction with their own role in the communication with the HCPs. Within the analytical perspective of symbolic interactionism, this can be interpreted as patients having learned to take on certain roles and behavior in the outpatient clinic through communication with the HCPs, interpreting the roles as an expected communication form, which they accepted, mirrored, and reproduced.

In summary, communication practice was perceived as changing during the course of their treatment trajectory. At the start of treatment, patients were provided with a great deal of treatment-related information and an opportunity to discuss more personal issues. However, communication was limited by time constraints and became more treatment-focused during the treatment trajectory, which some experienced as impersonal and made them feel like objects. For other patients, this overall development in the communication was perceived as sufficient. Those with existential concerns described feelings of depersonalization and loneliness, often feeling discouraged from seeking support from the HCPs about these concerns.

■ Discussion

This study explores how patients experience communication with HCPs to describe how their needs for support are met during their course of treatment in an oncology outpatient clinic. Our results show that patients appreciate the treatment-oriented communication they received from the HCPs, because it helped them to cope with side effects and reassured them during treatment. Although we have limited knowledge about the patients' points of view when it comes to receiving outpatient chemotherapy,[19,22] studies show that this informative type of communication is essential in a cancer care context, because it supports the patients in managing their illness and treatment at home.[7,9] Strikingly, however, most of the patients in our study did not expect the communication to be about anything other than treatment-related issues. The literature indicates, however, that cancer patients also require psychosocial support.[30,31] Several studies show that the patients lack psychoemotional support,[32,33] both in outpatient clinics[1–3] and during hospitalization.[34] Our study revealed that, although all the patients said they had thoughts and worried about death and other existential issues, these topics were absent from their communication with the HCPs. These worries were neither verbalized by the patients nor enquired about by the

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HCPs, just as very few patients considered sharing these kinds of thoughts with an HCP.

Various possible explanations exist as to why the patients did not share their worries with the HCPs. A systematic review investigating barriers to identifying the psychosocial needs of cancer patients found that one reason was that the patients did not see themselves as requiring psychosocial support.[30] At the same time, however, the study found that the patients did not feel that psychosocial care was a part of the routine care when interacting with the HCPs, besides the fact that the patients were also not aware of what psychosocial support was available.[30] Because people often find themselves in a new life situation when given a diagnosis of cancer, it can be difficult to gauge what they need.[14,35] Jones et al[14] found that, when HCPs enquire about the social and emotional needs of patients during cancer treatment, it can help them to clarify and legitimize these needs. Another explanation is that the patients observe that the HCPs are busy and consequently do not expect them to have time for that type of support.[6] An overly positive and upbeat style of communication, which they experienced between HCPs and patients, may also be a hindrance to identification of the patients' psychosocial needs. Despite that many patients valued this kind of communication because it helped them remain hopeful during their treatment for a potentially life-threatening disease, it can also be an impediment to discussing issues of a more grave psychosocial nature. In addition, this type of communication can be experienced as superficial and impersonal, which was an issue several patients mentioned. However, HCPs may also use small talk as a deliberate communication strategy to enquire discretely about the patients' needs[36] and without patients necessarily being aware of this purpose. Finally, another possible explanation as to why the patients do not verbalize their psychosocial needs is that they learn through their communication with the HCPs what constitutes the norm for the content of conversations in the outpatient setting. Because the patients are socialized to the specific communicative practice, the lack of communication on, say, existential issues cannot necessarily be interpreted as an expression of a lack of need. However, if patients' existential and psychosocial requirements are not being identified when they meet the HCPs, this means that they are left to their own devices to cope on their own and to seek support outside the outpatient clinic. This can create inequality, because not all patients are equally resourceful in seeking support.[37] Research shows that various patient-centered methods can help patients articulate their psychosocial concerns, promoting their identification through their communication with the HCPs[14,35,38]; for example, supportive screening tools, such as the needs evaluation questionnaire,[1] can encourage patients with cancer to reflect on their supportive needs, facilitating discussion with the HCP about these concerns.[14] Training both HCPs and patients to communicate has proven effective in patient-centered communication.[39,40] McCormack et al[35] found that formalized person-centered communication improves provision of psychosocial and emotional aspects of care and can be integrated into the everyday norm of the oncology outpatient clinic.

The patients expressed contradictory views about the importance of meeting the same HCP each time. Research shows that the patients' relationship with the HCPs during cancer treatment is important for reassuring them[41] and improving how they manage their illness,[12,19,35] which findings in other specialist fields corroborate.[42] Similarly, research shows that patient experiences of their relationships with HCPs are linked to their level of satisfaction with their care,[19,43] because the relationship between patients and the HCPs is seen as a fundamental aspect of communicating.[11,18] It is therefore surprising that many of the patients were not more critical about the lack of continuity they experienced. This could possibly be explained by the fact that their communication predominantly consisted of general information about treatment and side effects rather than personal subjects, which means it is most likely less important who administers the treatment. Studies show that treatment-oriented communication can impede relational aspects in the encounter between patient and HCP.[6,44,45] Unsurprisingly, our study found that the communication was formed by relational practices, that is, the relationship influenced what was talked about and how. When only a short amount of time is available to communicate with the individual patient,[19,22] however, the communication becomes ineffective if patients feel they have to start all over again every time they have a conversation with an HCP. This can also obstruct patient-centered care because the HCP is unfamiliar with the patient's values and preferences in advance.

One central finding in our study was that continuity in the clinical routines fostered a sense of security among the patients, in that the various HCPs carried out the same activities similarly. The patients were thus reassured through both the provision of information (verbal) and the activities performed by the HCPs (nonverbal). Our study also indicated that the patients were socialized into the communicative practice in the outpatient clinic through their verbal and nonverbal communication with the HCPs and through observation of other nurse-patient interactions. Strikingly, the patients placed more emphasis on continuity in the actions of the nurses when they received treatment than on continuity in relationships, but perhaps, the routine activities of the nurses compensated for the lack of personal continuity, making the patients feel comfortable and secure with the treatment. An umbrella review[42] found that patients feel reassured by, for example, the clinical and technical competence of the nurses, because their expertise makes them feel that they can trust the relationship. According to the US National Cancer Institute at the National Institutes of Health in the United States, trust in the technical skills and qualifications of HCPs is seen as a central element in fostering relationships.[11] However, another study confirms our findings that the interactions between patients and nurses in medication activities occur primarily based on routines rather than on individual assessment tailored to what is important to the patient.[46]

In general, interventions targeting the improvement of HCP communication skills mainly often focus on their verbal communication,[20,47] which is why our finding on the significance of nonverbal communication is so important. It is essential that HCPs increase their awareness of how they interact and act, because patients also interpret meaning and actions based on the symbolic significance of the nonverbal communication of HCPs. This is significant because it means that the content of conversation can be encouraged or discouraged through nonverbal

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communication, which may have implications for which needs are identified in conversations. An increased focus on the nonverbal communication of nurses in the treatment situation is imperative because research indicates that much communication in an oncology outpatient setting is brief and implied, increasing the risk of patients not receiving necessary information.[2]

Our study showed that the communication could be depicted as standardized, because it takes place in more or less the same way each time. Patients saw this as professional and reassuring but, on the other hand, also perceived it, at times, as mechanical and impersonal. Because the communication was standardized, it was less individually based. It is well documented, however, that a person-centered approach is a central aspect of quality cancer care.[11,48] Furthermore, political rhetoric in the health service talks of the patient being at the center,[25] of patient-centered care[35] and of greater patient involvement.[25,49] For example, Epstein and Street[48] pointed out that HCPs should encourage patients to be more active in their communication. Our study, however, found that this did not translate into practice and that there is a risk that the HCPs will render the patients passive through their communication because it was primarily the HCPs and clinical routines that determined the focus of the conversation. Accordingly, a patient-centered communication approach is fundamental to achieving patient-centered care, which also involves addressing the patient's perspectives in communication and means that the HCPs must gain an understanding of the individual patient's psychosocial context.[35]

Standardized and treatment-oriented communication, which we and other studies have shown to be characteristic of communication in outpatient meetings,[2,45,50] should not be interpreted as an unwillingness among the HCPs to provide person-centered care. On the contrary, McIlfatrick et al[45] described how nurses are unhappy about having to use most of the time they spend with the patients in an oncology outpatient clinic on administering chemotherapy, because it is at the expense of caring for the patients as a whole and seeing their individual needs. Moreover, the environmental conditions of the clinic provide difficult conditions for enabling HCPs to deliver person-centered care. Research shows that a productivity-oriented work environment can be a barrier to patient-centered communication.[39] There is a need to adjust the physical environment in outpatient clinics to facilitate patients in expressing their needs and for nurses to respond to them. These adjustments require both political action and local management. In Denmark, the health authorities have recently recommended rehabilitation conversations ("identification" and assessment of "rehabilitation needs" in patients with cancer)[49] as a way to meet the ideal of person-centered care.

We need to initiate methods to promote person-centered communication in outpatient settings based on the specific conditions—possibilities and limits—that exist. Studies suggest that implementation of a communication framework can enable person-centered communication during nursing care in outpatient settings.[51] In a pilot study, Epstein et al[27] found that structured "value" discussions facilitated by nurses in the daily routine at an oncological outpatient clinic were experienced as helpful by patients as well as feasible for nurses to incorporate in a busy workflow. Öhlén et al[51] observed that a person-centered practice model for communication that systematically focused on patient concerns and values had a positive effect on patients' quality of care. Although these studies had small sample sizes and both pointed to a need for further research, they highlight the significance of establishing a framework to support patient-centered communication in conjunction with providing recommendations for oncology nursing practice.

■ Methodological Considerations

This study has some limitations. First, the study was conducted at 1 hospital, which means the results may not be transferable to other oncology outpatient settings. Second, we must consider that patient experiences and needs may be specific to sex and diagnosis. However, our aim was to generate general knowledge about the phenomenon regardless of specific conditions, such as sex or tumor site, and thus points to some general aspects in the literature regarding communicative practice during treatment in this particular context. Third, the interviews took place at the hospital well knowing that context can influence the dialogue between the interviewer and the patient and, consequently, the knowledge generated.[24] Finally, some patients chose to have a family member present during the interview, which may have limited their narrative out of consideration to the relative; conversely, it might also have made them feel more comfortable in the interview situation. We could not confirm whether or not it was of significance in our analyses, which is why we did not differentiate between the interviews in the presentation of our findings. Despite these limitations, this study provided insight into patient experiences of being treated in an oncology outpatient clinic that can help to identify areas for improving care in this setting. To improve the validity, researcher triangulation was used during the data generation, analysis, and writing process, enhancing study credibility and methodological reflection.[24] For example, the interview transcriptions were reviewed twice by the research team to assess the quality of data generated and to discuss the need to adjust the interview guide. Furthermore, the validity was enhanced because of the researchers' clinical backgrounds: 2 oncology nurses (A.P./M.J.), a physician (D.N.) with a management perspective, and an anthropologist (K.H.P.), who broadened the assessment and confront blind spots.[24]

■ Conclusion

Communicative practice in the outpatient clinic was characterized as being informative, routinized, and encouraging and as having an instrumental focus, which the patients, on one level, experienced as reassuring and professional but, on another, as impersonal, mechanical, and superficial. The patients felt that they received support to cope with their treatment and its side effects. On the other hand, they were left on their own to cope with the psychological, social, and existential consequences of living with cancer. This was despite that all of the patients had thought about death, a topic that was absent from their communication with the HCPs. According to our study, the existential dimensions of cancer treatment require greater attention in the time-constrained and

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standardized environments of outpatient clinics, which is why we recommend initiating additional methods to promote person-centered communication.

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Appendices

Appendix A: Observation guide *

Appendix B: Interview guide (Individual interviews) *

Appendix C: Interview guide (Focus group) *

Appendix D: Description of the ambulatory context *

Appendix E: Co-author declarations

*Appendix in Danish

Appendix A

OBSERVATIONSGUIDE

Sted*:*

Et onkologisk ambulatorium, fokus er på rummene, hvor behandlingen forgår.

Aktører:

Primært patienter og sygeplejersker, men også pårørende og læger

Noter

Deskriptive, metodiske og analytiske

<u>Refleksioner inden pilotdag:</u>

Opmærksomhed på de **aktiviteter** der foregår i ambulatoriet, **herunder handlinger, adfærd, rum, interaktioner** og **tid** (varighed), f.eks.:

- Hvad sker der på onkologisk ambulatorium?
- Typer af aktiviteter?
- Hvordan ser en arbejdsdag ud?
- Beskrivelse af konteksten – forskellige rum
- Interaktionen
    - Hvad tales der om?
    - Hvem tager initiativet?
    - Hvilke handlinger udføres?
    - Hvordan responderer de på hinanden?
    - Forskel på at være ny pt eller genganger, køn, behandlingsform?
    - Inddragelse?
    - Pårørende?
    - Medpatienter?

- Tid?

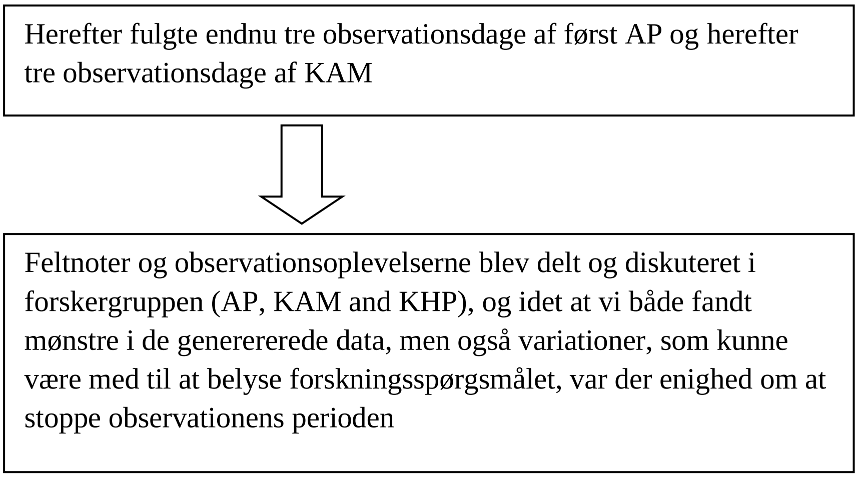
Vores observationsstrategi kan således illustreres som følge:

Indledningsvis blev foretaget 2 observationsdage af hhv. Anne Prip (AP) og Kirsten Alling Møller (KAM). På baggrund af disse blev der udviklet en observationsstrategi i samarbejde med antropolog Kathrine Hoffmann Pii (KHP)

Herefter blev tre observationsdage gennemført af først AP, efterfulgt af tre observationsdag af KAM

Disse observationer blev delt og drøftet blandt AP, KAM and KHP for at genfinde mønstre og variationer i data som kunne belyse forskningsspørgsmålet samt genoverveje observationsstrategi

Appendix A



Herefter fulgte endnu tre observationsdage af først AP og herefter tre observationsdage af KAM

Feltnoter og observationsoplevelserne blev delt og diskuteret i forskergruppen (AP, KAM and KHP), og idet at vi både fandt mønstre i de genererede data, men også variationer, som kunne være med til at belyse forskningsspørgsmålet, var der enighed om at stoppe observationens perioden

Appendix B

Jeg henvender mig til potentielle deltagere i ambulatoriet, hvor jeg kort præsenterer mig og fortæller om årsagen til min henvendelse. Hvis patienten har lyst til at høre mere, informerer jeg om flg.:
MUNDTLIGT SAMTYKKE
***1.* KORT PRÆSENTATION AF MIG OG PROJEKTET.**
2. TIDSHORISONT
3. ANONYMITET:
4. BÅNDOPTAGER:
5. KORT PRÆSENTATION AF INTERVIEWFORMEN:

SKRIFTLIGT SAMTYKKE udleveres til patienterne, så de kan gå hjem og tænke over, om de har lyst til at deltage i undersøgelsen, hvorefter jeg kontakter dem telefonisk og aftaler tid for evt. interview.

Inden selve interviewet gentages formålet med projektet samt pkt. 2-5.

INTERVIEWGUIDE:

TEMATIKKER	**INTERVIEWSPØRGSMÅL**	**HVILKEN VIDEN VIL JEG GERNE GENERERE**
Afdækning af baggrund	**Jeg vil gerne starte med at høre lidt om dig og hvordan dit sygdomsforløb har været, f.eks.:** - Hvornår du blev syg? - Hvor mange behandlinger har du fået i ambulatoriet? - Har du lyst til at fortælle mig lidt om dine familieforhold? (Er du gift? Har du en kæreste? Bor du alene? Har du børn?) - Hvordan er din arbejdssituation lige nu? (Er du i arbejde, sygemeldt, pensioneret eller andet?) - Hvad arbejder du med/har arbejdet med?	Viden om patientens forløb og sociale baggrund *(som kan have betydning for, hvilke behov for støtte man har)* (alder, diagnose og behandlingsforløb søges i journal)
Afdækning af behov og håndtering af og støtte til fysiske, psykiske og sociale følger af	**Hvordan har det været for dig at have fået stillet diagnosen kræft og efterfølgende...?** **Kan du prøve at beskrive, hvordan du klarer hverdagen, sygdommen og behandlingen her, mens du får din kemoterapi?** ***Hjælpe spørgsmål.:*** - har du nogen gener af sygdommen og behandlingen?	Viden om hvilke fysiske, psykiske og sociale følger sygdommen og behandlingen har haft for den enkelte (*som kan pege på, hvilke behov for støtte de har brug for i deres*

sygdom og behandling	- hvis ja: hvordan håndterer du de generne? - oplever du, at de gener, du lever med, forhindrer dig i noget, du gerne vil? - kan du prøve at give nogle eksempler på, hvordan sygdommen påvirker din hverdag og evt. arbejdsliv? - her under dit kemoterapiforløb, har du da oplevet at stå i en situation, hvor du mangler viden om, hvad du skal gøre? *(eksempler)* - hvad gør du i de situationer, hvor du har nogle spørgsmål eller noget, du er i tvivl om? - er der noget du savner/eller har savnet undervejs i dit forløb indtil videre? - hvem støtter dig i dit behandlingsforløb? - har du benyttet nogle støttemuligheder undervejs i dit forløb? (f.eks. i din kommune, patientstøtte foreninger, andet?) **Hvor får du overvejende din information omkring din sygdom og din behandling fra?**	*forløb - og om de oplever at få tilstrækkelig støtte til at håndtere sygdommen)*
At modtage kemoterapi i et ambulatorium	**Har du gjort dig nogle tanker om, hvordan det ville være at skulle behandles i et ambulatorium, inden du startede?** - Har du fået alle dine behandlinger ambulant? **Hvordan oplever du at få din behandling her i ambulatoriet? Hvad skete der f.eks. i dag, da du fik din behandling? Adskiller det sig fra de andre gange?** ***Hjælpe spg:*** - er der noget, du lægger særlig vægt på, som er vigtigt og betydningsfuldt for dig? - noget du vil fremhæve, som har mindre betydning? - hvordan oplever du de fysiske rammer i amb.? - oplever du tilstrækkelig tid til at tale med sygeplejerskerne (spl.) og lægerne om det, du har behov for? - hvis ikke: måske kan du give nogle eksempler på, noget du gerne vil have talt med dem om? - tager behandlingen den tid, som der er planlagt – eller kan der være ventetid på behandlingen? - jeg kunne godt tænke mig at høre lidt om, hvor meget du taler med de andre patienter i ambulatoriet - kan du give eksempler på, hvad du taler med dem om? - har du dine pårørende med, eller kommer du alene?	Afdække forventninger Afdækning af oplevelser og behov i relation til at modtage sin kemoterapeutiske behandling ambulant Afdækning af kontekstens betydning for kommunikation og relationsdannelsen mellem patient og spl./lægen

Appendix B

	- er der noget, du savner her i UG team? - måske du har nogle ideer til noget, der kunne være anderledes?	
Patienternes oplevelser, forventninger og behov til spl./lægen - herunder afdækning kommunikation og relationer mellem patient - spl./lægen	**Inden du startede behandlingen, gjorde du dig nogle tanker om, hvordan det ville være at modtage kemoterapi?** *Hjælpe spg.:* - havde du f.eks. nogle forventninger til behandlingsforløbet - og forventninger til spl. og lægerne? - ved du, hvilken hjælp du gerne vil have/ønsker fra hhv. spl. og lægen? - er der forskel i dine ønsker fra hhv. spl. og lægen? *(eksempler)* **Hvordan vil du beskrive din kommunikation og dit samarbejde med de hhv. sygeplejerskerne og lægerne?** *Hjælpe spg.:* - Hvordan vil du beskrive din relation og dit samarbejde med lægen? - kan du give eksempler på, hvordan du bruger lægerne, og hvad du typisk taler med dem om? - Hvordan vil du beskrive din relation og dit samarbejde med sygeplejersken? - kan du give eksempler på, hvordan du bruger sygeplejerskerne, og hvad du typisk taler med dem om? (er der forskel?) - når du taler med hhv. spl. og lægerne - hvem tager så typisk initiativet til samtale? *(eksempler på hvordan en samtale typisk starter)* - oplever du at kunne tale med spl. og lægen om, lige det, der er vigtigt for lige præcis dig? - eller kan der være noget, der forhindrer det? *(eksempler)* - oplever du f.eks., at du bliver meddraget i beslutninger omkring dig - eller prøv at beskrive hvordan det typisk foregår? - kan der være noget, som kan svært at tale om med hhv. spl. og lægen? *(eksempler - og er der forskel på om det er spl. eller lægen?)* - hvad betyder det for dig, at samtalen med spl. ofte foregår i et åbent rum i ambulatoriet?	Afdække forventninger til spl./læge Generere viden om, hvordan de oplever relationen og kommunikationen mellem pt og HCP/spl. - herunder hvad der kendetegner en god/mindre god relation og kommunikation mellem pt og spl./læge - er det vigtigt og hvorfor? *(hvad skal relationen bruges til)*

	Hvilke tanker fylder, når du går hjem fra behandlingen? - hvad gør du, hvis du kommer i tanker om noget, du ikke fik spurgt om, mens du var i amb.? **Hvordan vil du beskrive dit forhold til de sygeplejersker, der giver dig din kemo behandling?** - Er der noget, der er særligt betydningsfuldt for dig i jeres samarbejde? - Er der noget, du savner? - Har det betydning, hvem det er, der giver dig din behandling? (*Hvordan, hvilken?)* - Er det typisk den samme spl., der giver dig din behandling – har det betydning? **Kan du prøve at beskrive, hvad god kommunikation er for dig?** - kan du komme med eksempler på en "god samtale", du har haft? (*hvad gjorde den god?)* - og måske du også har eksempler på en samtale, som ikke var god? **Hvis du skulle beskrive det ideelle behandlingsforløb – hvordan vil det se så ud?** - Hvordan er det anderledes ift. dit pleje – og behandlingsforløb i dag?	
Debriefing	**Jeg har ikke flere spørgsmål. Det kan være, du har noget, du gerne vil supplere med – noget, jeg måske ikke fik spurgt om, som du synes, er væsentligt?**	

Appendix C

Fokusgruppe interview med specialister onkologisk klinik Herlev vedr. kommunikation

Steps	Spørgsmål	Hjælpespørgsmål
Åbning		
Formålet i dag er at diskutere hvilken betydning kommunikation i ambulant regi har for patienters håndtering af livet med kræft ud fra jeres perspektiv. Vi starter med en introduktionsrunde	Hvad er dit navn og profession og hvilken kontakt og opgaver har du typisk med patienter i dit arbejde?	
Intro		
Til at varme op vil vi gerne bede jer skrive lidt ned inden I deler jeres tanker. Det er med til at få tankerne ind på sporet og kan hjælpe med at huske jeres umiddelbare tanker undervejs i interviewet, så I kan inddrage dem, når det er relevant.	Hvad er god kommunikation for dig i fht din faglige rolle overfor patienten? Skriv en ting ned pr post it Hvad har I skrevet?	Formål Indhold Form Relation Hvad kan god kommunikation medføre af handlinger/adfærd (feedback/outcome) Hvordan vurderer I kvaliteten i god kommunikation?
Overgang		
Nu går vi fra et overordnet perspektiv på kommunikation til mere specifik at tale om kommunikation i jeres daglige arbejde i ambulatoriet? Spørgsmålene er delt ind i tre temaer inspireret af Annes observationer, teorier omkring kommunikation, interview med patienter		

Appendix C

Efter hvert tema vil jeg spørge Anne om hun har supplerende spørgsmål		
Temaer		
1: Kommunikation i ambulatoriet (Observationsstudie)	Er der noget særligt der kendertegner kommunikationen i jeres ambulatorium? Hvilken betydning har disse forhold for patienters håndtering af livet med kræft? Hvordan forholder I jer til det? Kan der være udfordringer? - Og hvad gør I for at imødekomme evt. udfordringer?	**Indhold** (hvad kommunikeres: udpræget medicinsk, symptom, bivirkningsorienteret) **Form** (hvordan kommunikeres) **Fysiske rammer** **Tid** **Kontinuitet** Hvordan forbereder I jer til mødet med patienten?
Annes supplerende spørgsmål		
2: Relationens betydning for patienters håndtering af livet med kræft? (Teori)	Hvilken relation skal der til mellem patient og professionel for at kommunikationen bliver god? Gør I noget særligt for at skabe en relation til patienten? Hvis ikke det er muligt at skabe en relation til patienten, gør I så noget for at skabe en god interaktion? Hvilken betydning tænker I, at relationen har for patienters håndtering af livet med kræft?	
Annes supplerende spørgsmål		
3: Patienters uopfyldte behov (Interview)	<u>Eksistentielle behov</u>	Kan I genkende det? Hvorfor tales der ikke om det?

Appendix C

	Patienter giver udtryk for at de ikke taler med jer om deres eksistentielle behov, fx død, alenehed og seksualitet Mogens fortæller, at han savner at kunne dele tanker og spørgsmål omkring døden med de sundhedsprofessionelle. Han siger bl.a. *Når man så overfor sin læge, og har en livstruende sygdom, så er det hvornår forventer du jeg dør? Fordi, der er en familie der skal forsørges, de skal leve videre bagefter. Der er en masse økonomisk blablabla. Og så er der også det, tiden lige op til jeg dør. Vil, vil jeg være så dårlig, så jeg måske helst vil dø lidt før? Og sådan nogle spørgsmål. […] det har jeg ikke snakket med nogen om, men det kører lidt rundt derinde. […] jeg har ikke kunne snakke med nogen om det. Heller ikke min kone*	Er det jeres ansvar at tale om det? Har I gjort noget for at imødekomme det behov? Er der noget man kunne gøre?
	Hvad tænker I om det?	(Tænker I, at det har betydning for patienternes håndtering?)
	<u>Kontinuitet</u> Patienter taler også om betydningen af kontinuitet Pernille fortæller i interview, at hun gerne vil møde den samme sygeplejerske, når hun skal have behandling (både en forventning hun havde og et ønske hun har). Hun fortæller bl.a. at det ville gøre hende mere tryg og skabe større tillid, og siger i den forbindelse: *"Lige nu så sætter man sig bare på en stol og så ser hvem det er der kommer, ikke?"*	Hvad tænker I om kontinuitet? Hvilken betydning har det for jer? Har man gjort noget for at sikre det? Har I nogle ideer til noget man kunne gøre anderledes? F.eks.: - Lave organisatoriske ændringer? - Klæde patienter bedre på? - Andet?

Appendix C

	Hvad tænker I om det?	
Annes supplerende spørgsmål		
Afrunding		
Vi skal til at opsummere og afrunde.	På baggrund af jeres drøftelser, har I så nogle input til hvordan man kan styrke/forbedre kommunikationen i ambulatoriet jf.? Tema 1: Ambulatoriet Tema 2: Relationen Tema 3: Patienters uopfyldte behov	
	Er der andre ting I ikke har fået sagt og som I tænker er relevant at få med her til sidst omkring kommunikationens betydning for patienters håndtering af livet med kræft?	
Tak		

Appendix D

Beskrivelse af ambulatoriekonteksten

Patienternes gang i ambulatoriet:

Når patienterne kommer til behandling i ambulatoriet, har de typisk været inden dagen før for at få taget blodprøver forud for behandlingen. Nogle patienter får taget blodprøver på lokalt sygehus. Patienterne taler typisk med en læge i forbindelse med ordineringen af behandlingen, enten dagen inden eller på selve dagen for behandlingen. Patienternes tager ophold i venteværelset når de ankommer, hvor de venter sammen med andre patienter på enten at skulle ind til lægen, på at behandlingen bliver klar fra apoteket eller på at der er en sygeplejerske der kan give behandlingen samt at der er en ledig stol i en af behandlingsrummene. Det er ikke ualmindeligt, at der er ventetid på behandlingen, hvorfor sygeplejerskerne nogle gange laver aftaler med patienterne om, at de sammen med deres eventuelle pårørende kan blive ringet op, når behandlingen er klar, hvis de hellere vil vente kantinen eller andet steds.

Sygeplejerskens dag i ambulatoriet:

Sygeplejerskerne arbejdsdag er fra kl. kl. 7:30 – 15:00. Nogle dage er der også senvager (til kl. 18:00), hvilket de skiftes til at have i de forskellig fire ambulatorier, som er på hospitalet. Når sygeplejerskernes arbejdsdag starter kl. 7:30 starter med at fordele dagens patienter og koordinere andre sygeplejerskeopgaver imellem dem.
Samtale med sygeplejerske*: ”Vi siger til patienterne, når de kommer som nye, at dem, de møder ved første samtale, er kontaktpersoner. Lægen er for hele forløbet, og sygeplejerskerne er i forhold til opstart af behandlingen. Sygeplejerskegruppen er delt op i diagnosegrupper, og der tilstræbes, at patienten får en af de sygeplejersker, der tilhører deres diagnosegruppe. Dvs. at hver patient har 5-6 kontaktsygeplejersker”* (feltnote fra observationsdag 6).

Beskrivelse af rum i ambulatoriet:

Når man går ind i ambulatoriet, går man ind i et venteværelse som er ca. 50-60 kvadratmeter, hvor der er plads til ca. 28 patienter og pårørende. Over i det ene hjørne er der en lille skranke, hvor patienterne henvender hos en sekretær, når de ankommer. Tæt ved skranken er opstillet et stativ, som er fyldt med pjecer. Alle pjecer kommer fra Kræftens Bekæmpelse, på nær en enkelt, som er fra en patientforening (netværk for modermærkekræft). Pjecerne indeholder overvejende tilbud den de kræftramte, eksempelvis samtale grupper, ”har du lyst til at sejle kajak”, hvad sker der i rådgivning i Lyngby m.m.

Appendix D

Der er 3 små rum som anvendes til lægekonsultation, herudover består ambulatoriet af; to små stuer med senge til primært akutte patienter eller patienter der har bruge for at være sengeliggende mens de får behandling, en lille stue med 3 behandlingsstole der primært er tiltænkt de patienter der kommer til lange behandlinger samt en stor behandlingsstue med 10 behandlingsstole, som man kan sidde behageligt i og som alle er dækket af et stiklagen. Langt de fleste patienter får behandling på den store behandlingsstue, som er ca. 30-40 m2, og delt op på midten af en lille skillevæg. Udover de 10 behandlingsstole, er der placeret et par almindelige stole i rummet rundt omkring, som kan de pårørende kan sidde på. Ovre i det ene hjørne er ligger en stor bunke blade på et bord, og der er nogle knagerækker, hvor patienter og pårørende kan hænge deres overtøj.
Der er 5 lange ruder i loftet, så der er et stort lysindfald. Rummet fremstår forholdsvist lyst – selvom der ikke er nogle vinduer ud til ”verden”. Der er to store malerier på begge endevægge i ”glade”/varme farver. Der er ikke en dør i rummet, men en stor åben indgang til rummet. Lige ude foran for rummet er en skranke, hvor patienter og pårørende kan henvende sig til en sygeplejerske, og kan man se skranken inden fra rummet fra nogle af stolene. Det kommer til at virke som et meget åbent og ”offentlig” rum.

Eksempel på feltnote fra det store behandlingsrum, hvor de fleste patienter modtog deres behandling:
Nu er der ikke flere ledige behandlingsstole på nogen af stuerne. Spl. C går rundt og forsøger at finde ud af, om der er nogen patient som er ved at være færdige med behandlingen. Det er der – en herre i det ene hjørne – som er inden til sin 3 behandling. Han begynder af egen hånd at pakke sammen, og signalere at han er helt med (som på en restaurant, hvor der står kunder og venter på et ledigt bord?)
Sygeplejersken begynder at gøre klar nede i hjørnet, men i mellemtiden har en anden sygeplejerske allerede hentet sin nye patient, og de går mod den tomme hjørnestol. Spl. C stopper dem ”Den har jeg reserveret”, jeg har en patient, der har ventet i 20 minutter på en plads nu”. De to sygeplejersker og den nye patient står midt på den store behandlingsstue mens sygeplejerskerne drøfter hvordan problemet kan løses. En tredje sygeplejerske finder en løsning og flytter resolut om på nogle stole, så der bliver plads til alle. (alle patienter, pårørende og sygeplejersker på stuen bliver involveret og både andre sygeplejersker og en enkelt pårørende involverer sig i løsningen på problemet.)
(Observation day 7)

Appendix D

Et eksempel på en feltnote som skildrer en behandlingssituation:

Sygeplejersken henter Eva i ventenværelset, og spørger hende på vejen ned af gangen til behandlingsrummet; "hvordan hun har klaret sidste behandling". Eva svarer kort, hvorefter de sammen ind i det store behandlingsrum. Det er en høj aktivitet i rummet, hvor alle stole på nær Evas er besat af patienter som i gang med deres behandling, og en enkelt vente på at blive sat i gang. Sygeplejersken siger "jeg havde tænkt mig, at du skulle sidde her". Eva sætter sig ned ved siden af en mand, som er i gang at få behandling. Han sidder hjemvant i stolen og læser en bog. På den anden side af Eva sidder en kvinde, som har taget sin datter med til behandling. Eva sætter sig til rette i stolen, rækker begge arme ud til sygeplejersken, og siger henvendt til sygeplejersken: "hvilken hånd vil du have". Sygeplejersken inspicerer Evas vener og beslutter sig for at lægge IV katetret i venstre hånd, der bliver ikke talt imens, og sygeplejersken arbejder koncentreret. Efter hun har lagt kateteret, tilslutter hun saltvand og notere tidspunktet i nogle papirer der ligger på bordet, hvorefter hun vender hun sig mod Eva og spørger: "har du noget du vil spørge mig om?". (Observationsdag 4)

APPENDIX E

Co-Authorship Declaration

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PHD-THESIS
DECLARATION OF CO-AUTHORSHIP

The declaration is for PhD students and must be completed for each conjointly authored article. Please note that if a manuscript or published paper has ten or less co-authors, all co-authors must sign the declaration of co-authorship. If it has more than ten co-authors, declarations of co-authorship from the corresponding author(s), the senior author and the principal supervisor (if relevant) are a minimum requirement.

1. Declaration by	
Name of PhD student	Anne Prip
E-mail	anpr@kp.dk
Name of principal supervisor	Mary Jarden
Title of the PhD thesis	Communication practice in an oncology outpatient clinic

2. The declaration applies to the following article	
Title of article	The Patient–Healthcare Professional Relationship and Communication in the Oncology Outpatient Setting. A Systematic Review
Article status	
Published ☒ Date: Sep-Oct. 2018	Accepted for publication ☐ Date:
Manuscript submitted ☐ Date:	Manuscript not submitted ☐
If the article is published or accepted for publication, please state the name of journal, year, volume, page and DOI (if you have the information).	Cancer Nurssing. 2018;41(5):E11-E22. doi:10.1097/NCC.0000000000000533

3. The PhD student's contribution to the article *(please use the scale A-F as benchmark)* Benchmark scale of the PhD-student's contribution to the article A. Has essentially done all the work (> 90 %) **B.** Has done most of the work (60-90 %) **C.** Has contributed considerably (30-60 %) **D.** Has contributed (10-30 %) **E.** No or little contribution (<10 %) **F.** Not relevant	**A, B, C, D, E, F**
1. Formulation/identification of the scientific problem	A
2. Development of the key methods	B
3. Planning of the experiments and methodology design and development	B
4. Conducting the experimental work/clinical studies/data collection/obtaining access to data	B
5. Conducting the analysis of data	B
6. Interpretation of the results	B
7. Writing of the first draft of the manuscript	A
8. Finalisation of the manuscript and submission	A

Provide a short description of the PhD student´s specific contribution to the article.[i]
Anne Prip has essentially done most of the work for this paper including, study design, analysis, interpretation, writing the manuscript and submission.

Latest update of the declaration: December 2018

4. Material from another thesis / dissertation[ii]	
Does the article contain work which has also formed part of another thesis, e.g. master's thesis, PhD thesis or doctoral dissertation (the PhD student's or another person's)?	Yes: ☐ No: ☒
If yes, please state name of the author and title of thesis / dissertation.	
If the article is part of another author's academic degree, please describe the PhD student´s and the author´s contributions to the article so that the individual contributions are clearly distinguishable from one another.	

5. Signatures of the co-authors[iii]

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6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.

Date: 6/7-2020

Principal supervisor: Mary Jarden Mary Jarden

7. Signature of the PhD student

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.

Date: 6/7-2020

PhD student: Anne Prip Anne Prip

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Title of the PhD thesis	Communication practice in an oncology outpatient clinic

2. The declaration applies to the following article	
Title of article	Observations of the Communication Practices Between Nurses and Patients in an Oncology Outpatient Clinic
Article status	
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Manuscript submitted ☐ Date:	Manuscript not submitted ☐
If the article is published or accepted for publication, please state the name of journal, year, volume, page and DOI (if you have the information).	European journal of oncology nursing. 2019;40:120-125. doi:10.1016/j.ejon.2019.03.004

3. The PhD student's contribution to the article ***(please use the scale A-F as benchmark)*** Benchmark scale of the PhD-student's contribution to the article A. Has essentially done all the work (> 90 %) **B.** Has done most of the work (60-90 %) **C.** Has contributed considerably (30-60 %) **D.** Has contributed (10-30 %) **E.** No or little contribution (<10 %) **F.** Not relevant	**A, B, C, D, E, F**
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6. Interpretation of the results	B
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8. Finalisation of the manuscript and submission	A
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If yes, please state name of the author and title of thesis / dissertation.	
If the article is part of another author's academic degree, please describe the PhD student´s and the author´s contributions to the article so that the individual contributions are clearly distinguishable from one another.	

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2.	5/7 2020	Kathrine Hoffmann Pii	Associate professor	Kathrine H. Pii
3.		Kirsten Alling Møller	MA, RN	
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6.	6/7-2020	Mary Jarden	Associate professor	Mary Jarden
7.				
8.				
9.				
10.				

6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.

Date: 6/7-2020

Principal supervisor: Mary Jarden Mary Jarden

7. Signature of the PhD student

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.

Date: 6/7-2020

PhD student: Anne Prip Anne Prip

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2. The declaration applies to the following article	
Title of article	Patients' experience of communication during their course of treatment in an oncology outpatient clinic – qualitative study
Article status	
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Manuscript submitted ☐ Date:	Manuscript not submitted ☐
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3. The PhD student's contribution to the article ***(please use the scale A-F as benchmark)*** Benchmark scale of the PhD-student's contribution to the article A. Has essentially done all the work (> 90 %) **B.** Has done most of the work (60-90 %) **C.** Has contributed considerably (30-60 %) **D.** Has contributed (10-30 %) **E.** No or little contribution (<10 %) **F.** Not relevant	A, B, C, D, E, F
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5. Conducting the analysis of data	B
6. Interpretation of the results	B
7. Writing of the first draft of the manuscript	A
8. Finalisation of the manuscript and submission	A

Provide a short description of the PhD student´s specific contribution to the article.[i]
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Latest update of the declaration: December 2018

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4.	6/7-20	Mary Jarden	Associate professor	Mary Jarden
5.				
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10.				

6. Signature of the principal supervisor

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 6/7-20
Principal supervisor: Mary Jarden Mary Jarden

7. Signature of the PhD student

I solemnly declare that the information provided in this declaration is accurate to the best of my knowledge.
Date: 6/7-2020
PhD student: Anne Prip Anne Prip

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