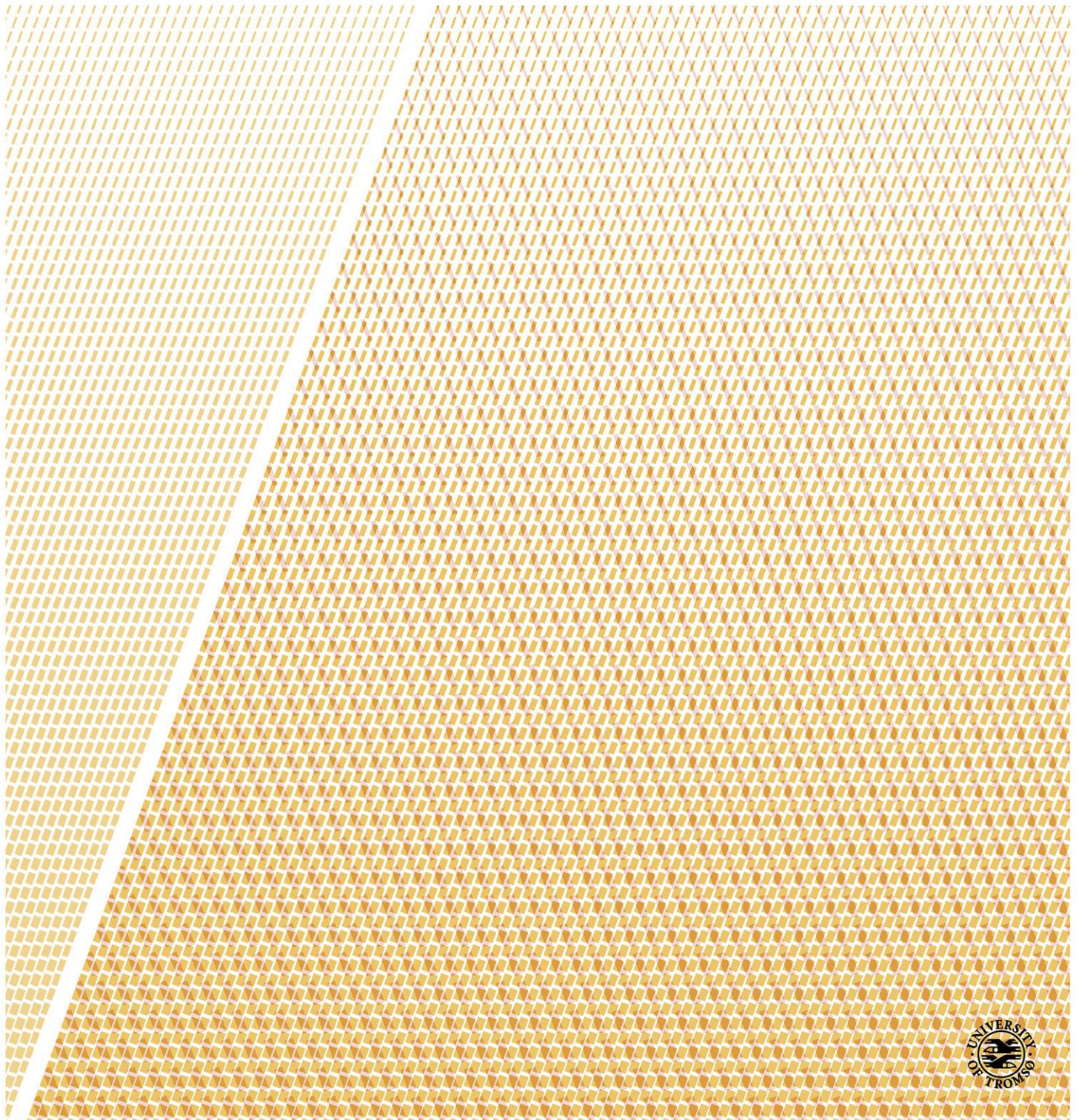


# **Supporting doctor-patient communication in oncology: Providing communication aids to cancer patients in an outpatient clinic**

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*A dissertation for the degree of Philosophiae Doctor – June 2018*





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## ACKNOWLEDGEMENTS

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The present work was carried out at the Oncology department at the University Hospital of North Norway between 2013 and 2017 and was funded by the Northern Norway regional health authority; Helse Nord RHF.

This work has been made possible by the kind contribution of patients at the Oncology Department. Thank you very much for your participation and thereby making this project happen! This applies to all physicians at the Oncology Clinic also, who willingly participated in the study despite already busy outpatient workdays. I am truly grateful!

My gratefulness especially includes my excellent supervisor Tone Nordøy for inviting me to take part in this project. It has been a very interesting and educative experience. Thank you for your unique way of always being enthusiastic and positive, and thereby carry the project forward. You have always been available when needed and you have an impressive way of coming up with intelligent solutions to any challenge we have encountered throughout these years. Thank you!

I also want to thank my skilled co-supervisor Svein Bergvik for immediately being enthusiastic to the project. Your expertise and extensive contributions (especially in training of coders) have been highly valued, and your thoroughness has improved the project considerably.

I am also grateful for the contribution of my great co-supervisor Tore Sørli. You always provide rapid and wise responses and your knowledge has been highly appreciated.

I would like to thank Bente Ervik for her contribution to the project in planning, executing and analyzing the qualitative parts of the study. I have learned a lot by working with you, and I appreciate your ability to stay calm in all situations in addition to your extensive knowledge.

The project is based on the previous work of Professor Phyllis Butow and Professor Martin Tattersall at the University of Sydney, Australia. We have truly benefited from your major expertise in this research field and I want to thank you both so much for your kind collaboration in the project.

Furthermore, I would like to thank Kristin Jensen for priceless practical help in the study. Your sense of systematics, flexibility and enthusiasm has been strictly necessary and highly valued.

Research is lonely work, and I appreciate my less formal research network consisting of mainly Line, Marita and Erna Elise. There are no limits to what can be discussed in such a knowledgeable and enjoyable forum! Moreover, thanks to my good friend Lars for reading through my manuscript from the other side of the world.

Finally, I would like to thank my mother and father for always being there for me, and my loved ones; Harald, Sondre, Sigrid and Gabriel for being patient when needed, and for reminding me of what is important in life.

# LIST OF PAPERS

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The thesis is based on the following papers:

Paper I:

Anita Amundsen, Bente Ervik, Phyllis Butow, Martin H. Tattersall, Svein Bergvik, Tore Sørli and Tone Nordøy. **Adapting an Australian question prompt list in oncology to a Norwegian setting - a combined method approach.** Support Care Cancer, 2017. 25(1): p. 51-58.

Paper II:

Anita Amundsen, Tone Nordøy, Kristine Emilie Lingen, Tore Sørli and Svein Bergvik. **Is patient behavior during consultation associated with shared decision making? A study of patients' questions, cues and concerns in relation to observed shared decision making in a cancer outpatient clinic.** Patient Educ Couns, 2018. 101(3): p. 399-405.

Paper III:

Anita Amundsen, Svein Bergvik, Phyllis Butow, Martin H. Tattersall, Tore Sørli and Tone Nordøy. **Supporting doctor-patient communication: Providing a Question Prompt list and audio-recording of the consultation as communication aids to outpatients in a cancer clinic.** Patient Educ Couns, 2018, article in press, doi.org/10.1016/j.pec.2018.04.011



## ABBREVIATIONS

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CAR	Consultation Audio Recording
CPEQ	Cancer Patient Experiences Questionnaire
CPS	Control Preference Scale
EACH	International Association for Communication in Healthcare
EORTC	European Organization for Research and Treatment of Cancer
MDT	Multidisciplinary Team
OPTION	Observing Patient Involvement in Decision Making
PPT	Patient Preference Trial
QoL	Quality of Life
QPL	Question Prompt List
REK	Regional Committee for Medical and Health Ethics
SDM	Shared Decision Making
SPSS	Statistics Package for the Social Sciences
UNN	University Hospital of North Norway
VR-CoDES	Verona Coding Definitions of Emotional Sequences
VR-CoDES-P	Verona Coding Definitions of Emotional Sequences – Provider Response





## ENGLISH ABSTRACT

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Good communication is essential between patients diagnosed with cancer and their physician. Norwegian patients have a legal right to participate in shared decision making (SDM), and they must be provided sufficient information to meet their individual needs.

Communication aids can assist patients in obtaining the necessary information about their disease and treatment options. In this study, we explored the effect of two such communication aids: A question prompt list (QPL) and a consultation audio record (CAR) for the patients to bring home.

A QPL is a list of suggested questions patients might want to ask their doctor. The Australian QPL “So you have cancer” was translated into Norwegian, and then culturally adjusted after feedback from focus groups consisting of Norwegian cancer patients, as well as a survey. Minimal changes were required to the wording of the original questions; however, focus groups identified three subjects to be added: Accompanying relatives, children as next of kin and rehabilitation. Most questions of the original QPL were considered useful by survey respondents, with only three questions omitted as they were not deemed useful.

The QPL was provided to patients as part of an explorative study, either alone or in combination with a CAR. Results from these intervention groups were compared to a previous control group. Audio files of the consultations from the control group were subject to analysis on questions and emotional cues and concerns, and their relation to physician SDM behavior. While such a relationship was not detected, our study found that patients with a high level of anxiety asked more questions and expressed a higher amount of emotional cues or concerns. The majority of questions asked by the control group related to treatment and practical issues. Few questions were raised about prognosis and treatment options, which are deemed essential for patients to participate in SDM.

Patients that were provided a QPL asked significantly more questions about their prognosis, the disease and the quality of treatment. The study did not find any relationship between the provision of a QPL and physician SDM, nor did it find any difference in the level of anxiety, depression and quality of life between the patients who were provided a QPL alone, a

combined QPL and CAR, or the control group. Providing patients with the QPL increased the consultation length significantly. However, patients rated both the QPL and the CAR positively.

In this thesis, we culturally adapted a QPL to a Norwegian setting and explored the effect of the QPL alone and in combination with a CAR. While our research has shed light on Norwegian cancer patients' information need, we could not determine any effect of patients' verbal behavior on physician SDM behavior.

## NORSK SAMMENDRAG

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God kommunikasjon er essensielt i møte mellom pasient og lege i kreftomsorgen. I Norge har pasienter en lovfestet rett til å medvirke i beslutninger som gjelder egen helse (samvalg) og sentralt i dette står god informasjon tilpasset den enkelte pasients behov.

Kommunikasjonshjelpemidler kan bidra til at pasienter får den informasjonen de ønsker om blant annet kreftsykdommen og behandlingsmuligheter. I denne studien har vi undersøkt effekten av to kommunikasjonshjelpemidler: En spørsmålsliste som på engelsk går under navnet «question prompt list» og lydopptak av konsultasjon, som pasienten får med hjem.

En spørsmålsliste er en liste med forslag til spørsmål pasienter kan ønske å spørre behandlende lege om. I denne studien har vi oversatt en eksisterende australsk spørsmålsliste og tilpasset den norske forhold. Dette har vi gjort gjennom litteratursøk, fokusgrupper og en spørreundersøkelse blant erfarne norske kreftpasienter. Prosessen ført til minimale endringer i ordlyd av spørsmål. I fokusgruppene kom det imidlertid frem tre tema som manglet og som senere ble formulert som nye spørsmål: Å ta pårørende med til konsultasjon, barn som pårørende og rehabilitering. I spørreundersøkelsen ble mange av spørsmålene i den opprinnelige listen vurdert å være nyttige for norske kreftpasienter, men tre spørsmål ble vurdert som mindre nyttige og ble dermed fjernet.

Vi utførte deretter en intervensjonsstudie der vi undersøkte bruken av spørsmålslista, også i kombinasjon med lydopptak av konsultasjonen. Data fra disse gruppene ble sammenliknet med en tidligere kontrollgruppe. I kontrollgruppa gjorde vi utvidede analyser der vi undersøkte om det var en sammenheng mellom antall spørsmål og emosjonelle hint/bekymringer fra pasienten og grad av samvalg. En slik sammenheng fant vi ikke. Derimot fant vi at pasienter som hadde høy angstscore før konsultasjonen stilte flere spørsmål og kom med flere emosjonelle hint og bekymringer. Hovedmengden av pasientsspørsmål i kontrollgruppa omhandlet behandling og praktiske forhold, mens pasientene i liten grad spurte om prognose og behandlingsmuligheter, tema som er essensielle for å kunne medvirke i samvalg.

I de gruppene som fikk spørsmålslista fant vi at pasientene spurte signifikant flere spørsmål om prognose, sykdommen og kvaliteten på behandlingen. Vi fant derimot ingen effekt av

spørsmålslista på samvalg, samtidig som tidsbruken økte. Pasienter vurderte begge kommunikasjonshjelpemidlene som nyttige, og vi fant ingen forskjell i angst, depresjon eller livskvalitet mellom gruppene som fikk spørsmålslista eller kombinasjon av spørsmålslista og lydopptaket, sammenliknet med kontrollgruppa.

I denne studien har vi tilpasset en Australsk spørsmålsliste til norske forhold og undersøkt effekten av denne alene og i kombinasjon med lydopptak av konsultasjonen. Mens vår forskning har kastet lys over norske kreftpasienters informasjonsbehov har vi ikke klart å finne noen sammenheng mellom pasientenes verbale adferd i konsultasjoner og i hvor stor grad leger tar pasienter med på samvalg.

# 1 INTRODUCTION

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The incidence of cancer is steadily increasing in Norway, and a total of 32 827 new cases were reported in 2016 [1]. The risk of receiving a cancer diagnosis increases with age, and approximately 36 % of men and 30 % of women will be diagnosed with cancer by the age of 75 years [1]. Despite the continuous development of new treatments, receiving a cancer diagnosis can be a life-threatening experience and in 2016 approximately 11 000 deaths were reported [2].

## 1.1 Clinical communication

While clinical communication has been present at all times, knowledge of the factors that affect effective patient-physician communication has evolved over time. Prior to the last four decades, this patient-physician relationship was characterized by a paternalistic approach (where the physician decided what was best for the patient), gradually moving towards a more patient-centered approach [3]. During this transition, communication has become an essential component of the physicians' role [4].

Patient centered care aims to provide care that is respectful and responsive to the individual patients' preferences, needs and values, ensuring patient values guide all clinical decisions [5]. Patient centered care has evolved due to political influences in society, and is fostered by the ethical imperative to share important decisions with patients [6].

An early study by Kaplan et al. [7] published in 1989 demonstrated that specific aspects of patient/physician communication was related to better health, better functional status, and better evaluation of overall health status. Moreover, the association between communication and health outcomes has been confirmed in later studies [8-10], and specific pathways have been proposed to link patient-physician communication to better health outcomes [11].

Patient-centered care is now widely endorsed as a central element of high-quality health care [12, 13]. In a review article by Robinson et al. [14], the characteristics of patient-centered care are identified as patients' involvement in care and the individualization of patient care. The authors further argue that effective patient-centered care is related to communication, shared decision making and patient education.



A more recent attempt to make a concept analysis of patient-centered care suggests it to be a bio-psycho-social approach and attitude, which aims to deliver care that is respectful, individualized and empowering [15]. In this paper, the concept “individual patient participation” is defined to revolve around patients’ right and opportunity to influence and engage in the decision making process through a dialogue concerning patients’ preferences and potential and the professionals’ expert knowledge [15]. The authors further argue that by focusing on patient participation as a strategy, a patient-centered approach is facilitated, thus binding the concepts together. When exploring patients’ perception of the term “patient participation”, Eldh et al. [16] identified the main issues to be information exchange and sharing respect.

Considerable amount of information is exchanged in every medical encounter. For cancer patients, almost all treatment decisions are made in the first consultation after the patient has received a cancer diagnosis [17]. As may be expected, patients’ information need is reported to be highest in the time close to receiving the diagnosis [18]. Most patients want truthful information about their disease, even if the information is bleak [19]. Patients’ desire to receive adequate information has been a consistent finding throughout more than 30 years of communication research [20]. A large UK study of 2331 cancer patients revealed that 87% wanted as much information as possible and that 98% wanted to know if their diagnosis was cancer [19].

In order to take an active part in consultations, cancer patients have to assimilate complex information. Studies show that up to one third of patients misunderstand the information they receive from their physicians, and some patients fail to understand if the treatment goal is cure or life prolonging [21, 22]. Thus, one of the main challenges that oncologists face is how to communicate information in a manner that is responsive to the individual patients’ need, and facilitate patient recall and understanding [23].

Even though most doctors in western countries tell patients their diagnosis of cancer, information about prognosis is less commonly provided [24, 25]. This reluctance to discuss prognosis is probably caused as much by doctors’ uncertainty about how to present prognosis, as it is by patients’ reluctance to ask [26]. There is evidence that cancer patients value prognostic information and that discussing life expectancy can reduce anxiety while maintaining hope [27-29]. In a study by Hagerty et al. [30], 98 % of patients with incurable cancer wanted their doctor to be realistic, provide an opportunity to ask questions and

acknowledge them as individuals when discussing prognosis. In this study, almost 70 % of the patients would have liked their physician to initiate a discussion about prognosis, while 10% did not want information about prognosis at all.

In a Norwegian study exploring physicians' attitude towards disclosure of prognostic information, 43% of the physicians agreed to the statement "Generally, physicians should wait until asked before offering prognostic information" [26]. This study also showed a tendency to skew prognostic information in an optimistic direction, and which was more common among less experienced physicians. Similarly, in a study by Lamont et al. [31] physicians in a US hospice setting reported to provide honest survival estimates only 37% of the time when their patients requested them to. This might reduce cancer patients' ability to choose treatments according to their preferences, as evidence has shown that honest prognostic estimates can influence treatment preferences [32].

Patient and physician communication is commonly extended to include one or more relatives, most often spouse or adult children, and less commonly other family and friends [33-36]. The term "patient- and family- centered care" incorporates caregivers in the concept of patient-centered care [37].

## **1.2 Emphasis on clinical communication**

There has been an increasing focus on medical communication, and it is now considered an important physician skill [38-40]. The effect of poor communication is evident from the annual rapport of the Norwegian National Patient Representative (reviewing patients' complaints), who found that nearly all reported cases included elements of inadequate or bad communication [41]. In addition, a number of international studies have shown failure in communication to be linked to increasing malpractice rates [42-44].

In 2015, the Consumer Council of Norway interviewed 1000 patients, and found that one third had at least one bad experience from their encounter with the Norwegian health care system in the past 5 years, and 48% related this experience to inadequate communication [45]. As a result, an official web site was created (#syktvelkommen) where Norwegian patients are encouraged to share their experience.

Research shows that well-designed physician training programs increase communication skills, as well as patients' experience with communication [46, 47]. However, a Cochrane

review of communication skills training for health professionals in cancer care concluded that while various types of training appear to improve some types of communication skills, they fail to demonstrate any effect on patients' mental or physical health [48].

Communication training is provided to all Norwegian medical students throughout their education [49]. This training is delivered through separate courses as well as being integrated throughout other parts of their studies. Ironically, there is a deterioration in communication skills as medical students enter clinical practice, a phenomenon believed to be caused by observing other physicians' bad habits [50]. In 2017, mandatory competency modules that include communication skills have been introduced for all clinical specialties in Norway. In addition, the clinical communication model "Four habits" has been implemented in some Norwegian hospitals [51, 52].

### **1.3 Elements of communication**

Communication in the medical setting is complex. Due to this complexity, we have chosen to look more deeply into selected elements of patient and physician verbal behavior that are particularly relevant to this thesis.

#### **1.3.1 Question asking**

Previous research has demonstrated a positive relationship between the number of questions asked by patients and the amount of information exchanged in the medical encounter [53]. Active patient behavior like asking questions contributes to a patient-centered approach [54]. In addition, research shows that patients who actively participate in the medical encounter receive more facilitating communication from their physicians [55].

The frequency of questions asked by patients varies across cultures and settings [35, 56, 57]. In a study by Street et al. [55], lung cancer patients asked more questions than patients in primary care or patients with systemic lupus erythematosus. In an Australian study, newly admitted cancer patients asked on average 11 questions [57], while an Italian study found that breast cancer patients asked on average 18 questions during their first oncology consultation [35]. On the other side, seriously ill cancer patients in an Australian palliative care unit asked only three questions during consultations [56].

Studies have shown that the number of questions asked by cancer patients is related to patient characteristics such as level of anxiety [56], preferred level of control [58], age (older patients tend to ask fewer questions) [34] and the patients' educational level [34, 55]. Regardless, in the study by Street et al. [55], which revealed an association between question asking and patients' educational level, the strongest predictor of question asking behavior was physicians' partnership building and supportive talk. However, there is evidence that physicians' endorsement of question asking alone may be insufficient to increase the number of questions [56].

There is increased attention for triadic consultations, in which a caregiver accompanies the patient. In a study of oncology "bad news" consultations, 80 % of patients were accompanied by one or more caregivers [34]. The study found that the caregivers asked more questions than the patients themselves, illustrating the important role of caregivers in medical communication.

### **1.3.2 Emotional cues and concerns**

One of the challenges physicians face in medical consultations is to be able to respond to patients' emotional cues of concerns, which is often related to the patients' medical condition. Cancer patients may experience emotional distress throughout the entire disease trajectory [59-62]. In a study of more than 3000 UK cancer patients, approximately one quarter met the criteria for clinically significant emotional distress [63]. In this study, patients' emotional distress was associated with younger age (<65 years), female gender and having active disease. In a hospice setting, Heaven et al. [64] found a strong positive association between psychological distress and the number of emotional cues and concerns expressed by patients.

A review article from 2007, addressing emotional cues and concerns, found the definitions of cues and concerns and the methodological approaches to differ widely [65]. The lack of consensus in coding emotional cues and concerns inspired a network of researchers to develop and validate a coding manual known as "The Verona coding definitions of emotional sequences (VR-CoDES)", which is available online on <http://www.each.nl>.

The developmental process is described in an article by Zimmermann et al. [66]. In this article, an emotional concern is defined as a clear expression of an unpleasant emotion, where the patient explicitly verbalizes this emotion. An example of an emotional concern might be: "I am worried about losing my hair". An emotional cue is defined as a verbal or non-verbal

hint, which suggests an underlying unpleasant emotion, but lacks clarity. There are different sub categories, but examples could include crying, sighing, and unspecific words/sentences to describe emotions like: “Everything seems useless”.

In a later work, a manual for coding physicians’ responses to emotional cues and concerns was developed [67]. A response to a cue or concern is described as either explicit or non-explicit. An explicit provider response includes a precise reference to the expressed cue or concern, while a non-explicit response lacks a reference. This response can be subdivided into focusing on the content or the emotion. Additionally, the provider responses can be classified to produce or reduce space, and each emotional cue and concern can be coded based on how and by whom it was initiated.

Physicians tend to be more responsive to patients’ information needs than to their emotions [68]. A Norwegian study from 2011, in which 96 videotaped consultations from a general teaching hospital were included, revealed that among 163 observed emotional cues and concerns, half of them were given reduced space responses, not allowing patients to further address their worries [69]. Another study showed that questions from patients and caregivers can include an emotional aspect, but is often responded to by providing space for the content, not the affective component [70]. In a study by Zacharie et al. [71], patient-perceived physician communication skills were related to the patients’ satisfaction, distress and self-efficacy following the consultations.

### **1.3.3 Shared decision making (SDM)**

Initially, evidence-based medicine focused on research evidence relevant to a clinical problem. Gradually, the definition of evidence-based medicine has expanded to include fields as clinical expertise and patient values [72]. This evolution is reflected in the national laws concerning patients’ rights, which legislates the patients right to participate in SDM [73].

SDM in the medical setting has been defined as an encounter in which at least two participants – physician and patient – are involved; both parties share information; both parties take steps to build a consensus about the preferred treatment; and an agreement is reached on the treatment to implement [74]. One of the key assumptions in SDM is that the provided information is comprehensible and adapted to the individual patients’ need [75]. SDM is particularly desired for preference-sensitive treatment decisions, in which multiple options with less clear evidence exists. For patients at the end of their lives, there is a growing

accept that choosing quality of life over length of life can be a rational option [76]. On the other hand, there is reason to believe that SDM is not yet standard practice, even in these situations [77, 78].

In recent years, the number of SDM publications in scientific journals have increased substantially [79]. In a systematic review from 2015, SDM (when perceived by patients as occurring) was related to improved affective-cognitive outcomes [80]. SDM has also been linked to better adherence to medication and improved clinical outcomes [81]. There is increasing support that SDM can reduce costs of care when patients are faced with preference-sensitive decisions [82]. Because of the lack of empirical data, there is no data to determine if SDM can affect malpractice litigations [83].

There is a clear relationship between cancer patients' prediction of prognosis and their treatment-preferences, leading to patients overestimating their life expectancy to favor life-extending therapy [32]. A well-known study by Temel et al. [84], has demonstrated that misunderstanding one's prognosis can contribute to poor decision making and poor quality of life and possibly decreased survival.

A meta-analysis by Singh et al. [85] showed that roughly 50% of patients diagnosed with cancer preferred to have a collaborative relationship with physicians in treatment decision making. The remaining patients were split equally between preferring active and passive roles. In the same study, most patients experienced the decision making role they preferred, but about 40% of patients experienced discordance between their preferred and actual roles. Gattellari et al. [86] found satisfaction to be highest for patients who indicated a collaborative role in decision making. The same study showed that role mismatch between preferred and perceived roles of SDM was associated with reduced emotional wellbeing, especially affecting anxiety levels.

In a Norwegian study of 60 patients with newly diagnosed cancer, only 8.3 % wanted an active role, 29 % preferred a collaborative role, while 62.7 % wanted a passive role in treatment decision making [87]. These findings indicate that relatively few Norwegian patients want to have an active role in SDM, compared to results from international studies.

Recent research has shown that patients asking targeted questions can influence physicians towards exhibiting more SDM behavior [88]. Contrary, other evidence indicates that changing patients' behavior might not be sufficient to facilitate SDM [89]. In a study of 252 men with



localized prostate cancer, the researchers found that physicians informed patients of options, risks and benefits, but infrequently engaged them in the core SDM process (discussing options, risks and benefits, and preferences) [90]. Interventions targeting patients and healthcare professionals together show more promise than targeting only one part alone [91].

## **1.4 Improving patients' communication**

A systematic review of intervention studies designed to increase patient participation in medical consultations found that half of the interventions did so [92]. Communication aids aim to provide patients with tools to improve elements of communication. Note taking, consultation audio record (CAR) and consultation summaries are examples of communication aids designed to facilitate the patients' recall of information [93, 94]. Moreover, encouragement to develop an own list of questions or a question prompt list (QPL) can help patients receive personalized information during medical encounters [94].

Patient decision aids are designed to support patients in making decisions regarding their own health that are congruent to their values in life [95]. Decision aids are developed for different cancer diagnosis and settings [96, 97] and has been developed as book/booklets [98] or videos ([www.minebehandlingsvalg.no](http://www.minebehandlingsvalg.no)). Furthermore, decision aids can be computerized/online to provide patients with interactive and individualized content [99]. A recent Cochrane review concluded that patients who were exposed to decision aids were better informed and probably had a more active role in decision making [100].

Communication aids and decision aids can be part of a preparation package, involving multiple interventions [89]. Evidence also exists, that patient coaching can improve patient-physician communication during medical encounters [101].

In this project, we have focused on two communication aids: QPL and CAR.

### **1.4.1 Question prompt list (QPL)**

A QPL is a structured list of questions patients could want to ask their physician. QPLs are designed to increase patient participation during the consultations by enabling patients to articulate questions that are important to them, and thereby obtain more customized information. QPLs are patient mediated interventions, with patients leading their use in the consultation. They have been developed for patients in different health care settings [102,

103], including various areas of cancer care [104-106]. Implementing QPLs in routine care is feasible, but identifying and addressing practical implications before implementation is proposed to be essential [107, 108].

In a review by Dimoska et al. [109] from 2008, the authors concluded that QPLs can increase the number of questions asked during consultations, especially concerning prognosis. Evidence also indicates that QPL interventions may influence both psychological (e.g. anxiety) and cognitive outcomes (e.g. recall of information) [110]. A shortened consultation length, reduced anxiety and better information recall has been found when the physicians explicitly addresses the QPL during the consultation [57]. Provision of a QPL along with physicians' endorsement of its' use, assisted terminally ill Australian cancer patients to ask more questions and promoted discussions about prognosis and end of life issues [111]. Equally important, providing the QPL to this vulnerable group of patients did not increase patient anxiety or impair satisfaction. In another study in an advanced cancer setting, combining a QPL with coaching and physician communication training, improved patient centered communication but did not affect secondary outcomes [112].

In an implementation study from 2012, 44% of patients provided with a QPL reported to have used it during the consultation [107]. In comparison, results from a survey among patients who were prompted to use communication aids, showed that 81 % of respondents had generated their own list of questions when prompted to [94]. Considering this result, the authors suggested QPLs to start with a blank space for patients to list their own unique questions.

Usually, QPLs are developed from information provided by patients and health care workers through focus groups and interviews [109]. Most QPL research has been done in areas where English is the main language. It is not clear to what extent this type of intervention translates to different cultural settings. In a study of a QPL for patients with advanced cancer in the final year of life [105], feedback from patients and healthcare professionals resulted in two separate US and Australian versions. The two versions diverged in terms of language, and two questions regarding treatment and costs were excluded from the Australian QPL as they were irrelevant to patients. Because of their experience, the authors of this study argued for QPLs to be tailored to individual populations [105].

No standard method exists for translating and adjusting QPL to different cultures and settings. In the cultural adaptation of an Australian QPL to Italian [113], a cross cultural adaptation process described by Guillemin [114] and Beaton [115] was used. In this Italian study, the expert group replaced the Italian word for “cancer” with “tumor” or “my illness”, suggesting Italian patients to be less willing to accepting a more direct language.

No cancer specific QPL has previously been developed, translated or adapted to a Norwegian health care setting.

#### **1.4.2 Consultation audio recording (CAR)**

A CAR is an audio recording of a consultation, and can serve as a communication aid when it is provided to the patient. In 2002, Tattersall et al. [116] strongly recommended CAR as a research tool, and also as a patient communication aid. In an RCT by Hack et al [117], men with prostate cancer were given a CAR of their initial consultation, and the patients who received the CAR reported to be significantly more informed about treatment alternatives and treatment side effects. Similar results were reported in a RCT of patients with esophageal cancer [118], where patients who received a CAR demonstrated significantly better information retention, without experiencing adverse psychological outcomes.

A Cochrane review from 2008 including 16 studies, concluded that providing adult cancer patients with CARs was beneficial, as patients in the reviewed studies used the CAR to inform family and friends, and reported better recall of information [119]. Moreover, some of these studies reported increased satisfaction with consultation, but no effect was found on psychological outcomes or quality of life.

In a recent study of more than 4000 patients, providing CAR or the combination of QPL and CAR improved patients’ perception of being adequately informed [120]. In this non-cancer setting, 31% of the CARs were replayed within 90 days. Among cancer patients, the reported replay of CARs seems to be higher. A review from 2014 reported a replay rate between 54 and 100 % [121]. The combination of QPL and CAR has been sparsely explored in oncology, except for a small study among men newly diagnosed with prostate cancer [122]. In this study, the 30 men assigned to receive the interventions, reported more active roles in medical decisions and had lower levels of anxiety 6 weeks after the consultation.

Even though identified as a helpful tool, there seems to be barriers to request a CAR. In a study published in 2012, less than 20 % of breast cancer patients reported to have successfully recorded the consultation when prompted to by a “Decision service team” [94]. Barriers to provide patients with a CAR also exists among hospital administrators and physicians, and their concerns were mainly that CARs could negatively affect the communication process and that patients could misunderstand information [108, 123]. In addition, they had worries about the legal aspect. As more people are in possession of a smartphone, there are reasons to believe that more patients will request to make a CAR. As proposed by Elwyn [91] in 2014: “It is doubtful to think that medicine could remain immune to our growing capacity of easily creating a digital record of all transactions.”



## 2 AIM OF THE THESIS

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The main goal of this study was to investigate the provision of a QPL and a CAR in a Norwegian oncology outpatient clinic, and to evaluate these communication aids' effect on clinical communication and patient outcomes.

More specifically, the aims of the thesis are:

- to develop a culturally adjusted Norwegian QPL.
- to study natural occurring questions and emotional cues and concerns, and their relationship to patient characteristics and physician SDM behavior.
- to investigate the QPLs effect on patient question asking and physician SDM behavior.
- to study the effect of the QPL and the combination of QPL and CAR on patient outcomes.





## 3 SUBJECTS AND METHODS

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### 3.1 Development of the Norwegian QPL (Paper I)

The aim of this study was to develop a culturally adapted Norwegian QPL. A combined method approach, including literature review, focus groups and a survey, was used to adjust an existing Australian QPL into a cultural sensitive Norwegian version. As a starting point we adopted the Australian QPL “So you have cancer...”, which was developed by researchers at the University of Sydney [109]. This QPL contains 49 questions divided into 12 domains (see Appendix 1) and applies to most areas of cancer care.

#### 3.1.1 Method and study population

The QPL was first translated into Norwegian according to EORTC quality of life translation process [124]. An extra question was added: “Is it normal to experience pain having my type of cancer, and if I experience pain, where can I get help for pain relief.” This question was added to address the finding in a nationwide survey of over 7000 Norwegian cancer patients, indicating that Norwegian cancer patients lacked information about pain/pain relief [125]. In addition, a contemporary Norwegian study reported that approximately 35 % of cancer outpatients experience pain [126].

Focus groups were conducted to ensure content validity [127]. Transcripts from the focus groups were subjected to a thematic analytic approach [128]. After slightly rephrasing of some of the existing questions and the development of three new questions, the revised QPL was reviewed by patients in a survey. The recruitment processes, collecting of data and data management are thoroughly described in Paper I of the thesis [129].

Eighteen patients participated in one of the three focus groups and they were recruited from a support center for cancer patients and survivors. Twelve of them (67 %) were women, and mean age was 54 years. Participants in the survey were recruited from the Cancer Outpatient Clinic at UNN and eligibility criteria included a minimum of 3 months experience as a cancer patient and being aged 18 to 75. Respondents to the survey were 16 (52 %) women and 15 (48 %) men. Mean age was 55 years.

Disease characteristics were not obtained for participants in this part of the study (focus groups and survey), and there are concerns that different cancer diagnoses and especially

different stages of the disease could have affected the result. For instance, there are reasons to believe that an issue such as rehabilitation (as emerged in our focus groups), might be more relevant to patients that have completed cancer treatment than to those with newly diagnosed or advanced cancer.

The limited information about cancer site/stage of the disease is a weakness and can have affected the sample representativeness in this part of the study.

### **Statistical analysis**

This work was mainly qualitative in nature. We conducted descriptive statistics to create a summary of responses and to display a percentage distribution of responses to each question in the survey. Data were handled using SPSS version 22/23.

## **3.2 Assessing patient-physician communication (Paper II and III)**

In this part of the project, we wanted to explore central elements of patient-physician communication in ordinary consultations and the effect of introducing the communication aids QPL and CAR.

### **3.2.1 Study population**

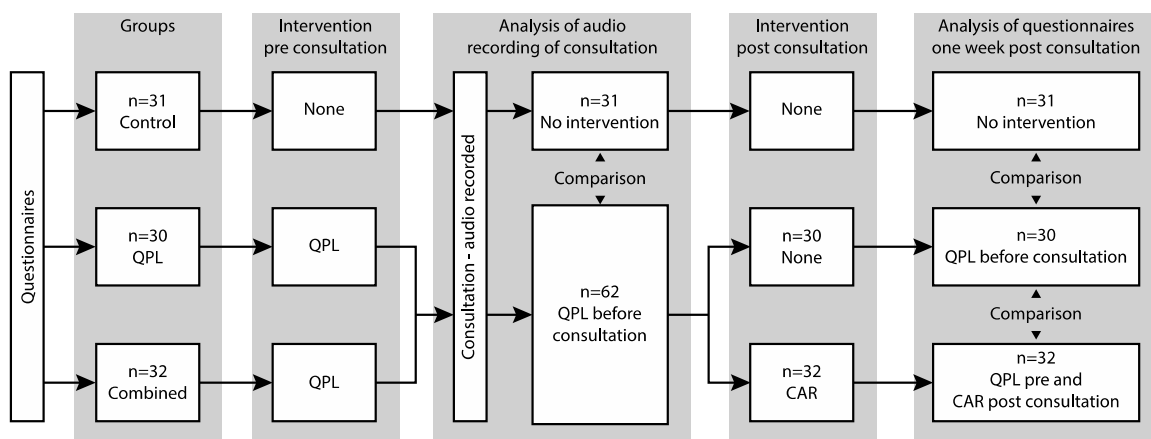
All physicians at the Cancer clinic UNN were asked to participate in this study, except for four senior physicians that were involved in this project (senior physicians being specialists in oncology). Everyone accepted the invitation, except for one physician who did not participate in the last part of the project (providing QPL and CAR). Written informed consents were collected prior to the study, and each of the 22 participating physicians had between one and nine study consultations. Male (56%), senior (61%) physicians, conducted most of the consultations.

Patients were recruited from the Cancer outpatient clinic UNN, which receives patients with a wide range of diagnoses from the three northernmost counties in Norway. Anita Amundsen (AA) identified the patients from the participating physicians' outpatient lists. Eligibility criteria included age 18-75, Norwegian speaking and being able to fill in questionnaire data. The patients in the combined group also had to have access to a computer to play the audio file.

Eligible patients were sent a letter of invitation, and if the patient accepted the invitation, he/she met with the study nurse to sign an informed consent before completing the first questionnaire. The following consultation was audio recorded by a handheld device put between the physician and the patient.

This part of the study included 93 patients, 50 % male and mean age of 60 years.

The study was designed as an exploratory study with a quasi-experimental design (see Figure 1). Data collection for the control group was completed prior to the intervention groups to avoid any learning effect on physicians. Patients were recruited in three different time spans, assuming no seasonal variation. The control group received no interventions and was recruited between May and June 2014. The second group (receiving the QPL in advance of the consultation) was recruited between May and June 2015. The last group (receiving the QPL before and a CAR after the consultation), was recruited between November and January 2015/16. These groups are hereafter called the Control group, the QPL group and the Combined group, respectively.



**Figure 1 – Flow diagram of the study design.**

### **3.2.2 Analysis of the consultation audio recordings**

Secretaries at the Cancer Department transcribed the audio files of the consultations verbatim. The following elements were coded from the transcripts: Number and type of questions from patients and any caregivers (separately) and physicians' verbal SDM behavior. In the Control group, emotional cues and concerns were additionally coded, along with physicians' response to them. Two psychology students at the Master level were trained to do the coding of the study consultations.

#### **Questions from patients and caregivers**

A Norwegian coding manual was developed to ensure coding agreement. The manual was developed after considering the question categories in the Norwegian QPL and four English coding manuals from previous QPL studies [57, 111, 130]. The manuals were provided by prof. Phyllis Butow, who has done extensive work on developing and testing QPLs along with her Sydney research group. After considering all manuals, a Norwegian manual was developed to include the most appropriate elements of both physician and patient/caregiver verbal behavior for this study.

If physicians invited patients to ask questions was coded as either absent, basic or extended, and whether it happened in the first/middle/last part of the consultation. Basic endorsement was coded when the physician only asked if the patient had any questions. Extended endorsement was coded when the physician in any way emphasized the importance of asking questions. In consultations where the patient received the QPL, the coding included if the physician addressed the QPL and in what part of the consultation it occurred (beginning, middle or end of the consultation). If the patient preceded the physician in addressing the QPL, it was coded as patient-initiated. If neither the physician nor the patient addressed the QPL, this behavior was coded as absent.

Patients' and caregivers' questions were coded into one of 14 categories, and later merged into seven related topics (Table 1).

One of the coders performed coding of questions in each consultation, except for 27 consultations where the coding was done by both coders. Inter rater reliability for total amount of questions was computed using intra class correlation coefficient (ICC=0.84) and indicated a good inter rater reliability.

**Table 1 – Coding categories and merged topics.**

<b>Coding Categories</b>	<b>Topics</b>
1. Treatment	Treatment
2. Practical	Practical
3. Prognosis	Prognosis
4. Diagnosis	The disease
5. Tests	
6. Sources of information	
7. Treatment options	Quality of treatment
8. Multi disciplinary team	
9. Optimal care	
10. Life style	Support
11. Costs	
12. Relatives	
13. When and how to ask questions	Other
14. Other	

### **Emotional cues and concerns**

Patients’ emotional cues and concerns, and physicians’ responses were coded from the transcripts according to the Verona coding definition of emotional sequences (VR-CoDES) and provider response (VR-CoDES-P) [66, 67]. Kristine Lingen (KL) coded the transcripts after completing training with training material provided at the EACH website ([www.each.eu](http://www.each.eu)). The training was supervised by Svein Bergvik (SB), a member of the group of developers of the VR-CoDES. Coding of each exercise was successively discussed with the supervisor until the coding was in accordance with the recommended values in the training material. During the coding process, the coder and supervisor met regularly to review the coding and discuss cases of uncertainty.

Due to the limited sample of consultations (the Control group only) and the relative low frequency of emotional cues and concerns, the subtypes of cues were not coded (only the frequency of events).



### **Physician SDM behavior (OPTION)**

The OPTION scale measures to what extent physicians involve patients in SDM in a medical encounter [131]. The scale includes 12 items evaluating different physician SDM behavior. All items are rated from 0 to 4, where 0 indicates absence of SDM behavior and 4 indicates an excellent performance by the physician.

The OPTION scale was translated according to best practice. Translators fluent in English with Norwegian as the main language made two separate translations, which were merged into one Norwegian translation by SB and AA. A professional translator fluent in Norwegian with English as the main language back translated this version into English. All translations were discussed by SB and AA to decide on a final Norwegian version.

SB and AA trained the two coders in our study. After three sessions of group training on transcripts of consultation sequences from the control group, individual coding was performed. All elements of each consultation were then discussed to agree on the correct coder response. For 11 consultations, the coding was decided upon consensus agreement between the two coders, SB and AA. Following this initial training, the rest of the transcripts were coded separately. Coding agreement was checked regularly (after each 10 to 15 consultations) to keep consistent coding throughout the process.

The data was analyzed based on the mean of the two rater scores (except for the 11 consensus scored consultations), and the sum OPTION score was transformed into a scale ranging from 0 to 100 as recommended by the developers of the scale [131].

Inter rater reliability was computed (from 82 consultations) using intra class correlation coefficient (ICC=0.85) and indicated good inter rater reliability.

### **3.2.3 Questionnaire data**

Patients were provided with questionnaires just before and one week after the study consultations.

### **Patient characteristics**

Data on patient characteristics were gathered in the pre-consultation questionnaire and included age, gender, marital status, education, occupation and main language.

### **Anxiety and depression**

The patients' anxiety level was measured before and one week after the consultation, using a Norwegian version of the Hospital Anxiety and Depression Scale (HADS) [132]. This widely used 14-item scale is a self-assessment tool that measures current level of anxiety and depression, and responses indicates the patients' assessment of the past week. The two seven-item subscales have the minimum value of 0 and maximum value of 21. A score of 0–7 on any of the subscales are regarded to be in the normal range, score of 8–10 being suggestive of mood disorder and a score of 11 or above indicating probable cases of mood disorder [133].

### **Quality of life**

Health related quality of life was measured before and one week after the consultations using the European Organization for Research and Treatment of Cancer (EORTC) QoL-C30 Version 3.0 [134]. This is a 30-item quality of life instrument for use in clinical trials, and it is found to be a reliable and valid measure of quality of life of cancer patients [135]. It consists of multi item scales as well as single items: five functional scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain, nausea/vomiting), single items assessing dyspnea, insomnia, appetite loss, constipation, diarrhea and financial impact, and a global health and quality of life scale.

### **Patient satisfaction**

Patient satisfaction can be defined as “a health care recipients' reaction to salient aspects of the context, process and result of their service experience” [136]. Patient satisfaction measurements are often used as quality assessment and to identify areas of improvement in health care.

The Cancer Patient Experiences Questionnaire (CPEQ) is a Norwegian validated self-report instrument covering important aspects of outpatient cancer care and it originally consists of 6 subscales: nurse contact, physician contact, information, organization, patient safety and next of kin [137].

The study patients' experience with the consultations was obtained one week after the study consultation. In this project, we only used the scales concerning physician contact (7 items) and information (7 items).

The scale concerning physician contact includes questions about the patients' experience of the physician; physician being updated on treatment, followed up on side effects, took concerns seriously, cared for the patient, provided enough time for dialogue, was understandable and was competent.

The scale concerning information included the information the patient received concerning; the illness, treatment options, examination/test results, side effects of treatment, effects of treatment, pain to be expected and pain relief.

The possible scores on both scales ranges from zero to 100, a higher score indicating higher satisfaction.

### **Control preference scale**

The Control Preference Scale (CPS) [138] was used to address the patients' preferred level of involvement in treatment decision making in the questionnaire before the study consultation. The control preference construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment". The CPS has been proven a valid and reliable measure of preferred roles in health care decision making [139]. The CPS originally consisted of 5 cards, but has also been used in questionnaires [140]. The CPS differentiates between patients preferring an active, passive or collaborative role in decision making. It has also been used to identify to what extent patients experienced to be involved in treatment decisions [141, 142]. In our project, we used a Norwegian CPS version from a previous project and made minimal changes to the wording [87].

### **Patients' experience with the QPL**

The patients were asked to evaluate the QPL one week after the consultation by responding to the following four questions:

1. Did you read the booklet "Spørsmål til kreftlegen" before the consultation?
2. Did you use the booklet "Spørsmål til kreftlegen" during the consultation?
3. Would you find the booklet "Spørsmål til kreftlegen" useful further, in the context of your cancer?

All three previous questions could be answered by ticking either yes, no or do not know.

4. Do you think the booklet “Spørsmål til kreftlegen” served as a useful tool for you?

This question could be answered by ticking: “not at all”, “to a minor extent”, “to some extent”, “to a large extent” or “to a very large extent”.

### **Physicians’ experiences with the QPL**

The physicians were addressed in a questionnaire after the final patient was included. The questionnaire consisted of four questions and one area reserved for other comments. The four questions were:

1. Did any of your patients use the booklet “Spørsmål til kreftlegen” during an outpatient consultation?

The question could be answered by ticking either yes, no or do not know.

2. Do you think the booklet “Spørsmål til kreftlegen” served as a useful aid for the/those of your patients who used it?

3. Was the booklet “Spørsmål til kreftlegen” a useful aid for you in conversation with your patient(s)?

These two questions could be answered by ticking: “not at all”, “to a minor extent”, “to some extent”, “to a large extent” or “to a very large extent”.

4. Did you feel that the consultation length was changed in these consultations?

The question could be answered by ticking: “yes, more time consuming”, “yes, less time consuming”, “no” or “do not know”.

### **Patients’ experience with the CAR**

All 32 patients receiving a CAR had five extra questions exploring their use of the CAR in the post consultation questionnaire:

1. Were you offered a CAR after the consultation?

The question could be answered by ticking either yes, no or do not know.

2. How many times did you listen to the CAR?

The question could be answered by ticking none, 1-2 or 3 and more.

3. Did you find the CAR to be a useful to you?

This question could be answered by ticking: not at all, to a minor extent, to some extent, to a large extent and to a very large extent.

4. Did anyone, except for you, listen to the CAR?

This question could be answered by ticking: spouse/partner, children, other family/friends, health personnel or no other.

5. If neither you nor anyone else listened to the CAR, can you specify a reason?

An answer could be given in free text.

### **3.2.4 Statistical analysis**

A sample size calculation was performed to be able to detect a significant differences in number of questions between patients receiving the QPL and the Control group. Initially there was no previous research from a Norwegian setting, and sample size calculation was based on international findings. We expected Norwegian patients to ask on average 12 questions (SD=6) during consultation. We assumed a 30% increase to be clinical significant. We chose a 2:1 ratio (merging the QPL and combined QPL and CAR vs no intervention). The sample size calculation revealed that we needed 27 patients in the control group to have 80% power to detect a difference on a 5% significance level.

Descriptive statistics were used to display frequency. Inter rater reliability for coding of the OPTION score and questions from patients and caregivers were computed by the Intra class correlation coefficient (ICC).

In the Control group (Paper II) simple and multiple linear regression analyses were used to find associations between patients' and caregivers' question asking behavior, emotional cues and concerns (dependent variables) and patient/consultation characteristics. Further, the Pearson correlation coefficient was used to address the relationship between question asking

and emotional cues and concerns. To explore the relationship between question asking and the OPTION score, we recoded consultations into three groups according to the number of questions asked: Few (0–10), medium (10–20) and many (> 20) questions. Oneway ANOVA was used to compare OPTION scores in these groups and independent sample T-test was used to compare OPTION scores in consultations where emotional cues or concerns appeared, to consultations where they did not appear. When including anxiety as a covariate in these analysis, ANCOVA was used.

Differences between the control group and the two merged intervention groups (Paper III) on total amount of questions, consultation length and the OPTION score were analyzed by independent sample t-test. Differences regarding subgroups of questions were analyzed with Mann-Whitney U-test, due to a skewed distribution with high proportion of zero counts. In the questionnaire data, differences between the three individual groups were analyzed using ANOVA and ANCOVA model. Effect sizes were provided by calculating Cohen's *d* and Partial Eta Squared.

All statistics were performed using Statistical Package for the Social Sciences (SPSS) version 23.

### **3.3 Ethics**

This study was performed according to the Code of Ethics of the world Medical Association (Declaration of Helsinki). Before starting this study, an application was directed to the Regional committee for medical and health ethics (REK nord). It was from their part declared as a quality assurance project and the study was then formally approved by the Data Protection Officer at UNN.

Cancer patients often experience high stress, and introducing a clinical trial in this patient population should therefore be considered carefully. There has been concerns that communication aids can lead to negative health effects for patients, like more anxiety. Multiple studies exploring QPLs and CARS during approximately 20 years have not given evidence to support this [121, 143].

All patients and physicians gave a written informed consent after being informed and before entering this study.



## 4 MAIN RESULTS

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### **Paper I**

In this paper, we aimed to culturally adjust an Australian QPL to be suitable in a Norwegian oncology setting. We used a combined method approach, including literature review, focus groups and a survey.

This study showed that most questions from the original QPL were considered both useful and understandable for Norwegian cancer patients. As expected, some questions concerning prognosis were found unpleasant by the patients, but the same questions scored high on being useful. Focus groups identified three questions to be added: Accompanying relatives, children as next of kin and rehabilitation. Questions regarding clinical studies, multi-disciplinary teams (MDT) and public versus private hospitals were rated lower on usefulness. After discussions in the research group, the question concerning private versus public hospitals was excluded. Likewise, two questions regarding clinical studies and MDT were excluded and two additional questions regarding the same topics were rephrased in the Norwegian QPL.

The results from this study suggests that adoption of QPLs require some adjustments to the local cultural context and a combined method approach might be a useful model. The final Norwegian QPL contains 50 questions and is culturally adjusted to a Norwegian setting.

### **Paper II**

In this observational study, we explored central elements of clinical patient-physician communication in primary consultations in a cancer outpatient clinic.

On average patients asked 17 questions (SD 15) and expressed 1.9 emotional cues or concerns (SD 1.9) in these 31 audio-taped consultations. Both question asking and expression of cues and concerns increased with level of anxiety. Most questions from patients and caregivers pertained to treatment and practical issues, while questions concerning prognosis and treatment options were few. The mean OPTION score was 12 (SD 7.9) and was neither associated with questions from patients/caregivers nor the presence of emotional cues and concerns from patients. This study demonstrates that despite patients being active by asking



questions, observed physician SDM behavior measured by OPTION was low and not associated with patient verbal behavior during consultation.

### **Paper III**

In this exploratory study, we compared two groups of patients receiving either a QPL or combined QPL/CAR, to a control group.

The study found that patients receiving the QPL asked more questions concerning prognosis ( $p < .0001$ ), the disease ( $p = .006$ ) and quality of treatment ( $p < 0.001$ ) than patients in the control group, without detecting a significant difference in total number of questions. Providing patients with the QPL had no impact on the OPTION score. An increase in mean consultation length was observed when patients received the QPL compared to the control group (44 vs. 36 minutes;  $p = .028$ ). Patients rated both the QPL and CAR positively, but no difference was detected on anxiety/depression/QoL between any of the groups. The study concludes that provision of a QPL facilitates patients to ask a broader range of questions, but increases the consultation length.

## 5 GENERAL DISCUSSION

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### 5.1 Discussion of main results

#### 5.1.1 Norwegian cancer patients' information need

In the process of adapting an Australian QPL to a Norwegian setting, we found that the information need of Norwegian cancer patients was comparable to that of Australian cancer patients. However, we did find some differences. After consulting Norwegian cancer patients through focus groups and a survey, three new questions were added to the Norwegian QPL, while three questions from the original Australian QPL were removed. In addition, the consensus group (consisting of two oncologists and one oncology nurse) agreed on some minor changes to the wording of questions after reviewing feedback from participants in the focus groups and the survey.

Prior research have revealed cultural and organizational disparities when translating quality of life questionnaires to various populations [114, 115]. In the process of developing a QPL for patients with advanced cancer, US health professionals were more reluctant about talking to patients about prognosis than their Australian colleagues [105]. Additionally, in a project adapting a QPL to Italian, researchers exchanged the word “cancer” with “tumor/my illness” [113]. In the Italian study, an expert group (consisting of translators, one oncologist, one methodologist, one psychologist, one sociologist and one linguist), decided to not use the word “cancer” in the QPL because its’ strong “connotation of malignancy”.

Our research did not reveal a need to moderate the language to protect patients from feeling distressed. As shown in previous studies, central European countries traditionally have maintained a preference to conceal medical information from the patients in a time when US physicians started favoring disclosure [144-147]. The development of the Italian QPL was part of a project called HUCARE (Humanization of cancer care), and included actions to improve patient-physician communication. Despite replacing the word “cancer” in the Italian QPL, the researchers acknowledged that some Italian experts thought the time was ready for the word to be used with patients. It is worth noting that cancer patients were not consulted, so their opinion is unknown.

No concerns were raised about the need to moderate the language for our study, and discussions of wording in the consensus group pertained to improve the questions to be in line with everyday-spoken Norwegian. The feedback from the survey also did not indicate any need to moderate the language, suggesting that Norwegian cancer patients are more similar to their Australian counterparts in accepting a more direct language.

There are reasons to believe that there is a need to adjust QPLs to different health care systems based on how they are organized [105]. The subject ‘children as next of kin’ was found by the two first focus groups in our study to be missing from the original QPL. This was a contemporary theme, reinforced in the Norwegian Health Professions Act in 2009 [148]. The Australian QPL “So you have cancer...” does not include any questions related to children as next of kin. On the other hand, it includes a question concerning private versus public health services, which was evaluated to be less useful by our survey respondents and removed from the Norwegian version as the Norwegian health service is mostly public.

The QPL “So you have cancer..” was advocated for in 2008 by a Sydney research group. The subject children as next of kin’ was introduced in a later Australian QPL (for advanced cancer patients), which was also developed at the University of Sydney [105]. The difference in the two QPLs is most likely due to the development in Australian health service. Such changes are also evident in the Norwegian health service where the number of citizens with private health insurance is increasing, and has exceeded half a million in 2017 [149]. The relevance of the question in the Australian QPL relating to private versus public health services could be greater to the Norwegian cancer patient in 2018 than it was in 2014 when the QPL for our study was developed.

In the observational part of the study (Control group), we explored cancer patients’ information needs from transcripts of their first consultations at the outpatient clinic. Of the 31 consultations reviewed, the majority of questions from patients and caregivers referred to treatment and practical issues. Even though our group of patients was actively asking questions, they asked very few questions regarding prognosis and treatment options. Prognostic questions from patients (and/or caregivers) occurred in only four of the 31 consultations, and questions concerning treatment options occurred in two of the consultations.

A weakness in our study is the lack of data on what information physicians provided to the patients, which was not obtained/coded due to limited resources. For instance, patients' few questions concerning prognosis could be due to information already provided by the physicians, or that patients' clearly expressed reluctance to receive this type of information. Prior research shows that most cancer patients want prognostic information, yet this information is seldom provided, even when faced with terminal illness [19, 24, 25].

From the analysis of the 31 patient-physician consultations in the control group, we found that number of questions asked varied considerably between the different consultations. Further, the multivariable analysis revealed that the number of questions asked to be related to patients' anxiety score prior to the consultation. Patients with high levels of anxiety in our study asked more questions. The relationship between the number of questions from patients and anxiety score has been identified in earlier studies [56]. However, what patient characteristics that are related to question asking varies between studies, and we did not find that the number of questions asked was related to age, education or level of control, as shown in previous studies [34, 55, 58].

### **5.1.2 Communication aids: QPL and CAR**

The patients in our study who were provided with a QPL asked a broader range of questions, including more questions concerning prognosis, the disease and quality of treatment. This is in line with previous studies, which found that QPLs help patients change their question asking behavior [57, 111, 130]. Similar to the results in our study, a review by Dimoska et al. [109] concludes that patients provided with a QPL tended to shift their focus away from disease history and treatment, to prognosis and diagnosis. There is evidence that physicians provide fewer details and less complex information to a passive patient [150]. There can be various reasons for patients to ask few questions, but a QPL can help patients to explore their own information need and to articulate questions. Our study did not include any analysis of what information the physicians gave. A study investigating the amount of information provided by physicians indicated a significant increase of information when patients are provided with the QPL [143].

In our study, we recommended the physicians to address the QPL and to encourage the patient to ask questions as early in the consultation as possible. The first time when the physician signed the consent form, then by providing a written suggestion of how to encourage question

asking before each study patient and third a written suggestion along with the hand held recorder. Nevertheless, only 37 % of the physicians addressed the QPL in the first part of the consultations and 15% encouraged question asking. In the consultations where physicians addressed the QPL early, patients and caregivers asked on average 35 questions, compared to 19 when the QPL was addressed later, suggesting an additional effect when physicians address the QPL early in the consultation. Despite a clear difference in number of questions, the consultation length was 45 minutes in both situations (unpublished results).

For our study, all physicians in the Oncology department participated. In a study by Brown et al. [57], only nine physicians from two university hospitals were included. It is possible that in a study that only includes a few physicians the selection of physicians can favor those who are most interested in communication, which might affect the result. While QPLs are simple and inexpensive tools that can empower patients to ask relevant questions, physician training and motivation may be more challenging due to time constraints. One might expect patients to have unmet information needs in circumstances where they are given a communication aid like a QPL, but no time to ask questions. If the patient is only allowed to ask questions at the end of the consultation, there is no surprise that the consultation length increases. Due to the growing number of communication and decision aids that are developed, the use of these should be addressed in future courses in clinical communication to ensure that physicians are aware of how to encourage their use.

Targeting physicians to address the provided QPL, was shown by Brown et al. [57] to shorten the consultation length. The investigators trained a random selection of physicians to address the QPL and to encourage question asking following a written protocol. In addition to the initial training, the physicians received personal feedback after five study consultations. The mean consultation length was 32 minutes when patients in the study received no intervention, compared to 29 minutes where a QPL was provided together with physician training. In the study by Brown et al. [57] it is worth noticing, that in the group of patients receiving the QPL without physician training, the consultation length increased to 34 minutes.

Providing the QPL to patients increased the consultation length significantly in our study. The consultations in the control group lasted on average 36 minutes, compared to 44 minutes when provided with the QPL. A review of QPLs with the number of questions ranging from 11 to 112, suggested that longer QPLs can increase consultation length [109]. In a review by Sansoni et al. [143] it was noted that the studies that found an increased consultation length

when using a QPL, were the studies with the positive findings (e.g. increased total number of questions, questions concerning prognosis). The effect of QPLs on consecutive consultations is sparsely investigated, and future research should address if the provision of extensive information in one consultation could reduce later information need and thereby possibly shorten future consultations.

It is well known that time constraint is a frequently reported barrier to clinical change [108, 151]. An increased consultation length when a QPL is provided might be a challenge due to focus on efficiency in the health sector. However, providing patients with all necessary information takes time. The provision of complex information concerning risks and benefits of the proposed treatment options should be done in a close dialogue with patients, to ensure the information is personalized and understandable. The QPL contributes to a patient-centered approach by empowering patients to ask a broader range of questions. The increased consultation length should be subject to further investigation, which could include identifying the optimal QPL length, physician training and the QPL effect on consecutive consultations.

The second communication aid to be investigated in our study was a CAR. In a study of 168 UK survey respondents, 69% indicated a desire to record clinical encounters [108, 152]. At the time of evaluation, one week after the consultation, only half of the patients in our study had listened to the CAR. This unfortunately limits our ability to conclude on the combined effect of a QPL and CAR on patient outcomes. However, it was well received by most patient who had listened to it, in accordance with previous studies [121].

Neither the QPL nor the combination of QPL and CAR showed an effect on anxiety, depression or QoL in our study. We also did not find any significant difference in patients' evaluation of physician contact or information retrieved, however, found a trend towards that those patients provided with communication aids evaluated their experience more positively. Most communication studies uses patient outcomes like anxiety, depression or quality of life as outcome measures. These measures can be influenced by numerous other factors, such as the disease itself and treatment. In the control group, anxiety level decreased significantly one week after the consultation, compared to pre consultation (unpublished results). At the same time, QoL decreased significantly from initial value, accompanied by a reduced role functioning, and increased fatigue and constipation scores, probably due to side effects of cancer treatment. While there are no consistent findings of reduced anxiety with the use of a

QPL or CAR, it is unlikely that these interventions would cause any unintended adverse effect on patients anxiety scores [119, 143].

Patient satisfaction ratings are important indicators of the quality of health care services, and can include patient satisfaction with their overall health care or patients satisfaction with their physician [153]. High patient satisfaction levels have been reported in several communication studies [154]. The high percentage of patients reporting high satisfaction in studies is called the ceiling effect, and makes it difficult to discriminate between responses and to monitor effect of interventions. In an essay, Steet [155] argues that communication measurements are complicated because communication behavior often has an indirect effect on different outcomes. He further argues that researchers should do more to model pathways linking communication to the process of interest. De Haes et al [156] argues that only by articulating the hypothesized relationship between specific communication elements and concrete endpoints, we have the chance to bring medical communication into the area of evidence-based medicine.

### **5.1.3 Shared decision making**

The Norwegian 1999 Patients' Rights Act has been amended to ensure patients has the right to be involved in decisions concerning their own health [73]. While SDM is a process, it relies on patients' receiving timely and personalized information about the disease and treatment(s) available. While the definition of SDM varies, it is accepted that it involves a decision of treatment to be made. However, few patients are capable of maneuvering through the medical information around their disease by themselves. Thus, medical information has to be provided in a way that is understandable, individualized and sufficient to make the patient capable of taking an active role in SDM, provided they want to. This study has aimed to investigate how patients' verbal behavior might affect physician SDM behavior in medical consultations.

For this study we chose to include newly admitted cancer patients with high information needs, with the knowledge that treatment decisions are often taken during their first consultations [17, 18]. Further, we hypothesized that if patients asked more questions it would affect physician SDM behavior. In a previous study, three specific questions concerning treatment options, their benefits and harms and the likelihood of these to happen, increased family physicians' SDM behavior significantly. In this study the OPTION score increased from 25 to 36 [88]. Our study did not find a similar result. Even though the QPL increased the

number of questions concerning prognosis and optimal treatment, both important for SDM, providing patients with the QPL did not increase physician SDM.

Patients' expression of emotional cues and concerns along with physicians' recognition of them appears to be related to the SDM process. In our study, approximately two third of the patients expressed one or more emotional cues and concerns during the consultation. The responses from the physicians were most often (78%) explicit and inviting. Empathy from physicians seems to affect patients' desire for more information during the consultation [157]. Entwistle et al. [158] suggests that aims to support patient autonomy should include the patient-physician relationship as a facilitator. In general, the patient-physician relationship is identified as one key element in SDM [8, 159, 160]. In the OPTION 12 instrument, one of the twelve physician behaviors scored is how well physicians explore patients' concerns about how the problem(s) are to be managed. Our study did not demonstrate any significant association between patients' verbal behavior in form of emotional cues and concerns and physician SDM behavior, as measured by OPTION 12.

The low OPTION scores in our study indicate that the physicians' effort to engage their patients in SDM is scarce. The low level of physician SDM may also be affected by the type of treatment decisions in the consultations, patients' desire to participate in SDM or challenges with the OPTION instrument.

SDM is considered most relevant in situations when patients are faced with a preference sensitive decision, in which multiple treatment options with less clear evidence exists. Where patients have aggressive lymphoma, receiving intensive curative chemotherapy is likely to be a non-preference sensitive decision, considering the clear evidence of its effectiveness. However, few decisions in oncology comes with such a clear evidence. Choosing between life-extending treatments with limited response rates and potential side effects, or maximizing quality of life, is regarded as a highly preference sensitive decision. It is worth noting that even decisions with clear evidence can be preference sensitive, faced with patients divergent preferences or special clinical circumstances [72, 161].

In this study, we had no data to suggest whether the treatment decisions are preference sensitive or not. As 25 % of patients were in a palliative setting, one could expect higher OPTION scores in these consultations, compared to the OPTION scores for consultations in a curative setting, but our analysis could not confirm this (unpublished data).



The Control Preference Scale (CPS) distinguishes between patients wanting an active, collaborative or passive role in decision making, and was used to address decision making preferences in our study. A meta-analysis of patient data from six clinical studies involving 3491 US and Canadian cancer patients found that 26% wanted an active role, 49 % a collaborative role and 25% wanted a passive role in decision making [85]. Compared to our study, where 57 % stated they wanted a passive role, US and Canadian patients appears to want greater involvement in decision making than our patients. The results from our study are similar to findings in another Norwegian study of 60 cancer patients at time of diagnosis where only 8.3 % of patients wanted an active role, 29% preferred a collaborative role and 62,7% wanted a passive role [87]. These results may indicate that Norwegian cancer patients have lower preference for participation in SDM.

The OPTION 12 score assesses the physician SDM only and the low scores indicate that the physicians in our study performed poorly in the SDM process. The mean OPTION score in our study was 12.1 in the control group and 14.8 in the merged intervention groups. A systematic review of 29 studies using the OPTION 12 scale reported a mean OPTION score of 23 [78]. There are reasons to believe that although SDM now is a statutory patient right, it is a complicated task and not fully implemented in the health service [78, 162]

The low OPTION score in our study could be due to a less preference sensitive nature of the decisions, few patients' preferring to share decisions or physician poor SDM behavior. It could also be due to methodological weaknesses.

There is no consensus in the literature on how to define the concept of SDM, and even less agreement on the most appropriate way to measure this behavior [163]. The OPTION 12 instrument, which is an observer measure of SDM, is a one-dimensional scale, measuring 12 items of physician SDM behavior [131]. It is the most frequently used observer measure of SDM and has previously been suggested as an efficient and sensitive coding system for SDM in oncology [164].

Lately, the OPTION 12 instrument has received criticism due to several scale items that seldom are used, and especially for lacking focus on the different perspectives of SDM. In response to this criticism, the OPTION 5 instrument was created, which is better at differentiating between various levels of patient involvement and includes assessment of patient SDM behavior [165, 166]. A limitation of our study is that we only measured

physician SDM behavior, which might have impact on the ability to address other aspects of SDM. Makoul et al. [163] proposed a more integrative definition of SDM as a basis for describing and operationalization of elements of SDM. Caregivers were present in approximately one fourth of the consultations in our study, and in most consultations they were active participants and asked many questions. Although caregivers' involvement in the SDM process was not assessed in our study, there are reasons to believe that their contribution in the SDM process is underestimated [167]. Caregivers' involvement in the SDM process was not assessed in our study. It is possible that if we had used a SDM model in our study that accounted for the contribution of each participant in all elements of decision making during consultations, it could have provided our study with a different result [168].

Previous research has found no correlation between observer and patients' assessment of SDM in consultations [169]. In our study, we found a weak but significant association between the OPTION score and the patients' judgment of their participation in SDM, as measured by CPS post consultation,  $R=.23$   $p=.046$  (unpublished results). This correlation was so weak that it is reasonable to believe that the OPTION score and CPS post consultation accounts for different perspective of the concept.

Given the increasing interest in SDM and the fact that it is required by law makes it even more important that we are able to measure to what extent patients actually are involved. SDM is a complex process and the current various SDM instruments measure only parts of the behavior. The fact that no existing instruments incorporates all elements and perspectives of SDM behavior is a challenge for SDM research.

## **5.2 Methodological considerations**

### **5.2.1 Cultural adaptation of the QPL**

In this study, we obtained feedback from focus groups and a survey to adjust an existing Australian QPL to fit a Norwegian setting, as no standard method is described for cultural adaptation of QPLs.

Our assumption was that Norwegian cancer patients might want to ask additional questions about topics that are not present in the Australian QPL, and that focus groups could identify potential missing questions. Consulting the target population by using focus groups is advocated as a good method for ensuring content validity [127]. While interviews can

enlighten the experiences and ideas of individuals, focus groups provide the added dimension of the interactions among members [170].

The recruitment process for the focus groups was not random. Participants were recruited through “Vardesenteret”, a support center for cancer patients and their caregivers, with posters presenting the study, and employees actively promoting the study to potential participants. This may have introduced a selection bias, which can occur in the process of identifying the study population, as one can assume that users of “Vardesenteret” differs from non-users [171]. In addition, employees might have been more likely to propose the study to certain users, to example those who were more outgoing or in better physical condition.

On the other hand, purposeful sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources [172]. Purposive sampling can be valuable, as qualitative research usually aims to reflect the diversity within a given population [173] [174]. Given that “Vardesenteret” attracts people seeking interaction with other cancer patients/survivors, they might be more outgoing and likely to share their experiences in a focus group.

The survey was conducted to test the generalizability of the results from the focus groups. The recruitment process for the survey was less exposed to selection bias, as all patients scheduled for an appointment at the cancer outpatient clinic at pre-specified days were invited.

One of the strengths in our process of cultural adaptation of the QPL is the combination of focus groups and a survey, aiming to redress diversity and afterwards ensure the generalizability of findings. We believe that our combined methods approach may provide a useful model for future cultural adaptation of QPLs.

### **5.2.2 The intervention study**

The gold standard when conducting clinical trials is a randomized control trial (RCT), which is proposed to provide the most reliable evidence about the effects of healthcare interventions [175]. Preferably, a RCT is designed to be double blinded to keep the allocation group hidden to both patient and investigator. Studies on communication are often less suitable for blinded trials as the intervention is often apparent to both patients and physicians. In addition, communication studies often target patients or physicians to behave differently, and thereby use the participants’ knowledge of the intervention as an intervention itself.

Our intervention study was conducted with a quasi-experimental design [176]. We chose to conduct an exploratory study with the entire control group preceding the two intervention groups. This was done to minimize any learning effect on physicians, as the intervention in itself could have encouraged physicians to behave differently to all patients in the study, including patients in the control group.

The study was not blinded to neither patients nor physicians, as patients that received the QPL were encouraged to bring the QPL booklet to the consultation. To utilize the full effect of the QPL, the physicians were encouraged to address the QPL as early as possible in the consultation, and therefore the intervention could not be blinded to the physicians either.

If more resources had been available for this study, a Patient Preference Trial (PPT), which accounts for patients' treatment preferences, might have been a better model when exploring the use of communication aids [177]. While RCTs assume clinical equipoise, a PPT takes patients specific preference for (or against) the intervention into account [178]. Patients' preferences may moderate intervention efficacy, especially where motivation can affect outcome, which might be the case with QPLs and CARs.

### **5.3 Limitations**

We acknowledge that a limitation of this study is the small sample size, which can limit the possibility to detect a difference between groups, if a difference truly exists (type 2 error) [179]. Such error can be limited by sample size calculations to determine the right number of patients to include in the study. To do this one needs to have access to information of the study population. For this study, we had little data to help us determine the sample size, so we chose to use international numbers as a guide. After coding of the consultations, it was clear that we estimated a far too low standard deviation, compared to what was actually observed in the control group, which reduced our chance of detecting a difference between the groups regarding total question asking.

The generalizability of study results largely depends upon whether the study population is representative of other population or not. This study was a single center study, and included only newly admitted patients that were well enough to attend outpatient consultations or focus groups. This makes it difficult to generalize the results to an inpatient setting, where patients

often receive treatment that is more aggressive or have poorer health, or to further consultations.

In addition, the data from the group that received both the CAR and the QPL was insufficient to conclude on the added effect of a CAR on outcomes. At the time the second questionnaire was provided, only half of the patients had listened to the CAR, while most of the remaining patients stated they would or might listen to it later. To better identify outcomes affected by the CAR, the post consultation questionnaire should have been provided at a later stage to allow more patients to have experience with the use of the CAR.

## **6 CONCLUSION AND IMPLICATION FOR FURTHER RESEARCH**

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Today, patient-centered care is recognized as a central element of high-quality health services and aims to provide care that is respectful and responsive to the individual patients' preferences, needs and values. As a result, communication has become an essential component of the physicians' role. While patients' informational needs, emotional cues and concerns, and SDM are considered independently in the main discussion of the theses, they are all embraced in the concept of patient centered care. Prior research has shown an association between elements of communication and health outcomes, and there has been a growing interest to improve clinical communication, among other, by exploring the use of communication aids.

This thesis presents the results of three studies in which we have developed a Norwegian QPL, and explored central elements of communication with or without introducing communication aids. During this work, we have investigated Norwegian cancer patients' information need, the effect of providing patients with communication aids and physician SDM behavior in relation to patients' verbal behavior and the provision of a QPL.

In the first paper, we conclude that combining focus groups and a survey can be a useful method for adjusting QPLs to different cultural and organizational contexts. Further, there are reasons to believe that existing QPLs should be reviewed and revised regularly to retain their relevance.

The audio recordings from the control group were subject to extended analyses in paper II. Patients in this part of the study were active asking questions, and we found that both questions and emotional cues and concerns were related to their anxiety level. Contrary to our hypothesis, we found no association between patients' verbal behavior in form of question asking and expression of cues and concerns, and observed physician SDM as measured by OPTION.

In the third paper, we found that providing patients with the QPL resulted in more questions concerning prognosis, the disease and quality of treatment, all which are important in SDM. This also resulted in a significantly longer consultation with their doctor. However, we did not find any relationship between the provision of a QPL and physician SDM. Both the QPL and

the CAR were rated positively by the patients in our study, yet we found no effect on patient outcomes or patients' experience with the consultation.

Our research has demonstrated the culturally adapted Norwegian QPL to broaden the range of questions asked by newly diagnosed cancer patients in an oncology outpatient setting. A QPL can easily be incorporated into regular doctor/patient interaction, provided in a pamphlet or website, while a CAR requires more technical resources. There are concerns that the increased consultation length can be an obstacle to implementing the QPL as standard of care. However, the study has highlighted aspects of clinical communication and communication aids and the challenges with outcome measures in communication research. Further QPL research should address the effect of the QPL on subsequent consultations and as part of communication studies involving both patient and physician interventions.

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# PAPER I

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# PAPER II

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# PAPER III

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# APPENDIX I

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When you see your medical or radiation oncologist today you may have questions and concerns. Often these are forgotten in the heat of the moment, only to be remembered later. We have compiled a list of questions to help you to get the information you want from your oncologist about your illness, and possible treatments.

These questions have been developed after discussion with many people. Your oncologist is keen to answer any questions you may have, either now or at future consultations. You and your family may choose to use this list at any time.

We suggest you tick the questions that you want to ask and write down any that you may think of which are not listed. In many cases, your oncologist will have answered the questions without you even asking, and in that instance this pamphlet can serve as a checklist.

### HOW AND WHEN TO ASK QUESTIONS

- Do you have time today to discuss my questions?
- Can I ask you to explain any words that I am not familiar with?

### DIAGNOSIS

- What kind of cancer do I have?
- Where is the cancer at the moment? Has it spread to other parts of my body?
- How common is my cancer?

### TESTS

- Are there any further tests that I need to have? What will they tell us? Will they confirm my diagnosis?
- What will I experience when having the test/s?

### PROGNOSIS

- How bad is this cancer and what is it going to mean for me?
- What symptoms will the cancer cause?
- What is the aim of the treatment? To cure the cancer or to control it and manage symptoms?
- How likely is it that the cancer will spread to other parts of my body without any more treatment?



- How likely is it that the cancer will spread to other parts of my body if I do have more treatment?
- What is the expected survival for people with my type of cancer?
- Is the treatment going to improve my chance of survival?
- How likely is it that the treatment will improve my symptoms? Is it worth going through?
- Will the treatment or illness reduce my sexual drive?

### OPTIMAL CARE

- Do you specialise in treating my type of cancer?
- How well established is the treatment you are recommending?
- Are there guidelines on how to treat my cancer?
- Is there another specialist who treats this type of cancer that you recommend for a second opinion?

### THE MULTI-DISCIPLINARY TEAM

- Do you work in a multi-disciplinary team and what does this mean?
- Can you explain the advantages of a team approach?
- How do you all communicate with each other and me?
- Who will be in charge of my care?
- What do I do if I get conflicting information?

### TREATMENT INFORMATION AND OPTIONS

#### Options

- Is it necessary to have treatment right now?
- If so, do I have a choice of treatments?
- What are the pros and cons of each treatment option?
- What can I expect if I decide not to have treatment?
- How much time do I have to think about this? Do you need my decision today?
- What is your opinion about the best treatment for me?

### Treatment

- What exactly will be done during the treatment and how will it affect me? When are these effects likely to happen?
- What is the treatment schedule, e.g. how many treatments will I have, how often, and for how long will I have treatment?
- Where will I have the treatment?
- Are there any advantages/disadvantages of the private versus public health system?

### Clinical Trials

- What are clinical trials? Are there any that might be relevant for me?
- Will I be treated any differently if I enrol in a trial?

### Preparing for Treatment

- Is there anything that I can do before or after my treatment that might make it more effective, e.g. diet, work, exercise, etc?
- What are the do's and don'ts while having treatment?
- What problems should I look out for and who do I contact if they occur?
- Are there long-term side effects from the treatment?
- Will I need any additional treatment after this? If so, what might that be?
- What is my long-term follow up plan?

### Costs

- What will be the costs throughout my treatment, e.g. medication, chemotherapy, etc?
- Am I eligible for any benefits if I cannot work?

### Support Information

- What information is available about my cancer and its treatment, e.g. books, videos, websites, etc?
- Are there any complementary therapies that you believe may be helpful or that are known to be bad for me?
- Is there someone I can talk to who has been through this treatment?
- Are there services/support groups that can help me and my family deal with this illness?

# APPENDIX II

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## Spørsmål til kreftlegen

Når du møter din kreftlege kan du ha spørsmål og bekymringer.

For å hjelpe deg å få den informasjonen du ønsker om sykdommen og mulige behandlinger har vi satt sammen en liste med spørsmål du kanskje ønsker svar på. Dette er spørsmål som har blitt utviklet etter diskusjon med mange mennesker som har/har hatt kreft eller jobber med kreft. Spørsmålene er generelle og ikke alle spørsmål trenger å være relevante for deg.

Din kreftlege ønsker å svare på spørsmål du måtte ha, enten nå eller i fremtidige konsultasjoner. Ta gjerne denne lista med til første konsultasjon, men du og din familie kan velge å bruke lista når som helst.

Vi foreslår at du haker av spørsmålene du ønsker å spørre og skriver ned de spørsmålene du har som ikke omfattes av lista. Vi vet at det er lett å glemme å ta opp spørsmål/bekymringer under legetimen, for så å huske på dem i etterkant. I mange tilfeller vil legen besvare spørsmålene dine uten at du trenger å spørre, i så tilfelle kan lista tjene som en sjekkliste.

# Mine spørsmål

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## Når og hvordan man kan stille spørsmål

- Har du tid til å svare på noen spørsmål i dag?
- Kan du forklare noen ord jeg ikke forstår?

## Diagnose

- Hvilken type kreft har jeg?
- Hvor finnes det kreftceller akkurat nå?
- Har kreften spredd seg til andre deler av kroppen min?
- Hvor vanlig er den typen kreft jeg har?

## Undersøkelser

Trenger jeg å ta flere undersøkelser/prøver? Hva vil disse kunne vise? Vil

- de kunne bekrefte diagnosen jeg har fått?
- Hva går denne/disse undersøkelsen(e) ut på?

## Prognose

- Hvor alvorlig er den krefttypen jeg har, og hva betyr det for meg?
- Hvilke plager kan jeg få som følge av kreftsykdommen?  
Er det vanlig å oppleve smerter ved min type kreftsykdom og hvor kan
- jeg eventuelt få hjelp til å lindre smerter?  
Hva er målet med behandlingen? Å kurere kreftsykdommen eller holde
- den i sjakk og lindre plager?  
Hvor sannsynlig er det at kreftsykdommen vil spre seg til andre deler av
- kroppen dersom jeg ikke får mer behandling?  
Hvor sannsynlig er det at kreftsykdommen vil spre seg til andre deler av
- kroppen om jeg får videre behandling?

- Hvor mange med min type kreft blir friske?
- Vil behandlingen øke min sjanse for å bli frisk?  
Hvor sannsynlig er det at behandlingen vil lindre mine plager? Er det verd  
 å forsøke den?
- Vil behandlingen eller sykdommen påvirke seksuallivet mitt?

### Optimal behandling

- Har du/dere erfaring med å behandle min type kreft?
- Hvor godt utprøvd er den behandlingen du anbefaler?
- Finnes det retningslinjer for hvordan min type kreft bør behandles?
- Finnes det et annet sykehus hvor jeg kan be om en ny vurdering?

### Tverrfaglig team

- Er min behandling diskutert i et tverrfaglig møte?
- Hvordan kommuniserer dere med hverandre, fastlegen og med meg?
- Hvem har ansvaret for min behandling?
- Hva gjør jeg om jeg får motstridende informasjon/opplysninger?

### Valgmuligheter

- Er det nødvendig at jeg starter behandling nå?
- Finnes det i så fall ulike behandlinger å velge mellom?
- Hva er fordelene og ulempene med de ulike behandlingene?
- Hva kan skje hvis jeg velger å ikke få behandling?
- Hvor lang tid har jeg til å tenke over dette? Må jeg bestemme meg i dag?
- Hva mener du er den beste behandlingen for meg?
- Finnes det noen kliniske studier det kan være aktuelt for meg å delta i?

### Behandling

- Kan du forklare meg nøyaktig hva det er som skjer under behandlingen, og hvordan dette kan påvirke meg? Når vil jeg mest sannsynlig merke dette?
- Hvordan er behandlingsplanen, f.eks. hvor mange behandlinger skal jeg ha, hvor ofte og hvor lenge vil jeg få behandling?
  - Hvor vil jeg få behandlingen?

## Under behandling

Er det noe jeg selv kan gjøre før eller etter behandling som kan gjøre behandlingen mer effektiv, f.eks. når det gjelder kosthold, arbeid,

- trening?
- Hva kan jeg gjøre, og hva bør jeg ikke gjøre i behandlingsperioden? Hvilke bivirkninger bør jeg være oppmerksom på, og hvem tar jeg
- kontakt med dersom de oppstår?
- Har behandlingen noen langsiktige bivirkninger/seneffekter? Når vil livet normaliseres igjen? Finnes det rehabiliteringstilbud for kreft-
- pasienter? Vil jeg trenge videre behandling etter dette? Hvis ja, hvilken type
- behandling er det snakk om?
- Hvordan blir jeg fulgt opp videre etter avsluttet behandling?

## Kostnader

- Hvilke ekstra utgifter kan jeg forvente som følge av kreftsykdommen?
- Vil jeg ha krav på ytelser dersom jeg ikke kan jobbe?

## Andre informasjonskilder

Hva slags informasjon er tilgjengelig om min kreftsykdom og

- behandlingen, f.eks brosjyrer, nettsider eller bøker? Finnes det alternativ/komplementær behandling som du mener kan
- hjelpe meg, eller som man vet kan være skadelig for meg? Finnes det noen jeg kan snakke med som har vært igjennom denne typen
- behandling?

## Pårørende

Er det greit at jeg har med pårørende på samtalen? Vil de få dekket

- utgifter til reise og opphold? Finnes det tjenester/støttegrupper som kan hjelpe meg og min familie
- med å takle sykdommen? Hvordan bør jeg informere mine barn om kreftsykdommen? Hvor kan jeg
- eventuelt få råd eller hjelp til dette?



# APPENDIX III

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# FOKUSGRUPPE INTERVJU GUIDE

TANKER OM SPØRSMÅL TIL DISKUSJON 09.04.2014

”KOMMUNIKASJON MELLOM PASIENT OG LEGE PÅ KREFT POLIKLINIKK”

## Introduksjon til fokusgruppen

- Takk for at dere har sagt ja til å delta
- Presentasjon av forskere – de ulike rollene
  - o Anita
  - o Bente
  
- Presentasjon ved navn deltakere

## FOKUS I INTERVJUET - HVA ER HENSIKTEN

- Skjemaet utviklet i Australia for australske forhold – oversatt og tatt i bruk i andre land/ Italia
- Vi vet at det er noen kulturelle forskjeller mellom landene OG noen forskjeller i hvordan helsevesenet er organisert
  
- Nå ønsker å ta dette i bruk i Norge og tilpasse det til norske forhold
  
- Så langt som mulig sikre at det er godt tilpasset norske forhold og norske kreftpasienters behov
  
- Grunnstammen i skjemaet er der allerede – men ønsker innspill, tanker og hjelp fra dere ift.

- 1) Er dette relevante spørsmål for norske kreftpasienter?**
- 2) Er det noe annet som burde være med, noe dere ser noen mangler?**
- 3) ( ---- (evt noe som skal bort/ er irrelevant))

Samlet dere som gruppe fordi har et felles utgangspunkt i = erfaringer med å være kreftsyk OG erfaringer fra møter i poliklinikken

Tas opp på bånd ...

Spørre om noen har spørsmål til den skriftlige/muntlige informasjonen om FOKUSGRUPPENE

- TAUSHETSPLIKT -- deltakerne imellom, OG forskernes taushetsplikt

## **PRAKTISK GJENNOMFØRING**

Mange spørsmål – som vi har delt opp i litt større bolker – som naturlig hører sammen

Jeg leser opp spørsmålene i hver bolk SÅ diskuterer dere/vi spørsmålene i hver bolk for seg i forhold til:

- 1) Ser/høres det greit ut sånn som det står nå?
- 2) Er det noe som mangler – noe annet som burde vært med?

-Språklig forståelig

-Noe irrelevant

-Mange spørsmål

## **OPPSUMMERE**

Når vi nå har gått gjennom alle spørsmålene:

- 1) Helhetlig – er det noe som mangler når man nå lager en norsk oversettelse eller utgave?
- 2) Er det noen spørsmål som dere tenker – opplever som ubehagelig å spørre om?