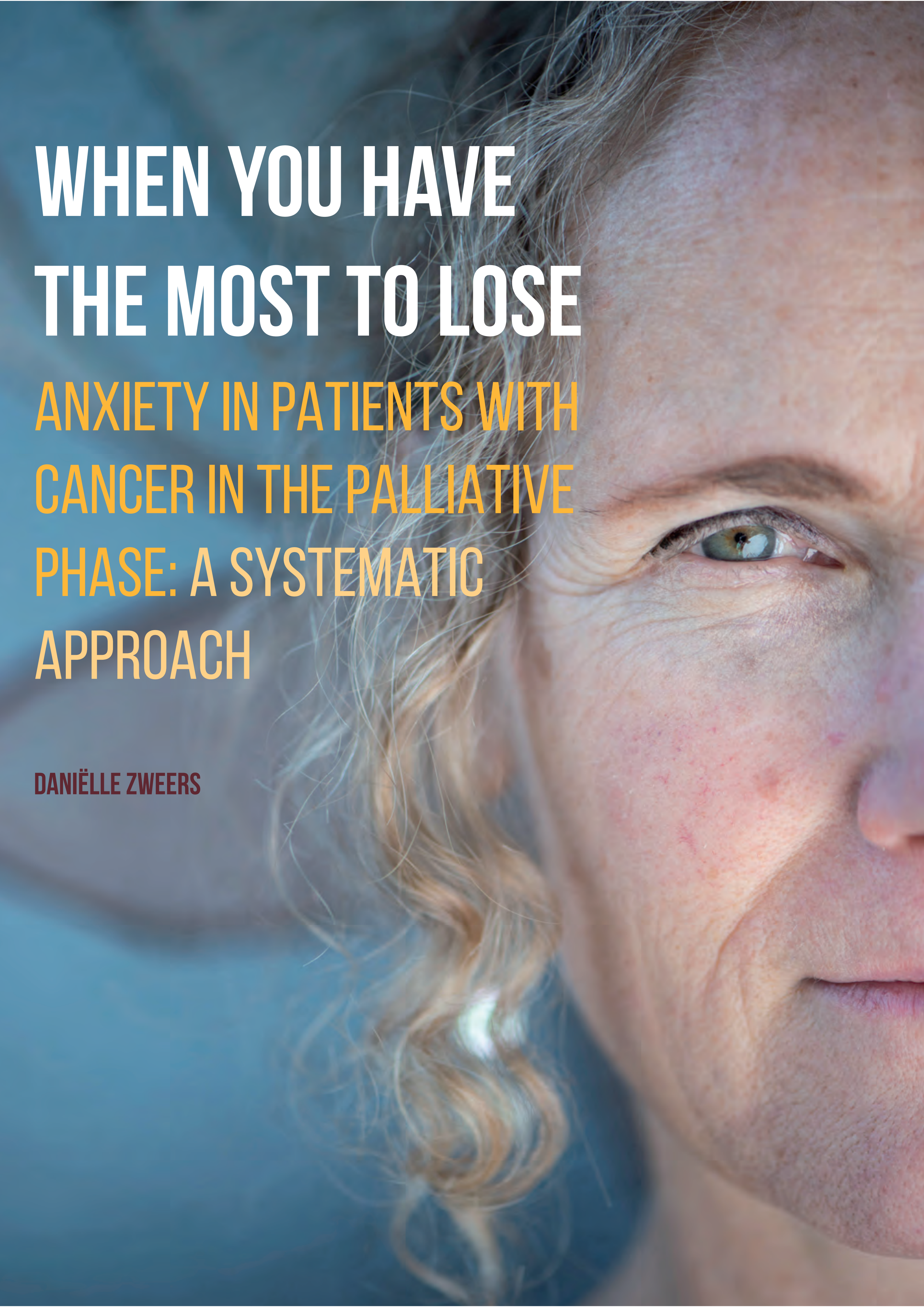

WHEN YOU HAVE THE MOST TO LOSE

ANXIETY IN PATIENTS WITH CANCER IN THE PALLIATIVE PHASE: A SYSTEMATIC APPROACH

DANIËLLE ZWEERS

“When you have the most to lose”

Anxiety in patients with cancer in the palliative phase: a systematic approach

"When you have the most to lose"
Anxiety in patients with cancer in the palliative phase: a systematic approach
PhD thesis, Faculty of Medicine, Utrecht University, the Netherlands

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"When you have the most to lose"

Anxiety in patients with cancer in the palliative phase: a systematic approach

"Wanneer je het meest te verliezen hebt"

Angst bij patiënten met kanker in de palliatieve fase: een systematische benadering

(met een samenvatting in het Nederlands)

Proefschrift
ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de
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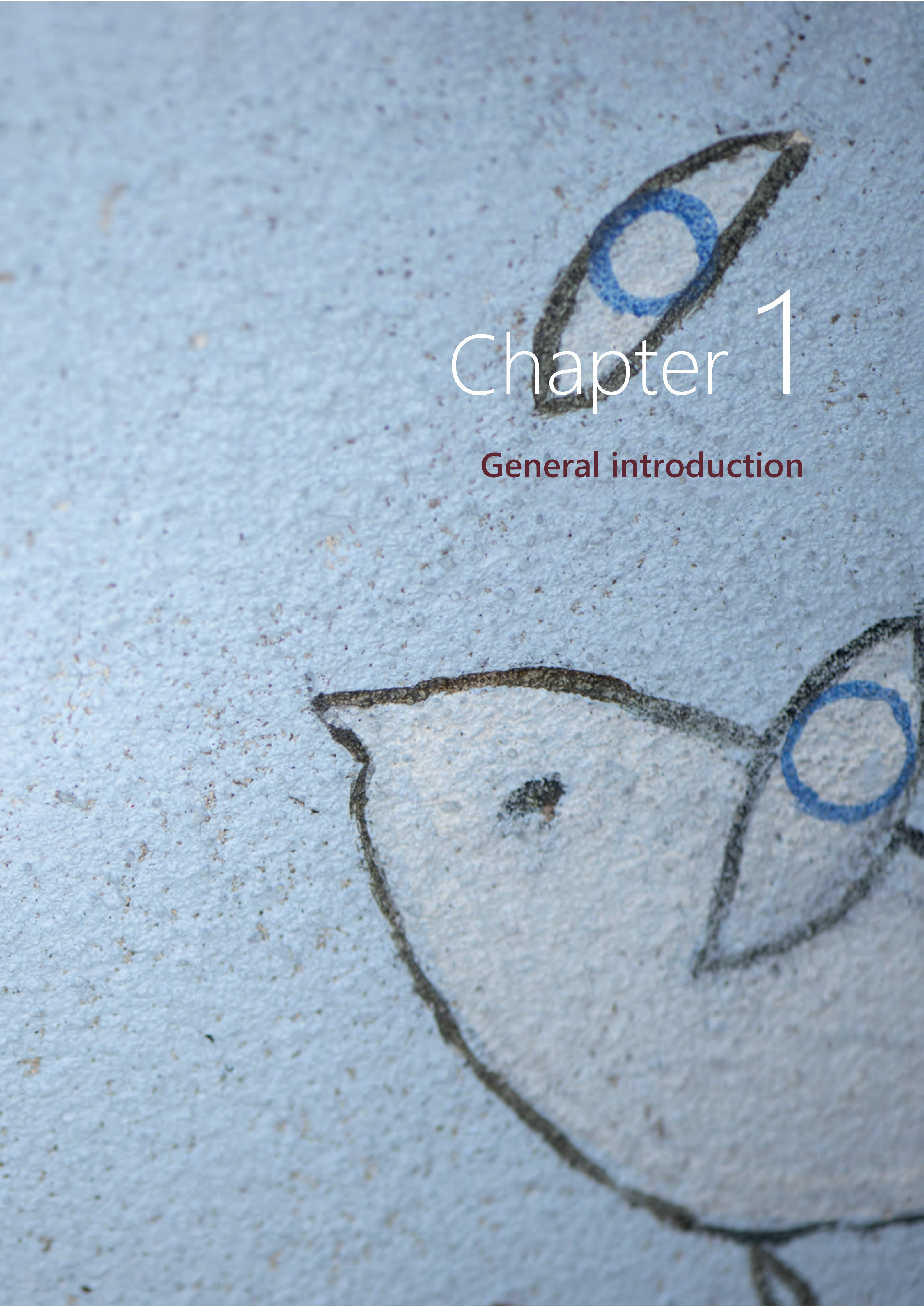
CONTENTS



Chapter 1

General introduction

A 72 year old female went to her general practitioner with severe coughing. It became clear quickly that something really bad was going on. Her oncologist told her that she had metastatic lung cancer. The first thing she wanted to know was if the cancer could be cured because she had so much to live for. Her husband died two years ago. Since then she took care of her disabled son on her own. She really enjoyed to be involved in the lives of her two daughters and four grandchildren. She played tennis with her girlfriends every week, and she still visited her students after her career as an English teacher.

She underwent palliative chemotherapy. And after that she was doing okay for a while, but she knew this would not be not for long. Although she had hope, she told that she never lost that threatening feeling that the cancer would be progressive. The only question for her was when. Thinking of what would happen if the tumor started growing again made her anxious: the mental and physical deterioration which would make her dependent of others, not being able to take care of her son anymore, the pain, the shortness of breath and the thought to suffocate. This feeling of anxiety took over her life. She did not sleep anymore, her pain and shortness of breath became worse and she was not able to take care of her son anymore. After two months her worries became reality and no treatment options were available. She was admitted to a hospice because she did not feel safe in her own house. After a couple of weeks in the hospice she said that she accepted her fate in some way. She had experienced that they managed to treat the pain and shortness of breath. She felt safe because there always was a nurse to call. The nurse also explained why suffocation in her case was not expected. Although she had had many losses, she found peace after a while and enjoyed the presence of her children and grandchildren. In one of the interviews, described in chapter 3 of this thesis, she said: "Looking back, for me anxiety is the highest when you have the most to lose".

When a person is confronted with a diagnosis of incurable cancer and no further treatment options are available, someone's life turns upside down. Although the person becomes a patient from the moment of the diagnosis of cancer, the patient is still a person who has a lot to lose. Most patients can cope adequately with their feelings of anxiety. Some do not and anxiety may influence their mood and daily activities in their remaining life.

Anxiety may be expressed with a variety of expressions by patients and their loved ones. Nurses are more often confronted than other health care professionals with a variety of anxiety expressions, particularly caring for these patients during the late evening hours and at night. It is a real challenge for professionals to know what is behind the individual expressions, because it is not always what it seems. Some patients are struggling in silence, some have heavy panic attacks and some express their feelings of anxiety verbally. Due to the differences in the expressions of and coping with anxiety, anxiety management in the vulnerable palliative care population is a real challenge.

Cancer and palliative care

Cancer is the number one cause of death in The Netherlands. Despite better results of treatment, as a result of aging and population growth, the absolute number of patients dying with cancer has increased during the last decade[1]. The palliative phase in cancer patients starts when curation is no longer a possibility[2].

Palliative care is described as "care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment and treatment of problems of a physical, psychological, social and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy and the opportunity to have access to information and to make choices"[3].

Palliative care patients suffer from a mean of six symptoms concurrently in the last year before death[4], emphasizing the importance of adequate symptom management to maintain or ameliorate quality of life[5]. A symptom is defined as a complaint or problem expressed by a patient in the physical, psychological, social or spiritual domain caused by an underlying illness or its treatment[2]. This definition emphasizes the inherently subjective character of symptoms.

Anxiety

Anxiety is one of these symptoms affecting palliative care patients. Anxiety is defined as "a normal human reaction when confronted with danger" and is directed towards a target[6]. It is known by every human being and increases our attention and awareness which has a function to act upon danger[6]. Although anxiety in advanced cancer patients is understandable, this function may be harmful rather than helpful. Anxiety may lead to the inability to concentrate, to restlessness, depressed mood and somatic symptoms by activation of the autonomic nervous system such as dyspnea, palpitations or sweating and may thus interfere severely with daily functioning and quality of life.

This thesis focuses on anxiety as a symptom, or, in other words, anxiety as a consequence of cancer and/or its treatment, in patients with progressive disease in the last months of life. Anxiety and fear are words that are commonly used interchangeably. According to the American Diagnostic and Statistical Manual of Mental Disorders, fear is different from anxiety primarily in having an identifiable stimulus[7], whereas anxiety is defined as a response to a nonspecific threat[8]. In the existing literature, a distinction between anxiety and fear is rarely made because anxiety and fear are clinically overlapping. In line with the literature we studied anxiety as an overlapping concept, regardless of the presence or absence of a specific threat. Anxiety is mostly studied in relation with depression. Although anxiety and depression are related and may occur simultaneously, these symptoms require a different approach. Therefore, this thesis focuses on anxiety as a single symptom.

A common clinical classification of the etiology of anxiety in cancer patient is situational, organic, existential and psychiatric anxiety[6].
Situational anxiety is related to stressful life events, e.g. cancer and its treatment. Unrealistic thoughts may intensify situational anxiety. Organic anxiety is related to somatic processes such as physical symptoms. Metabolic disorders such as hypercalcemia and a variety of drugs commonly used in palliative care, can also evoke anxiety. Existential anxiety is related to the spiritual and existential domain, e.g., loss of dignity, physical dependence, hopelessness and loss of meaning of life. Psychiatric anxiety is about anxiety arising from psychiatric disorders as in general anxiety disorders, adjustment disorders or phobias. Anxiety disorders based on the Diagnostic and Statistical Manual of Mental Disorders occur in 10% palliative care patients[9]. Psychiatric anxiety may be pre-existent to the diagnosis of cancer[5,10]. Having a psychiatric diagnosis is associated with increased anxiety as a symptom in end of life care[10]. Psychiatric anxiety requires psychiatric care and is outside the scope of this thesis.

Anxiety as symptom is experienced by 20-50% of palliative care patients with advanced cancer[11-14]. Patients who suffer from anxiety require intensive care. Anxiety may cause difficulties in decision making and lead to exacerbation of other symptoms, e.g. pain or dyspnea[15, 16]. Anxiety is also associated with more readmissions in palliative care patients with cancer[17].

The recently developed framework for quality of palliative care in the Netherlands (Kwaliteitskader Palliatieve Zorg)[3], underpins the need for attention and support for psychological symptoms like anxiety as a standard of adequate palliative care. Although the management of anxiety requires an interdisciplinary palliative care approach, nurses have an important and sometimes crucial role during evening and night shifts. They observe the patients frequently, are often the liaison between the team, the patient and family, and provide basic psychosocial care. The lack of reimbursement for specialized treatment of anxiety outside the context of an anxiety disorder further highlights the need for nurses to take this responsibility within their profession[18]. A common misconception is to assume that anxiety is regarded as a natural and understandable reaction to incurable cancer and that nothing needs to be done[6, 19]. Some nurses are even reluctant to discuss emotional difficulties with patients, making the patient feel worse [20]. However, research has shown that only a minority of the patients discloses anxieties spontaneously[21]. As nurses inadequately assess anxiety[22] and are not always able to adequately support patients with anxiety in the last phase of their life [9, 21], there is a need for more research in palliative care in order to reach the

ultimate aim to optimize the quality of care for vulnerable patients facing anxiety.
After identification of anxiety the management of anxiety like all symptom management asks for a systematic approach, including:

- i) assessment,
- ii) analysis,
- iii) decision about treatment goals,
- iv) selection of treatment,
- v) effect monitoring,
- vi) evaluation and
- vii) follow up.

Continuous and individualized communication with the patient and family is a prerequisite for the efficacy of the approach. For this purpose, the stepwise approach of the Medical Research Council (MRC) framework for Developing and Evaluating Complex interventions was used in this thesis[23]. We focused on the first step of the development phase concerning identifying the evidence (figure 1).

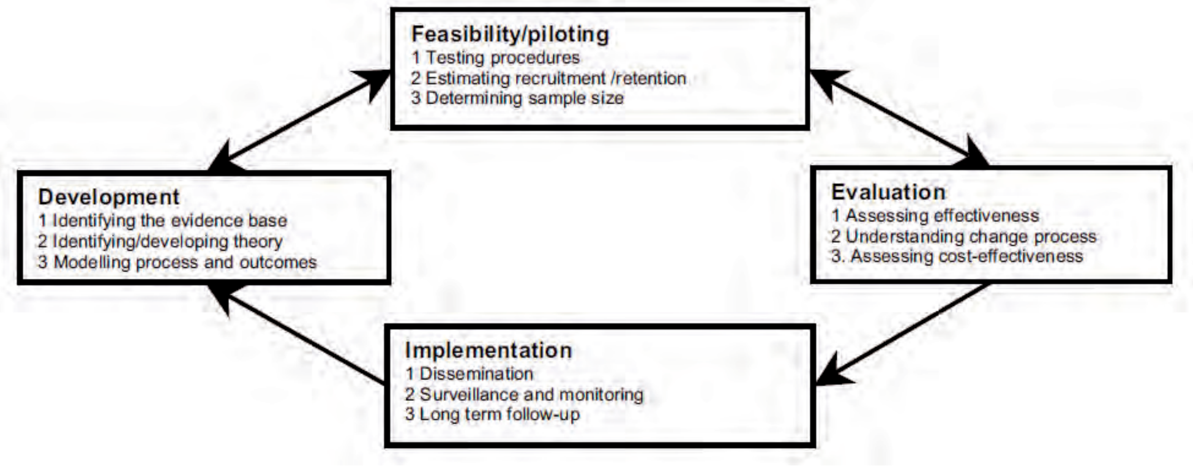
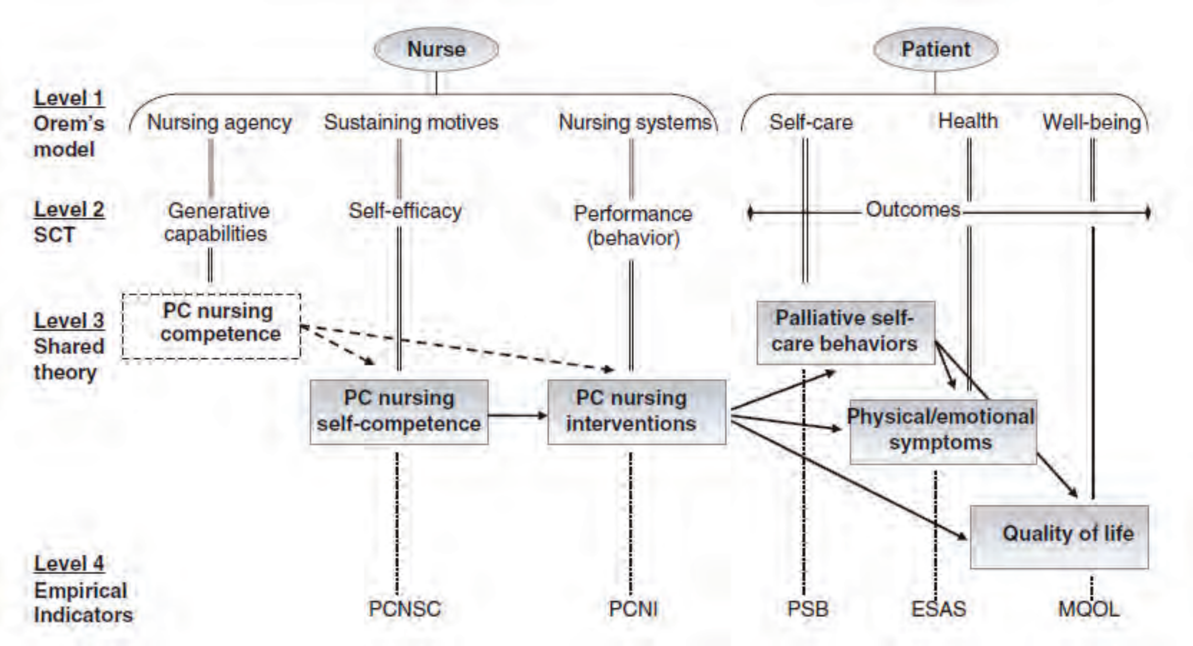


Figure 1: MRC guidance: Key elements of the development and evaluation process

To provide insight into the rationale leading to the change in nurses and patients outcomes we use the Shared Theory of Desbiens and collegues[24] (figure 2). The development of this theoretical framework was based on tenets from Bandura`s Social Cognitive Theory and Orem`s conceptual model, and specially focused on palliative nursing care. The Shared Theory hypothesizes that nursing (self-)competence and nursing interventions will have an impact on palliative self-care behavior of palliative care patients and their symptoms and will improve their quality of life. This theory has not yet been extensively studied. One study in the development of an standardized end-of-life home-care program for pediatric patients dying of brain tumors used the theory successfully [25]. Based on this theory early recognition and management of anxiety can be improved by educating and empowering nurses.



Abbreviations: PC=palliative care; PCNSC=Palliative Care Nursing Self-Competence scale; PCNI= Palliative Care Nursing Interventions index; PSB=Palliative Self-care Behaviors index; ESAS= Edmonton Symptom Assessment System; MQOL=McGill Quality of Life questionnaire.

Figure 2: Model of the Shared Theory[24] based on Bandura`s Social Cognitive Theory (SCT) and Orem`s conceptual model.

Aim and overview of the thesis

To support nurses in ameliorating early recognition and management of anxiety this thesis aimed to provide more insight into the evidence and current practice of anxiety management as well as into the needs for support in patients with incurable cancer, from the perspectives of the patients themselves, their loved ones and their nurses.

This thesis is divided into three parts.

Part I describes current nursing practices in early recognition and management of anxiety in patients with advanced cancer. Chapter 2 is a systematic literature review of nurse-led non-pharmacological interventions with regard to anxiety in patients with advanced cancer. In chapter 3 we studied whether nurses use instruments in order to assess anxiety and the reasons for (not) using them.

We realized that there were two major issues influencing our findings. First a lack of clarity of patients who could benefit from the intervention regarding the heterogeneity in patient characteristics, stage of cancer, needs and underlying causes of anxiety. Second, that there are deficiencies in the basic knowledge of anxiety and the different perspectives in patients with advanced cancer.

Therefore, Part II includes a series of explorative studies which emerged from the lack of effective evidence based non-pharmacological interventions and the rational behind them. We explored the supportive needs of anxious patients from their own perspective, as well as from the perspective of their loved ones and nurses. To clearly define the population we decided to focus on an easy to recognize and define group of incurable cancer patients admitted to an hospice, all in the final stage of life with a limited life expectancy of less than three months.

In chapter 4 a qualitative exploration of patients' needs regarding anxiety management is described. We qualitatively explored anxiety of the patient from the perspectives of the loved ones in chapter 5. Chapter 6 contains the analysis of the outcomes of a patient reported outcome measure in order to gain insight into the predictive value of other symptoms for anxiety. To provide insight into the views of nurses on anxiety management, we studied what nurses know, do and need by a mixed method study, described in chapter 7.

Part III describes the implications of this work and possible improvement of palliative care for anxious advanced cancer patients by a systematic approach for practice and research in Chapter 8. A summary of the findings completes this thesis.

The research questions are:

- What non-pharmacological nurse-led interventions are available and what is their effectiveness in managing anxiety in advanced cancer patients?
- Which instruments are used by nurses to assess anxiety in advanced cancer patients admitted to a hospice or hospital, and what is the rationale behind it?
- What are the needs of patients with advanced cancer admitted to a hospice regarding anxiety management?
- What are the experiences of loved ones concerning the anxiety of the patients with advanced cancer admitted to a hospice?
- Are fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall perceived well-being predictors for anxiety in advanced cancer patients admitted to a hospice?
- What do nurses know, do and need to support cancer patients with anxiety admitted to a hospice?

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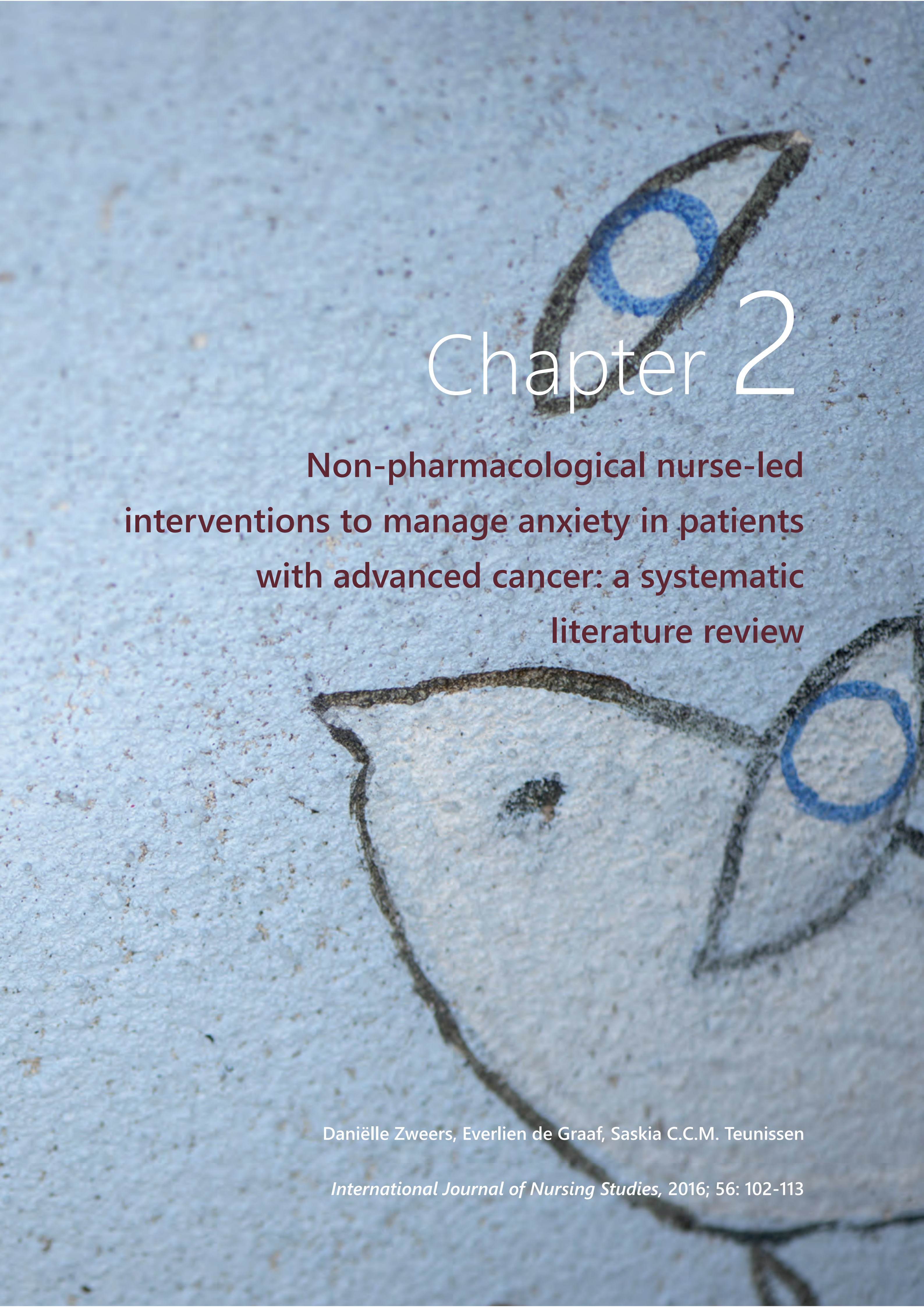
Part I



Chapter 2

Non-pharmacological nurse-led interventions to manage anxiety in patients with advanced cancer: a systematic literature review

Daniëlle Zweers, Everlien de Graaf, Saskia C.C.M. Teunissen

International Journal of Nursing Studies, 2016; 56: 102-113

Abstract

Background: Anxiety is a common symptom in patients with advanced cancer. Although pharmacological and psychosocial interventions are recommended, it remains unclear which role nurses can play in supporting patients with anxiety.

Objective: The objective was to provide an inventory of non-pharmacological nurse-led interventions and evaluate the effectiveness in managing anxiety in advanced cancer patients.

Design: A systematic literature review was performed from xx-xx-xxxx until March 2013. Four databases (MEDLINE, CINAHL, PsycINFO and Cochrane) were searched using predefined search terms without date limits. Randomized controlled trials, focusing on non-pharmacological nurse-led interventions in the management of anxiety in patients with advanced cancer were, identified. Due to the heterogeneity of the included studies, results are presented in a descriptive way.

Results: A total of seven studies were included. The interventions were categorized into patient education, telemonitoring, psychotherapy, complementary care or a combination of these. Two studies showed significant improvements in anxiety levels in patients who received a psychoeducational intervention and in those who participated in a telemonitoring program. However, both studies were judged with a high risk of bias due to attrition, the randomization process and the lack of blinding which was not described. A complementary care intervention, a focused narrative interview and a telemonitoring program identified improvement in anxiety after each time the intervention was provided. However, no significant differences between intervention and control group were found.

Conclusion: Although there is no firm evidence due to the high risk of bias, two studies showed that nurses could play a meaningful role in the management of anxiety with regard to early recognition and even in a specific set of psychotherapeutic interventions. Obviously, interventions should be adapted to the underlying cause of anxiety. However, the results of this systematic literature review show a limited degree of evidence to realize this goal. Future research should focus on the interpretation of the findings in order to understand why certain interventions are effective. Furthermore, clarification of which nurse competencies are needed to perform these interventions successfully must be defined. Nevertheless, this systematic literature review encourages nurses to take a key role in the management of anxiety and shows that it is worthwhile to investigate the difference that can be made by nurses in supporting advanced cancer patients with anxiety.

Introduction

The prevalence of anxiety in hospitalized patients with advanced cancer is 34% based on the Hospital Anxiety and Depression Scale (HADS)[1] and commonly increases as patients become aware of the ineffectiveness of their medical treatment, progression of their illness and limited life expectancy[2, 3]. Anxiety is dynamic and changes over time in response to disease-related events [4]. Nurses in palliative care settings are often the first professionals confronted with anxiety experienced by patients. The definition of anxiety in terms of a nursing diagnosis is "The state in which an individual experiences a vague feeling of dread or apprehension; it is a response to external or internal stimuli that can have behavioral, emotional, cognitive, and physical symptoms"[5 p.75].

Anxiety can be caused by stressful events, psychiatric disorders, metabolic problems, inadequate symptom control, adverse drug effects, drug withdrawal and/or spiritual and existential concerns[6]. Due to the many different causes of anxiety together with the difficulty in distinguishing psychological and somatic symptoms, treatment of anxiety in daily practice is a challenge in palliative care[2, 6]. Interventions are necessary since anxiety can affect patients' decision-making[7] and might cause an exacerbation of other symptoms e.g. pain and dyspnea[4].

Traeger et al. (2012) have recommended the use of psychosocial and psychopharmacological treatment to prevent or alleviate anxiety as a symptom and have emphasized the ongoing evaluation using validated measures. If anxiety is identified, in depth assessment is necessary to rule out potential medical causes and to determine the extent to which anxiety is functionally impairing. Furthermore, anxiety management should be guided by the underlying cause of anxiety[6] Anxiety as a symptom can be managed via brief interventions while anxiety disorders require treatment with more lasting effects (Traeger et al., 2012).

Management of anxiety in advanced cancer patients requires an interdisciplinary palliative care team approach[2]. Within this interdisciplinary palliative care team, the nurse has an important role in identifying anxiety since nurses are often the 'common stable factor' in in- and outpatient facilities as well as at home. In addition, nurses are often the liaison between the team and the patient and carry out the treatment plan in the bedside setting[8]. While the review of Traeger et al. (2012) has demonstrated some very important issues, there is a lack of knowledge regarding which role nurses can have in effectively supporting patients with anxiety[9].

Therefore, the aim of this systematic review was to provide an inventory of non-pharmacological nurse-led interventions and their effectiveness in managing anxiety in advanced cancer patients as well as to equip nurses with evidence-based interventions and to effectively support patients with anxiety.

Method

This systematic review was conducted according to the procedure of the Cochrane Handbook for Systematic Reviews of interventions [10]. The results were described using the PRISMA statement [11].

Medline, Embase, Cinahl, PsycINFO and Cochrane databases were searched from xx-xx-xxxx until March 2013. No data limits were imposed in order to include as many studies as possible. Selection and analysis was done from March to July 2013. The search terms are specified in Table 1. This string was used for Medline and was adapted to the other databases. The studies of interest had a broad range of keywords, which is why the search strategy includes a broad range of search terms in order to include as many studies as possible. In contrast to the scope of this review, the search term "anxiety disorders" was included in the search string because the distinction between anxiety as a symptom and anxiety disorders was rarely clear.

Table 1: Search strategy

Patient	#1	"Carcinoma"[Mesh] OR Neoplasms [Mesh]
	#2	"Carcinoma" OR "cancer" OR "neoplasms" [Title/Abstract]
	#3	"advanced" OR "incurable" OR "metastasized" [Title/Abstract]
	#4	(#1 OR #2) AND #3
Intervention	#5	"Palliative Care"[Mesh] OR "Social Support"[Mesh] OR "Imagery (Psychotherapy)"[Mesh] OR "Complementary Therapies"[Mesh] OR "Self Care"[Mesh] OR "Cognitive behavior therapy" [Mesh] OR "Spiritual Therapies"[Mesh] OR "Aromatherapy"[Mesh] OR "Art Therapy"[Mesh] OR "Music Therapy"[Mesh] OR "Holistic Health"[Mesh] OR "Holistic Nursing"[Mesh] OR "Massage"[Mesh] OR "Touch"[Mesh] OR "Exercise"[Mesh] OR "Relaxation Therapy"[Mesh] OR "Counseling"[Mesh] OR "Psychotherapy"[Mesh] OR "Nurses"[Mesh] OR "Nursing Care"[Mesh] OR "Hospice Care"[Mesh] OR "Terminal Care"[Mesh]
	#6	"palliative care" OR "social support" OR "imagery psychotherapy" OR "complementary therapies" OR "self care" OR "Cognitive behavior therapy" OR "spiritual therapies" OR aromatherapy OR "art therapy" OR "music therapy" OR "holistic health" OR "holistic nursing" OR massage OR touch OR exercise OR "relaxation therapy" OR counseling OR psychotherapy OR nurses OR "nursing care" OR "hospice care" OR "terminal care" OR "family support" OR "guided imagery" OR information OR "best supportive care" OR "psychosocial support" OR nurse* OR nursi* [Title/Abstract]
	#7	#5 OR #6
Outcome	#8	"Quality of life"[Mesh] OR "Anxiety"[Mesh] OR "Fear"[Mesh] OR "anxiety disorder"[Mesh]
	#9	"Quality of life" OR anxiety OR fear OR "quality of dying" OR "anxiety disorder" [Title/Abstract]
	#10	#8 OR #9
Search	#11	#4 AND #7 AND #10

Eligibility criteria

Eligible studies were randomized controlled trials (RCT) that included patients diagnosed with metastatic cancer irrespective of the stage of the cancer and location of care (in- or outpatient) and were written in English. Eligible nurse-led interventions were interventions aimed at reducing anxiety as a symptom. The outcome of interest was anxiety as a symptom due to progressive illness and/or side effects of treatment. As a result, studies including patients with anxiety disorders classified by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition [12], were excluded. Quality of Life (QoL) and Quality of Dying (QoD) defined as health-related quality of life with a focus on physical, psychological, social wellbeing and even existential and spiritual aspects of the quality of dying, coping strategies and involvement of family members were taken into account [13]. Studies were eligible if they reported separate results for anxiety as a symptom. However, studies which did not met the eligibility criteria and/or had no full text available even after emailing the first author, were excluded.

Search

One reviewer (DZ) conducted the search and made a first selection based on title. A second selection based on abstract and third selection based on full text were done by two researchers (DZ, EdG) working independently from each other. After the second and third selection, differences in selection by both reviewers were discussed with an additional researcher (ST). Differences in the outcome of the selection procedure were caused by the lack of clarity regarding which healthcare professional performed the intervention. Therefore, we contacted the first author of the selected studies to verify which healthcare professionals were involved.

Data extraction

Data extraction was conducted by means of a purpose-developed format for 1) general characteristics of the study such as: intervention, control, sample, measurement tool, time points of measurements, statistical analysis, results and risk of bias and 2) intervention characteristics. General characteristics of the study were extracted by both reviewers (DZ, EdG) whereas the intervention characteristics were extracted by only one reviewer (DZ).

The risk of bias in the included studies was analyzed using the risk of bias tool since assigning a quantitative score only has been criticized as misleading rather than useful[10].

Individual components of the risk of bias tool were assessed independently by two reviewers (DZ, EdG) and consisted of: 1) random sequence generation, 2) allocation concealment, 3) blinding of participants and personnel, 4) blinding of outcome assessment, 5) incomplete outcome data, 6) selective reporting and 7) other bias.

Assigning a judgment relating to the risk of bias for the seven domains consisted of low, high or unclear risk. If two or less items were considered as high or unclear risk, then the study was deemed to have a moderate risk of bias. If three or more items were considered as high or unclear, then the study was deemed to have a high risk of bias[10]. Both authors were in agreement with each other concerning the risk of bias for all studies. The risk of bias in the individual studies will be integrated in the results and discussion section.

Data synthesis

The heterogeneity of the included studies made a descriptive synthesis appropriate[10]. Tabulation of the studies enabled the reviewer to compare study designs, findings and the relationship between studies. The focus of the analysis was to provide insight into the effect of nursing interventions to manage anxiety in advanced cancer patients.

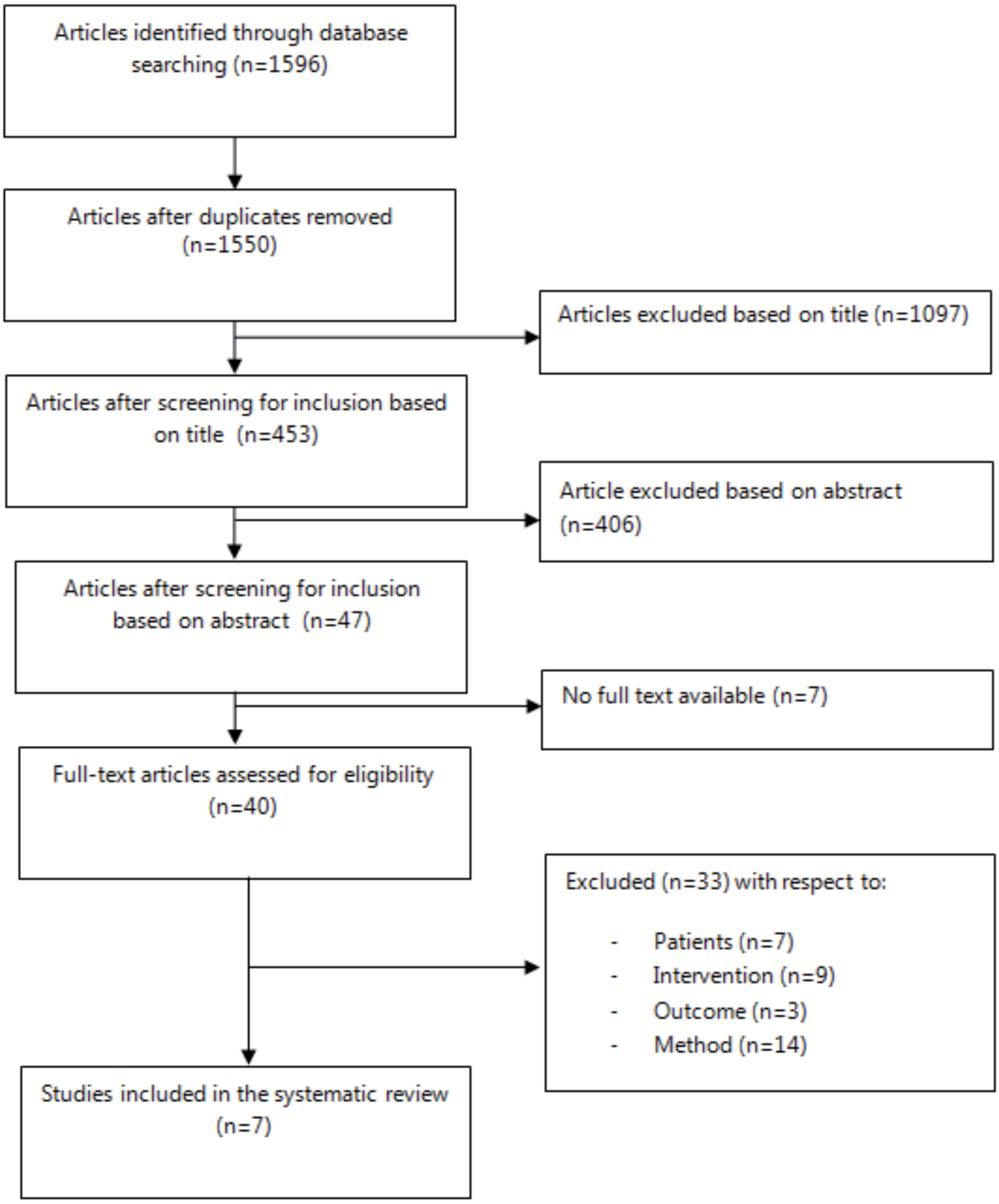


Figure 1: Flow diagram

Results

Study selection

In total 1550 studies were identified after exclusion of duplicate studies (n=46). The first selection based on title resulted in the exclusion of 1097 studies. Subsequently, 406 studies were excluded after the second selection based on the abstract. In total, 40 full text articles were assessed for eligibility. Studies were excluded because a) the intervention under study was not performed by a nurse (n=9), b) the sample consisted of a heterogeneous group of early stage and advanced cancer patients with no separate results for both groups (n=7) c) the method was not a RCT (n=14) and d) no separate results for anxiety were described (n=3). In total seven studies were included in this systematic review. The study selection procedure is demonstrated in figure 1.

Study characteristics

The studies were undertaken in the USA (n=2)[14, 15], the UK (n=2)[16, 17], Australia (n=1)[18], Korea (n=1)[19] and Hongkong (n=1)[20]. All studies were published between 1999 and 2013. Sample sizes ranged between 24 and 189 participants. In five out of seven studies the setting was an outpatient facility. The remaining two studies included a combination of in- and outpatient settings. Furthermore, anxiety was measured by three different measurement tools: Hospital Anxiety and Depression Scale (HADS) (n=3)[15, 18, 19], State-Trait Anxiety Inventory (STAI) (n=3)[14, 17, 20] and the Edmonton Symptom Assessment Scale (ESAS) (n=1)[16]. A broad range of statistical analyses were applied. Table 2 summarizes the characteristics of the included studies.

Risk of bias

According to the risk of bias tool six out of seven studies were judged with a high risk of bias. In one study [19] 2 items scored as unclear and was therefore the only study with a moderate risk of bias.

Most items were scored as an unclear risk of bias due to poorly described methodological procedures. All studies reported that patients were randomly allocated to the intervention and control group. However, three out of seven studies specify how they generate the allocation sequence through the luck of the draw, coin toss simulation and a computer-generated randomized table [17, 19, 20]. Allocation concealment was included in one study where they used opaque envelopes[16]. One study described blinding procedures for physicians and nurse practitioners who were not informed about the randomization process[19]. Other biases consisted of early closure of the study due to limited adherence, failure in the randomization process and differences for QoL measures between patients within the study and patients who dropped out.

An overview of the risk of bias tool across all included studies is summarized in figure 2. The risk of bias assessment within studies is described in table 2.

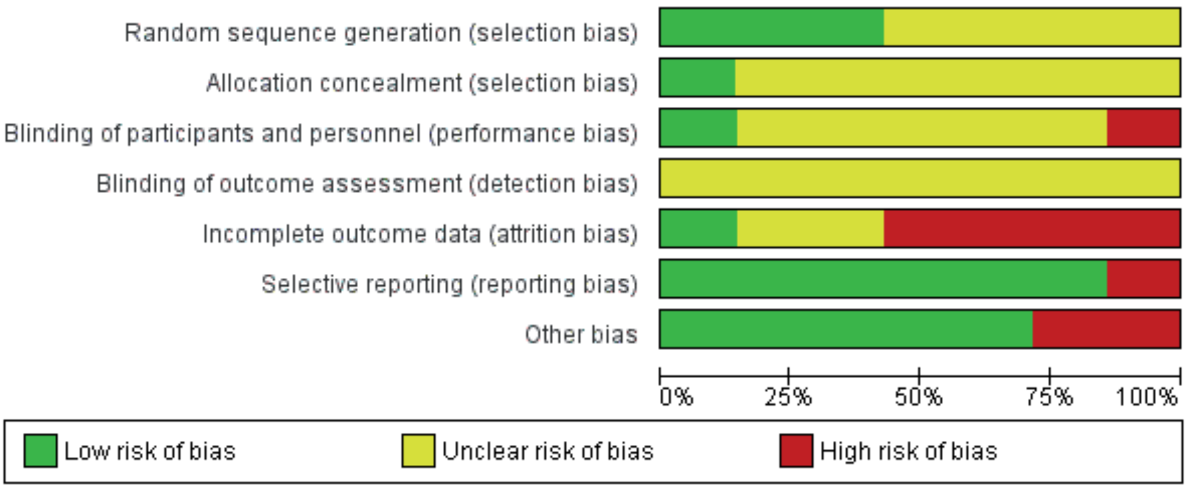


Figure 2: Overall risk of bias

Synthesis of results

Characteristics of the interventions

The content of the interventions was diverse. Four out of seven interventions consisted of an educational element[15, 18-20]. In some studies patient education was combined with telemonitoring[15, 19], or psychological interventions such as progressive muscle relaxation[20]. Monitoring symptoms in combination with counseling and coaching in self-care strategies were present in two studies[15, 19]. While Kornblith et al. (2006) focused on the overall symptom distress in elderly patients, Kim et al. (2013) focused on pain education and monitoring. Two interventions focused on emotional expression through expressive writing [14] and a focused narrative interview[16]. Both studies emphasized the need to allow patients to tell their story. Complementary care interventions were present in the study of Wilkinson et al. (1999) that compared aromatherapy with massage.

Interventions were performed by nurses and research nurses with[15-19] and without additional training or education[14, 20].

The duration of the intervention in terms of contacts or sessions were in most cases a fixed number, ranging between 1 and 3 contacts in 1 week to 6 months. In one intervention the number of contacts between nurse and the patient were tailored to the symptom burden of the patient[15]. Contacts between patient and nurse were face to face (n=4), by telephone (n=2) or mixed (n=1).

One study provided full access to the intervention protocol. Although the studies encouraged adherence to the intervention protocol in several ways, none of the studies described if adherence to the intervention protocol was achieved. Furthermore, the development process of the intervention was poorly described and limited to literature reviews. Characteristics of the interventions are summarized in table 3.

Table 2: Characteristics of the included studies

First author (year)	Intervention	Control	Study sample	Measurement tools and time points	Statistical analysis	Results	Risk of bias + high risk/ - low risk/ ? unknown risk							
							Random sequence generation	Allocation concealment	Performance bias	Detection bias	Attrition bias	Reporting bias	Other bias	Overall judgment*
1. Bruera (2008)	Expressive writing	Neutral writing group	24 advanced cancer patients	State-Trait Anxiety Inventory, pre and post writing sessions	Descriptive statistics	The median score of pre/post EW group was 34.5 compared to a score of 40. The median score of pre/post NW group was 35 compared to a score of 37	?	?	?	?	?	-	+	+
2. Chan (2011)	Psycho educational intervention	a) Briefing of the RT procedure b)optional group talk	140 advanced (stage 3 or 4) lung cancer patients	State-Trait Anxiety Inventory, baseline (T0), at week 3 (T1), week 6 (T2) and three months (T3)	MANOVA Missing data: carry-forward method based on intention-to-treat analysis	Significant differences between the two study groups across T0-T3 (p=0.005)	-	?	+	?	+	-	+	+
3. Kim (2013)	a) Education b) Telemonitoring	Education only	108 advanced cancer patients	Hospital Anxiety and Depression Scale, baseline (T0) and at one week (T1)	Paired t test for continuous data and generalized estimating equation for categorical data	No significant between group differences (p=0.34). Significant effect within the intervention group across T0-T1 (p<0.01)	-	?	-	?	-	-	-	+/-
4. Kornblith (2006)	a)Telephone monitoring b) Education materials	Education materials only	189 advanced breast, colon or prostate cancer patients aged 64 years or older	Hospital Anxiety and Depression Scale, baseline (T0) and at 6 months (T1)	ANCOVA Missing data: no imputation	Significant lower anxiety in intervention group (p<0.0001) after 6 months	?	?	?	?	+	-	-	+

Table 2: continued

First author (year)	Intervention	Control	Study sample	Measurement tools and time points	Statistical analysis	Results	Risk of bias + high risk/ - low risk/ ? unknown risk							
							Random sequence generation	Allocation concealment	Performance bias	Detection bias	Attrition bias	Reporting bias	Other bias	Overall judgment*
6. Sloman (2002)	a) Progressive muscle relaxation training b) Guided imagery training c) a+b	The nurse spend an equal amount of contact time as the intervention through general discussions about concerns relating to health, nursing care and medical treatments.	56 advanced cancer patients with emotional distress according to the referring doctor	Hospital Anxiety and Depression scale, baseline (T0) and at 3 weeks after initial session (T1)	ANCOVA Diagnosis, gender and level of education were tested for moderator effects by two-way ANOVA	No significant group differences (p=0.057). Neither were there any significant moderator effects for diagnosis, gender of level of education	?	?	?	?	?	?	+	+
7. Wilkinson (1999)	Aromatherapy group	Massage group	87 advanced cancer patients	State-Trait Anxiety Inventory, before and after each massage	Wilcoxon matched pair test Bonferonni correction	No significant group differences (No p value available). For all patients regardless of intervention there was a statistically significant reduction in anxiety following all three massages comparing pre and post massage (p<0.0001)	-	?	?	?	+	-	-	+

Table 3: Characteristics of the interventions

First author (year)	Characteristics of those delivering the intervention	Duration, intensity	Adherence to delivery protocols by performers of the intervention	Patient adherence	Summary of intervention content	Process of intervention development	Rationale behind the intervention *	Access to manuals/ protocols
1. Bruera (2008)	Research nurse	Telephone calls twice a week for 2 weeks	No data	No data	• Prewriting anxiety assessment. • 20 minute writing time. • Post writing anxiety assessment.	No data	1	No data
2. Chan (2011)	Registered nurses with two years of clinical experience	2 contacts over 4 weeks. First contact consisted of 40 minutes	2day training of the deliverers	An intervention activity log was set up in which the research assistant recorded patients` involvement Simple health diary	• Educational package plus coaching of PMR[1] one week prior to radiotherapy course. • Reinforced three weeks after commencing RT[2].	Literature on PEIs[3]	1	Protocol of intervention in appendix
3. Kim (2013)	NP[4] who is specialized in pain management and had no specific training for other psychosocial interventions	Individualized education session on the first visit for approximately 30 minutes. Telemonitoring everyday for one week from the first visit	No data	No data	• Standardized pain education using a video and a booklet. • Telemonitoring focusing on pain.	No data	1	No data
4, Kornblith (2006)	Trained telephone monitors and oncology nurses	1 telephone call lasted approximately 10/15 minutes each month during 6 months	Training of telephone monitors	No data	• Education materials. • Telemonitoring: Patients were identified as in distress if they scored above specified cutoff levels for anxiety, the nurse was called by the telephone monitor within 4 hours. The oncology nurse called the patient to discuss these findings and if warranted made a treatment recommendation.	No data	2	No data

Table 3: continued

First author (year)	Characteristics of those delivering the intervention	Duration, intensity	Adherence to delivery protocols by performers of the intervention	Patient adherence	Summary of intervention content	Process of intervention development	Rationale behind the intervention *	Access to manuals/ protocols
5. Lloyd-Williams et al. (2012)	Researcher with nursing and psychology background, member of the health care staff	One focused narrative interview, duration is not described.	A random selection of digital recordings were assessed to ensure consistency and rigor of intervention during the trial	No data	Focused narrative interview to discuss patient`s sense of meaning and suffering, their psychological, physical, social and spiritual well being. The emphasis was on allowing the patient to tell their story.	No data	2	No data
6. Sloman (2002)	Community nurse trained in the use of relaxation and imagery techniques	One face to face session lasted approximately 30minutes, follow up appointments twice weekly	No data	Tape recorders and cassettes were use to teach PMR[1] and GI[6]	• Explanation of the nurse. • A audio tape with instructions for the group to which they were assigned: PMR[1], GI[6] or a combination of PMR[1] and GI[6]. • Brief discussion concerning their feelings about the session. • Patients were asked to practice the technique twice daily by means of the audiotape. • Follow up appointments to repeat the sessions.	No data	3	No data
7. Wilkinson (1999)	Nurses with recognized diplomas in massage	Three full body massages over 3 consecutive weeks	Training to ensure that all masseurs were using the same technique. A check was carried out monthly.	No data	• Full body massage with carrier oil and Roman chamomile essential oil (aromatherapy group). • Full body massage with carrier oil (massage group).	No data	1	No data

Abbreviations: 1. PMR: Progressive muscle relaxation. 2. RT: Radiotherapy. 3. PEIs: Psycho educational interventions. 4. NP: Nurse Practitioner. 5. QoL: Quality of Life. 6. GI: Guided imagery.

* 1: Rationale behind the interventions was well described based on literature. 2: Rationale behind the intervention was described in the article without any references.
3: Rationale of the intervention was not described.

Outcome

Table 2 summarizes the effect of the interventions on anxiety. Two studies with different interventions showed significant differences between the intervention and the control group [15, 20]. Kornblith et al. (2006) demonstrated that telemonitoring in combination with education focused on overall symptom distress, decreased anxiety levels at 6 months based on the HADS (p<0.0001) in comparison with the control group which received education only. Due to the attrition bias, the lack of description of the randomization process and blinding, a high risk of bias was given. Although the dropouts were well described, the attrition rate was a major problem. Although the attrition rate was similar for both treatment arms, patients in the telemonitoring arm had higher scores on quality of life measures in comparison with the patients who were not assessed at 6 months. No significant differences in sociodemographic and disease site characteristics or psychosocial factors at baseline were found. However, pain scores tended to be higher in the telemonitoring arm (p=0.0502).

The effect of the telemonitoring program of Kornblith et al (2006) is in contrast with the study of Kim et al (2013). They performed a similar intervention of education with and without a telemonitoring program for one week. No significant effect was found between intervention and control group (p=0.5), although anxiety scores post intervention were significantly improved (p<0.01) compared with baseline anxiety scores for the intervention group. The study of Kim et al (2013) was the only study judged with a moderate risk of bias.

Chan et al. (2011) showed that there was a significant difference in anxiety on the STAI at week 6 (p=0.001) and week 12 (p=0.005) for the psychoeducational intervention group. The psychoeducational intervention consisted of progressive muscle relaxation during radiotherapy course for advanced lung cancer patients. The control group received an individual briefing of the radiotherapy procedure and side effects. Patients in both groups were also invited to an optional group talk about general care before and/or after radiotherapy. In addition, a major problem in the study of Chan et al. (2011) was the difference in attrition rate for both groups; 42% for the control group versus 11% for the intervention group after 12 weeks. The main reason for attrition was death, due to the fact that more patients in the control group had a more advanced stage of cancer and metastases. Additional analysis showed no significant effect on the outcome of interest between the two study groups. Missing data in the study of Chan et al (2006) were assigned by a carry-forward method based on the intention-to-treat analysis.

Although no significant effect on anxiety between aromatherapy and massage therapy was established, Wilkinson et al. (1999) found a statistically significant decrease in anxiety after each massage (with or without essential oils) on the STAI (P<0.001). This was the same in the study of Llyod-Williams (2013) where they found improvement in anxiety on the ESAS only after each interview. The greatest change in anxiety was seen at 4 weeks where there was a mean change improvement of 1.0 in anxiety score on the ESAS. Sloman et al (2002) found no significant improvement for anxiety (p=0.057). However, significant changes occurred for depression and QoL. In Bruera et al (2008), they found no significant differences on the STAI between both groups due to a lack of power. There was a high level of poor adherence; only 8% of the patients completed the 2-week study. Therefore, the authors concluded that the intervention under study was not feasible for this patient population.

Discussion

The aim of this systematic literature review was to arrange an inventory of non-pharmacological nurse-led interventions and their effectiveness in managing anxiety in advanced cancer patients. To the best of our knowledge, this is the first systematic literature review which revealed the characteristics and effects of nurse-led interventions for reducing and/or preventing anxiety as a symptom. Seven RCT's were included. Descriptive synthesis of the studies allowed us to draw some conclusions, whereas a quantitative meta-analysis would have been inappropriate due to the heterogeneity of interventions, population and measurement tools.

Principle findings

Studies on the effect of nurse-led interventions in advanced cancer patients with anxiety are scarce. Only seven studies met the inclusion criteria. The content of the interventions could be categorized into: patient education, telemonitoring programs, psychotherapeutic interventions, complementary care interventions or a combination of these.

Two out of seven studies showed significant improvement in anxiety when comparing the intervention and control group. However, both studies were judged with a high risk of bias due to the high attrition rate, lack of a detailed description of the randomization and blinding process. There was difficulty in establishing statistically significant effects in the included studies due to attrition and consequently a lack of power. Attrition was mainly caused by a lack of a short-time effect and difficulties in accessibility. Unfortunately, attrition in relation to the outcome was rarely analyzed and/or discussed. In addition, no clear entrance criteria were defined which patients could benefit from the intervention under study. Furthermore, difficulties in the heterogeneity of the population, exclusion of patients with a poor performance status and problems with randomization were found. Also the lack of blinding of participants or personnel could seriously affect the outcome under study, because anxiety is a highly subjective symptom for patients as well as nurses. Additional possibilities for available interventions besides the interventions under study, was also a problem. In several studies a common issue was that the patients in the control group sought out additional possibilities for support when they realized that they had not received the intervention they preferred. This was even a problem when deviation from the study protocol was in the best interest of the patient at that moment. Therefore clinical relevance versus the study protocol made it difficult to draw conclusions.

All together these difficulties were often seen in patients with progressive disease. The findings of the included studies should be generalized with caution as a result of the small sample sizes, overall high risk of bias and the lack of clarification of the target population.

Although there is no firm evidence due to the high risk of bias, two studies showed that nurses could play a meaningful role in the management of anxiety[15, 20].

Ko[5, 19]rnblith et al. (2006) described an early recognition and monitoring intervention, which is the first step in the management of anxiety[4]. Structural attention to anxiety seems to be essential in the management of anxiety. Kornblith et al. (2006) have demonstrated that given the various barriers that prevent patients from talking about their psychosocial problems, the opportunity to talk with a nurse may be an under-appreciated aspect of the success of the telemonitoring program. However, two studies which emphasized allowing patients to tell their stories by focused narrative interviews or expressive writing found no significant effect on anxiety[14, 16, 17]. To succeed, the telemonitoring program should include short communication lines with other healthcare professionals within the interdisciplinary approach as a precondition.

Furthermore, Chan et al. (2011) have demonstrated that nurses are able to perform some specific psychotherapeutic interventions. According to Chan et al. (2011) trained nurses are able to perform interventions including psychological and educational components which have resulted in self-care strategies with a significant improvement in anxiety.

Although Stiefel and Razavi (1994) have advocated different approaches for different causes of anxiety, none of the included studies focused on the underlying causes of anxiety or defined specific entrance criteria which patients could benefit from the intervention. As a result patients had different anxiety levels at baseline. Therefore, it remains unclear if the intervention was meant to prevent or decrease existing anxiety or a combination of both.

In all the included studies it remains unclear which element of the intervention was responsible for the effect. Interventions to manage anxiety could be seen as complex care interventions because of the several interacting components, the practical and methodological difficulties and the lack of standardization in design and delivery of the interventions[21]. None of the studies included a framework to develop and evaluate the interventions such as the Medical Research Council (MRC) model[21]. The lack of a theoretical framework in the included studies made it difficult to interpret these findings in relation to understanding why some interventions are effective and others are not.

Based on this and other lessons learned from the included studies we suggest that effective and feasible nurse-led interventions to support advanced cancer patients who suffer from anxiety should be developed along 7 criteria: 1) tailored to the needs of the patient, 2) based on the underlying causes of anxiety, 3) the opportunity to tell stories, 4) routine measurement of anxiety, 5) effective in a short time period, 6) based on multi-dimensional domains and 7) easily accessible[15, 20].

Limitations of this review

The findings of this review may have limited relevance to non-western countries as a consequence of inclusion of only full text English language studies. Furthermore, only electronic databases were searched. Even though we tried to get full text articles by emailing the first author of the study, there was a high proportion of studies were there was no full text article available. In addition, we used a broad search strategy due to the heterogeneity of keywords used by the studies of interest in order to identify most possible studies. This resulted in a high number of studies which increased the risk of bias in the selection process. However, we limited this risk through an additional reviewer who performed the second and third selection independently. As a result of the issues mentioned above, it is possible that some related studies may not have been identified.

Future research

Development of evidence based nurse-led interventions in the management of anxiety is necessary since the management of anxiety depends on location of care and individual nurse competencies rather than evidence based interventions. In addition, there is a need for a variety of evidence based nurse-led interventions that can adjust to the underlying causes of anxiety. Furthermore, understanding of the potential underlying mechanisms is needed: why some interventions are effective and others not, and which competencies are necessary to perform these interventions effectively. Therefore, using a theoretical framework such as the Medical Research Council (MRC) model could help to develop interventions and interpret these findings to understand the outcome and underlying effects[21]. Finally, studies should have a higher methodological quality. It is essential that study designs and objectives are clear and proactive regarding the risk of bias, which is well recognized in palliative care.

Conclusion

Due to the overall low quality of the included studies, we are under the impression that effective non-pharmacological nurse-led interventions with regard to anxiety in patients with advanced cancer are scarce. In spite of this tentative conclusion, this systematic literature review does show a key role for nurses in the management of anxiety with regard to early recognition and monitoring of anxiety and even in a specific set of psychotherapeutic interventions. Obviously, interventions must be adapted to the underlying cause of anxiety. Nevertheless, the results of this systematic literature review show a limited degree of evidence to achieve this goal. We suggest that effective and feasible interventions to support patients with anxiety in advanced cancer should be developed along 7 criteria: 1) tailored to the needs of the patient, 2) based on the underlying causes of anxiety, 3) the opportunity to tell stories, 4) routine measurement of anxiety, 5) effective in a short time period, 6) based on multi-dimensional domains and 7) easily accessible. Future research should primarily focus on the interpretation of the findings in order to understand why certain interventions are effective. Furthermore, there is a need to understand which competencies are needed to perform the intervention successfully. This review confirms that it is worthwhile to investigate the difference that can be made by nurses in supporting patients with advanced cancer who suffer from anxiety.

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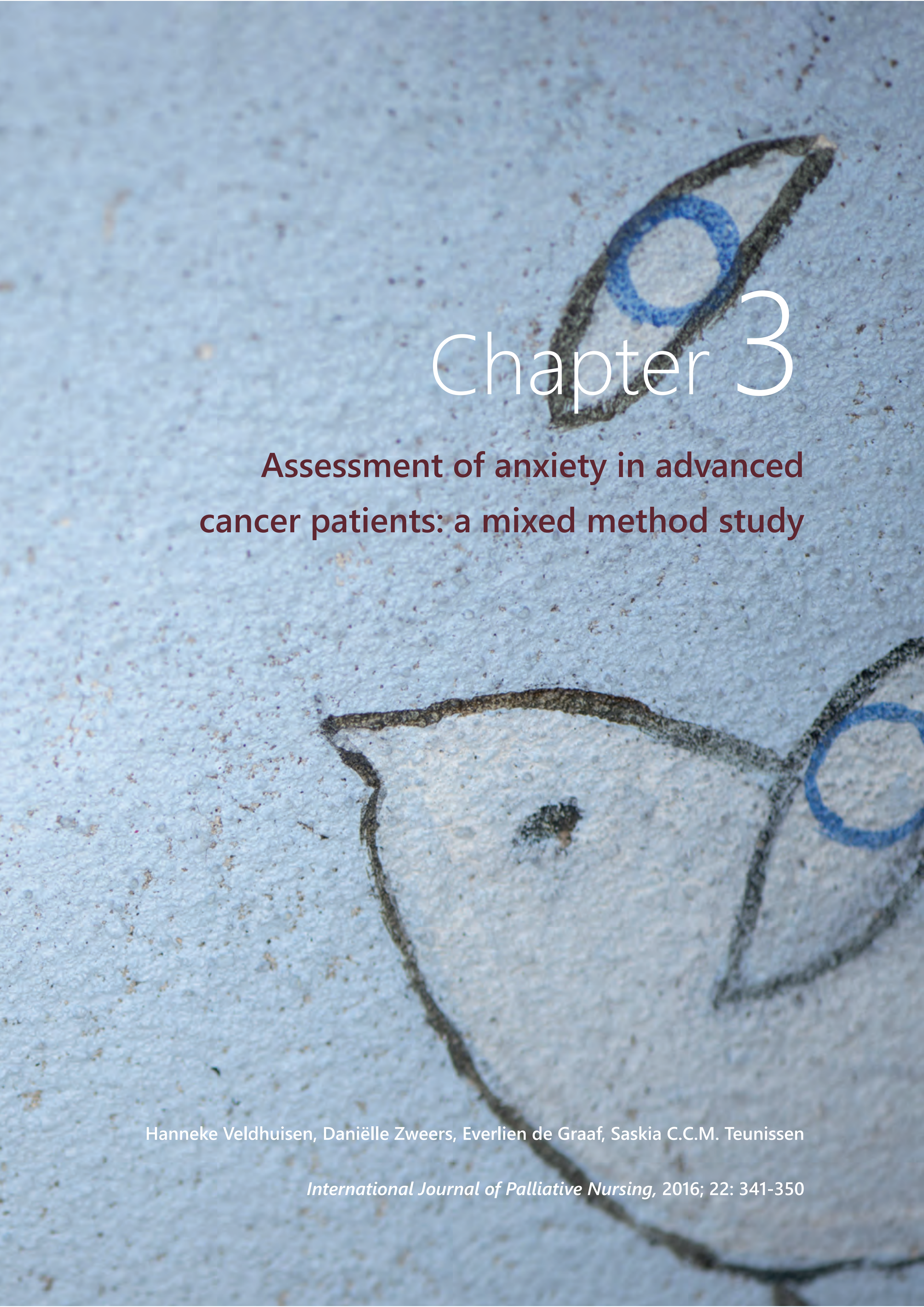

Chapter 3

Assessment of anxiety in advanced cancer patients: a mixed method study

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Abstract

Background: Anxiety is a risk for reduced quality of life in advanced cancer patients. However, it is an overlooked symptom without routine use of instruments to assess anxiety.

Aim: To gain insight into the use of instruments by nurses to assess anxiety in advanced cancer patients and the rationale behind.

Methods: Data with regard to nurses' use of instruments were collected from medical records of 154 patients in three settings. Additionally, 12 nurses were interviewed.

Findings: Four instruments were used to assess anxiety. The frequency of assessed anxiety differed among settings. The application of instruments guided patient care and improved communication. Lack of knowledge was the main reason not to use instruments.

Conclusions: Application was influenced by patient- and environmental factors, knowledge, attitudes and beliefs of nurses. Multifaceted strategies, leadership and education of nurses in the assessment and analysis of anxiety is needed to improve symptom management in advanced cancer patients.

Introduction

Anxiety is a common symptom in advanced cancer patients and data from 7270 patients showed a pooled prevalence of 30%[1]. Carpenito-Moyet (2010) described anxiety as: 'A state in which an individual experiences feelings of uneasiness and activation of the autonomic nervous system in response to a vague, nonspecific threat'[2].

Anxiety can fluctuate at critical time points in the illness trajectory and is often seen as an understandable reaction to the threat of cancer, treatment and progression of illness[3]. Moreover, anxiety may affect effective decision-making and could cause exacerbation of other symptoms, for example pain and dyspnea[3, 4]. Furthermore, anxiety is associated with impaired quality of life[5, 6].

Symptom management, as a systematic approach to observe, monitor and treat symptoms and evaluate the effect of interventions, is a key component of palliative care[7]. Adequate symptom management should start with routine assessment using appropriate instruments to facilitate early identification of symptoms and monitor symptom intensity over time[1].

The studies of Rhondali et al and Mehle et al have demonstrated that anxiety is one of the most underrecognised symptoms without assessment with validated instruments[8, 9]. Research has shown that decisions based on clinical impression alone have the potential to be biased and have an overall low accuracy to detect patients' distress[8]. In addition, patients rarely express their feelings of anxiety directly during regular consultations[10]. Therefore, anxiety should be routinely assessed, which means daily, weekly or monthly depending on the situation of the patient, using appropriate instruments within a systematic approach[3, 11-13]. Routine assessment of anxiety in daily care for admitted patients is necessary to 1) ameliorate early identification of anxiety, 2) understand the underlying causes of anxiety and influencing factors, 3) assess if anxiety is significantly impairing, and 4) improve and facilitate interdisciplinary communication and collaborative care[3, 4, 11, 13, 14]

Although routine assessment of anxiety using appropriate instruments is well recognised, Bruera (2008) and Rhondali et al (2012) have shown that these instruments were seldom used in daily care for admitted patients[8, 11]. The main reasons for clinicians not to use instruments in the assessment of anxiety were the assumptions that 1) patients are not able to grade their symptom intensity, 2) routine assessment is too time-consuming for patients, families as well as for professionals and 3) the standard consultation and the clinical observations of the bedside nurse are sufficient to recognise all symptoms[11, 12, 15]

Particularly outside office hours, nurses are generally the first professionals to be confronted with patients who suffer from anxiety and are therefore in the best position to assess. Although some of the barriers for clinicians to use instruments have been identified, it remains unclear why nurses do not take advantage of instruments to assess anxiety in vulnerable advanced cancer patients.

To improve routine assessment of anxiety and consequently decrease the amount of unrecognised needs in advanced cancer patients, more insight into the use of instruments in nursing practice is needed. Therefore, this study aims to evaluate the nursing practice in using instruments to assess anxiety and gain insight into the rationale behind the choice of nurses whether or not to use instruments in the assessment of anxiety.

Method

Design

This study is a descriptive study using a sequential explanatory mixed methods design combining quantitative and qualitative data (*Figure 1*)[16]. In this study, the quantitative data on instrument use was collected from medical records retrospectively. To explain the quantitative results, semi-structured interviews were performed to understand the rationale behind the choice of nurses whether or not to use instruments in the assessment of anxiety.

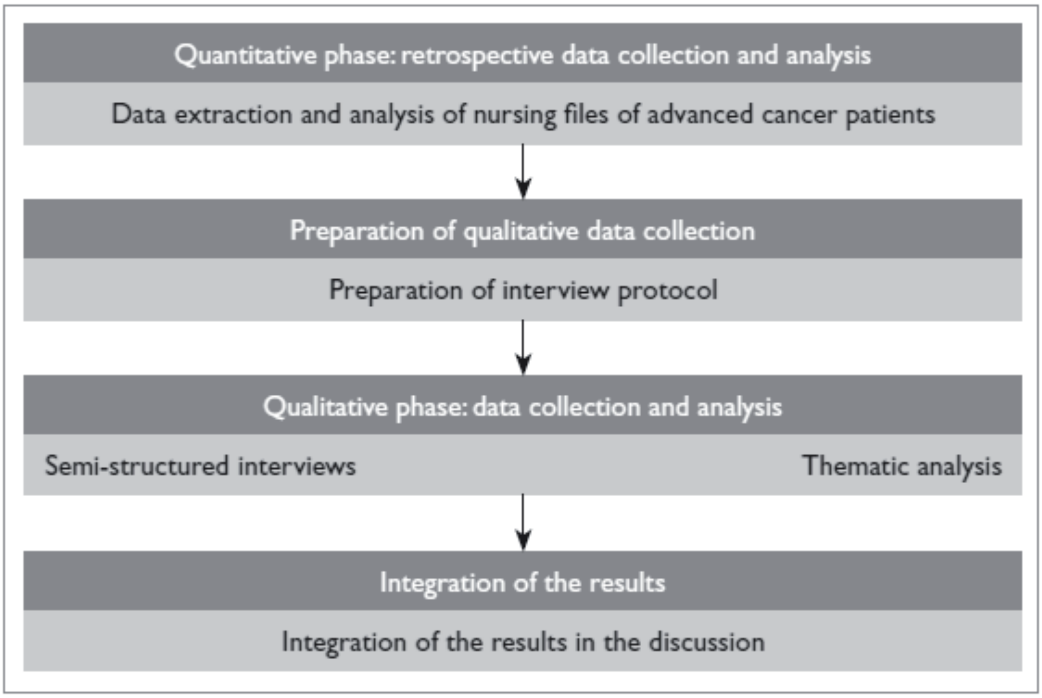


Figure 1: Schematic representation of the explanatory mixed method design

For the quantitative phase, consecutive sampling was used to select all discharged or deceased patients in the included settings during 5 months (October 2012—February 2013). Eligible patients had to be >18 years of age and diagnosed with advanced cancer before or during admission. If a patient was admitted before the start of the study, but was discharged or deceased during the research, data from the entire admission were analysed. Readmissions and transfers of patients among settings were analysed as ‘new encounters’ to get insight into the full range of possible assessments.

For the qualitative phase, registered nurses and nursing students working at one of the three settings were invited to participate. Nursing students were also invited to take part to evaluate the contribution of their education regarding instrument use to assess anxiety (*Box 1*).

In the Netherlands nursing students are involved in daily patient care in a supervision model together with (specialised) registered nurses (RNs). Each ward in each hospital in the Netherlands has a blended team structure with RNs, specialised RNs and nursing students. Depending on the level of complexity of nursing diagnoses or problems, nurses and nurse students will be involved in the care of the patient.

Box 1: Nursing students in the Netherlands

The key individuals in the settings were asked to send an email with study information to all eligible nurses and nursing students. The nurses who agreed to take part sent an email to the researcher. Initially, three nurses per setting were interviewed. Sampling continued until saturation was reached.

Sample/participants

A convenience sample was drawn to select three settings in the Netherlands: 1) a university hospital (department of medical oncology), 2) a general hospital (department of respiratory lung diseases), and 3) a hospice.

Data collection

Quantitative phase

Data on the applied instruments were extracted from the medical records using a purpose-developed data collection tool[17]. An overview of applied instruments to assess anxiety was collected by type and frequency of used instruments. Anxiety in the medical records was analysed by three items: 1) presence or absence on admission, 2) presence or absence during admission, 3) in case of prevalent anxiety, the frequency anxiety was mentioned in the medical record. After a pilot test on face validity and feasibility of the data collection tool the intensity score of anxiety measured by the instruments was added.

The following demographics were collected: age, gender, primary cancer site, duration of admission in days, survival from the day of admission, and functional status assessed with the Karnofsky's Performance Scale (KPS)[18].

The KPS runs from 100 to 0 where a higher score indicates a better performance of daily activities. The KPS score was obtained from the nursing assessment in the first 24 hours after admission. If the KPS was not described, a researcher classified the KPS score based on the available information about physical functioning described in the medical record.

Qualitative phase

After the quantitative phase, the interview schedule was developed, directed by the quantitative results. The interview questions aimed to clarify how nurses discuss anxiety with the patient and if nurses use instruments to assess anxiety. Furthermore, why nurses use or do not use instruments, how the use of applicable instruments was integrated into daily care and the use of setting specific methods with regard to how, when and why instruments were used to assess anxiety. Finally, if nurses used instruments to assess anxiety, they were asked to describe a patient situation in which they had done so. Before the interview, demographics of the participating nurses were collected. One of the researchers interviewed all the nurses.

Ethical considerations

Ethical permission to conduct this study was obtained from the local research ethics committee (protocol number 13-006/C) based on Dutch regulations. Furthermore, the management of the facilities gave permission to perform this study within their setting and to use the patient information anonymously. Written informed consent was obtained from the nurses taking part in the interviews.

Data analysis

The quantitative data was analysed descriptively. To analyse group differences the Pearson's Chi-square for categorical data was used. Continuous data were analysed using the Kruskall-Wallis test and if appropriate, the Mann-Whitney U test, to analyse differences between two settings[19, 20]. All statistical analyses were performed using the Statistical Package for the Social Sciences (Version 22.0; IBM Corp, US), with a two-sided alpha of 0.05. Thematic analysis was performed by two researchers to reduce the transcribed interviews into themes using NVivo for Windows (Version 10; QRS international, US).

Validity and reliability

Several precautions were taken to ensure reliability and validity of the data. First, because data selection took place in the same setting, comparison of quantitative and qualitative data was realised. Second, the development and testing of the data collection tool resulted in a systematic approach, which has improved the reliability, validity and reproducibility of the results[17].

Trustworthiness

To increase credibility, the researcher was trained in interviewing the participants. The interviews were digitally recorded and transcribed verbatim by one researcher. Dependability of the interviews was enhanced by the use of an interview schedule with standardised questions and by analysing data by two researchers working independently. Both researchers came to an agreement about the formulation of the themes. Furthermore, member checks were carried out, peer-debriefing discussions were organised and methodological memos were used to reflect on the interviewers' role and to record methodological issues[21]. To establish the transferability of the data, thick description was performed. Furthermore, a native speaker translated the quotations.

Results

Quantitative phase

In total, 154 eligible patients were included in this study, 42% were male, the average age was 63 years (range 27-92). Demographics are presented in Table 1. At the moment of analysis, 69 patients were deceased with a median survival of 29 days after admission (range 1–173). Readmission took place in 32 patients at the university hospital and in 73 patients at the general hospital. The main reason for readmission was chemotherapy treatment. Three patients were transferred from a hospital to the hospice.

Table 1: Demographics of patients (n=154)

	University hospital	General hospital	Hospice	Total
Patients N (%)	69 (45%)	59 (38%)	26 (17%)	154 (100%)
Gender:				
Male N (%)	28 (40%)	26 (44%)	11 (42%)	65 (42%)
Age in years:				
Mean (range)	58 (27-81)	66.7 (40-87)	70.2 (33-92)	63.4 (27-92)
Primary cancer site N (%):				
Breast	7 (10%)	1 (1%)	4 (15%)	12 (8%)
Gastrointestinal	28 (41%)	0 (0%)	3 (12%)	31 (20%)
Respiratory tract	3 (4%)	56 (95%)	9 (35%)	68 (44%)
Genitourinary tract	23 (33%)	1 (1%)	6 (23%)	30 (19%)
Other or unknown	9 (13%)	1 (1%)	4 (15%)	14 (9%)
Mean days of admission (range)	6.2 (1-20)	5.6 (1-48)	31.3 (2-173)	8.44 (1-173)
Number of admissions	101	132	26	259
Readmissions N (%)				
2-3 periods	25 (25%)	46 (35%)	0 (0%)	71 (27%)
>3 periods	7 (7%)	27 (21%)	0 (0%)	34 (13%)
KPS per admission				
10-20	2 (2%)	2 (2%)	8 (31%)	12 (5%)
30-40	8 (8%)	5 (4%)	13 (50%)	26 (10%
50-60	16 (16%)	19 (14%)	2 (8%)	37 (14%)
70-80	50 (50%)	71 (54%)	2 (8%)	123 (48%)
90-100	6 (6%)	10 (8%)	1 (4%)	17 (7%)
Unknown	19 (19%)	25 (19%)	0 (0%)	44 (17%)

Instruments to assess anxiety were used in 67% of the admissions at the university hospital and in 100% of the admissions at the hospice. In the general hospital, no instruments were used. In total, four different instruments to assess anxiety were found (Table 2):

- The Distress Thermometer (DT)[22]
- The Utrecht Symptom Diary (USD), a Dutch adapted translation of the Edmonton Symptom Assessment System where patients score their symptoms on 10-point scale[23]
- The Utrecht Symptom Diary Professional (USD–P), an adapted version of the USD where symptoms are scored by the professional on a 5-point categorical scale
- The Hospital Anxiety and Depression Scale (HADS)[24]

The mean application of the USD was higher for patients admitted to the hospice (11.1) as compared to patients admitted to the university hospital (1.8).

Table 2: Mean Anxiety in medical record and mean application of instrument per setting

	University hospital	General hospital	Hospice	Total
Application of one or more instruments per admission N (%)	6 (67%)	0 (0%)	26 (100%)	93 (36%)
Frequency of used instruments:				
Distress thermometer (median)	2 (1)	0 (-)	0 (-)	2
USD (median)	179 (2)	0 (-)	246 (2)	425
USD-P (median)	0 (-)	0 (-)	521 (12)	521
HADS (median)	5 (1)	0 (-)	0 (-)	5
Median application per admission				
USD (range)	1.8 (0-9)	- (-)	11.1 (0-94)	3.4
USD-P (range)	- (-)	- (-)	19.6 (1-125)	-

USD=Utrecht Symptom Diary; USD–P=Utrecht Symptom Diary Professional; HADS=Hospital Anxiety an Depression Scale.

As indicated in Table 3, anxiety was explicitly mentioned thirteen times at admission in the medical records of the university hospital patients, three times in the general hospital patients and for eight patients in the hospice population. The prevalence of anxiety in the medical records was 33 (33%) at the university hospital, 15 (11%) at the general hospital and 16 (62%) at the hospice.

Table 3: Assessment of anxiety per admission/per setting (n=259 admissions)

	University hospital N=101 admissions	General hospital N=132 admissions	Hospice N=26 admissions	Total N=259 admissions	P-value
Prevalence of anxiety on admission (%)	13 (13%)	3 (2%)	8 (31%)	24 (9%)	
Prevalence of anxiety during admission (%)	33 (33%)	15 (11%)	16 (62%)	64 (25%)	0.000[1]
Application of one or more instruments per admission (%)	68 (67%)	0 (-)	26 (100%)	93 (36%)	

[1] Pearson's chi-square test

As shown in Table 4, the intensity of anxiety scored on the USD was significantly higher (*p*=0.019) in patients admitted to the university hospital as compared to those admitted to the hospice.

Table 4: Anxiety scores (n=259 admissions/ n=154 patients)

	N	University hospital	General hospital	Hospice	Total	P-value (95% CI)
Distress thermometer [A]	2	1	-	-	1	-
Mean score USD anxiety (SD) [range]	425	1.8 (2.4) [0-10]	-	1.1 (1.8) [0-10]	1.4 (2.1)	P= 0.019[1]
Scores > 1 on USD anxiety N (%)	425	97 (54%)	-	135 (55%)	232 (55%)	-
Mean score USD-P anxiety (SD) [range]	521	-	-	0.3 (0.7) [0-4]	0.3 (0.7)	-
Scores > 1 on USD-P anxiety N (%)	521	-	-	117 (23%)	117 (23%)	-
Mean score HADS-A (SD) [range]	5	10.3 (4.0) [7-16]	-	-	10.3 (4)	-

CI= Confidence interval; [A] Anxiety present on Distress thermometer; USD= Utrecht Symptom Diary; USD-P= Utrecht Symptom Diary Professional; HADS-A= total score on Hospital Anxiety and Depression Scale Anxiety subscale; SD= Standard Deviation; [1] Mann-Whitney U test.

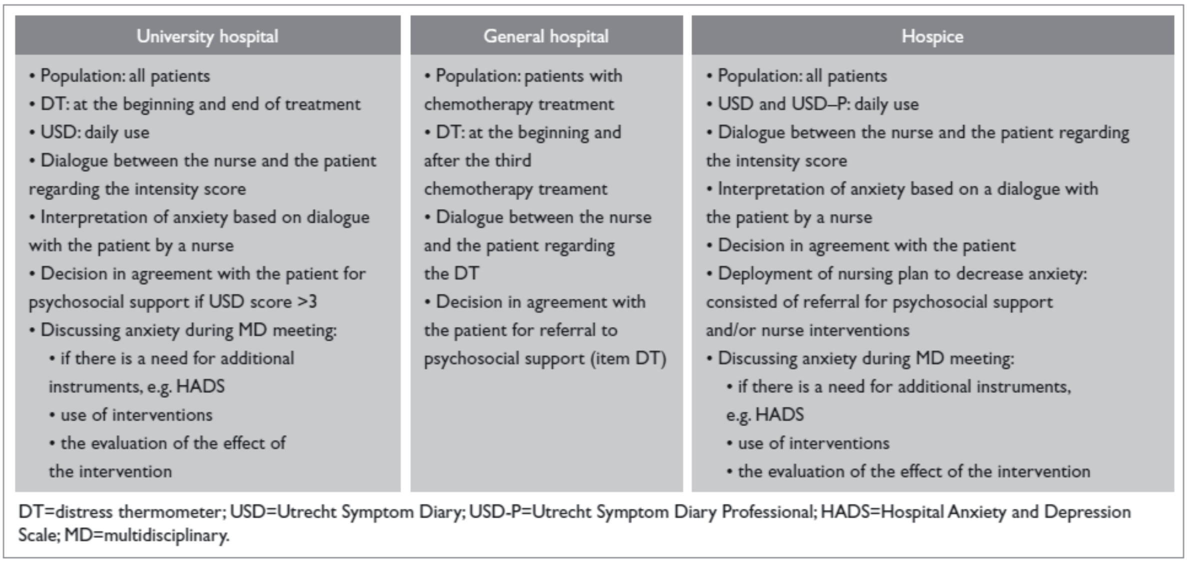
Qualitative phase

From April to May 2013, eleven registered nurses and one nursing student in the final year of her bachelor study took part in the interviews. Of this group, three were not experienced and nine were experienced in the use of instruments to assess anxiety. The mean age was 41 (range: 23–61) and most nurses had 11–15 years of work experience (Table 5). Saturation was reached after interviewing three to five nurses per setting. Member checks were performed whereas in two transcripts minor adjustments were made: one sentence was nuanced and a spelling mistake was corrected.

Table 5: Demographics of interviewed nurses (n=12)

	University hospital	General hospital	Hospice	Total
N	4	5	3	12
Female	3	5	3	11
Mean age [range]	39.8	42.6	40	41
	[23 – 53]	[25 – 61]	[30 – 52]	[23 – 61]
Work experience in years				
0-4	1	1	1	3
5-10	1	1	1	3
11-15	2	3	1	6
Average workweek in days	3.6	3.2	2.7	3.2
Education				
Vocational	-	2	2	4
Bachelor	2	2	1	5
Master	1	-	-	1
Bachelor nurse student	1	-	-	1
Advanced education				
None	1	1	1	3
Pulmonology	-	2	-	2
Oncology	3	2	-	5
Palliative care	-	-	2	2
Geriatric	-	-	1	1
Mean duration interview in minutes [range]	26.8	20.6	37	26
	[24 – 32]	[14 – 27]	[31 – 44]	[14 – 44]

In all three settings, different methods were used to assess anxiety with one or more instruments (*Figure 2*). In both hospitals the DT was used to identify symptoms, as well as anxiety. The nurses in the university hospital used the DT at admission whereas specialised cancer nurses at the general hospital used the DT at admission as well as before the first and third dose of palliative chemotherapy. In the university hospital the USD was applied after the first identification with the DT to monitor the intensity of anxiety over time and to evaluate the effect of interventions. During the study no instruments at all were applied in the general hospital and further assessment of anxiety was not carried out. At the university hospital and at the hospice the HADS was used if the USD anxiety score was >3, to determine if a patient might meet the criteria for an anxiety disorder. In the hospice, application of the HADS was reserved for highly experienced nurses.



University hospital	General hospital	Hospice

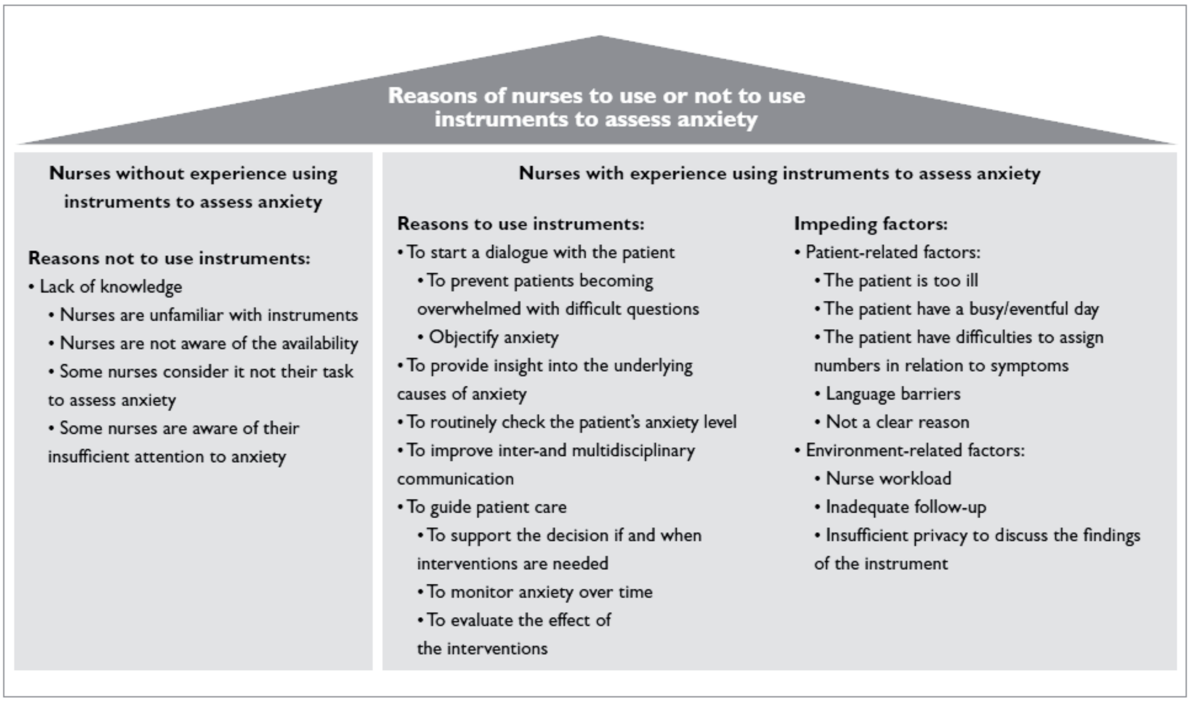
• Population: all patients
• DT: at the beginning and end of treatment
• USD: daily use
• Dialogue between the nurse and the patient regarding the intensity score
• Interpretation of anxiety based on dialogue with the patient by a nurse
• Decision in agreement with the patient for psychosocial support if USD score >3
• Discussing anxiety during MD meeting:
  • if there is a need for additional instruments, e.g. HADS
  • use of interventions
  • the evaluation of the effect of the intervention
	• Population: patients with chemotherapy treatment
	• DT: at the beginning and after the third chemotherapy treament
	• Dialogue between the nurse and the patient regarding the DT
	• Decision in agreement with the patient for referral to psychosocial support (item DT)
		• Population: all patients
		• USD and USD–P: daily use
		• Dialogue between the nurse and the patient regarding the intensity score
		• Interpretation of anxiety based on a dialogue with the patient by a nurse
		• Decision in agreement with the patient
		• Deployment of nursing plan to decrease anxiety: consisted of referral for psychosocial support and/or nurse interventions
		• Discussing anxiety during MD meeting:
		  • if there is a need for additional instruments, e.g. HADS
		  • use of interventions
		  • the evaluation of the effect of the intervention

DT=distress thermometer; USD=Utrecht Symptom Diary; USD-P=Utrecht Symptom Diary Professional; HADS=Hospital Anxiety and Depression Scale; MD=multidisciplinary.

Figure 2: Multidisciplinary methods to assess anxiety with instruments per setting

In the university hospital and the hospice the assessment of anxiety was integrated in the multidisciplinary approach of care and in the routine of daily practice.

The findings were summarised by two themes (*Figure 3*): nurses with experience using instruments to assess anxiety and their reasons to use or not to use instruments, versus nurses without experience in using instruments and their reasons not to.



Reasons of nurses to use or not to use instruments to assess anxiety

Nurses without experience using instruments to assess anxiety

Reasons not to use instruments:

- Lack of knowledge
  - Nurses are unfamiliar with instruments
  - Nurses are not aware of the availability
  - Some nurses consider it not their task to assess anxiety
  - Some nurses are aware of their insufficient attention to anxiety

Nurses with experience using instruments to assess anxiety

Reasons to use instruments:

- To start a dialogue with the patient
  - To prevent patients becoming overwhelmed with difficult questions
  - Objectify anxiety
- To provide insight into the underlying causes of anxiety
- To routinely check the patient's anxiety level
- To improve inter-and multidisciplinary communication
- To guide patient care
  - To support the decision if and when interventions are needed
  - To monitor anxiety over time
  - To evaluate the effect of the interventions

Impeding factors:

- Patient-related factors:
  - The patient is too ill
  - The patient have a busy/eventful day
  - The patient have difficulties to assign numbers in relation to symptoms
  - Language barriers
  - Not a clear reason
- Environment-related factors:
  - Nurse workload
  - Inadequate follow-up
  - Insufficient privacy to discuss the findings of the instrument

Figure 3: Perceptions of nurses to use instruments to assess anxiety

Nurses with experience using instruments to assess anxiety

A lack of knowledge of appropriate instruments to assess anxiety was the main reason why nurses in the general hospital did not use instruments. Nurses in the general hospital indicated that they were not aware of the availability and unfamiliar with instruments to assess anxiety. Furthermore, some nurses at the general hospital noted that the assessment of anxiety was not required. In the general hospital only specialised cancer nurses were responsible for the assessment of anxiety. One of the nurses expressed an awareness of probable insufficient attention to anxiety (Box 2).

> *'The only thing I am vaguely aware of is a measure of wellbeing for cancer patients, but even for that, I do not really know how to use the instrument.' (Nurse 3: general hospital)*

Box 2

Nurses with experience using instruments to assess anxiety

For nurses with experience in the application of instruments (DT, USD) to assess anxiety, the main motivation for use was to start a dialogue about anxiety with patients and family caregivers (*Figure 3*). Through a close dialogue nurses were able to obtain insight into the underlying causes of anxiety that otherwise had not emerged. They felt that most patients appreciated the opportunity to share their feelings. Furthermore, nurses indicated that daily use of instruments can assure a routine focus on anxiety, objectify anxiety and prevent patients becoming overwhelmed (Box 3).

> *'It is also a good starting point to initiate a dialogue. Then you don't have to ask difficult questions out of the blue, so you are less likely to overwhelm them. (Nurse 4: university hospital)*

Box 3

To interpret the burden for the patient, nurses discussed the results measured by the applied instrument in a dialogue with the patient. The results of this discussion were used in the multidisciplinary team to support the decision-making process with regard to the individual patient care. For example, during interdisciplinary consultation the appropriateness of the HADS to assess if anxiety is significantly impairing or if the patient might meet the Diagnostic and Statistical Manual of Mental Disorders criteria was discussed (Box 4, 5).

'I have noticed over the last year that it really does work, especially if you have a dedicated weekly meeting with other professionals. Then a standard way to measure things is extremely useful to gain more insight into patient's problems.' (Nurse 3: hospice)

Box 4

'Now we really should do something about that, then I will make it a point of discussion in the team to see if it's something that we should discuss with someone external, with whom we can think it through.' (Nurse 4: university hospital)

Box 5

The results of the patient USD were also used to monitor anxiety in the course of time and to evaluate the effect of interventions. The rationale behind the use of instruments among nurses can be categorised into patient-related and environmental-related factors. Patient-related factors were 1) patients were too ill, which made it difficult for nurses to burden them, 2) there were too many activities for patients because of medical examinations in the hospital or visits from family and friends, 3) it was difficult for patients to assign numbers in relation to their feelings of anxiety, 4) patients had difficulties with understanding the Dutch language, 5) patients preferred not to complete the instrument without a clear reason to do so.

Nurses respected the choice of patients not to fill out an instrument for all reasons. In some cases nurses made adjustments based on the individual needs of the patient. The information was filled in biweekly instead of twice a week (Box 6, 7).

'The only difficult thing for me is when patients are unwilling or unable to fill in an instrument. Then you have to find another way to discuss symptoms with them.' (Nurse 3: hospice)

Box 6

'Thinking in terms of numbers is only suitable for a certain type of person. For some patients it is very hard to give feelings a number.' (Nurse 2: university hospital)

Box 7

According to the interviewed nurses, the main environmental factor was workload. The most time-consuming instrument to use was the HADS. Other environmental factors were a lack of privacy and inadequate follow-up, especially in the general hospital (Box 8, 9).

> *'For example, that you have had a busy shift, with lots of patients to care for and then, I see it happen to colleagues regularly, there is no time to fill in the USD. There was just no time to go and sit with the patients'. (Nurse 1: hospice)*

Box 8

> *'We do worry a bit that you can fill it all in nicely, but that you cannot really do a lot with it after that.' (Nurse 2: general hospital)*

Box 9

Discussion

Anxiety is felt as a difficult symptom to address in advanced cancer patients. The aim of this explanatory mixed methods study was to understand the current nursing practice in the use of instruments to assess anxiety in advanced cancer patients and to provide insight into the rationale behind the use of instruments by nurses. To the best of the authors' knowledge this is the first study about the application of instruments to assess anxiety by nurses in cancer care in different settings.

Quantitative and qualitative data together suggest that assessment of anxiety with instruments in daily nursing practice is influenced by different assessment methods within the setting, patient-related factors and nurse-related factors.

Reflection on used instruments

Nurses in this study used only four different instruments. A non-systematic exploration of the literature shows an availability of at least eleven different instruments to assess anxiety. The authors hypothesise that the selection of the used instruments came up in relation to the Dutch national guidelines for palliative care[25]. However, the authors' results show that the DT and the HADS were rarely used by nurses. This is especially interesting because the DT and HADS are internationally validated measurement instruments, whereas the USD is only validated in the Netherlands (validation study submitted for publication).

Methods to assess anxiety

This study showed differences between the settings regarding the used instruments and the specific application. This seemed to be more a management decision than an individual decision of the nurses. This remained underexposed in this study. The differences between both hospitals may also be explained by the specialisation of the departments and the academic nature of the university hospital, which encourages the use of instruments. A finding was that nurses were seldom aware of the underlying objective of the used instrument in relation to other instruments. Adherence in using instruments increased when clear methods were implemented on how to interpret the results of the instrument and how to integrate these findings in daily care. This is in line with the findings of Bruera's study, which showed that nurses found it demoralising to assess anxiety if there was no treatment plan[11].

Patient-related and environmental factors

The use of instruments could be affected by patient-related factors. Nevertheless, the mean application of the USD in the hospice was higher compared to the university hospital. This result supports the findings of the Graaf et al, a study that demonstrated that most patients were able to self-assess their symptoms[26].

Only the oldest and very ill patients were less able to assess their symptoms. Most patients admitted to the hospice had reduced KPS scores, but were nevertheless able to self-assess their symptoms. Other influencing factors such as differences in length of admission and readmissions could possibly have affected the mean application of instruments, which were not analysed. According to the interviewed nurses and confirmed by the study of Bergh et al, some patients have difficulties in ranking the intensity of their experienced anxiety[15]. This can cause doubt regarding the accuracy of the results of the use of instruments. Therefore, the dialogue with the patient and family caregivers is essential to give meaning to the results of the instruments for that individual patient. The lack of a clear explanation by nurses for the patient as to why instruments were used and how patients should fill out the instrument could, be a cause of the patient-related barriers as well. Still, as mentioned earlier, not all patients are able to fill out an instrument.

However, we can learn from the hospice setting. Hospice care nurses used the USD-P to assess the patient's symptom burden and evaluate the effect of interventions if the patients were not able or not willing to self-assess their symptom intensity. Although professionals appear to underestimate anxiety[8], the use of professional-rated instruments is a strategy to maintain routine awareness to anxiety and support professionals in starting a dialogue with the patient and their family caregivers. This study also emphasises that the environmental factors should be addressed as a precondition to use instruments. Although some of those factors are management issues, nurses should be educated on how they can implement the use of instruments in the daily care efficiently.

Nurse-related factors

Besides patient- and environmental-related factors, this study also highlights the attitudes and beliefs of nurses. The decision whether or not to use instruments to assess anxiety is associated with the need to provide insight into the patient's anxiety versus the burden for the patient and the workload of the nurse. However, most nurses emphasised the importance of using instruments to initiate a dialogue, to give meaning to the intensity score and get insight into the symptom burden of the patient.

Nurses without experience lacked knowledge in the assessment of anxiety and on how and when to use the instruments. Furthermore, some nurses explained that using instruments was not their responsibility. Apparently, nurses did not always take the responsibility to assess anxiety and to routinely ensure awareness. These findings emphasise the importance of the required knowledge and competencies on how to use instruments and nursing leadership to implement the integration of the results in daily care. Standard consultations covering symptom assessment and time investment, were not mentioned by nurses in this study, which is in contrast with the findings of Bruera et al[11].

Limitations

This explanatory mixed methods study resulted in a rich and unique explanation of nursing practice in the application of instruments to assess anxiety in advanced cancer patients. The strength of this study is the inclusion of three settings, including early palliative care patients as well as end-of-life care patients. Furthermore, saturation was reached in interviews in a population of nurses with a variety in age, experience and education.

However, there are some limitations. First, the findings may not be generalisable to a homogeneous population because the population consisted of a heterogeneous cancer population in three settings in the Netherlands. Second, retrospective findings using medical records can be limited due to incomplete documentation of anxiety. Third, selection bias may have occurred because the authors only selected nurses who were interested to take part. Fourth, the influence of the management within the settings was not included in this study. Fifth, eligible nursing students were scarce, which resulted in the inclusion of only one student. Sixth, the attitudes and beliefs of the student did not differ from registered nurses and was therefore not highlighted in this study. Finally, during the interviews the researcher worked in the general hospital, which could have influenced the results with nurses from the same workplace.

Recommendations

The authors propose that more attention needs to be paid to the different objectives of the instruments. They suggest an integrated approach of instrument use along the different objectives of instruments: early identification, monitoring, screening or diagnosing. This approach with an increasing level of a narrowing scope supports nurses to use appropriate instruments to assess anxiety in line with the patients' needs and use instruments as a way to provide essential information and initiate a dialogue rather than an aim on its own. In addition, competency levels of nurses should be integrated in this approach. For example, instruments for early identification of anxiety could be used by nurses with a basic competency level, whereas using instruments to judge if anxiety is significantly impairing, requires a more advanced level. Nursing leadership, multifaceted strategies and education is needed to stimulate nurses to use instruments and address patient- and environmental-related barriers. Further research should focus on patient-related barriers. In the meantime, nurses should clearly explain to the patient why and how instruments are used. For patients who are not able to self-assess their symptoms, professional-rated instruments like the USD–P can be used to maintain structural awareness. The results of observer rate instruments in relation to patient-rated instruments should be further analysed. Considering daily patient care, development of an algorithm should be a next step in anxiety management to translate the scores and interpretation into a standard for selection of interventions based on the underlying causes of anxiety.

Conclusion

Nursing practice to assess anxiety through the use of instruments differs among inpatient settings. The used instruments were a selection of four out of at least 11 instruments, according to the literature. The use of instruments was influenced by the methods to assess anxiety within the setting, patient- and environmental-related factors and most important, by the knowledge, competencies, attitudes and beliefs of the individual nurse. All settings had different methods on how and when to use instruments to assess anxiety despite available national guidelines. Most nurses emphasised the importance of using instruments to assess anxiety to initiate a dialogue, to give meaning to the intensity score and the burden of the patient. A lack of knowledge and competencies in using instruments in the assessment of anxiety was the main reason for nurses in this study not to use instruments. The authors assume these findings will be similar in other European countries. Therefore, more clarity about the objectives of the instruments is needed for the application of instruments to assess anxiety in the nursing domain. Moreover, ongoing passionate leadership along with multifaceted strategies is needed to improve nurses' knowledge and competencies. If nurses are supported by the management and equipped with the right education and tools on how and when to use appropriate instruments, routine assessment will presumably increase, which is essential to decrease the unmet needs regarding anxiety in advanced cancer patients.

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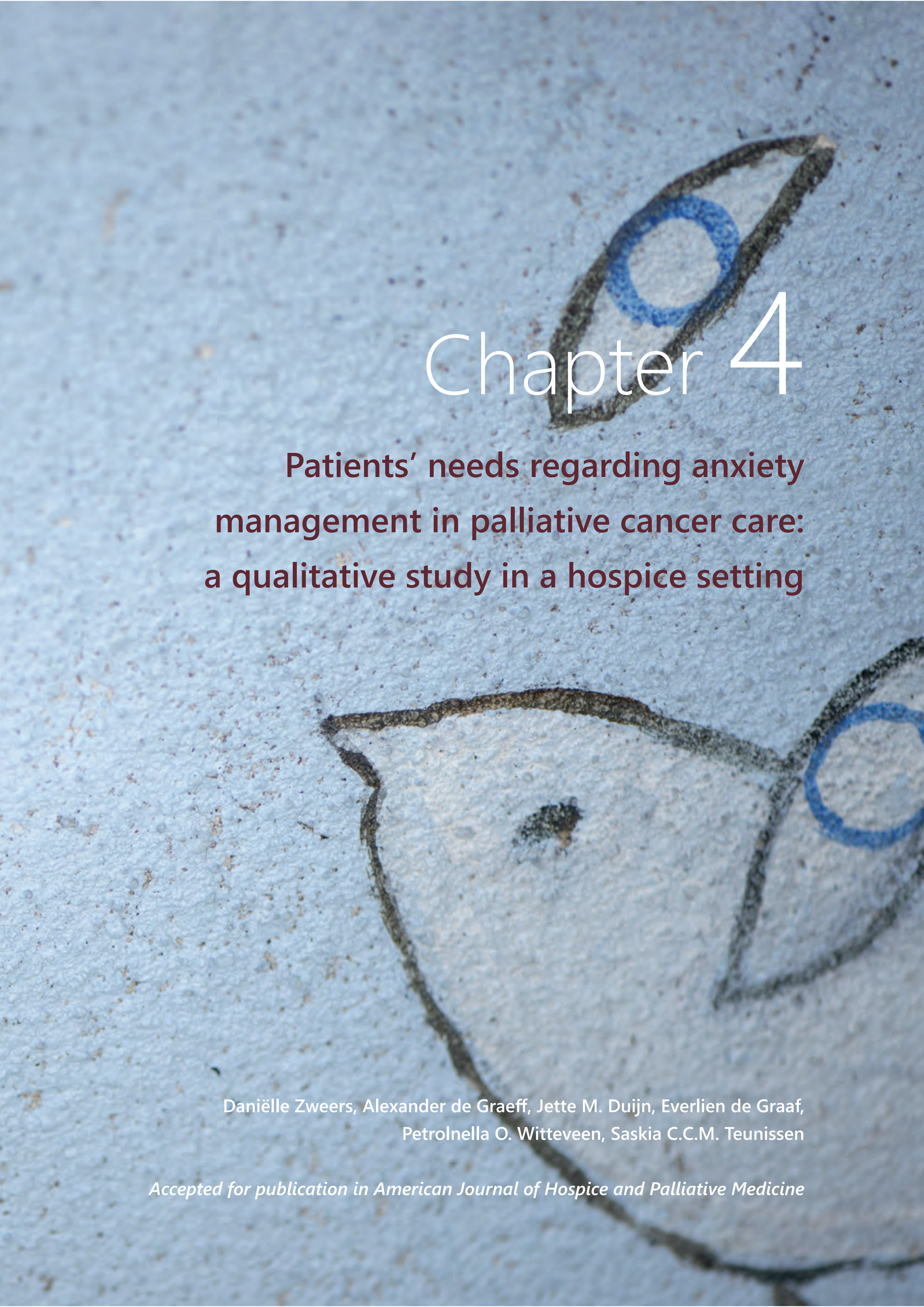
Part II



Chapter 4

Patients’ needs regarding anxiety management in palliative cancer care: a qualitative study in a hospice setting

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Abstract

Introduction: Anxiety is a common symptom in the palliative phase and symptom management depends on the competencies of individual professionals. This study aims to get insight into the needs of anxious hospice patients with advanced cancer regarding support.

Method: Semi-structured interviews were performed in admitted hospice cancer patients . Patients admitted from May 2017 till May 2018 were eligible whether they were anxious or not. Interviews were analysed and coded within predefined topics.

Results: Fourteen patients were included: ten female, median age 71 and median WHO performance score 3. Most patients were highly educated. Thirteen patients were interviewed within 6 months before death. Information, open communication, sense of control, safety, adequate symptom management and respect for patients' coping strategy were the six main expressed needs.

Conclusion: Assessing patients' needs regarding anxiety provided important angles where healthcare professionals can make a difference, in order to support anxious patients in their final stage of life to realize tailored palliative care. Future research should focus on the development of a systematic approach for healthcare professionals to manage anxiety in daily care of terminal patients.

Introduction

Anxiety has been reported in 20-50% of patients with advanced cancer[1-5]. Anxiety is associated with increased symptom burden, depression, decreased physical, emotional, cognitive, role and social functioning and decreased quality of life[2, 6, 7]. In a German study, anxiety in patients admitted to a palliative care unit was one of the main reasons for palliative sedation8, emphasizing the impact of anxiety in the final stage of life.

Although the impact of anxiety is recognized, anxiety management in palliative care is a major challenge, due to the variety in contributing factors and expressions of anxiety, frequent presentation with physical symptoms and its bidirectional relationship with other symptoms[8]. One of the prominent unmet needs in patients with advanced cancer is the support for feelings of anxiety (e.g. for physical suffering), hopelessness and uncertainty about the future[9].

Hospice care nurses often struggle in supporting anxious patients, especially during late and night shifts when the presentation of anxiety is more intense[10]. Timely identification, support and treatment of anxiety are essential in patients with a limited life expectancy.

Management of anxiety benefits from a multidimensional team approach[11]. The consisting evidence regarding anxiety management is mainly focused on specialized psychosocial care[11]. Although specialized psychosocial care in hospices is provided by chaplains and social workers[12], nurses are confronted with anxious patients 24 hours a day, including difficult moments at night, when chaplains and social workers are not available[10]. Anxiety management in daily practice depends on nurses' individual competencies[10]. There is hardly any evidence about anxiety management by hospice nurses and doctors[13].

It is essential to realize the best fit between patients' needs and provided support[14]. The aim of this study is to get insight into the needs of anxious hospice patients with advanced cancer regarding their needs of daily support.

Methods

A qualitative interview study was performed. Eligible patients had advanced cancer, were admitted to a hospice in the Netherlands with 24/7 professional support, had an estimated life expectancy of <3 months, were >18 years of age and able to communicate in Dutch. Convenience sampling was applied, meaning all eligible patients were asked to participate in the study, whether they were anxious or not. Verbal and written information was provided by hospice nurses. Care after the interview, if needed, was provided by nurses and/or chaplain of the hospice. After informed consent an appointment was scheduled. The medical ethical committee determined the study to be outside the scope of the Medical Research Involving Human subjects Act (protocol number 17-082 March 2017).

Semi structured, face-to-face interviews were conducted by a trained researcher (DZ) between May 2017 and May 2018. The researcher had no professional relationship with the participants. An interview guide (appendix A) was developed, based on clinical expertise. The main topic of the interview was the patients' needs regarding anxiety. Two pilot interviews were conducted to test the interview guide and to reflect on the interview style. Minor textual adjustments were made. The pilot interviews are included in the final analysis. Patient characteristics, diagnosis, WHO performance score and the most recent anxiety score (a numerical rating scale from 0-10, 0 representing absence of anxiety, 10 the most severe anxiety), were collected beforehand. This anxiety score is included in the Utrecht Symptom Diary (USD) a translated and adapted version of the validated Edmonton Symptom Assessment System (ESAS)[15], which is part of standard care in the hospice and is completed twice a week by patients themselves. The interviews started with a discussion about the patients score on the USD and their reflection on anxiety. Then, underlying themes were explored in depth.

Data were analysed and structured by Nvivo (v11, QRS International). The topics of the interview guide formed the preconceived framework in which the codes and overarching themes were placed by two researchers (DZ, JD) independently after each interview (Appendix B). Data collection continued until code saturation was achieved[16].

To ensure trustworthiness interviews were audio-recorded, transcribed verbatim and field notes were made directly after the interview. During the analysis, theoretical and methodological memo's were made. Three peer debriefing sessions with specialist palliative care nurses of the hospices were organised during the process of analysis. Member checks were carried out by a spoken summary of the interviewer and the end of each interviews. An audit trail of those documents were kept to systematize, cross-reference and follow the data. Discrepancies were discussed in a broader research team until consensus was reached.

Results

Fourteen patients were included (Table 1): ten female, median age 71 and median WHO performance score 3. Most patients were highly educated. Thirteen patients were interviewed within six months before death. One patient was transferred to a nursing home, since his medical conditions improved.

Table 1: Patient characteristics

		Patients (n=14)
Age	Median	71
	Range	58 – 81
Gender	Male	4
	Female	10
Marital status	Married/ living together	8
	Single	6
Education	Community college	3
	Bachelor degree	4
	Master degree	7
Presence of caregiver	Yes	14
	No	0
Cancer diagnosis	Gastrointestinal	4
	Lung	2
	Breast	2
	Other	6
WHO performance score	Median	3
	Range	2-4
Survival after the interview (N=13)	Median	10 wks
	Range	1-27 wks

The interviews lasted 6-33 minutes. One interview was paused and one ended prematurely because the patients were too exhausted. After 14 interviews, saturation of codes was reached (Figure 1).

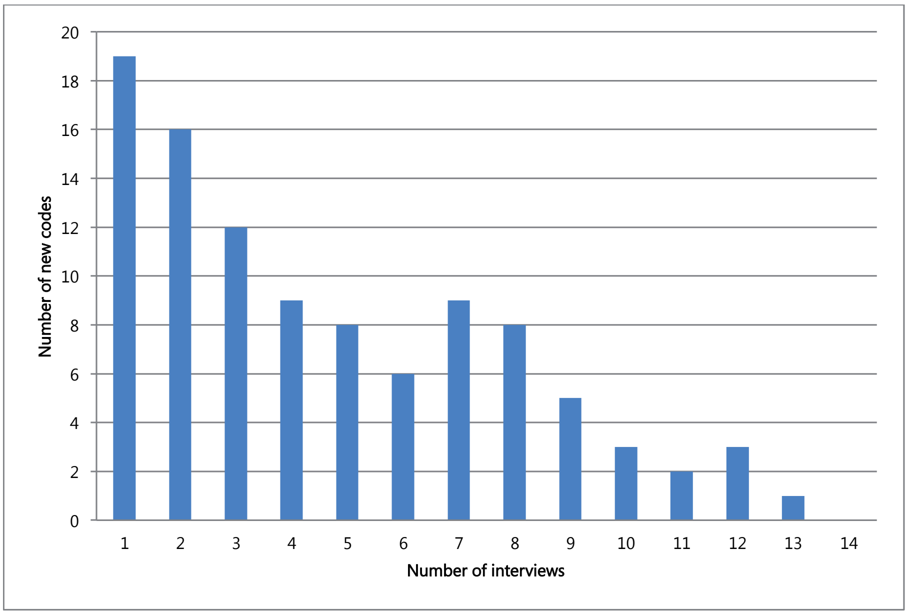

Figure 1: Number of new codes per interview

Level, impact and course of anxiety

The USD anxiety scores were 0 (9 patients), 1 (1), 3 (2), 6 (1) and 7 (1). During the interview all nine patients with a score of 0 came up with some type of anxiety, although it did not affect their daily life. These patients connected there low levels of anxiety to acceptation of their situation and stated that hope for cure was not relevant anymore and as a consequence, they felt less anxious (Box 1).

> *"When there is no hope there is no anxiety"* (patient 13)

Box 1

One patient told that her anxiety was manageable because she already lost so many things at this stage of her life. (Box 2).

> *"Anxiety is the highest when you can lose the most"* (patient 7)

Box 2

Synonyms of anxiety

More than half of the patients with a zero USD anxiety score described themselves as worried, tense, insecure or scared, but not as anxious.

Influencing factors regarding needs

When patients were asked about their needs regarding management of anxiety by the professional team, they predominantly focused on nursing support and sometimes medical support. None of the fourteen patients referred to the chaplain. Nurses are the most nearby according to most of the patients (Box 3).

> *"The nurses are the closest to me. The doctor is more like an intermediary to me. For me, the nurses should take care of anxiety, they know everything about it"* (patient 7)

Box 3

Patients talked about needs in order to decrease and prevent anxiety. Patients acknowledged that needs changed over time and depended on the level and source of anxiety at a specific moment. Prevention of crises and panic attacks was felt as crucial. This patient stated that her needs depended on the level of anxiety on that moment:. (Box 4).

"the deeper you are in, the more difficult it is to get out" (patient 8)
"which support will work depends on how deep you are in" (patient 8)

Box 4

Information and sense of control

The most frequently expressed need was honest information about their illness and what to expect regarding progression, treatment options, life expectancy and trajectory towards death. A major trigger for anxiety was the feeling that information "too worse to share" was kept behind. One patient mentioned that access to her patient record and checking information was helpful to reduce her anxiety. Another patient appreciated nurses discussing pain management in the room of the patient, instead of separate professional talks in another room. This also applied to a patient who frequently needed tracheal cannula care. These care moments were anxious for him, especially when nurses left the room to discuss what to do when something was wrong (Box 5).

"During daily care, when something was not right, they left the room to discuss with each other. I feel it when something is wrong, please tell me, maybe I can help. But don't leave me alone…" (patient 3)

Box 5

This need for information extended to many daily aspects of care, for example changes in medication.

The need for informed care was connected to the wish to be in control. Having no control of the situation was a major source of anxiety. Information about for example daily schedules gave them a sense of control (Box 6).

"I really need to know what is going to happen, not that you can always count on it because things are changing, but information takes away a lot of uncertainty and as a consequence I am feeling less anxious" (patient 2)

Box 6

Involvement in the way things were planned and in forthcoming decisions contributed to control of the small aspects of daily life. Consequently, patients felt less overwhelmed and feelings of anxiety decreased.

In contrast, other patients did not want to know details about their illness and the trajectory to death. They preferred to wait and see what would happen, rather than to worry about things that might happen.

Safety

A safe environment was another important need to feel less anxious. The continuous availability of nurses, the idea of not being alone, was expressed as a precondition to feel safe. Patients stated that professional competencies and knowledge about their personal situation and care plan contributed to feeling safe. Safety connects to the need to be in control. Some patients said that their need to be in control was more intense when they had doubts about the expertise of an individual professional. According to one patient, nurses informing each other at a shift of change at the bedside improved her sense of safety.

Adequate symptom management

Most patients stressed the importance of adequate symptom management. Pain and dyspnea were most frequently mentioned as causes of anxiety. The thought of increased pain and dyspnea in the future was an important source of anxiety as well. Alleviation was required to decrease anxiety. The experience of effective interventions decreased anxiety for increasing pain and dyspnea in the future. Patients emphasized that their anxiety was reduced significantly when they felt that their symptoms were taken seriously by competent and reliable professionals. Another patient specified that education about dyspnea was the key issue in not feeling anxious to suffocate (Box 7):

> *"The anxiety was extreme, just caused by the breathlessness. And then your doctor is telling you that you have metastasis in your lungs. Logically, I was thinking that I would suffocate. Although they cannot guarantee it, the doctor and nurses reassured me in that suffocation is very uncommon. In the meantime, I experienced that they can do so much about it, and that takes away a lot of anxiety"* (patient 11)

Box 7

Having a good night of sleep also contributed to reduce worrying during the night and to be able to cope with feelings of anxiety during daytime.

Talking about anxiety (or not)

Patients expressed diverse needs with regard to talking about anxiety. Some patients liked to discuss their anxiety with nurses or the doctor, either when they were actually anxious or reflection on a later moment. A prerequisite to talk about anxiety is a relationship based on trust and safety. Some patients were reluctant to call a nurse when they felt anxious, especially during late or night hours. They were concerned to bother the nurse because they might be too busy. Patients reported that they felt invited to express their feelings by nurses who took a chair instead of standing beside the bed. They wanted to express their thoughts, feelings and insecurities and never expected that the nurse came up with a solution because most patients stated that their anxiety could never taken away completely. They just expected being listened to, attention, compassion and kindness. Some patients found it difficult to discuss anxiety and liked to be encouraged to do so. Talking about anxiety and ventilating their thoughts decreased anxiety (Box 8).

"*Talking extensively about anxiety helps, but it cannot take all the anxiety away*" (patient 13)
"*It is not easy to talk about anxiety by myself*" (patient 4)

Box 8

Some patients preferred to talk about anxiety with professionals rather than with loved ones because they could express feelings without having to deal with emotions of the loved ones. Although patients emphasized the need to express feelings of anxiety, they also indicated that there should be a balance between conversations about anxiety and positive aspects of life.

Other patients did not want to talk about anxiety but preferred to cope with their anxiety and emotions on their own. They wanted to be left alone to face their thoughts on their own when they experienced anxiety and did not want to share these thoughts with others.

Respecting for coping strategies by professionals

No patient was bothered by questions of nurses about feelings of anxiety, even when they were not anxious or did not want to talk about anxiety. One patient compared questions about anxiety with questions about defecation which were more inconvenient for her. Respect for the individual way of coping and respect whether to explore feelings of anxiety or not, were important needs. For some patients distraction and focusing on other issues was a common strategy and more helpful than talking about anxiety. Some patients stated that they did not always feel respected by professionals about their choice not to talk about anxiety. They would rather be supported in their choice not to talk about it than being forced to face their feelings of anxiety.

Discussion

This study provided insight into the needs of hospice inpatients with advanced cancer regarding anxiety management. As far as we know this is the first study which focused on the needs of cancer patient regarding anxiety in the last phase of life.

Routinely collected Utrecht Symptom Diary (USD) anxiety scores were relatively low. Some patients did not recognize themselves in the word "anxiety", Terms like worry, feeling tense or being scared were more recognizable. Patients with an anxiety score of 0 did express feelings of anxiety during the interviews based on their own reflections, but used different terms and said that those feelings did not interfere with daily life. Anxiety was frequently experienced during the night, whereas anxiety scores were routinely collected in daytime. Most patients had suffered from so many losses, that there was not much to lose anymore. They expressed acceptation of their situation and less anxiety in the final months of life. This is in line with the existing literature showing that acceptance-coping is associated with less anxiety and better quality of life [17].

Remarkably, patients only mentioned the role of nurses and doctors with regard to anxiety management, disregarding specialized professionals such as chaplains. Some patients were explicit that nurses should take support anxiety because of their 24/7 presence. As a result, nurses may be regarded as "the eyes and ears" of the multidisciplinary hospice team, which emphasizes the vital role nurses have to recognize anxiety and support patients as part of their professional competence. Besides, they need competencies to identify patients with complex needs for referral to specialized professionals.

Five important needs emerge from the interviews: information and a sense of control, safety, adequate symptom management, talking about anxiety (or not) and respect for coping strategies by professionals.

The most prominent need for most patients was information. Poor or incomplete information may generate mistrust and therefore increase anxiety[18, 19]. Fallowfield et al. (1997) described that patients perceptions can be worse than the facts[20]. Patients do not automatically ask for further information. Since information is one of the top three unmet needs of advanced cancer patients and their loved ones, addressing misconceptions and providing adequate tailored information should be a priority in clinical care[9].

Feeling in control was connected to the needs information and safety. Control is associated with decreased anxiety[21]. Involvement in daily schedules and being informed contribute to this sense of control as well as feeling safe and having faith in the professional team. Safety

was experienced in 24/7 availability of a competent professional and not feeling alone. It is crucial to address what control and safety mean for the individual.
Adequate symptom management was indicated as essential for the reduction of anxiety. Although findings in studies are not consistent, symptoms such as pain, dyspnea, fatigue, nausea, insomnia may be associated with increased anxiety[5, 22]. Physical symptoms such as pain and dyspnea were described as a direct cause and source of anxiety. Insomnia, on the other hand, was more indirectly related to anxiety. A good night sleep helped to not feel anxious during the night and to restore energy for coping with anxiety.

Respect for the patients' way of coping was an important need as well. This means that patients should be supported according to their coping style, which may vary from being left alone to avoidance by distraction or to have a dialogue. Remarkably, patients never minded active questioning about anxiety, regardless of their coping strategy. Patients expressed the importance of respect for their choice to either accept or decline the invitation for a talk. Patients never expected a solution and were aware that anxiety could not always be alleviated. They did expect attention, kindness and that their problems and/or symptoms are taken seriously. Patients valued the inviting behavior of the professional, for example by taking a chair rather than standing at their bedside. These findings were confirmed in an interview study of loved ones of hospice patients[23]. Professionals should be aware of their behavior and how this affects the results of a dialogue about anxiety.

Although there are some recognizable patterns not all patients have the same needs. The attitude towards their illness and their individual coping strategies influence their desire, for example for information and efforts to obtain it[24]. It is therefore essential that patients' own resources are recognized and supported[25].

This study is an essential part of a series of explorative studies[5, 10, 13, 26] and contributes to the improvement of anxiety management with insight into the needs of patients themselves suffering from advanced cancer in the last phase of life. There are some shortcomings. First, a relatively low number of patients was included and, due to the physical condition of the patients prolonged interviews were not possible. However, these short interviews had immediately an in-depth character since patients were found to be very well prepared. Data saturation concerning the main topics was reached after 14 interviews. Second, most patients were well educated, >58 years of age, female and well educated., Younger, male and less educated patients may have different needs[17].

In conclusion, information, open communication, sense of control, safety, adequate symptom management and respect for patients' coping strategy were the six main needs of patients with regard to anxiety management. Insight into patients' needs provided important angles where nurses and doctors can make a difference in an effective personalized approach.

According to patients optimal recognition and anxiety management should contain:

- timely recognition of anxiety by proactive questioning using multiple synonyms of anxiety;
- adequate information and education;
- ensuring feelings of safety and sense of control of patients;
- adequate symptom management;
- recognition and enhancement of the patient's coping strategy to deal with anxiety.

Future research should focus on the development of a systematic approach for tailored psychosocial care for anxious patients in the last phase of their life.

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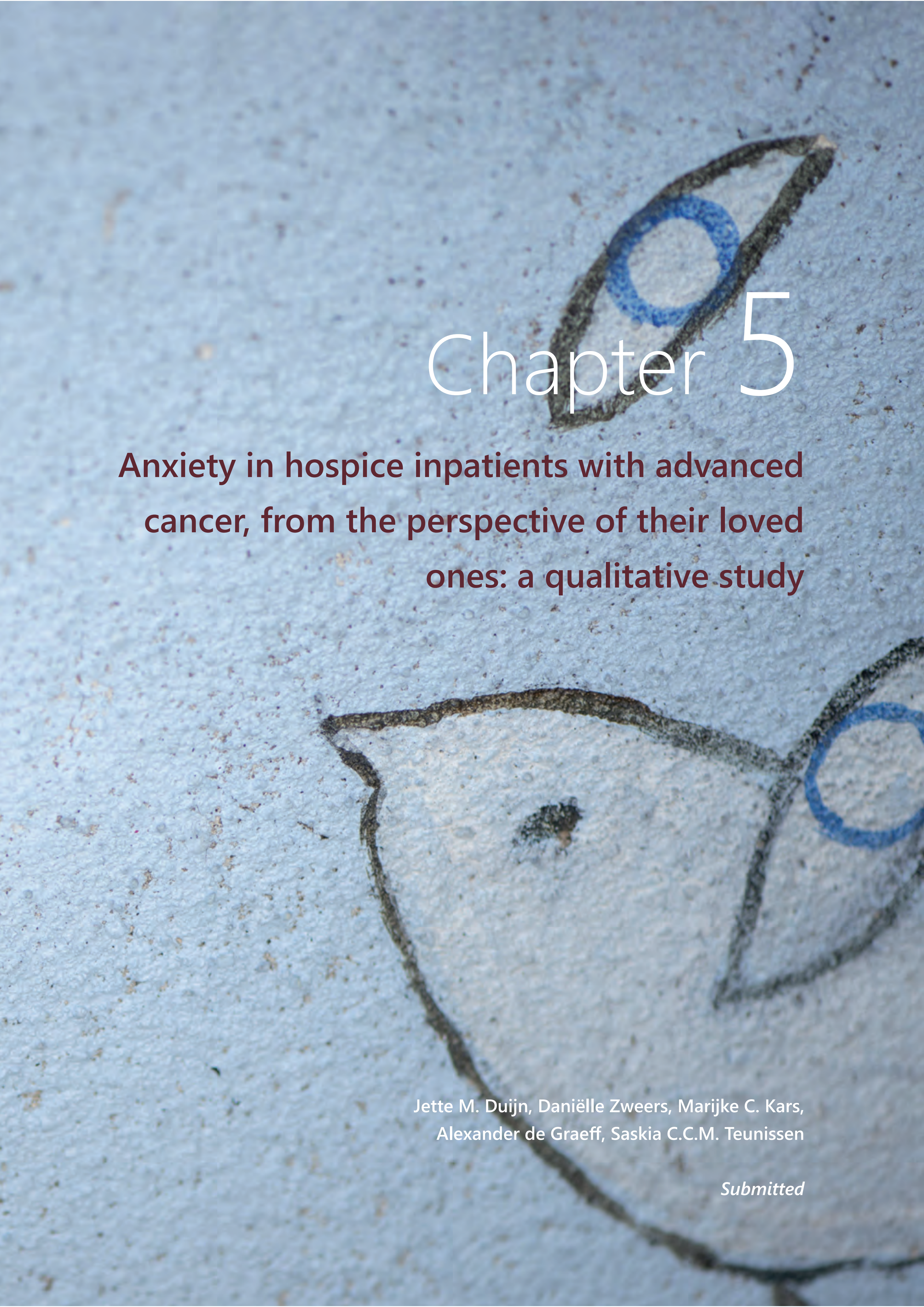

Chapter 5

Anxiety in hospice inpatients with advanced cancer, from the perspective of their loved ones: a qualitative study

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Submitted

Abstract

Purpose: Anxiety is a common symptom in patients with advanced cancer. However, it is not always recognized in clinical practice. There is a need for interventions to support patients with anxiety, especially when patients are not able to communicate about their concerns. Here, loved ones may be a valuable source of information. The purpose of the article is to explore the experiences and views of loved ones concerning anxiety in hospice inpatients with advanced cancer.

Design: Prospective, qualitative research. Loved ones of patients with advanced cancer, admitted to a hospice were eligible if they were >18 and able to communicate in Dutch. 14 loved ones were interviewed between January 2017-July 2017. 64% was female, median age was 55 years. The interviews were mostly performed in the hospice.

Methods: Semi-structured, face-to-face interviews with loved ones were conducted to collect data, using an interview guide. Framework analysis and coding of fragments was performed.

Findings: Loved ones rated the current level of the patients' anxiety at a median score of 6.5 (range 3-8). They indicated a variety of verbal and non-verbal expressions of anxiety and mentioned physical and mental deterioration as an important source of anxiety. They recognized patients' needs such as a safe environment, presence of people around and control. Loved ones assessed patient's anxiety as moderate to severe, and identified a negative impact on physical, psychological, social and spiritual dimensions of the patients' life.

Conclusions: Although the patients' perspective is the golden standard, loved ones can be a valuable source of information in identifying anxiety and providing personalized support.

Clinical relevance: Since loved ones know the patient the best, they can be a valuable source of information and may provide an unique perspective in identification of anxiety and personal support, especially when patients are not able to communicate about their concerns. Therefore, loved ones should be more involved in the assessment and care of anxious patients.

Introduction

Anxiety is a common symptom in advanced cancer patients[1]. It is defined as a dynamic response to a perceived threat[2]. Common expressions are restlessness, worrying, gastrointestinal problems, sleeping problems, and palpitations[3, 4]. In clinical practice anxiety is difficult to identify, since its expressions may also be caused by the underlying disease or treatment[2, 4, 5]. Pain, shortness of breath, disability, disfigurement, dependency, separation from loved ones, being a burden to others, losing control and approaching dying and death are possible sources of anxiety in this population[3, 4, 6]. From a clinical point of view it is difficult to distinguish between sources and consequences of anxiety; there may also be a bidirectional relationship. Anxiety is generally associated with impaired quality of life[7, 8], which emphasizes the importance of adequate treatment[3, 4]. Zweers et al. showed the struggle of hospice nurses in anxiety management and indicated that nurses are in need of evidence based interventions[9]. Insight into the needs of patients is essential to develop optimal treatment and support.

McPherson showed that loved ones are a valuable source of information concerning patients' anxiety because they know the patient's character and preferences before they got ill[10]. Loved ones may play an important role in clarifying preferences and needs of the patient to realize suitable support, especially in the final weeks of life since patients often are too frail to communicate about their concerns[10]. Previous research mainly consisted of retrospective studies regarding the overall experiences of loved ones caring for cancer patients[10-14] .Recall bias may negatively influence the validity of these retrospective studies[15, 16].
The aim of this prospective study is to explore experiences and views of loved ones concerning anxiety in advanced cancer patients in order to contribute to the development of interventions which adequately support anxious advanced cancer patients to maintain the quality of their remaining life[1, 8].

Methods

Design

We performed a prospective, explorative, qualitative interview study using framework analysis and coding of fragments[17].

Sampling and Recruitment

Eligible participants were loved ones of cancer patients admitted to a hospice in the Netherlands with a life expectancy of <3 months. Participants were included when >18 years and able to communicate in Dutch. Loved ones are defined as ''persons who are close to the patient according to the patient, regardless of whether they are spouses, relatives, adult children or friends"[18]. Patients identified their loved ones at admission. Convenience sampling until saturation was applied, meaning that all identified loved ones present at admission were asked to participate in the study, irrespective of whether the patient was anxious or not. Verbal and written information was provided by hospice nurses. The interviewer (JD) scheduled an appointment after agreement for participation.

Data Collection

Semi-structured, face-to-face interviews with loved ones were conducted by a trained researcher (JD) (January 2017-July 2017). During the interviews, the patient was not present because of their possible influence on the response of the loved one. The researcher had no professional relationship with the participants. An interview guide (Appendix C) was developed based on clinical expertise (JD,DZ,ST,MK) and literature[4, 9, 10, 13, 14]. The five interview topics were presence and severity of anxiety, expressions, sources, impact, and needs of patients, as experienced by their loved ones. The severity of anxiety of the patient was scored on a 0-10 numeric scale (0=no anxiety, 10=extreme anxiety). Two pilot interviews, also included in the final analysis, were conducted to test the interview guide and to reflect on the interview style. Minor adjustments were made. Loved ones' age, gender, relationship with the patient and level of participation in daily care were collected prior to the interview. Interviews were audio-recorded, transcribed verbatim and field notes were made directly afterwards.

Analysis

The five main interview topics were the starting point of the analysis and formed the themes for the preconceived framework in which relevant coded fragments were placed. The transcripts were independently coded and placed into the framework by two researchers (JD, DZ). Discrepancies were discussed until consensus was reached[17]. During this process one theme (influencing factors) was added. Some of the themes were divided in subthemes. Nvivo (v11, QRS International) was used to structure and analyse data.

Ethical Aspects

The medical ethical committee determined the study to be outside the scope of the Medical Research Involving Human subjects Act (protocol number 16-805/C, 28-12-2016[19]. Prior to the interview, written informed consent was obtained from the loved one(s). The study was executed according to the principles of the Declaration of Helsinki and the Guidelines of Good Clinical Practice[20, 21]. The handling of data complied with the Dutch Personal Data Protection Act[22].

Results

Loved ones of 20 eligible patients were asked to participate. 14 loved ones of 12 patients agreed to participate. Two loved ones could not be interviewed because the patient passed away before the planned interview. Six loved ones did not participate because they felt burdened to be interviewed. Twelve interviews were conducted including two interviews with two loved ones simultaneously. The interviews took place in the hospice, except for two interviews which were at the loved one's workplace and home. Demographic characteristics are depicted in Table 1. Median age was 55.5 years, 64% was female. Most loved ones were children (*n*=7) or spouse (*n*=3), 57% was in contact with the patient daily or several times a day. The mean duration of the interviews was 43 minutes (range 25-60). After ten interviews, code saturation was reached (Figure 1)[23]. Two more interviews were conducted to confirm code saturation. Appendix D shows the final themes, subthemes and codes.

Table 1: Socio-demographic data of the loved ones

		Loved ones (N=14)
Age (years)	Median (range)	55,5 (33-73)
Gender N (%)	Women Men	9 (64,3) 5 (35,7)
Religion N (%)	No religion Catholic	12 (85,7) 2 (14,3)
Origin N (%)	Dutch Eastern-European	13 (92,9) 1 (7,1)
Relationship to patient N (%)	Spouse Daughter Son Brother Daughter-in-law Sister-in-law Friend	3 (21,4) 5 (35,7) 2 (14,3) 1 (7,1) 1 (7,1) 1 (7,1) 1 (7,1)
Living with patient before admission N (%)	Yes No	3 (21,4) 11 (78,6)
Participate in daily care (at the moment of interview) N (%)	Yes No	4 (28,6) 10 (71,4)
Frequency of participation in daily care, if applicable N (%)	Multiple times a day Several times a week	3 1
Frequency of contact with patient N (%) (by phone, e-mail, visit, etc.)	Several times a day Daily Several times a week	5 (35,7) 3 (21,4) 6 (42,9)

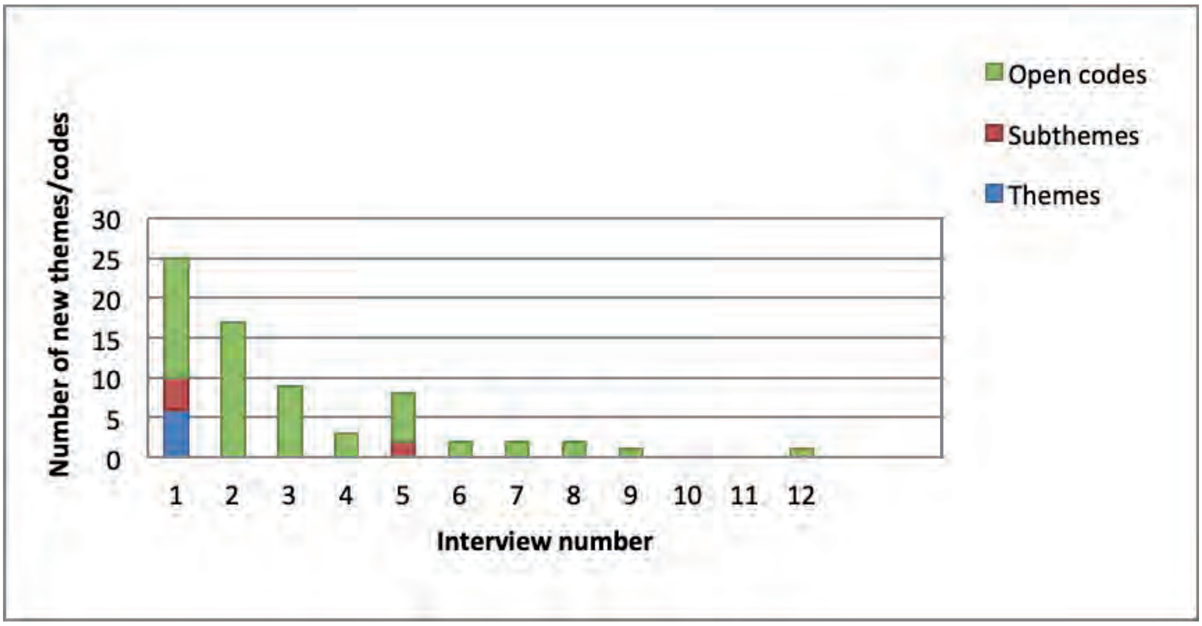

Figure 1: Saturation of data: new (sub)themes and codes per interview

Presence and Severity of Anxiety

Almost all loved ones indicated that they experienced or presumed that patient's anxiety on a daily basis, especially at late-night hours and lonely moments. Some stated that patients were currently resigned to their fate and, as a result, seemed less anxious than earlier in the disease trajectory. Loved ones rated the current level of the patients' anxiety at a median score of 6.5 (range 3-8). Several loved ones thought that the patient expressed less anxiety than they actually experienced, in order to protect them.

She does not want it to be obvious for me. [...], that's the other side of the story. She does not want me to worry or something like that. But no, I know it's there. (Loved one 5, daughter, aged 52)

Box 1

Expressions

Loved ones indicated a variety of expressions they interpreted as anxiety of the patient. Verbal expressions, literally or interpreted as such, were often mentioned.

Anxiety was also recognized in non-verbal expressions. Facial expressions and emotions like crying, irritation or insecure behaviour were named frequently. Furthermore, restlessness, hostility, avoidance and withdrawal, being absent-minded, acting harshly towards others, and not wanting to talk about sensitive topics were identified as expressions of anxiety. Small gestures such as twisting a ring on a finger, putting a hand to the forehead or clinging to people and objects and keeping control in an extreme way, for example, over their medication, were also interpreted as expressions of anxiety. Loved ones indicated that they were able to identify anxiety by the expressions mentioned above as they had been involved intensively and for a long time.

> *I am a loved one who [...] has been involved very intensively [...]. So I can put it in the context of the whole process of the disease, which is why I can give these answers.... (Loved one 14, partner, aged 66)*

Box 2

Sources and Influencing Factors

Since sources of anxiety and factors of influence are closely related, they were described in relation with each other.

According to the loved ones, physical and mental deterioration were the most important sources of anxiety in patients. Patients were anxious for deterioration in general and specifically for possible consequences of deterioration, such as choking, not being of clear mind or not being able to say goodbye consciously. According to loved ones, these kinds of anxieties were often based or reinforced by negative experiences in the past.

Loved ones specified that patients felt anxious to lose control over their body and mind, to be dependent on others and to lose dignity. According to the loved ones, the internal values of some patients shifted as the disease progressed and as a result, they accepted their fate. For these patients, anxiety decreased towards death.

Loved ones indicated that mental deterioration could influence anxiety either in a positive or in a negative way. For example, a loved one specified that the patient was probably less anxious due to brain metastases, which caused a flattening of emotions and resignation. Another loved one felt that the patients' anxiety increased, due to feeling drowsy after medication.

Anxiety triggered by the unknown course of the disease or the overall uncertainty were also frequently mentioned. Loved ones observed patients worrying about what would happen and how they were going to die. They noted that patients were anxious about end-of-life decisions and the acceptance of their family concerning their decision(s). Finally, four loved ones indicated that patients were anxious of letting go of their family member and did not want to leave them in grief.

> *I think [...] she worries about 'what if my body declines?' and 'what if I am in a lot of pain?' or 'what if I don't know who you are anymore?' [...]. These are things that she finds terrible (Loved one 7, daughter, aged 34)*

Box 3

Impact

Loved ones expressed that anxiety had an impact on all dimensions of patients' lives. They mentioned a physical impact such as sleeping problems, a psychological impact such as difficulty in controlling thoughts and a spiritual impact such as struggling in saying goodbye. A social impact was mentioned as well, since patients' hostile or avoiding behaviour had led to irritations in their relationship.

Yeah, well, you try to do your best, but you cannot always take that tension away and I find it very difficult when she is so tense. And then, when I go home and that tension stays – that is not a pleasant feeling. (Loved one 2, daughter, aged 50)

Box 4

Although it was not the focus of this study, loved ones emphasized the impact of anxiety of the patient on their own life – particularly the psychological and social dimensions. They found it hard to see the patient's anxiety and felt powerless because they could not take away the suffering. Loved ones felt sometimes claimed and hence their own lives were put on hold. Obviously, the impact was dependent on the severity of the anxiety.

Needs

Several needs of patients were identified by the loved ones. Some could be summarized as the need for a safe environment. In particular, loved ones claimed that the competencies and attitude of healthcare professionals was important, such as being familiar with the personal care plan and providing adequate honest information. Secondly, the presence of people around the patient was identified as a precondition to feel safe. Thirdly, the importance of tailored care based on the preferences and specific needs of the patient was acknowledged.

It has to be a very safe environment if you want to suppress that anxiety. (Loved one 11, brother, aged 73)

Box 5

The influence of the hospice atmosphere on anxiety in the patient was also mentioned. The green surroundings decreased anxiety, as did the pleasant and homely atmosphere and the company of others. On the other hand, some loved ones indicated that being confronted with the death of other patients increased anxiety.

Respecting and facilitating coping strategies of the patient to prevent or alleviate anxiety were also mentioned. Distraction, e.g. by watching TV and relaxation, e.g. by massage, were strategies for controlling anxiety that were listed by all loved ones. Talking with patients about anxiety but also about the normal things in life were important, according to many loved ones. Several loved ones pointed out that professionals had to initiate a dialogue about anxiety because patient did not do this by themselves. As mentioned, having control over daily life, body and mind is important to cope with anxiety.

Loved ones discussed the patients' character in relation with how they coped with anxiety. It was also indicated that the needs regarding anxiety management depend on the personal coping strategies. Age and generation were also mentioned as influencing needs with anxiety. Some loved ones stated that older patients were poorly practiced in talking about emotions like anxiety.

Discussion

Main Findings

To the best of our knowledge, this is the first prospective study exploring anxiety in cancer patients facing death from the perspective of their loved ones.

Loved ones stated that anxiety was not continuously experienced by the patient. When present, it was judged as moderate to severe. Loved ones identified a negative impact of anxiety on physical, psychological, social and spiritual dimensions of the patient. They indicated a variety of verbal and non-verbal expressions of anxiety and identified physical and mental deterioration as the most important sources of anxiety. A safe environment, the presence of loved ones and professionals, tailored care, respecting and facilitating coping strategies, talking about anxieties and having control were identified as patients' needs regarding anxiety management.

Loved ones identified a broad range of sources of anxiety. Anxiety for deterioration or anxiety for the unknown were mentioned by most. Remarkably, Parkes noted that anxiety for separation from loved ones, homes and jobs was the most frequent expressed anxiety in hospice inpatients[6]. In the current study, only 4/14 loved ones describes letting go of loves ones as a source of anxiety. No loved one mentioned separation of home and jobs as a source of anxiety. An explanation for this could be that the topic of letting go of loved ones and daily life was too sensitive to discuss for both patient and loved one. It could be a way of self-protection of either the loved ones or by the patient.

Loved ones were able to identify specific expressions such as small gestures and hostile behaviour as also found among bereaved loved ones[10]. However, these were not found in studies from the patient or healthcare professional perspective[2, 3, 3, 4, 24]. This suggests that loved ones have a unique perspective on anxiety, based on understanding of the patient's character, coping strategies, and possibly negative experiences in the past. This competence is helpful in identifying and understanding anxiety[10]. A prerequisite of having this foreknowledge is a close and meaningful relationship with the loved one during the disease process. Some physical expressions of anxiety such as pain and palpitations identified by patients[24], were not mentioned by the loved ones. Probably, these were not recognized as expressions of anxiety.

As expected, the loved ones indicated that anxiety had an impact on all dimensions of the patient's life[4]. The social dimension was mentioned as most impeding from the perspective of the loved ones, probably because the loved one is part of the social system.

Loved ones stated that healthcare professionals should initiate a dialogue about anxiety if the patient does not do this by his or her own. Respecting and facilitating coping strategies were mentioned as important needs, also when this includes avoiding behaviour. Furthermore, being aware of patients' lack of control and searching for ways where the patient has a sense of control should be helpful from the perspective of the loved one. Overall, anxiety management should be tailored to the needs of the patient[2].

What This Study Adds

This is the first prospective study about the view of loved ones on anxiety in cancer patients in their last phase of life. It shows that loved ones are able to identify and understand expressions of anxiety and can place them in the broader context of the patient. These findings are important in developing tailored interventions regarding anxiety management.

Strengths and Limitations

Although anxiety is a sensitive topic, especially for loved ones facing the imminent loss of their dearest, it is possible to perform a prospective qualitative study in the hospice setting. Some participants discussed anxiety with the patient in order to prepare for the interview, which was for some the first time to talk about anxiety. This may have influenced the results. The results were not crosschecked by the patient. However, this study is a reflection of daily hospice care where most patients, especially in the last days before death, lack the ability communicate about their concerns.

Data saturation is likely to have been reached and meaning saturation has been reached concerning the main topics. We were able to include loved ones with diversity in relationships and a wide range in age. The impact of age and culture was not explored which could be of influence on the generalizability of the findings.

Implications for Practice

The results of our study point out three important concepts: Protection, control and safety. Protection was present in two ways: Protection of the loved one by the patient and possible self-protection by both the loved ones and patients. The behaviours of hostility, withdrawal and avoidance of patients with anxiety may be viewed as a form of self-protection or a coping strategy in a fear-avoidance cycle, as discussed by Traeger et al[2]. Protection may influence the perception of loved ones concerning anxiety in patients. However, previous research has shown that loved ones bear this in mind and use their foreknowledge to judge anxiety in patients[10]. Protection enables control, which proved to be an important aspect in several ways. Subsequently, control enables safety, which emerged as an important need. Protection, control and safety could be mechanisms for maintaining patients' capacity to deal with anxiety. Therefore, tailored care is essential. Additional research is needed to check these assumptions, especially by patients themselves.

This study highlights the importance of the perspective of loved ones in the recognition of and support regarding anxiety in hospice inpatients with cancer. Therefore, loved ones should be involved in the care for anxious patients. Although loved ones can add valuable information, it remains unclear if their perspective matches the patients' perspective. Ultimately, the patients' experience remains the golden standard.

Our findings provide insight into anxiety of patients from the perspective of loved ones. This contributes to the development of interventions regarding anxiety in advanced cancer patients in the last phase of life. Supportive interventions should focus on creating a safe environment, tailored care, preserving control and autonomy of the patient, initiating conversations regarding anxiety actively and respecting and facilitating coping strategies of patients. Given the impact of anxiety in patients and loved ones, interventions should be aimed at both patients and loved ones to improve quality of life and dying. Future research should focus on the influence of age and culture on anxiety and explore the interaction and the meaning of the concept's protection, control and safety in patients with advanced cancer.

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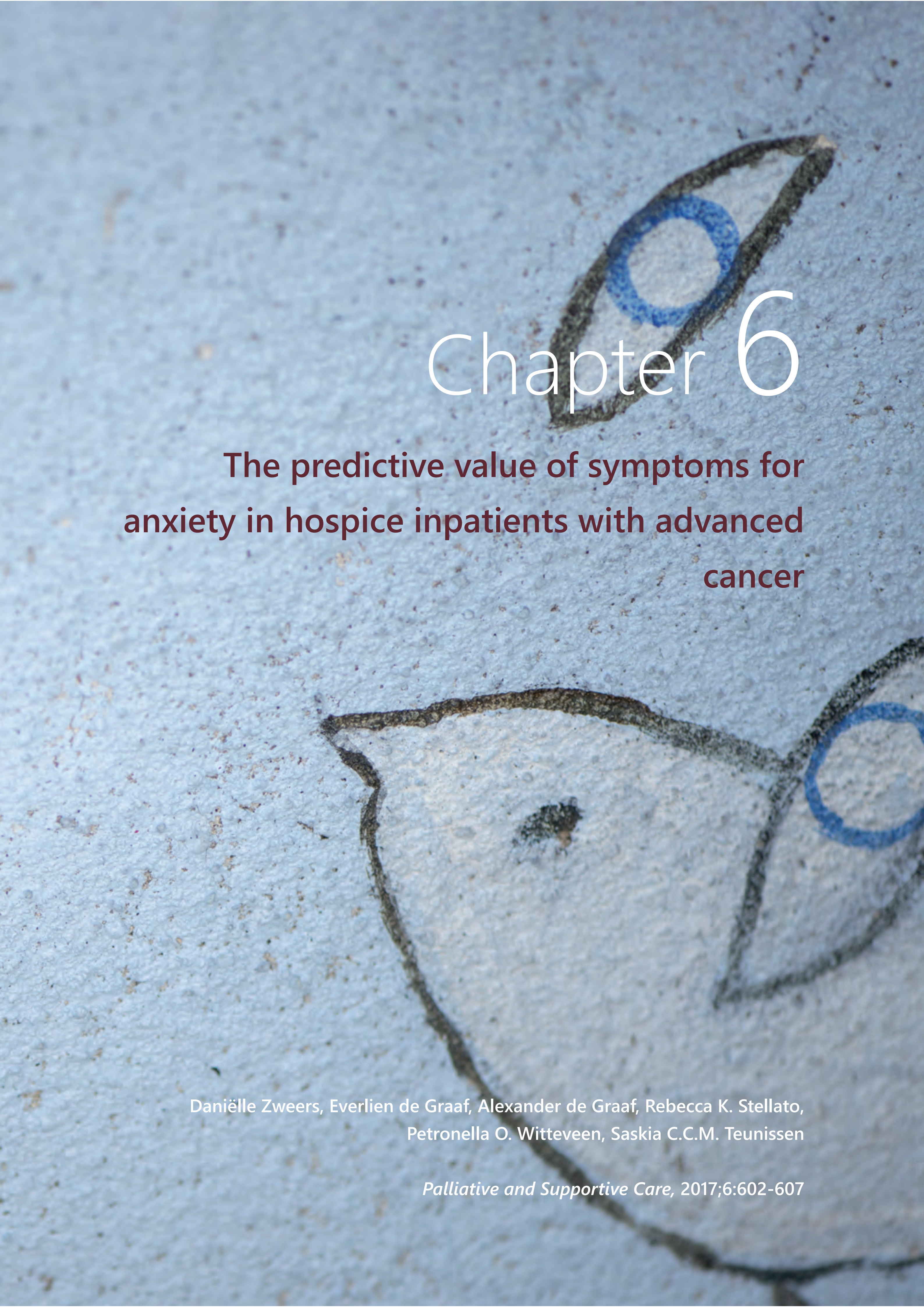

Chapter 6

The predictive value of symptoms for anxiety in hospice inpatients with advanced cancer

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Abstract

Objectives: Insight into symptoms as predictors for anxiety may help to early identify anxiety and ameliorate anxiety management. The aim of this study is to determine which frequently occurring symptoms are predictors for anxiety in advanced cancer patients recently admitted to a hospice.

Methods: Symptom burden was measured in patients admitted to a hospice who died ≤3 month after admission by the Utrecht Symptom Diary. This is a Dutch translated and adapted version of the ESAS to self-assess the 11 most prevalent symptoms and an overall well-being on a 0 -10 numerical rating scale. Multiple linear regression analysis was used to analyze the predictive value of fatigue, nausea, pain, dyspnea, depressed mood, insomnia and well-being on anxiety.

Results: A total of 211 patients were included, 42% of whom were men and the median age was 71 years (range 31-95). Anxiety was uncommon and rarely severe: 25% had a score of ≥ 1; 14% had a score >3. After correction for age, gender and marital status, depressed mood (p=0.00) and dyspnea (p=0.01) were independent predictors for anxiety and explained 23% of the variation in anxiety.

Significance of results: Hospice inpatients with advanced cancer who suffer from dyspnea and/or depressed mood are at increased risk for anxiety. Treatment of dyspnea and depressed mood may contribute to adequate anxiety management. Further research should explore other factors associated with anxiety, especially in the psychological, social and spiritual domain.

Introduction

Anxiety is a common response to threats of uncertainty, suffering and mortality[1]. Anxiety is present in 18-38% of patients with incurable cancer[2-4]. Anxiety as a symptom is prominent in cancer patients, since it is a physiological reaction to signal danger to human beings[5]. Although the clinical presentation varies from person to person, anxiety is associated with common symptoms and signs , some of which are related to hyperactivity of the sympathetic nervous system[5, 6]. Younger patients are significantly more anxious than older patients and females report more anxiety than males[7]. Furthermore, social support and belief in afterlife are significant predictors of anxiety[3, 8]. Furthermore, more research is available about the role of attachment styles in the prediction of anxiety; a fearful-avoidant attachment and preoccupied attachment styles significantly predicted a higher level of death anxiety[9]. Overall, anxiety is associated with poor quality of life[1, 10].

Because of the non-specific associated symptoms of anxiety, anxiety is difficult to identify and is often inadequately assessed by healthcare professionals[1, 11]. Insight into symptoms which affect anxiety could help to early identify anxiety and ameliorate anxiety management.

The relation between anxiety and other symptoms is complex. From a clinical point of view, it is often assumed that the relation is bidirectional: on the one hand, anxiety affects the presence and intensity of other symptoms and on the other hand, other symptoms affect the presence and intensity of anxiety. In this study, we will focus on the influence of other symptoms on anxiety.

Previous studies found a variety of symptoms in advanced cancer patients to be significantly associated with anxiety, such as fatigue[4, 7, 12-14], nausea[4, 7, 12], pain[12, 15, 15], dyspnea[7, 12, 16], depressed mood[17]; [12, 18], drowsiness[7, 15], insomnia[15, 19] and/or overall well-being[4, 7]. However, the findings were inconsistent. The heterogeneity of the study populations, assessment tools, cut-off levels and statistical methods could explain some of these inconsistencies.

No studies are available about symptoms associated with anxiety in hospice inpatients. These associations could be different, since hospice patients are confronted with a limited life expectancy and most of the patients included in previous studies were still receiving cancer treatment.

The aim of this study is to determine whether the symptoms found in the previous studies (fatigue, nausea, pain, dyspnea, depressed mood and insomnia) as well as overall perceived well-being are predictors for anxiety in advanced cancer patients at admission to a hospice.

Methods

Patients

In this cross-sectional study, we retrospectively analyzed the prospectively collected data of symptoms in advanced cancer patients admitted to a hospice in the Netherlands from June

2007 until September 2015. Inpatient hospice care in The Netherlands is available if patients have a life expectancy of <3 months; almost all patients die in the hospice.

The study population consisted of all adult cancer inpatients who filled out a symptom diary (the Utrecht Symptom Diary, USD) within one week after admission. Patients who were unable or unwilling to self-assess their symptoms using the USD were excluded from the study. In order to select a homogenous population, we included only patients who died within three months after admission.

Data collection

Anxiety, fatigue, nausea, pain, dyspnea, depressed mood, insomnia, and overall well-being were assessed using the USD. The USD is an adapted and translated version of the Edmonton Symptom Assessment System (ESAS) that has been implemented in daily Dutch hospice care. The USD is an instrument to self-assess the 11 most prevalent symptoms and a global sense of well-being, on a 0-10 numerical rating scale. A higher value implies a more severe symptom or a lower level of well-being. Patients can add more symptoms if necessary. The USD was filled out twice a week as part of standard care to guide tailored patient care. For the analysis, we used the first USD completed by the patient within one week after admission. Baseline characteristics (including age, gender, marital status, primary diagnosis and performance status) and duration of admission were extracted from the patient files. All USD data, patient and illness characteristics were entered in a database.

Data were collected anonymously. Only the administrator of the database could link data to individuals using a decryption key, stored separately within the database. The use of the database for research purposes was approved by the local ethics committee of the Utrecht University Medical Center (11-113/C).

Data analysis

The prevalence of the symptoms was described by frequencies, dichotomizing the symptoms scores in the absence of a symptom or presence of a symptom (scores 0 and ≥1, respectively). Symptom scores greater than 3 were regarded as clinically relevant. To gain insight into potential confounders, the relation between patient and illness characteristics and anxiety were analyzed using the Mann-Whitney or Kruskal-Wallis test. To determine the independent influence of symptoms on anxiety, a linear regression model was created with the USD anxiety score as a dependent variable and symptom scores of fatigue, nausea, pain, dyspnea, depressed mood, insomnia and overall well-being as the independent variables. Potential confounders (gender, age and marital status) were selected based on known relevance [3, 7] and included in the multiple regression model; the symptoms were then added using a forward stepwise selection procedure. The final model included only statistically significant symptoms plus gender, age and marital status as potential confounders. Assumptions of the multivariate regression analysis were checked by residuals analysis. As the distribution of the residuals was found to be skewed, as a result of the many zero scores on anxiety, a logistic regression analysis was added as a sensitivity analysis to confirm the findings of the multiple regression model. In this analysis, the outcome anxiety was dichotomized in no anxiety (anxiety score USD=0), and anxiety (anxiety score USD ≥1).

Statistical significance (two-sided) was set at p<0.05. All analyses were performed using SPSS statistics 23.

Results

In total, 481 patients were admitted to the hospice of whom 211 were enrolled in this study. Those patients were diagnosed with cancer, had a survival of <3 months and completed a USD in the first week of admission. In total, 88 (42%) were men and the median age was 71 years (31-95) (Table 1). The gastrointestinal tract was the most common primary cancer site. No significant differences in anxiety levels were found for gender, age and marital status and primary cancer site. There was low to moderate correlation among the explanatory symptom variables, (0.011 to 0.494).

Table 1: Patient characteristics (N=211)

Variable		N (%)		Differences in anxiety levels
Gender	Male		88 (42%)	$p=0.77^a$
	Female		123 (58%)	
Marital status	Married/ living together		95 (45%)	$p=0.52^a$
	Single		115 (55%)	
Primary cancer site	Gastrointestinal		64 (30%)	$p=0.06^b$
	Lung		48 (23%)	
	Gynecological		24 (11%)	
	Breast		16 (8%)	
	Urological		16 (8%)	
	Other		40 (19%)	
WHO score	1		2 (1%)	$p=0.17^b$
	2		33 (16%)	
	3		101 (48%)	
	4		65 (31%)	
		Mean (SD)	**Median (range)**	
Age		69.6 (12.8)	71 (31-95)	$p=0.54^{b,1}$
Admission duration in days		27.4 (21.4)	20 (1-93)	$p=0.86^{b,2}$

[a]Mann-Whitney test; [b]Kruskal-Wallis test; [1]Divided in categories 0-40, 40-65, 65-75, 75-85, >85; [2]Divided into categories 1,2 and 3 months.

Prevalence and intensity of the selected symptoms

Table 2 presents the prevalence and intensity scores of the selected symptoms. Anxiety was uncommon and seldom severe: only 24.6% had a score of 1 or higher and 14.2% of patients had an anxiety score >3. Fatigue was the most prevalent symptom (92.4%) and was also the symptom with the highest intensity score (mean: 6.5; SD: 2.4).

In total, 8% of the USD anxiety scores was missing. No significant differences were found for patients with or without a missing item on the USD anxiety score. Well-being was the item with the highest number of missing values (36.5%). Further analysis of the missing patterns showed that patients with a missing score on well-being were older than patients without a missing item on well-being. Since age was not a primary outcome, and since the Little MCAR test produced a p-value of 0.925, data were considered to be missing at random. No significant differences were found for the symptom prevalence and intensity with regard to the primary cancer site, with the exception of dyspnea, which was more prevalent in lung cancer patients (p=0.006).

Table 2: Prevalence and intensity of selected symptoms (N=211)

Symptoms	Mean (SD)	Median	USD-score ≥1 N (%)	USD-score >3 N (%)	Missing N (%)
Anxiety	1.2 (2.2)	0	52 (25%)	30 (14%)	17 (8%)
Fatigue	6.5 (2.4)	7	195 (92%)	181 (86%)	9 (4%)
Nausea	1.4 (2.5)	0	67 (32%)	40 (19%)	6 (3%)
Pain	2.7 (2.9)	2	123(58%)	72 (34%)	4 (2%)
Dyspnea	2.1 (2.9)	0	87 (41%)	53 (25%)	9 (4%)
Depressed mood	1.8 (2.6)	0	76 (36%)	46 (22%)	10 (5%)
Insomnia	2.5 (3.0)	1	105 (50%)	71 (34%)	8 (4%)
Well-being	2.7 (2.4)	5	-	-	77 (37%)

Influence of symptoms on anxiety

After correction for age, gender and marital status, depressed mood (B=0.335, SE=0.063, p=0.00) and dyspnea (B=0.155 , SE=0.059 , p=0.01) were independent predictors for anxiety (Table 3). Depressed mood and dyspnea together with age, gender and marital status explained 22.8% of the variance of anxiety.

The logistic regression analysis confirmed that patients with depressed mood (B=0.312, SE=0.084, p=0.00) and dyspnea (B=0.181, SE=0.074, p=0.015) had a greater chance to experiencing anxiety, after correction for age, gender and marital status.

Table 3: Multiple regression analysis

Covariates	Unstandardized B	SE	95% CI Lower bound	Upper bound
Gender (Male=0, female=1)	0.231	3.44	-0.449	0.911
Age	-0.013	0.013	-0.038	0.013
Marital status (married=0, single=1)	0.120	0.340	-0.554	0.793
Depressed Mood	0.335	0.063	0.210	0.459
Dyspnea	0.155	0.059	0.037	0.273

B: Indication of the contribution of each predictor to the model; SE: standard error; CI: Confidence Interval

Because of the missing values, especially for well-being, the data were analyzed after multiple imputation. Depressed mood was a significant predictor for increased anxiety in 20/20 imputed datasets and dyspnea was a significant predictor for increased anxiety in 13/20 imputed datasets. The pooled estimates for depressed mood (pooled B=0.0363, SE=0.067, p=0.00) and dyspnea (pooled B=0.104, SE=0.052, p=0.048) confirmed the findings of the unimputed data.

Discussion

Our study was performed to obtain insight into the predictive value of fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall well-being for anxiety in patients recently admitted to a hospice. In total, 75% of the patients did not express anxiety (score 0). We found that depressed mood and dyspnea were the only independent predictors for anxiety.

As in previous studies, the majority of patients reported low levels of anxiety. Hospitalized patients and patients at home had a higher prevalence and intensity of anxiety in comparison with this inpatient hospice sample[7, 15, 15, 20]. Differences in anxiety between hospitalized and hospice patients may be explained by the absence of uncertainty in hospice patients about effects of cancer treatment and by their acceptance that death is inevitable. In clinical practice, specialized nurses recognized that patients at home may be more anxious due to the fact that they usually often have to cope on their own and do not have the availability of 24/7 professional care. Overall, severe anxiety appears to be more common in the early stage of a life threatening illness.

Another explanation for the low anxiety scores is related to the meaning of the term 'anxiety'. When nurses were confronted with discrepancies in the score of the patients on anxiety and their own observations, patients explained their low anxiety scores by "Yes, I am feeling tensed and scared sometimes, but no, I am not anxious". It appears that patients do not always recognize themselves in the word "anxiety". A recent study also highlighted the concerns about the difficulty in scoring anxiety possibly resulting in underreporting of anxiety[21].

As expected, depressed mood and dyspnea were significant predictors for increased anxiety and explains only 23% of the variance of anxiety. A similar study in advanced cancer patients receiving radiotherapy found that 16% of the variance in anxiety was explained by age, gender, nausea, drowsiness and a global sense of well-being. Why demographic characteristics, other symptoms and well-being were not related with anxiety in this hospice sample remains unclear and needs further exploration.

Only 23% of the variance of anxiety was explained by physical (dyspnea) and psychological (depressed mood) symptoms. Because of the limited life expectancy, anxiety in hospice care patients may be dominantly related to psychological, social and spiritual problems[22, 23]. Murray Parkes (1998) describes that, in addition to anxiety for worsening pain or other worsening symptoms, loss of loved ones, homes and jobs, becoming a burden to others and losing control are the most common causes of anxiety in hospice patients which supports this hypothesis[23]. Unfortunately, we have no data on psychological, social and spiritual problems as determinants of anxiety.

As far as we know this is the first study on anxiety in inpatient hospice patients. However, our study does have some limitations. First, the assumptions for multiple linear regression analysis were not completely met, due to skewed residuals for almost all symptom scores with the exception of well-being. We therefore performed a logistic regression analysis on dichotomized anxiety scores to confirm the findings of the linear regression analysis. Second, there is a possibility of selection bias because we selected only patients who completed a USD in the first week of admission; patients who were not able to do so were excluded. Therefore, we may have underestimated anxiety in this population. Third, we had to deal with missing values, especially for well-being, which is a common issue in palliative care research. To examine the effect of this potential bias, we analyzed the data after multiple imputation. The pooled estimates for depressed mood and dyspnea confirmed the findings of the unimputed data. Fourth, data about pre-existent anxiety disorders and data about anxiolytics during admission were not available. Finally, the findings are valid only for patients who die within 3 months after admission to a hospice.

Since anxiety is a difficult symptom to observe and to treat, insight into the predictors may help healthcare professionals to early identify patients at risk for anxiety[1].

Further research is needed to explore whether additional predictors of increased anxiety in hospice patients exist, especially with regard to the psychological, social and spiritual dimensions. Furthermore, we need to understand the variety in predictors for anxiety along the patient journey, in order to develop interventions and set up an anticipatory care plan tailored to the individual needs to increase quality of life and dying.

Meanwhile, healthcare professionals need to assess the overall symptom burden in a structured way to monitor symptoms over time. With the knowledge that depressed mood and dyspnea are predictive symptoms for anxiety for this inpatient hospice population, healthcare professionals need to intensify the monitoring of anxiety for patients who suffer from these symptoms by observing verbal and non-verbal expressions of anxiety. Assessment tools can be helpful to systematically assess the symptom burden and to initiate a conversation about anxiety with the patient and/or their loved ones[24].

In conclusion, in this sample of hospice patients we found a relatively low level of anxiety. Depressed mood and dyspnea were significant predictors for increased anxiety. However, these symptoms, together with gender, age and marital status, explained only 23% of the variance in anxiety. Future research should focus on different patient populations, on the complex reciprocal relationship between anxiety and other symptoms and on psychological, social and spiritual problems as predictors for anxiety. In the meantime, healthcare professionals should monitor symptom burden over time and intensify monitoring of anxiety for patients who suffer from a depressed mood and dyspnea to identify anxiety in an early stage and provide individual support and treatment.

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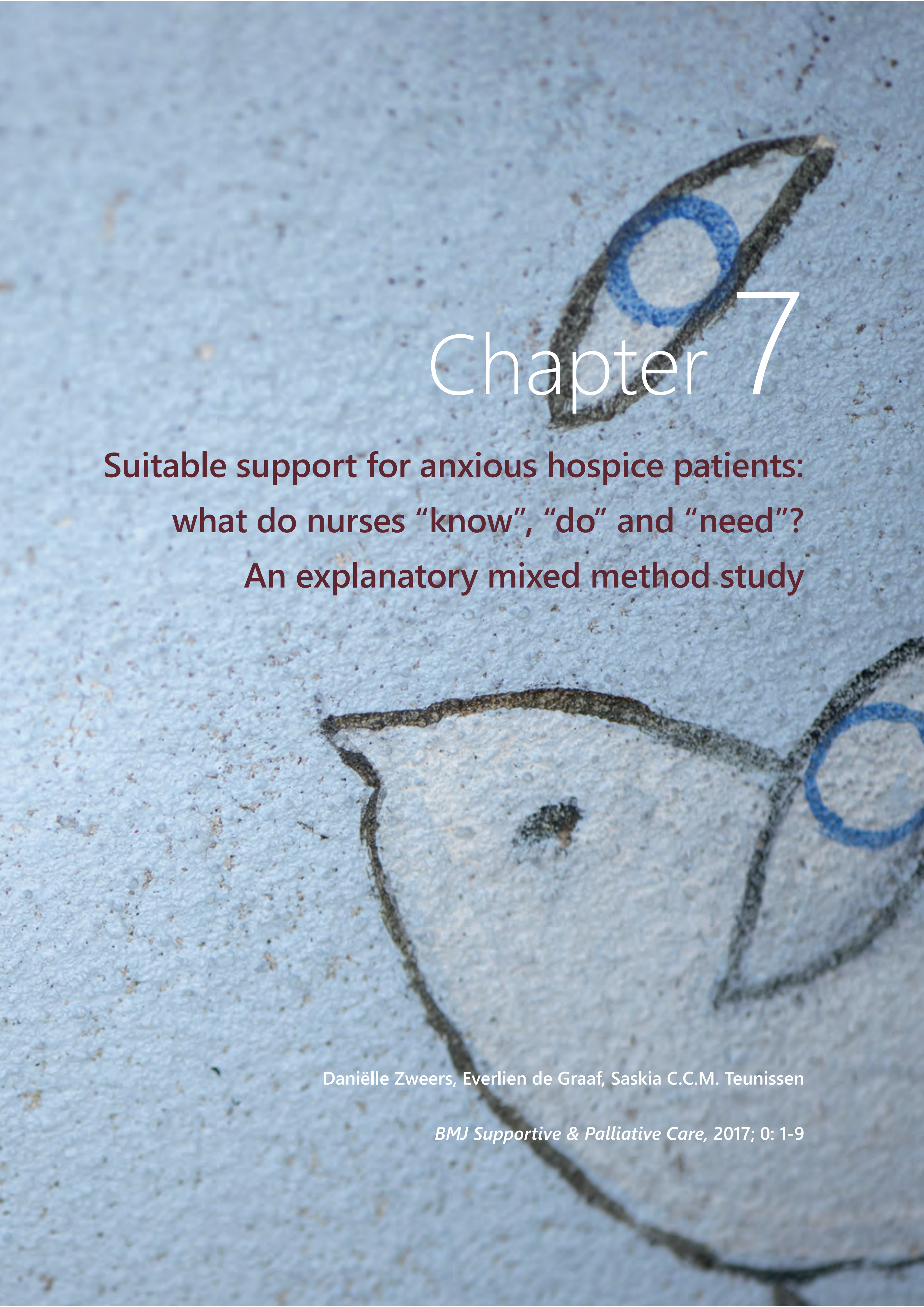

Chapter 7

Suitable support for anxious hospice patients: what do nurses “know”, “do” and “need”? An explanatory mixed method study

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Abstract

Objective: To provide insight into what nurses know, do and need to provide support to anxious patients in hospice care (HC).

Methods: A mixed method study consisted of an online survey and focus groups (FG) about what nurses know, do, and need was conducted. 336 HC nurses were invited to participate. Descriptive statistics were computed using SPSS. The $\chi 2$ and t-tests were conducted to compare the groups. The FGs were transcribed verbatim and thematically analyzed.

Results: The survey was completed by 265 nurses (79%), 5 FG (N=25) were formed. Most nurses had >10 years working experience, mean age was 52. The majority (59%) felt that they were equipped with sufficient knowledge; on the other hand, lack of knowledge (31%) as well as lack of time (50%) were hampering factors. Identification was difficult due to the variety of its expression. Tools for identifying anxiety were used by 37%. Interventions were generally chosen intuitively. A major responsibility was caring for patients with panic attacks during late night shifts, making immediate decisions necessary.

Conclusion: This study highlights the struggles of nurses caring for anxious HC patients. Anxiety management is dependent on the competencies and preferences of the individual nurse. One-third of the nurses require additional training. According to HC nurses, the intervention set should include guidelines for applying assessment tools, effective communication strategies, and decision models as well as prediction models in order to select tailored interventions. Future research should focus on patients' perspectives in order to understand crucial measures for anxiety management.u

Introduction

In the last two weeks before death, at least 30% of advanced cancer patients suffer from anxiety[1]. Anxiety can be classified on the basis of underlying etiology, such as situational, organic, existential, and psychiatric anxiety, and can have cognitive, emotional, and behavioral components[2]. Anxiety can affect patients’ decision-making, exacerbate other symptoms, and can be a threat to the patients` quality of life[3, 4]. Therefore, interventions for symptom management and self-care strategies are necessary[5]. Psychosocial and psychopharmacological treatment for the prevention or alleviation of anxiety as well as ongoing monitoring and evaluation using validated measurement tools are recommended[5].

The management of anxiety requires an interdisciplinary team approach. Nurses, who are generally a common stable factor within this interdisciplinary team, are ideally situated to identify anxiety because of their day-to-day observation[6, 7]. In addition, the lack of regular access to mental health professionals in hospice care (HC) highlights the need for nurses to take on this responsibility[8]. While the review of Traeger et al. (2012) identified important issues, there is a lack of understanding as to which role and responsibilities oncology and palliative care nurses have in the management of anxiety[9].

A common misconception among nurses is the assumption that anxiety represents nothing more than an understandable reaction to having an incurable illness and that nothing can be done about it[10]. Furthermore, assessment of anxiety on a regular basis is lacking[11]. Both can result in an under-identification of anxiety. It is important to identify anxiety because anxiety adds to patients’ suffering on physical, psychosocial, and spiritual well-being levels. As far as we know, no previous studies on what nurses do, know, and need in caring for anxious HC patients are available. Some previous studies focused on nurse-patient communication with regard to psychological distress. Blocking behavior by nurses, e.g. reactions with non-emphatic language or medical explanations, was more prevalent than supportive communication behavior to encourage further disclosure[12, 13]. In addition, some nurses were afraid to discuss emotional difficulties with patients because they worried that they would make the patient feel worse[14]. However, the generalizability of these studies should be questioned since some are dated, focused primarily on solitary nurse-patient communication and psychological distress in general.

To ameliorate the management of anxiety in HC, we wished to develop an intervention set according to the Medical Research Council (MRC) Framework[15]. A fit between the intervention set and daily practice was a precondition for its successful implementation. Therefore, a better understanding of the current nursing HC regarding anxiety management was needed. The primary aim of this mixed method study was to gain insight into what nurses know, do and need to support HC patients suffering from anxiety. The secondary aim was to explore which additional factors influence knowledge about anxiety, performed interventions, and the needs of HC nurses.

Method

Design

A prospective explanatory and triangulated component design was conducted using quantitative and qualitative methods. An online survey was conducted to establish a broad understanding of the current practice regarding anxiety management. The focus groups provided a deeper and multifaceted insight[16].

This study lies outside the scope of the Medical Research Involving Human Subjects Act and has therefore not been reviewed formally by the ethics committee. However, the study has been conducted in compliance with the principles of good clinical practice.

Subjects

Nurses caring for patients within 28 Dutch in-patient hospice facilities affiliated with the Dutch Association of Hospice Care (DAHC) were solicited to participate. The estimated target population based on an earlier HC exploration in The Netherlands consisted of 336 nurses. Invitations to fill in the online survey were sent to the managing directors, who forwarded the invitation to the nursing teams with the link to the survey.

Data collections

Online survey

A 40-item online survey was developed (Figure 1). The answer options were based on the Dutch National Anxiety Guideline[17]. Feasibility was assessed by two hospice nurses. As a result, minor alterations were made to increase the readability of two questions. Open questions were used to obtain items for the focus groups. Nurses filled out the survey anonymously from February to April 2015. It took 25 minutes to complete. Demographics were also collected.

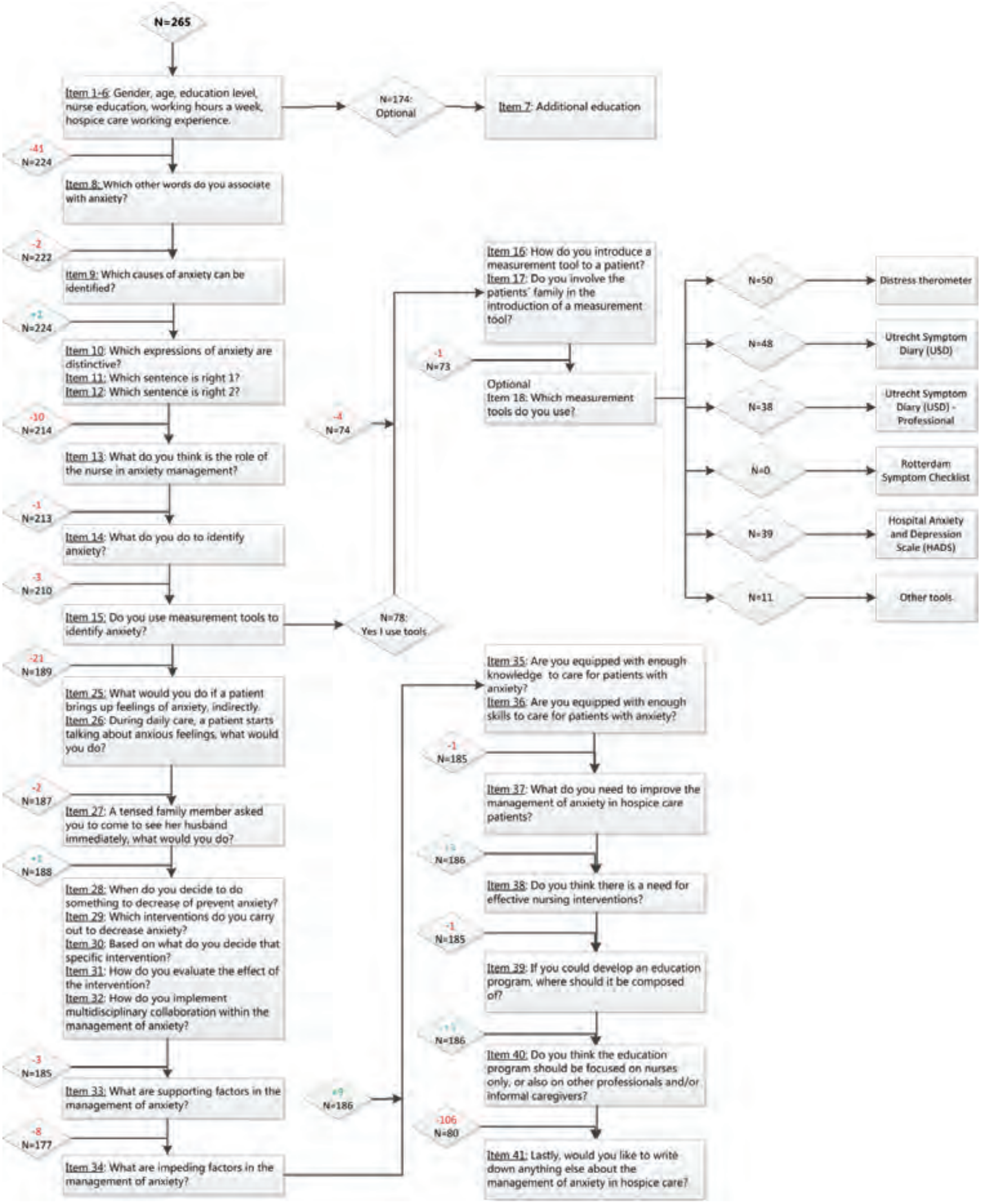

Figure 1: Illustration of the items of the online survey and detailed description of the item non-response

Focus groups

To acquire a deeper understanding of the outcome of the survey, focus groups sessions (FG) were conducted. Nurses who completed the survey were asked to participate. Since only nine nurses responded, we also asked nurses to participate (max. two nurses per hospice) via an email sent directly to the director of the hospice. Data collection continued until no new issues were identified and no new codes emerged[18]. Two researchers, a moderator (DZ) and an observer (EdG), were present during the FGs and the meetings were audio recorded. The FGs began with reporting the outcome of the online survey per domain. Nurses were asked to share their perceptions, thoughts, and ideas. Additional questions were used to support the discussions (Table 1).

Table 1: Additional questions to support the debate.

Domain	Questions
1. Knowledge	• What are your thoughts about the percentage of nurses who answered the knowledge questions correctly? • Do you recognize these percentages in your own workplace? • Which knowledge is needed to care for patients with anxiety?
2. Identification	• How do you identify anxiety (with and without measurement tools) and can you give an example? • Why, in your opinion, are measurement tools rarely used in daily care? • If you use measurement tools, how do you introduce them to the patient and family?
3. Interventions and decision making	• Do you recognize a variety of interventions in your own workplace? • How do you decide which intervention you will choose? • How do you decide whether the intervention is within or outside of the nursing domain? • How do you integrate multidisciplinary collaboration? • Which competencies are needed to perform those interventions? • How do you ensure continuity?
4. Needs	• Which factors support and which factors hamper the care of patients with anxiety? • What do you need to improve the management of anxiety?

Analysis

Online survey

Data were transferred automatically from the online survey program into the IBM Statistic Package for Social Sciences 23. Descriptive statistics were computed to present the frequencies, mean, SD, and range. The independent t-test was computed to test whether age, educational level, HC working experience, and working hours/week were influencing factors on knowledge about anxiety, performed interventions, and needs of nurses, as well as to assess whether the respondents differed from the non-respondents. If the data did not meet the assumptions of a normal distribution, the chi-squared test was used. The chi-squared test for years of working experience did not meet the assumption of expected frequencies <5; therefore the answers were transformed from 0-1, 1-5, 5-10, and >10 years into 0-5, 5-10, and >10 years. Based on the explorative nature of this study, no multiple test correction was performed. P-values of 0.05, two-sided, were established as an acceptable indication of statistical significance.

In order to minimize non-response, a reminder was sent after 2, 6, and 7 weeks[19]. The item non-response rate was analyzed to establish if this was systematic or correlated with the variables under study. It was not possible to predict how nurses would respond to the items since the perceptions of nurses were of interest. It was therefore decided that using a method of imputation to compensate for the item non-response would be inappropriate[19].

Focus groups

After each FG, the process and content were evaluated. The researcher (DZ) listened to the audiotapes several times. The tapes were transcribed verbatim with detailed notes between brackets. Thematic analysis was performed to reduce the sentences into codes, labels, and themes using MaxQda11.[20] The coding process was peer-reviewed, iterative, and based on pre-established domains. Member checks to ensure trustworthiness were carried out within one week after the FG had taken place. One minor adjustment on word choice was made, which had no influence on the results.

Results

In total, 265/336 (79%) nurses participated in the online survey of whom 173/265 (65%) completed the survey without missing items. Nurses who filled out the survey with missing items were significantly older (t(228.74)=2.5, p=0.01) and, based on their nursing school degree, more highly educated ($X^2(2)=7.1$, p=0.03) (Table 2).

As illustrated in Figure 1, the highest proportion of the item non-response was after completing the baseline characteristics (n=41) and after item 15 about the use of measurement tools (n=21). Those nurses (n=62) did not complete the survey later on. Five FGs were conducted with a total of 25 nurses. Demographics are presented in Table 3.

Table 2: Differences between nurses

		With missing items (N=92)	Without missing items (N=173)	P value	Statement correct	Statement incorrect	P value	Nurses who use tools	Nurses who did not use tools	P value
Mean age (SD)		53.2 (6.4)	50.9 (8.3)	*P=0.01*^{1}	1) 49.6 (7.6) 2) 51.4 (8.1)	1) 52.2 (8.2) 2) 50.6 (7.9)	*1)P=0.01*^{1} 2)P=0.50^{1}	52.2 (6.5)	50.3 (8.8)	P=0.08^{1}
Education*	Community college	38 (35.5%)	69 64.5%)	P=0.77^{2}	1) 37 (41.1%) 2) 57 (63.3%)	1) 53 (58.9%) 2) 33 (36.7%)	1)P=0.09^{2} 2)P=0.33^{2}	25 (29.8%)	59 (70.2%)	*P=0.04*^{2}
	Bachelor degree	51 (34.9%)	95 (65.1%)		1) 55 (45.1%) 2) 75 (77.3%)	1) 67 (54.9%) 2) 47 (44.7%)		45 (39.5%)	69 (60.5%)	
	Master degree	3 (25%)	9 (75%)		1) 9 (75%) 2) 10 (83.3%)	1) 3 (25%) 2) 2 (16.7%)		8 (66.7%)	4 (33.3%)	
Nursing school	RN	44 (34.1%)	85 (65.9%)	*P=0.03*^{2}	1) 45 (42.1%) 2) 70 (65.4%)	1) 62 (57.9%) 2) 37 (34.6%)	1)P=0.13^{2} 2)P=0.66^{2}	34 (33.3%)	68 (66.7%)	P=0.26^{2}
	RN with bachelor degree	17 (24.6%)	52 (75.4%)		1) 35 (55.6%) 2) 37 (58.7%)	1) 28 (44.4%) 2) 26 (41.3%)		21 (35.6%)	38 (64.4%)	
	Other	31 (46.3%)	36 (53.7%)		1) 21 (38.9%) 2) 35 (64.8%)	1) 33 (61.1%) 2) 19 (35.2%)		23 (46.9%)	26 (53.1%)	
Mean working hours a week (SD)		19.7 (8.6)	21.0 (7.7)	P=0.20^{1}	1) 21.1 (8.1) 2) 20.0 (8.3)	1) 20.2 (7.5) 2) 21.7 (6.9)	1)P=0.41^{1} 2)P=0.08^{1}	22.2 (8.2)	19.7 (7.5)	*P=0.02*^{1}
Working experience in hospice care	0-5 years	28 (32.2%)	59 (67.8%)	p=0.73^{2}	1) 35 (46.1%) 2) 49 (64.5%)	1) 41 (53.9%) 2) 27 (35.5%)	1) P=0.50^{2} 2) P=0.80^{2}	26 (35.1%)	48 (64.9%)	P=0.90^{2}
	5-10 years	25 (33.8%)	49 (66.2%)		1) 32 (50%) 2) 42 (65.6%)	1) 32 (50%) 2) 22 (34.4%)		24 (38.7%)	38 (61.3%)	
	>10 years	39 (37.5%)	65 (62.5%)		1) 34 (40.5%) 2) 51 (60.7%)	1) 50 (59.5%) 2) 33 (36.6%)		28 (37.8%)	46 (62.2%)	

1: independent t-test, 2: chi-squared test; 1): statement 1, 2): statement

Table 3: Demographics of the nurses in the survey and focus groups

Nurses who took part in the online-survey N=265			Nurses who participated in FG N=25					
			FG1 N=5	FG2 N=3	FG3 N=8	FG4 N=4	FG5 N=5	Total N=25
Age (years)	Mean	51.7	44	47	53.8	47.8	50.8	49.4
	Median	53	44	49	55	51	51	50
	Range	28-64	33-56	39-53	47-61	32-57	39-58	32-61
Gender	Men	9 (3%)	0	0	1	0	1	2
	Women	256 (97%)	5	3	7	4	4	23
Education level*	Community college	107 (40%)	1	1	3	2	0	7
	Bachelor degree	146 (55%)	5	2	3	2	3	15
	Master degree	12 (5%)	0	0	1	0	2	3
Nursing school*	RN	129 (49%)	1	1	0	1	2	5
	RN with bachelor degree	69 (26%)	1	2	3	1	0	7
	Other	67 (25%)	3	0	5	2	3	13
Working hours a week	Mean	20.5	20.2	29.3	22.5	25	28.8	23.7
	Median	24	20	24	24	24	32	24
	Range	1-40	16-25	16-28	8-32	24-28	24-32	8-32
Working experience in hospice care (years)	0-1	5 (2%)	0	0	0	0	0	0
	1-5	82 (31%)	1	2	2	0	2	7
	5-10	74 (28%)	3	0	1	2	3	9
	>10	104 (39%)	1	1	5	2	0	9

As expected, most nurses were female with a mean age of 51.7 for the online survey and 49.4 for the FG participants. The majority of the nurses had worked >10 years in HC. The FGs lasted 60-75 minutes.

Knowledge

Psychiatric 169/222 (76%) and drug-induced causes 146/222 (66%) of anxiety were less frequently mentioned than physical 200/222 (90%), psychological 209/222 (94%) and existential causes 201/222 (91%). Most of the common expressions of anxiety were recognized, with the exception of diarrhea 61/224 (27%) and hot flashes 58/224 (26%). Based on the national anxiety guideline, two statements had to be answered as correct or incorrect, and those were answered correctly by 101/224 (45%) and 142/224 (63%). Nurses who answered statement one correctly were significantly younger than the nurses who did not (t(222)=2.49, p=0.01). This was in contrast to statement two (Table 2). In addition, nurses stated that they were equipped with sufficient knowledge 110/186 (59%) and skills 123/186 (66%) to care for anxious patients. FG participants were disappointed with the number of nurses who had answered the statements correctly. They suggested that an overestimation of their own knowledge could be an explanation. Some nurses acknowledged that they do not use guidelines for anxiety as often as they do for physical symptoms (Box 1).

Nurse 3C (57 years old): *"Yes, for many symptoms, such as pain or nausea, it's usually clear what to do according to the guidelines, but this is not the case for anxiety. There are many influencing factors to consider, such as where the fear is coming from but also the personality of the patient, or even the personality of the nurse. It's not as clear cut as with giving medication for nausea or pain."*

Box 1

Identification

Nurses asked patients on a regular basis if they were anxious: 134/213 (63%). In total, 34/213 (16%) nurses discussed anxiety only if the patient brought it up himself. Measurement tools for identifying, monitoring, or analyzing anxiety were used by 78/210 (37%) nurses. The distress thermometer, the Utrecht Symptom Diary (USD), a version of the Edmonton Symptom Assessment System (ESAS) translated into and adapted for Dutch, and the Hospital Anxiety and Depression Scale (HADS) were commonly used tools. Knowledge about the correct application of those tools differed as well as when to use which tool based on institutional guidelines. Nurses who did use measurement tools worked significantly more hours per week (t(150.6)=2.23 p=0.03) and were more highly educated than nurses who did not use tools ($X^2(2)=6.71$, p=0.04) (Table 2).

Nurses experienced difficulties in the identification of anxiety due to the variety of expressions, as in emotional, cognitive, and behavior components. Expressions of anxiety were observed more frequently during evenings and nights. Identification of symptoms was mainly focused on physical problems rather than psychological problems. If anxiety was identified, a common way to initiate a conversation was to discuss observations of emotional, cognitive, and behavior components that could be caused by anxiety. This was an opening to talk about emotional issues. A question to facilitate further disclosure of anxiety was, for example, to ask patients how they were accustomed to coping with feelings of anxiety in the past.

Nurses who used measurement tools were surprised by the number of nurses who did not use those tools. Nurses who used tools were convinced of the added value, since appropriate tools initiate dialogue with the patient and make possible routine checks of the patient`s anxiety level without overwhelming them with questions. Furthermore, communication with the patient, family, and physician improved when measurement tools were applied. However, it was important to introduce and provide a clear explanation of the purpose of the tools in order to achieve adherence to their use.

Some nurses deliberately did not use instruments. Those nurses were convinced that filling out a questionnaire placed a burden on patients. Other nurses were not aware of the existence of measurement tools and their implementation in daily care. Several nurses, initially convinced that it was a burden for patients to fill out a questionnaire, changed their opinion after using it (Box 2).

Nurse 1 (44 years old): *One and a half years ago I thought that it was a great burden for patients to fill out a questionnaire. But now I know the advantages; it's a way to enter into dialogue with the patient. Not that it works that way for everyone but, if you've had success with this method, you start thinking differently about its use. Furthermore, patients feel that they are being taken seriously and they find it fine to do, because you gain insight into the total range of their problems. I think that the reluctance has to do with not being familiar with the method and the feeling that you don't want to burden patients during the last phase of their lives.*

Box 2

Interventions and decision making

The open-end items in the survey about the provided interventions resulted in a large amount of commonly performed interventions. Basic communication skills such as listening and observing were mentioned. Also mentioned were complementary care, patient education, physical presence, and being nearby, as well as referring patients to specialized professionals such as physicians, social workers, psychologists, creative therapists, or spiritual caregivers. FG participants recognized these interventions in their own practice. They indicated that a precondition to support patients with anxiety was to build a relationship of trust and safety. Some of the nurses indicated that medication was generally the first choice of intervention.

The selection of interventions was generally intuitive, influenced by the feasibility and availability of interventions, nurse availability and workload, the intensity and underlying causes of anxiety, and the needs of the patient. Decision-making was influenced by the time of the day that anxiety was expressed. For instance, based on past experience, nurses realized that conversations about anxiety before going to sleep were more harmful than helpful and therefore interventions that focused on relaxation were preferable. The decision-making process to select an effective intervention was described as trial-and-error. Nurses experienced a major responsibility and struggled in caring for patients with panic attacks in particular. During panic attacks, communication became difficult and nurses had to made rapid decisions on their own, since they were mostly the only professional present. They could rarely fall back on an anticipatory care plan and were required to consult a physician who, at times, such as during out-of-office hours, did not know the patient.

Consulting specialized professionals depended on the availability of those professionals and differed per hospice. Decisions to refer were mostly nurse-driven and depended on the total workload as well (Box 3).

Nurse 3 (33 years old): "*When a patient who is extremely anxious needs so much attention from me that I can't get on with my daily tasks or can't offer any solution, that's the moment I call a psychologist for advice.*"

Box 3

Some nurses were allowed to decide themselves whether to call in an expert, while others had to decide with the entire (multidisciplinary) team. The collaboration between nurses and specialized professionals was unclear according to the FG participants and their tasks often overlapped.

Generally, nurses had access to the reports of other professionals. However, the common way of informing nurses about the progress of the support of the specialized professionals was in the multidisciplinary team meeting. The frequency of those meetings differed from twice a week to once every two weeks. Instructions as how nurses should cope with a patient after a psychological session were seldom provided.

Working with volunteers was commonly experienced as a supporting factor in anxiety management. Volunteers were able to sit next to the patient without being disturbed and were skilled in performing massage. However, some nurses struggled with the role of volunteers since the volunteers are not always aware of the effect of in-depth dialogues for the patient. In addition, the patient meets a lot of different people during the day, which can cause a disquieting situation. For this reason, some nurses preferred to restrict the number of volunteers visiting the patient.

According to some nurses, preventing and decreasing anxiety is not always possible and should not always be the objective. Anxiety can be seen as a way of learning, and patients are allowed to feel anxious. Doing nothing, however, was experienced as difficult (Box 4)

Nurse 5 (57 years old): "*It is difficult to do nothing but it is really important. As we mentioned earlier, a relationship of trust. The patient should know that we are there when he or she needs us. But also that we will accept and respect their choice if they don't do anything about it. And I think that could help." [laughing]*

Box 4

Needs

A lack of time 93/186 (50%) and a lack of knowledge 57/186 (30.6%) were considered the most impeding factors in anxiety management. The majority of nurses who filled out the survey reported that there is a need for evidence-based nursing interventions 164/186 (88.2%). These results were supported in the FGs.

A lack of time and being rushed were the most impeding factors to care for anxious patients according to the FG participants as well. One nurse mentioned that the core ingredient of caring for patients with anxiety is patience as well as feeling calm (Box 5).

> Nurse 12 (44 years old): “….*Well, I think you bring yourself with you and you have to trust yourself that when there is an acute situation you will act automatically. It is really important to be calm caring for those patients…. For example, you have to be completely accessible, have an open mind, and should not think about your issues in your own family or about Ms. Jansen, the patient next door. When you have an open mind, you can keep calm and think clearly about what is needed. You are an instrument in yourself as well.*”

Box 5

Nurses acknowledged that the survey was an eye-opener, resulting in the conclusion that more knowledge about anxiety is needed, particularly with regard to the interaction between physical symptoms and anxiety. They stated that anxiety should be prioritized in a manner similar to that in which physical symptoms are, since they influence one another. Another impeding factor that came to light was the fact that nurses sometimes react too late to expressions of anxiety. At a later time, following an evaluation with the team, useful ideas and interventions were proposed. However, the moment at which the situation for that individual patient could be changed had passed. Nurses indicated they need a prediction model to predict whether patients are at risk for experiencing high levels of anxiety. This can help to intensify monitoring and set up an anticipatory care plan. For example, some nurses proactively refer the patient to a specialized professional if a patient has a psychiatric history, although this often only happens after the problem becomes evident.

Consistency in the nursing and multidisciplinary team was also pointed out as an important factor to consider. Diversity in the team was experienced on the one hand as a supporting factor, since there is generally someone with whom a patient would connect. On the other hand, diversity in caring for patients with anxiety can lead to contradictory advice, which could be harmful. During the FGs it became clear that the care for anxious patients differs among nurses and depends on the knowledge, skills, and preferences of the individual nurse, and that continuity of care is a problem due to a lack of daily reports about anxiety.

Discussion

Nursing practices in caring for anxious HC in-patients were studied in order to use these insights for the development of an intervention set that fits in with daily practice.

This study highlights the struggle of nurses caring for patients suffering from anxiety, especially during late night shifts. Early identification and monitoring of anxiety, as well as proactive treatment and a support plan to prevent crisis situations, is lacking. Measurement tools to support this process were used by only one-third of the participants. Lack of knowledge was one of the foremost reasons for not applying measurement tools. This is in line with the findings that nurses who use tools have a more advanced training level, although the differences between those groups were small. Another problem was the continuity of care, sometimes resulting in a proposed care plan that did not reach the nurse who needed these recommendations in caring for the patient during late night shifts. Furthermore, nurses need a method to predict the risk that a patient may experience high levels of anxiety. This would help in setting up pro-active interventions to prevent anxiety and/or adequately support patients with high levels of anxiety, particularly during the late night shifts.

Anxiety management in nursing practice depends mainly on the competencies and preferences of the individual nurse. A wide range of interventions is available, but these are mostly selected on the basis of intuition. Furthermore, whether or not a referral to specialized professionals is made is commonly based on the availability of those professionals and the nurses' workload rather than the patient's needs.

Although >50% of the nurses are confident about their knowledge and skills, still 41% and 34% are not. Furthermore, 31% conclude there is a need for more knowledge about anxiety management. Age was a significant influencing factor, although the difference between the groups was small.

In comparison with existing literature, our results show that hospice nurses initiate conversations about anxiety. This is contrary to the study of Heaven et al. (1997), who found that only a minority of nurses initiate conversations about psychosocial concerns. Although research has shown that patients who suffer from anxiety are less likely to disclose their concerns spontaneously, only 16% of the participants discuss anxiety only if the patients bring it up themselves[21]. A lack of knowledge was a major reason why nurses do not use measurement tools to assess anxiety and is in line with previous findings in Veldhuisen et al (2016)[11].

To the best of our knowledge, this is the first mixed method study that provides insight into the current nursing practices in supporting HC in-patients who suffer from anxiety. The combined quantitative and qualitative approach allowed us to acquire an in-depth insight into the current practices of anxiety management. Nevertheless this study does have some limitations.

The item non-response of the online survey was not random. Furthermore, the online survey had a risk of socially desirable answers. This seemed not to be the case in the focus groups. FG participants were really curious about how other participants intervened. Based on the exchange of experiences about situations in which nurses did not always handle things properly, we conclude that the focus groups were a safe environment where nurses dared to share their practices. Most FG participants who filled out the survey, acknowledging that completing the survey made them more aware of what they did not know. This served as an incentive to increase their knowledge regarding anxiety management and could have influenced the perceptions of the nurses who participated in the FGs. This study was conducted in the Netherlands, therefore the findings should be generalized with caution since HC nursing competencies could be different in other countries. However, the findings are useful in creating a successful fit between an intervention set and current practice.

Conclusion

This study highlights the struggle of nurses in anxiety management, especially during late night shifts. Anxiety management in HC depends mainly on the competencies and preferences of the individual nurse. Most of the nurses are in need of an evidence-based intervention set and additional education. Based on nursing practices, we conclude that an intervention set should include clear guidelines for the application of assessment tools, effective communication strategies, and a decision model to help select tailored interventions. Naturally, education would be a prerequisite for implementation. Future research should focus on the patient's point of view. Patients' perspectives would help nurses and other professionals to understand crucial issues of anxiety management in order to prevent or decrease anxiety and ameliorate quality of life.

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Part III

Chapter 8

General Discussion

Introduction

Anxiety as a symptom is experienced by 20-50% of palliative care patients with advanced cancer[1-4]. Timely recognition and treatment of anxiety is essential for optimal palliative care[5,6]. However, management of anxiety in these patients is a real challenge due to the variety of expressions and underlying causes in the context of a short life expectancy.

We realized that causes of anxiety did not cover it all since thoughts, ideas, images and memories could be a reason for anxiety as well. Therefore we introduced the term "sources" of anxiety as a broad concept defined as all matters a patients may be afraid of.

Nurses have an important role in the early recognition and management of anxiety[7, 8]. However, there is a lack of knowledge in this field[9] and consequently, early recognition and management of anxiety is often dependent on the motivation and the competencies of the individual nurse[10]. To provide adequate management of anxiety, multiple influencing factors should be addressed in a complex clinical practice. The number of interacting components, the difficulty of the required behaviors of those delivering and receiving the support and the degree of flexibility to provide tailored care makes it complex care[11]. Therefore, there is a need for a systematic approach to optimize the quality of care for vulnerable patients facing anxiety.

To support nurses in ameliorating early recognition and management of anxiety this thesis aims to provide more insight into the evidence and current practice of anxiety management as well as into the needs for support in patients with incurable cancer, from the perspectives of the patients themselves, their loved ones and their nurses.

The following research questions were posed:

- What non-pharmacological nurse-led interventions are available and what is their effectiveness in managing anxiety in advanced cancer patients?
- Which instruments are used by nurses to assess anxiety in advanced cancer patients admitted to a hospice or hospital, and what is the rationale behind it?
- What are the needs of patients with incurable cancer admitted to a hospice regarding anxiety management?
- What are the experiences of loved ones concerning the anxiety of the patients with incurable cancer admitted to a hospice?
- Are fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall perceived well-being predictors for anxiety in advanced cancer patients admitted to a hospice?
- What do nurses know, do and need to support cancer patients with anxiety admitted to a hospice?

In the current chapter, the main findings of the studies will be summarized. Next, the strengths and shortcomings of these studies will be discussed. Finally, a proposal for a systematic approach for early recognition and management of anxiety in patients with incurable cancer and directions for future research will be suggested. In this process, the Medical Research Council (MRC) framework[11] was used which is commonly used in developing complex interventions in nursing care[12].

Summary of the findings of our studies

Non-pharmacological nurse-led interventions for anxiety

In Chapter 2, we systematically searched the literature for non-pharmacological nurse-led interventions for anxiety and their effectiveness in advanced cancer patients. Seven studies were included. The interventions were categorized into patient education, telemonitoring, psychotherapy, complementary care or a combination of these. Two studies showed significant improvements in anxiety levels in patients who received a psychoeducational intervention and in those who participated in a telemonitoring program, respectively. However, both studies were judged to have a high risk of bias due to attrition, the randomization process and blinding which was not described.

Although there was no firm evidence due to the high risk of bias, two studies showed that nurses could play a meaningful role in the management of anxiety with regard to psychoeducation and early recognition in a telemonitoring program. Importantly, in none of the studies described, attention was given to specific causes of anxiety.

Assessment of anxiety by nurses using measurement instruments

In Chapter 3, we studied which instruments are used by nurses to assess anxiety as a specific construct or as a part of a broad symptom diary, by means of an analysis of medical records (n=154) and nurse interviews (n=12). We broadened the population by including patients and nurses from a general and university hospital as well. At least one instrument was used in 67% of patients of the academic hospital and 100% of patients of the hospice. In the general hospital no instruments were used. If an instrument was used, the Utrecht Symptom Diary (completed by the patient) was used in all cases, supplemented by the Utrecht Symptom Diary Professional (completed by the nurse or other caregivers, exclusively in the hospice). Occasionally, the Distress Thermometer combined with a problem list (Lastmeter) and the Hospital Anxiety and Depression Scale (HADS) were used. The mean anxiety score of patients admitted to the hospice was significantly lower compared to the mean anxiety score of patients admitted to the university hospital (1.8 vs. 1.1, p=0.019).

Lack of knowledge was the main reason not to use instruments in the general hospital. For nurses familiar with the use of instruments, they helped to identify and monitor anxiety, to start a dialogue with the patient and to prevent patients becoming overwhelmed, to get insight into the possible causes and to evaluate the effect of interventions. The nurses indicated that the Utrecht Symptom Diary was a feasible and valuable instrument for the assessment of anxiety. Impeding factors to use instruments to assess anxiety were patient related factors (the patient being too ill or too busy; problems with the Dutch language) and environmental related factors (workload or lack of privacy to discuss the findings).

Needs of patients with incurable cancer admitted to a hospice

In Chapter 4, we qualitatively explored the needs of patients (n=14) with cancer admitted to a hospice. It became clear that patients did not always identify themselves with the word "anxiety", but used other words like scared, tense or worried. Five important needs emerge from the interviews: information and a sense of control, safety, adequate symptom management, talking about anxiety (or not) and respect for coping strategies by professionals.

The prominent need for most was information. This included information about all aspects of care. Poor or incomplete information may generate mistrust of the involved professionals and therefore increase anxiety.

A sense of control was associated with decreased anxiety. Involvement in their own daily schedule and being informed contributed to this sense of control. The patients' sense of control was also dependent on feeling safe and having faith in the professional team. Safety was experienced by the 24/7 availability of a professional, not feeling alone and expertise of the professional. Therefore, it is essential to address what control and safety mean for the individual patient.

Adequate symptom management was indicated as essential in decreasing anxiety. Physical symptoms (e.g. pain or dyspnea) were most often described as a direct cause of anxiety. Insomnia was more indirectly related to anxiety. A good night sleep helped 1) not to feel anxious during the night, and 2) to restore energy to cope with anxiety during the day.

Respect for the patients' way of coping was an important need as well. This means that patients should be supported in their coping style at that moment, which may vary from being left alone to avoidance by distraction or explicit discussion of their feelings. It was important for patients to feel respected for their choice to either accept or decline the invitation for a talk. Patients expressed that they never minded questions about anxiety, regardless of their coping strategy. Patients never expected a solution and were aware that anxiety could not always be alleviated. They did expect attention, kindness and their problems and/or symptoms to be taken seriously.

Insight into patients' needs provided important angles where healthcare professionals can make a difference in an effective and personalized approach. Optimal recognition and management of anxiety should consist of timely recognition of anxiety by proactive questioning using multiple synonyms of anxiety, adequate information and education, ensuring feelings of safety and control, adequate symptom management and recognition and enhancement of the patient's coping strategy to deal with anxiety.

The perspective of the loved ones

In Chapter 5, we qualitatively explored the needs of the patients from the perspective of their loved ones (n=14). Loved ones gave high anxiety scores for the patient (median score 6.5, range 3-8) and indicated a high impact of anxiety in all domains: physical, psychological, social and spiritual. Loved ones were able to identify a broad range of sources of anxiety: in particular physical and mental deterioration and anxiety for the unknown, but also loss of control over mind and body, dependency on others and loss of dignity. With regard to the patient needs, loved ones mentioned the need for a safe environment, honest information, the presence of people around and tailored care based on the preferences of specific needs of the patient. Loved ones indicated a variety of verbal and non-verbal expressions of anxiety by the patient such as restlessness, hostility, avoidance and withdrawal, being absent-minded and acting harshly towards others. Also small gestures such as twisting a ring on a finger, putting a hand to the forehead or clinging to people and objects were recognized as expressions of anxiety. The loved ones provided important information, based on their long relationship with the patient.

Since loved ones know the patient the best, they can be a valuable source of information and may provide a unique perspective in identification of anxiety and personal support, especially when patients are not able or willing to communicate about their concerns. Therefore, loved ones should be involved in the assessment and care of anxious patients.

Symptoms predicting for anxiety

In Chapter 6, we studied whether fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall perceived well-being are predictors for anxiety in advanced cancer patients admitted to a hospice. The included symptoms were based on the already demonstrated relationships with anxiety in earlier studies.

Remarkably, the prevalence of anxiety was low in this population. This indicates that anxiety may be more severe in earlier stages of a life-threatening illness. This is in line with one of the patient interviews in Chapter 4, in which the patient indicated that she had much less to lose in this stage of her disease and, as a result, felt less anxious than before.

However, the word “anxiety” was not always identified by patient. Words like scared, tense or worried were more commonly used words. This together with the difficulties in scoring anxiety could result in underreporting of anxiety.

After correction for age, gender, and marital status, depressed mood and dyspnea were independent predictors for anxiety. Depressed mood and dyspnea together with age, gender, and marital status explained 22.8% of the variance of anxiety.

With regard to symptom management as part of the treatment of anxiety, specific attention should be given to depressed mood and dyspnea.

The role of nurses

In Chapter 7 we provide insight what hospice nurses know, do and need to support cancer patients with anxiety admitted to a hospice using an online survey and focus group interviews. 134 out of 213 (63%) nurses asked patients on a regular basis if they were anxious. 16% of the nurses discussed anxiety only if the patient brought it up himself. Measurement tools for identifying, monitoring or analyzing anxiety were used by 37% of the nurses. Some nurses deliberately did not use instruments. These nurses were convinced that filling out a questionnaire placed a burden on patients. Other nurses were not aware of the existence of measurement tools and their implementation in daily care. Nurses experienced difficulties in the identification of anxiety due to the variety of expressions: emotional, cognitive and/or behavioral. Expressions of anxiety were observed more frequently during evenings and nights. 50% of the nurses experienced lack of time to deal with anxiety and 31% indicated a lack of knowledge. Interventions were generally chosen intuitively. A major responsibility was experienced in caring for patients with panic attacks during late and night shifts, making immediate decisions necessary.

This study highlights the struggles of nursing caring for anxious hospice patients with cancer especially during late and night shifts. Hospice care nurses need guidelines for applying assessment tools, effective communication strategies and decision models as well as prediction models in order to identify patients in need of selected tailored interventions.

The results of the six studies led to the following answers to our research questions:

- Very few evidence-based nurse-led interventions for anxiety in patients with advanced cancer were identified. Two interventions, psychoeducation and early recognition using telemonitoring, seem to be effective nurse-led interventions for anxiety in patients with advanced cancer.
- The Utrecht Symptom Diary (completed by patients) and the Utrecht Symptom Diary Professional (completed by nurses and other health care professional, exclusively used in the hospice) were frequently used instruments to assess anxiety by nurses. Nurses experienced these instruments as feasible and valuable to identify and monitor anxiety, to start a dialogue with the patient, to get insight into the possible causes and sources, to prevent patients becoming overwhelmed and to evaluate the effect of interventions. Lack of knowledge was the main reason not to use instruments.
- Patients expressed five needs with regard to anxiety management during their stay in a hospice: information and a sense of control, safety, adequate symptom management, talking about anxiety (or not) and respect for coping strategies by professionals.
- Loved ones of patients admitted to a hospice experienced that anxiety has a negative impact in the physical, psychological, social and spiritual domain. Loved

ones have a unique perspective and are able to identify patient needs, recognize expressions and sources of anxiety based on their long relationship with the patient before the illness.

- Dyspnea and depressed mood are predictors for anxiety after correction for age, gender and marital status in advanced cancer patients admitted to a hospice.
- One third of the nurses working at a hospice experiences a lack of knowledge and 50% a lack of time in order to adequately support patients with anxiety. Interventions were chosen intuitively and were dependent on the motivation and competencies of the individual nurse. Nurses needed guidelines for applying assessment tools, effective communication strategies and decision models as well as prediction models in order to identify patients in need and select tailored interventions.

Methodological reflections

Due to the multifactorial nature of anxiety in patients with incurable cancer with a limited life expectancy the MRC framework to develop complex interventions was used. The first step was to identify the evidence[11]. Since high quality evidence for effective interventions for anxiety was lacking, we set out with an analysis of anxiety from the perspectives of patients, their loved ones and nurses to gain more insight into the subject. The rationale for this approach, the required changes and how these changes are to be achieved was based on the "Shared Theory" of Desbiens[14]. The findings of these studies may help nurses to improve their self-competence and their performance. As a result, patient outcomes in self-care behavior, symptom burden and quality of life should be improved. The analysis provided important angles for nurses to improve management of anxiety and gave insight into the relation of process and outcomes as well.

In this thesis a variety of methods were used.
In Chapter 2, a systematic literature review of randomized controlled trials was conducted. Several comments may be made about the studies included. First, the assessment of the validity of the findings by the Cochranes' risk of bias tool showed several shortcomings. Second, in none of the studies attention was payed to the potential underlying mechanisms. The effectiveness of any intervention for anxiety is likely to be influenced by the type and causes of anxiety. Third, qualitative studies were excluded, potentially disregarding effective interventions. Fourth, all studies dealt with specific interventions and not with a broad management approach of anxiety. Despite the lack of evidence, we strongly believe that a systematic and multidimensional approach as part of basic psychosocial care will prove to be an effective strategy to manage anxiety in patients with incurable cancer.

Two mixed methods studies were performed (chapters 3 and 7). In line with the MRC framework, this method enables better understanding of how processes and outcomes are related and may be used for the design of subsequent studies[15]. It enabled us to do a broad exploration, using an analysis of the medical and nursing files and an online survey, respectively, both followed by focus groups to reflect on and understand the outcomes. In our opinion, combining a quantitative and qualitative model in one study results in a richer and more comprehensive picture[16].

Two qualitative studies (Chapters 4 and 5) were performed, which is inherent to the subject under study. Because of the amazing openness and willingness of the participants they were able to give us rich information, not only about their needs but also how these needs are related to interventions to decrease their anxiety. Recruitment of the patients was a challenge because they often had a high symptom burden, and their situation deteriorated sometimes very quickly. This required an intense collaboration between the researchers and nursing staff to make a suitable appointment with the participants.

Gatekeeping, defined as the process whereby healthcare professionals or other involved parties prevent eligible patients from entering a trial as a research subject[17], may have played a role in our study. In some cases the nursing staff had some concerns to ask patients or loved ones to participate. The ethical committee restricted the length of the interviews arguing that patients should be protected in their final stage of life. By discussing the staffs' concerns we agreed by searching for the right moment to ask the patient. Due to the collaboration between the researchers and the nursing staff it was feasible to recruit participant in this critical phase in their life. Despite the low number of patients and the short duration of the interviews, the study provided important data on the perspective of the patient.

One quantitative study (Chapter 6) was performed, retrospectively analyzing the predictive value of symptoms for anxiety in a hospice population. This study was performed using data which were primarily collected and used for clinical care. Due to the retrospective design, we had to deal with missing items and lack of knowledge about relevant issues such as the use of anxiolytics. Longitudinal analyses would have given us information how these associations may change near death. However, the sample was to small to do so, since patients near death were less able to complete the USD due to physical and cognitive impairment.

Overall, we mostly included highly educated Caucasian patients. This may be explained by the fact that the recruitment took place in a hospice in a village where highly educated people are relatively overrepresented. Furthermore, it may be due to selection since higher educated people are likely more willing to participate in studies than lower educated people[18]. This may influence the generalizability of our results.

Development of a systematic approach: implications for clinical practice

The development of a systematic approach in the management of anxiety should be integrated into a clinically relevant method frequently used in daily palliative care in The Netherlands. Therefore, we chose to use the method of palliative reasoning[19-22].

Palliative reasoning is an adapted version of clinical reasoning, to be used in patients in the palliative phase of their disease. The method aims to support individual professionals and multi-professional teams by a stepwise approach as presented in figure 1. It starts with a systematically assessment of symptoms and problems of patients in their individual context (phase 1), followed by the formulation of a working hypothesis, a treatment plan and its aim (phase 2), an evaluation of the effects of treatment (phase 3) and adaptation of treatment if necessary and possible (phase 4). The involvement of patients and loved ones about their whishes and priorities is essential in all phases. If used in a multidisciplinary setting effective communication should be improved by this method.

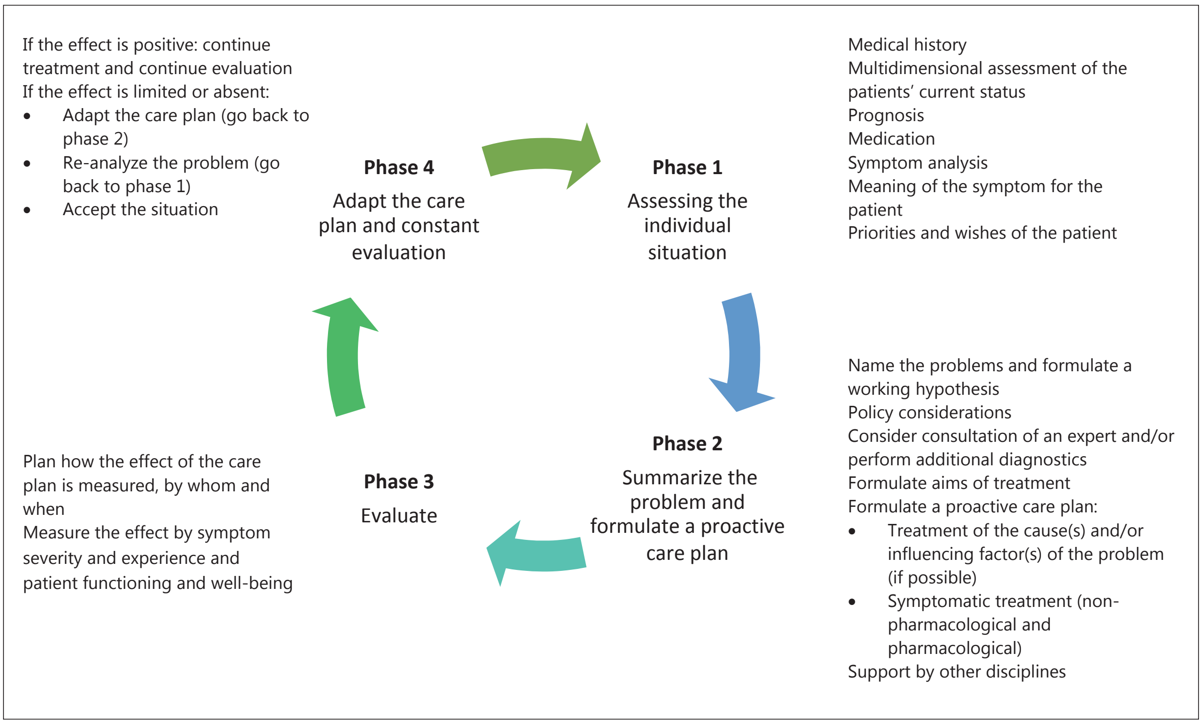

Figure 1: Decision-making model of palliative reasoning

This comprehensive method has first been published in 2007 (thesis of Teunissen[21]) to be used as a mono- or multidisciplinary framework for symptom management. Although most studies in this thesis focus on the role of nurses in management of anxiety, we strongly advocate a multidisciplinary approach of anxiety. The proposed model should be used by nurses and doctors in collaboration. In this way, the patient will receive optimal care.

A systematic stepwise approach for management of anxiety will be described along the four phases of palliative reasoning. For these phases the general aspects are described and specific anxiety related aspects are added, using the results of studies published by ourselves and others for steps 1 and 2.

Phase 1: Assess the individual situation

Medical history

As anxiety in patients with cancer in the palliative phase is often related to the underlying illness, its treatment (previous and current) and/or comorbidity (e.g. advanced stage COPD or heart failure), information about these issues is essential. A history of anxiety disorders, depression or other psychiatric disorders increases the risk to experience anxiety during life threatening illness[23] and should be asked explicitly. Information and open communication are very important needs of patients. Therefore, it is important to continually check to which extent the patient is informed about and understands his or her situation.

Multidimensional assessment

It is important to know who the human being is behind the patient. This information helps to set up a tailored care plan. How did his/her life look like before the illness and how does it look like now? Who or what is of great value? What would he or she like to share with the professionals? The use of a "personal patient profile"[24] is recommended in which a patient has the opportunity to share information and pictures about who is the human being behind the patient.

Our research and the literature[9, 25-27] clearly shows that anxiety in the palliative phase is highly influenced by a combination of physical, psychological, social and existential factors. Therefore, a multidimensional assessment and description of the patient is required. In this assessment, attention should be given to potential anxiety risks and key factors for treatment and support.

The following items should be explicitly explored:

- Physical dimension: general physical performance of the patient, impairment of activities of daily living (ADL)
- Psychological dimension:
    - General psychological performance: cognitive condition, communication possibilities, capacity to process information
    - Mood: worrying, tenseness, anger, depressive feelings
    - Coping mechanisms, in relation to the situation in general and to anxiety in particular: how does the patient cope with his or her anxiety and how does he or she wants to be approached (or not) by the professional?
    - Extent to which a patient would like to be informed

- Social dimension:
    - The role (positive or negative) of the loved ones in general and in dealing with anxiety
    - Decreasing roles as partner, parent, friend or colleague leading to feelings of incompetency and/or incompleteness
- Existential dimension:
    - Spiritual and/or religious rites expressed and/or experienced related to anxiety
    - Existential factors (e.g., loss of autonomy, loss of dignity, hopelessness) influencing anxiety28, 29,30

It is strongly recommended to involve the loved ones in the multidimensional assessment, as they are often able to add important information.

Estimated life expectancy

The multidisciplinary estimation of the remaining life time sets the scope for interventions and the related continuity of care. Obviously, interventions are only indicated if their effect occurs within the estimated life span of the patient.

Medication

Information about medication is relevant for two reasons:

1. Current and previous pharmacological treatment for anxiety;
2. Medication or changes in medication as a cause of anxiety, which are not always recognized as a cause of anxiety by nurses, patients and loved ones. Anxiety may be a side-effect of medication, in particular corticosteroids, opioids, sympaticomimetic drugs, anti-emetics, benzodiazepines, dopaminergic drugs, ketamine, methylphenidate, haloperidol and other neuroleptics [25, 31,34], but may also occur after discontinuation of medication (e.g., opioids, corticosteroids or benzodiazepines).

Symptom analysis and meaning, and the use of measurement instruments

It all starts with timely recognition of anxiety, based on i) 24/7 observations (often by nurses), ii) listening, iii) asking and/or iv) using a measurement instrument which includes anxiety.
In palliative care patients, anxiety should be routinely assessed (daily, weekly or monthly, depending on the situation of the patient) using appropriate instruments since clinical impression has poor concordance with patient reported anxiety[32, 33]. In this analysis, it is important to also assess the underlying causes, influencing factors and sources of anxiety, the frequency, the severity, the pattern and the impact of anxiety on the patient and his loved ones[34].

If there are signs of anxiety, it should be discussed with the patient whether he is anxious or not. Suitable wording and the flexible use of synonyms like 'worried', 'scared' or 'tense' is of the utmost importance. Attention for non-verbal signs of anxiety is essential[34]. The recognition of anxiety may a real challenge, the expressions of anxiety being very diverse: facial expressions, emotions, irritation or insecure behavior, restlessness, hostility, avoidance and withdrawal, being absent-minded, acting harshly towards others and not want to face sensitive topics were identified as expressions of anxiety. As a result of the activation of the autonomic nervous system, palpitations, shortness of breath, tachycardia, nausea and diarrhea can be expressions of anxiety as well[9]. Even small gestures such as twisting a ring on finger, clinging to people and objects, keeping control in an extreme way may be expressions of anxiety.

The patient should be asked about[34]:

- the severity, pattern and the course of anxiety over time;
- possible causes, influencing factors and sources of anxiety and their fluctuation over time in all domains (physical, psychological, social and spiritual/existential);
- organization of care (which may also be a cause of anxiety[29]);
- poor communication, lack of information, feelings of loss of control and unsafety, as experienced by the patient;
- the impact of anxiety on quality of life and on psychological and social functioning;
- his or her way of coping with anxiety and how he or she wants to be approached in this respect by caregivers.
- the perceived effect of previous interventions (both non-pharmacological and pharmacological);

As anxiety is related to uncontrolled symptoms, attention should be given to other symptoms, with specific attention for depressed mood, dyspnea and insomnia. In addition, fatigue, nausea, pain, anorexia and drowsiness are related to increased anxiety[29, 35-4041]. These associations should be addressed bidirectionally. For example, anxiety may result in increased dyspnea but, reversely, dyspnea may also increase anxiety. As anxiety may also be a prodrome of delirium[42] special attention should be given to cognitive impairment, hallucinations and/or delusions suggestive of delirium[34].

It is recommended to apply measurement instruments to systematically assess anxiety[34]. Instruments are needed since patients do not always address their anxiety spontaneously and, as a result, anxiety may be overlooked. In addition, instruments provide continuity of care and are independent of the continuity of the caregiver. Instruments should not be used as an aim on its own. Discussion of the results of the measurement instruments with the patient is essential.

Instruments to assess anxiety are:

- The Distress Thermometer combined with a problem list (Lastmeter)[2]
- The Utrecht Symptom Diary (USD), a Dutch adapted and translated version of the Edmonton Symptom and Assessment System[43]
- The Utrecht Symptom Diary Professional, an adapted version of the USD in which the symptoms are scored by the professional
- The Hospital Anxiety and Depression Scale (HADS)[44,45]

To use these instruments in a appropriate and feasible way a four-stage assessment approach, in which instruments are used sequentially, is proposed. This approach consists of four stages: 1) early recognition, 2) monitor, 3) deepen and 4) diagnosis[15]. Since a diagnosis of an anxiety disorders requires specific expertise and is a prerogative to experts as a psychiatrist this stage is not described extensively.

1) Early recognition

There is no validated instrument to early recognize anxiety in clinical practice. For practical purposes, we propose the Lastmeter (the Dutch version of a combination of the The Distress Thermometer (DT) and a problem list (PL) including a question about anxiety) as the first instrument to apply. The DT has been developed to early recognize distress in patients with cancer[2]. The Dutch national guideline 'Detecting the need for psychosocial care' recommends to use the Lastmeter to detect and monitor distress[46].

Distress is defined as an unpleasant emotional experience of a psychological, social and/or spiritual nature that may interfere with the ability to manage effectively with cancer, including its physical symptoms and its treatment[46]. Anxiety may be an important aspect of distress. Although the DT aims to identify distress as a broad concept, it also has an accuracy to predict anxiety. Correlating the DT at the cut-off of 4 with the anxiety score of the HADS, the DT has a sensitivity of 0.79 (95 % CI 0.76–0.81) and a specificity of 0.80 (95 % CI 0.78–0.82) [47]. The AUC of the SROC curve is 0.8618, indicating a good overall accuracy of the DT to predict anxiety.

Thus, the arguments for the use of the Lastmeter to early recognise anxiety in patients with incurable cancer are:

- The use of the Lastmeter has been recommended by the Dutch guideline 'Detecting the need for psychosocial care'; as a result, the Lastmeter has been implemented in daily practice and is already widely used;
- The Distress Thermometer has predictive value for anxiety;
- The Problem List includes a question about anxiety;

- The Problem List also screens many other symptoms, which may be related to anxiety.

The Lastmeter has the disadvantage that it is applied infrequently. Although firm evidence is lacking[46] the DT is also suitable for repeated use[48]. However, it detects changes over time only over a period of 4 to 8 weeks which is a too long in patients with a limited life expectancy. Anxiety developing after the first use of the Lastmeter in a patient may thus be recognised too late. In this context, the USD may be used to early recognise anxiety. The Edmonton Symptom Assessment System (ESAS, from which the USD has been directly derived) has been proposed as a screening instrument for anxiety[49]. It has been shown that multiple anxiety scores of the ESAS of 2 or higher have a sensitivity of 86%, a specificity of 56%, a positive predictive value of 0.60 and a negative predictive value of 0.84 for anxiety, as measured with the Hospital Anxiety and Depression Scale[49]. If a cut-off of 4 is used, the figures were 0.97, 0.43, 0.22 and 0.99, respectively. The authors advised the cut off score of 2 to screen for anxiety. The poor positive value of USD scores of 2 or higher (0.60) highlights the importance of discussing the scores with the patient to check whether these scores are meaningful or not.

2) Monitor

Subsequently, the Utrecht Symptom Diary, or, if the patient is no longer able to score, the Utrecht Symptom Diary Professional, is recommended to monitor anxiety, creating the opportunity for a regular follow-up to get more insight into the fluctuation of anxiety and other symptoms, which may influence or cause anxiety. It should be noted that earlier research showed that nurses who filled in the USD professional had a poor agreement with patients' anxiety scores on the USD [50]. The ESAS (and presumably also the USD) is able to detect changes over a relatively short time and therefore a feasible monitoring instrument in palliative care patients with a limited life expectancy[51, 52].

3) Deepen

The HADS may be used to assess the probability of an anxiety disorder[14,15]. An updated literature review included 10 studies in cancer patients (N=1803) assessing the HADS as a case finder for anxiety disorders[14]. Using a cut-off score of 9 or higher for the anxiety subscale of the HADs the mean sensitivity and specificity for anxiety disorders were 0.66 and 0.83, respectively.

Thus, if a patient scores 9 or higher on the anxiety subscale of the HADS, he or she should be referred to a psychologist or psychiatrist to exclude the diagnose of an anxiety disorder based on the DSM criteria.

An overview of the use of measurement instruments for anxiety is presented in figure 2.

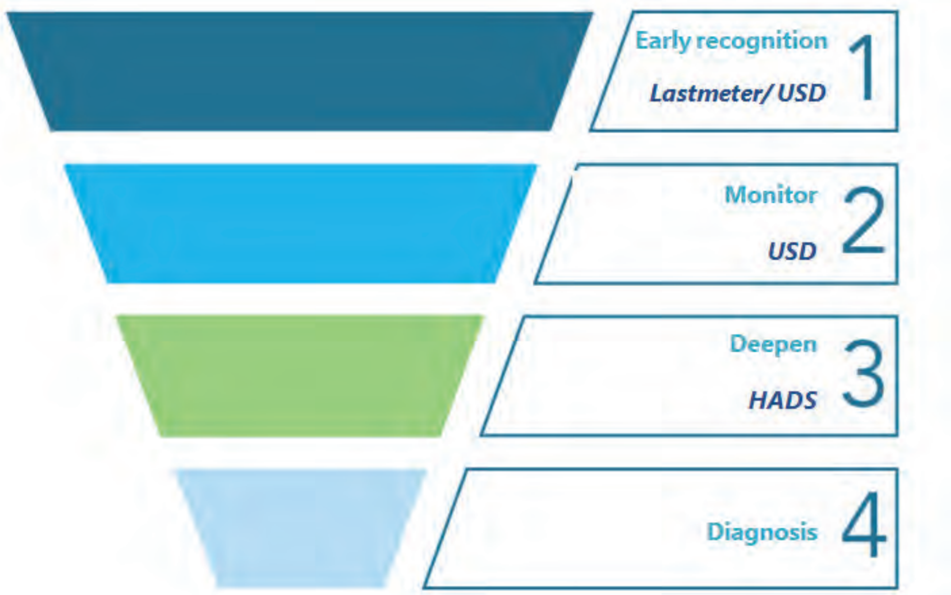

Figure 2: A four-stage assessment approach using measurement instruments to assess anxiety based on measurement instruments in palliative care[53]

This proposed four-stage assessment approach is line with a generally reached consensus in a broad range of experts in The Netherlands about the use of measurement instruments in palliative care[53]. A recent study proposed a similar multiple stage assessment approach with regard to anxiety measures as well[54]. Here, a single item question was used as a first step in identifying patients with anxiety. Although the psychometric properties of the single item question are promising, we prefer to use the Lastmeter and/or the USD for early recognition and monitoring anxiety because other symptoms which could be of influence of anxiety are included.

Priority and whishes of the patient

Since tailored care is essential, it is important to assess whether the patients is motivated to address his anxiety and if so, how. Patients may state that they do not want their anxiety to be addressed by their professional caregivers. It is therefore important to explore and document the priority and wishes of the patient.

Phase 2: Formulate the problem, a working hypothesis and a treatment plan

The data collected in step 1 are used to formulate the problem (including the source(s) of anxiety, if present) and a working hypothesis, summarizing the most plausible explanation of the current anxiety by i) underlying causes and ii) influencing factors.

The working hypothesis is the basis for a patient tailored treatment plan, consisting of[34]:

- treatment of the cause(s) and influencing factor(s),
- symptomatic treatment (non-pharmacological and pharmacological), and/or
- supportive care/referral for specialized psychosocial treatment,

all in the context of a multidimensional approach, paying attention to adequate information, communication, supportive care and continuity of care.

Treatment of the cause and influencing factors

The most effective initial step is to treat the cause. 'Correcting the correctable'[55] is also essential in anxiety management[9, 25, 26]. If the cause cannot be treated, pharmacological and non-pharmacological approaches should be explored.

With regard to causal treatment, special attention should be given to[9, 25, 26,34]:

- Treatment of uncontrolled symptoms, in particular (but not exclusively) depressed mood, dyspnea, insomnia, drowsiness, pain, nausea, anorexia and fatigue
- Change of medication causing anxiety
- Treatment of underlying medical conditions (e.g., delirium, hypercalcemia, hyperthyroidism, fever, infections)

Non-pharmacological treatment

Basic non-pharmacological support by nurses and/or doctors may consist of:

- Psycho-education[56] with regard to anxiety and related symptoms, e.g. dyspnea and suffocation
- Structural attention on a regular basis [57]
- Information about (the expected course of) the underlying disease
- Enhancing feelings of control and safety
- Enhancement of patients' coping strategies
- Discussing care plans
- Support of loved ones

These interventions should be tailored to the specific wishes and coping mechanisms of the patient. The loved ones should be actively involved in this process.

Clearly, specialized non-pharmacological treatment is outside the scope of nurses and doctors. They together should be able to judge whether referral to a psychiatrist (e.g. for treatment of a depressive or anxiety disorder), psychologist (e.g., for behavioral or cognitive interventions) or a chaplain is required[34]. As stated above, the HADS may be used to select patients who should be referred to a psychiatrist.

Pharmacological treatment

Pharmacological interventions lie outside the scope of this thesis. Medication may be an essential part of the treatment plan, especially in case of severe anxiety with a risk of panic attacks. Although there is no firm evidence of the effect of pharmacological treatment of anxiety in palliative care[58] benzodiazepines are commonly used for acute anxiety[34,59,60,61]. For longer-term anxiety treatment with selective serotonin reuptake inhibitors (SSRI's) or other drugs (e.g., mirtazapine, trazodone, quetiapine, olanzapine) should be considered[26,34].

Step 3: Evaluate
For each intervention, it should be planned how, when and by whom the effect of the care plan is evaluated, using the severity of anxiety and other symptoms, functioning and well-being as outcome measures. As continuity of care in person is commonly lacking, the outcome measures and the process of evaluation should be clearly documented in the patients records. The Utrecht Symptom Diary (USD) may be helpful as a monitoring instrument. If the patient is unable to complete the USD, the USD-Professional (completed by the caregiver) may be used. In addition, loved ones should be involved in the evaluation of the effect of interventions on patients' anxiety as well.

Step 4: Readjust the individual care plan if necessary and possible
- If the effect is positive: continue treatment and keep monitoring en evaluating anxiety using the Utrecht Symptom Diary.
- If the effect is limited or absent:
    - Adapt the care plan (go back to phase 2)
    - Re-analyze the problem (go back to phase 1), paying attention to unrecognized or new causes or influencing factors
    - Accept the situation and discuss with the patient and loved ones why the effect is lacking.

Be aware that the underlying cause of anxiety can change over time which emphasizes the importance of constant evaluation of the effect. Keep in mind that anxiety cannot always be taken fully taken away.

The systematic approach is summarized in table 1.

Suggestions for future research

There is an urgent need for studies addressing the effect of non-pharmacological (both basic and specialized) and pharmacological interventions for anxiety in palliative care patients. The effectiveness of the proposed systematic approach with regard to improving the competence of nurses and, as a result, patient outcomes should be evaluated in a prospective study.

With regard to nursing interventions, future research should focus on the steps of the MRC framework, implementing the approach and piloting the feasibility and effectiveness of interventions for anxiety, primarily using patient outcome measures. A series of studies may be required to progressively refine the design before embarking on a full scale evaluation[11]. It is recommended to use instruments already used as part of standard care. Mixed methods studies (combining a quantitative and qualitative design) are recommended. Studies should be stratified for patients with different levels of anxiety and the causes of anxiety should be taken into account.

Research in palliative care is a challenge. Resources and patients' time and effort should be used effectively. Future research about anxiety should be in line with the existing literature which creates a body of knowledge.

Final conclusions

Management of anxiety in cancer patients in the palliative phase is a challenge given the limited remaining life time, the different expressions and communication styles, causes, sources, contributing factors, coping strategies and individual needs of patients and their loved ones on the one hand and the lack of evidence based interventions on the other hand. Management of anxiety requires transparent communication based on a systematic, multidisciplinary and comprehensive approach, starting with early recognition, followed by adequate assessment, formulating a treatment plan, monitoring, effect evaluation and, if necessary and possible, adapting the care plan. This thesis highlighted important angles how management of anxiety may be improved and how nurses and other health care professionals can make a difference for anxious patients in the last phase of their life to optimize quality of life and, ultimately, quality of dying.

Table 1: Systematic approach using palliative reasoning

Phases	General aspects	Anxiety related aspects
Phase 1: Assess the individual situation	Medical history: diagnosis, current and previous therapy, comorbidity	• Ask if the patient has had an anxiety disorder, depression of other psychiatric disorders • Check to which extent the patient is informed and understands his situation
	• Multidimensional assessment of the patients' current status: • Use of a personal patient profile • Physical: performance status, impairment of ADL • Psychological: - General psychological performance: cognitive condition, communication possibilities, capacity to process information - Mood: worrying, tenseness, anger, depressive feelings - Coping mechanisms • Social • Existential	• Psychological dimension: how does the patient wants to be approached (or not) by the professional, to what extent would the patient like to be informed and what is the meaning of safety and control for the patient? • Social dimension: what is the role of loved ones in general in dealing with anxiety, and which aspects of the patients' role are hampering and causing feelings of incompetency and/or incompleteness? • Existential dimension: which spiritual and/or religious rites are related to anxiety? Which existential factors influencing anxiety?
	Estimated life expectancy	Remaining life sets the scope for interventions and the related continuity of care
	Medication	• Assess the current and previous pharmacological treatment for anxiety • Assess medication or changes in medication as a cause of anxiety: - use of corticosteroids, opioids, sympaticomimetic drugs, anti-emetics, benzodiazepines, dopaminergic drugs, ketamine, methylphenidate, haloperidol and other neuroleptics - discontinuation of opioids, corticosteroids or benzodiazepines
	Symptom analysis	• Routinely assess anxiety using appropriate instruments h and discuss the results of the instruments with the patient and their loved ones - For early recognition: Lastmeter or Utrecht Symptom Diary (USD) - For monitoring: Utrecht Symptom Diary - To deepen anxiety and screen for anxiety disorder: Hospital Anxiety and Depression Scale (HADS) • Observe non-verbal expressions and physical signs that could be related to anxiety and/or delirium • Use suitable wording and synonyms of anxiety like worried, scared, tense • Ask about: - the severity, pattern and the course of anxiety over time - possible causes, influencing factors and sources of anxiety and their fluctuation over time in all domains (physical, psychological, social and spiritual/existential) - organization of care - poor communication, lack of information, feelings of loss of control and unsafety - the impact of anxiety on quality of life and on psychological and social functioning - his or her way of coping with anxiety and how he or she wants to be approached in this respect by caregivers - the perceived effect of previous interventions (both non-pharmacological and pharmacological

Table 1: continued

Phases	General aspects	Anxiety related aspects
	Priorities and wishes of the patient	• Assess whether the patient is motivated to address his anxiety and if so, how? • Explore and document the priority and whishes of the patient
Attune to the patient and loved ones and use measurement instruments		
Phase 2: Summarize the problem and formulate a proactive care plan	Name the problems and formulate a working hypothesis	• Include the sources of anxiety (if present) • Specify underlying causes and influencing factors of anxiety
	Treat the cause	• Treat uncontrolled symptoms, in particular depressed mood, dyspnea, insomnia, drowsiness, pain, nausea, anorexia and fatigue. • Change medication causing anxiety • Treat underlying medical conditions (e.g. delirium, hypercalcemia, hyperthyroidism, fever, infections)
	Non-pharmacological treatment	• Basic non-pharmacological support may consist of: - Psycho education with regard to anxiety and related symptoms (dyspnea, suffocation) - Structural attention on a regular basis - Information about the underlying disease - Enhancing feelings of control and safety - Enhancement of patients' coping strategies - Discussing care plans - Support of loved ones • Tailor interventions to the specific wishes and coping mechanism of the patient. • Actively involve the loved ones • Assess whether referral to a psychiatrist, psychologist or a chaplain is required, consider the use of the HADS to screen for an anxiety disorder and referral to a psychiatrist
	Pharmacological treatment	• Consider the use of: - Benzodiazepines - Selective Serotonin Reuptake Inhibitors (SSRI's) - Other drugs (e.g. mirtazapine, trazodone, quetiapine, olanzapine)
Attune to the patient and loved ones and use measurement instruments		
Phase 3: Evaluate	• Plan how the effect of the care plan is measured, by whom and when • Measure the effect by symptom severity and experience and patient functioning and well-being • Document the outcome measures and the process evaluation in the patients records	• Involve the loved ones in the evaluation of the effect of interventions on patients' anxiety
Attune to the patient and loved ones and use measurement instruments		
Phase 4: Adapt the care plan and constant evaluation	• If the effect is positive: continue treatment and continue evaluation • If the effect is limited or absent: - Adapt the care plan (go back to phase 2) - Re-analyze the problem (go back to phase - Accept the situation	• Be aware that the underling cause of anxiety can change over time • Keep in mind that anxiety cannot be fully taken away

Attune to the patient and loved ones and use measurement instruments

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Summary

Anxiety as a symptom is experienced by 20-50% of palliative care patients with advanced cancer. Timely recognition and treatment of anxiety is essential for optimal palliative care. However, management of anxiety in these patients is a real challenge due to the variety of expressions and underlying causes in the context of a short life expectancy.
Nurses have an important role in the early recognition and management of anxiety. However, there is a lack of knowledge in this field and consequently, early recognition and management of anxiety is often dependent on the motivation and the competencies of the individual nurse. To provide adequate management of anxiety, multiple influencing factors should be addressed in a complex clinical practice. The number of interacting components, the difficulty of the required behaviors of those delivering and receiving the support and the degree of flexibility to provide tailored care makes it complex care. Therefore, there is a need for a systematic approach to optimize the quality of care for vulnerable patients facing anxiety.

To support nurses in ameliorating early recognition and management of anxiety this thesis aims to provide more insight into the evidence and current practice of anxiety management as well as into the needs for support in patients with incurable cancer, from the perspectives of the patients themselves, their loved ones and their nurses.

The following research questions were posed:
Part I

- What non-pharmacological nurse-led interventions are available and what is their effectiveness in managing anxiety in advanced cancer patients?
- Which instruments are used by nurses to assess anxiety in advanced cancer patients admitted to a hospice or hospital, and what is the rationale behind it?

Part II

- What are the needs of patients with incurable cancer admitted to a hospice regarding anxiety management?
- What are the experiences of loved ones concerning the anxiety of the patients with incurable cancer admitted to a hospice?
- Are fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall perceived well-being predictors for anxiety in advanced cancer patients admitted to a hospice?
- What do nurses know, do and need to support cancer patients with anxiety admitted to a hospice?

In part III we describes the implications of this work and possible improvement of palliative care for anxious advanced cancer patients using a systematic approach for practice and research.
In this process, the Medical Research Council (MRC) framework was used which is commonly used in developing complex interventions in nursing care.

Part I

Non-pharmacological nurse-led interventions for anxiety

In **Chapter 2**, we systematically searched the literature for randomized controlled trials regarding non-pharmacological nurse-led interventions for anxiety and their effectiveness in advanced cancer patients. Four databases (MEDLINE, CINAHL, PsycINFO and Cochrane) were searched using predefined search terms without date limits. Seven studies were included. The interventions were categorized into patient education, telemonitoring, psychotherapy, complementary care or a combination of these. Two studies showed significant improvements in anxiety levels in patients who received a psychoeducational intervention and in those who participated in a telemonitoring program, respectively. However, both studies were judged to have a high risk of bias due to attrition, the randomization process and blinding which was not described.

Although there was no firm evidence due to the high risk of bias, two studies showed that nurses could play a meaningful role in the management of anxiety with regard to psychoeducation and early recognition in a telemonitoring program. Importantly, in none of the studies described, attention was given to specific causes of anxiety.

Assessment of anxiety by nurses using measurement instruments

In **Chapter 3**, we studied which instruments are used by nurses to assess anxiety as a specific construct or as a part of a broad symptom diary, by means of an analysis of medical records (n=154) and nurse interviews (n=12). Data were collected from a university hospital, a general hospital and a hospice. At least one instrument was used in 67% of patients of the academic hospital and 100% of patients of the hospice. In the general hospital no instruments were used. If an instrument was used, the Utrecht Symptom Diary (completed by the patient) was used in all cases, supplemented by the Utrecht Symptom Diary Professional (completed by the nurse or other caregivers, exclusively in the hospice). Occasionally, the Distress Thermometer combined with a problem list (Lastmeter) and the Hospital Anxiety and Depression Scale (HADS) were used. The mean anxiety score of patients admitted to the hospice was significantly lower compared to the mean anxiety score of patients admitted to the university hospital (1.8 vs. 1.1, p=0.019).

Lack of knowledge was the main reason not to use instruments in the general hospital. For nurses familiar with the use of instruments, they helped to identify and monitor anxiety, to start a dialogue with the patient and to prevent patients becoming overwhelmed, to get insight into the possible causes and to evaluate the effect of interventions. The nurses indicated that the Utrecht Symptom Diary was a feasible and valuable instrument for the assessment of anxiety. Impeding factors to use instruments to assess anxiety were patient related factors (the patient being too ill or too busy; problems with the Dutch language) and environmental related factors (workload or lack of privacy to discuss the findings).

Part II

Needs of patients with incurable cancer admitted to a hospice

In **Chapter 4**, we qualitatively explored the needs of patients with cancer admitted to a hospice with regard to anxiety. Semi-structured interviews were performed. Fourteen patients were included with a median age of 71. Twelve patients were interviewed within 10 weeks before death. It became clear that patients did not always identify themselves with the word "anxiety", but used other words like scared, tense or worried. Five important needs emerge from the interviews: information and a sense of control, safety, adequate symptom management, talking about anxiety (or not) and respect for coping strategies by professionals.

The prominent need for most was information. This included information about all aspects of care. Poor or incomplete information may generate mistrust of the involved professionals and therefore increase anxiety.

A sense of control was associated with decreased anxiety. Involvement in their own daily schedule and being informed contributed to this sense of control. The patients' sense of control was also dependent on feeling safe and having faith in the professional team. Safety was experienced by the 24/7 availability of a professional, not feeling alone and expertise of the professional. Therefore, it is essential to address what control and safety mean for the individual patient.

Adequate symptom management was indicated as essential in decreasing anxiety. Physical symptoms (e.g. pain or dyspnea) were most often described as a direct cause of anxiety. Insomnia was more indirectly related to anxiety. A good night sleep helped 1) not to feel anxious during the night, and 2) to restore energy to cope with anxiety during the day.

Respect for the patients' way of coping was an important need as well. This means that patients should be supported in their coping style at that moment, which may vary from being left alone to avoidance by distraction or explicit discussion of their feelings. It was important for patients to feel respected for their choice to either accept or decline the invitation for a talk. Patients expressed that they never minded questions about anxiety, regardless of their coping strategy. Patients never expected a solution and were aware that anxiety could not always be alleviated. They did expect attention, kindness and their problems and/or symptoms to be taken seriously.

Insight into patients' needs provided important angles where healthcare professionals can make a difference in an effective and personalized approach. Optimal recognition and management of anxiety should consist of timely recognition of anxiety by proactive questioning using multiple synonyms of anxiety, adequate information and education, ensuring feelings of safety and control, adequate symptom management and recognition and enhancement of the patient's coping strategy to deal with anxiety.

The perspective of the loved ones

In **Chapter 5**, we qualitatively explored the needs of hospice patients from the perspective of their loved ones. Semi-structured interviews were performed. Fourteen loved ones of patients with cancer admitted to a hospice were included. Loved ones gave high anxiety scores for the patient (median score 6.5, range 3-8) and indicated a high impact of anxiety in all domains: physical, psychological, social and spiritual. Loved ones were able to identify a broad range of sources of anxiety: in particular physical and mental deterioration and anxiety for the unknown, but also loss of control over mind and body, dependency on others and loss of dignity. With regard to the patient needs, loved ones mentioned the need for a safe environment, honest information, the presence of people around and tailored care based on the preferences of specific needs of the patient. Loved ones indicated a variety of verbal and non-verbal expressions of anxiety by the patient such as restlessness, hostility, avoidance and withdrawal, being absent-minded and acting harshly towards others. Also small gestures such as twisting a ring on a finger, putting a hand to the forehead or clinging to people and objects were recognized as expressions of anxiety. The loved ones provided important information, based on their long relationship with the patient.

Since loved ones know the patient the best, they can be a valuable source of information and may provide a unique perspective in identification of anxiety and personal support, especially when patients are not able or willing to communicate about their concerns. Therefore, loved ones should be involved in the assessment and care of anxious patients.

Symptoms predicting for anxiety

In **Chapter 6**, we studied whether fatigue, nausea, pain, dyspnea, depressed mood and insomnia as well as overall perceived well-being measured by the Utrecht Symptom Diary are predictors for anxiety in advanced cancer patients admitted to a hospice. The included symptoms were based on the already demonstrated relationships with anxiety in earlier studies. Multiple linear regression analyses was employed to analyze the predictive value.
Remarkably, the prevalence of anxiety was low in this population. This indicates that anxiety may be more severe in earlier stages of a life-threatening illness. However, the word “anxiety” was not always identified by patient. Words like scared, tense or worried were more commonly used words. This together with the difficulties in scoring anxiety could result in underreporting of anxiety.
After correction for age, gender, and marital status, depressed mood and dyspnea were independent predictors for anxiety. Depressed mood and dyspnea together with age, gender, and marital status explained 22.8% of the variance of anxiety.
With regard to symptom management as part of the treatment of anxiety, specific attention should be given to depressed mood and dyspnea.

The role of nurses

In **Chapter 7** we provide insight what hospice nurses know, do and need to support cancer patients with anxiety admitted to a hospice using an online survey and focus group interviews. Nurses caring for patients within the 28 Dutch inpatient hospice facilities affiliated with the Dutch Association of Hospice Care were asked to participate. The survey was completed by 265 nurses (79%) and five focus groups interviews (n=25) were conducted. 134 out of 213 (63%) nurses asked patients on a regular basis if they were anxious. 16% of the nurses discussed anxiety only if the patient brought it up himself. Measurement tools for identifying, monitoring or analyzing anxiety were used by 37% of the nurses. Some nurses deliberately did not use instruments. These nurses were convinced that filling out a questionnaire placed a burden on patients. Other nurses were not aware of the existence of measurement tools and their implementation in daily care. Nurses experienced difficulties in the identification of anxiety due to the variety of expressions: emotional, cognitive and/or behavioral. Expressions of anxiety were observed more frequently during evenings and nights. 50% of the nurses experienced lack of time to deal with anxiety and 31% indicated a lack of knowledge. Interventions were generally chosen intuitively. A major responsibility was experienced in caring for patients with panic attacks during late and night shifts, making immediate decisions necessary.

This study highlights the struggles of nursing caring for anxious hospice patients with cancer especially during late and night shifts. Hospice care nurses need guidelines for applying assessment tools, effective communication strategies and decision models as well as prediction models in order to identify patients in need of selected tailored interventions.

Part III

In **Chapter 8** we described the summary of the findings, reflected on methodological issues and discussed the implications for clinical practice and research.

Based on the findings described above we developed a systematic approach for the management of anxiety, integrated into the method of palliative reasoning, a clinically relevant method frequently used in daily palliative care in The Netherlands. This systematic approach starts with a systematically assessment of symptoms and problems of patients in their individual context (phase 1), followed by the formulation of a working hypothesis, a treatment plan and its aim (phase 2), an evaluation of the effects of treatment (phase 3) and adaptation of treatment if necessary and possible (phase 4). The involvement of patients and loved ones about their whishes and priorities is essential in all phases. If used in a multidisciplinary setting effective communication should be improved by this method.

This systematic approach is summarized in table 1. The effectiveness of the proposed systematic approach with regard to improving the competence of nurses and, as a result, patient outcomes should be evaluated.

Final conclusions

Management of anxiety in cancer patients in the palliative phase is a challenge given the limited remaining life time, the different expressions and communication styles, causes, sources, contributing factors, coping strategies and individual needs of patients and their loved ones on the one hand and the lack of evidence based interventions on the other hand. This thesis highlighted important angles how management of anxiety may be improved and how nurses and other health care professionals can make a difference for anxious patients in the last phase of their life to optimize quality of life and, ultimately, quality of dying.

Table 1: Systematic approach using palliative reasoning

Phases	General aspects	Anxiety related aspects
Phase 1: Assess the individual situation	Medical history: diagnosis, current and previous therapy, comorbidity	• Ask if the patient has had an anxiety disorder, depression of other psychiatric disorders • Check to which extent the patient is informed and understands his situation
	• Multidimensional assessment of the patients' current status: • Use of a personal patient profile • Physical: performance status, impairment of ADL • Psychological: - General psychological performance: cognitive condition, communication possibilities, capacity to process information - Mood: worrying, tenseness, anger, depressive feelings - Coping mechanisms • Social • Existential	• Psychological dimension: how does the patient wants to be approached (or not) by the professional, to what extent would the patient like to be informed and what is the meaning of safety and control for the patient? • Social dimension: what is the role of loved ones in general in dealing with anxiety, and which aspects of the patients' role are hampering and causing feelings of incompetency and/or incompleteness? • Existential dimension: which spiritual and/or religious rites are related to anxiety? Which existential factors influencing anxiety?
	Estimated life expectancy	Remaining life sets the scope for interventions and the related continuity of care
	Medication	• Assess the current and previous pharmacological treatment for anxiety • Assess medication or changes in medication as a cause of anxiety: - use of corticosteroids, opioids, sympaticomimetic drugs, anti-emetics, benzodiazepines, dopaminergic drugs, ketamine, methylphenidate, haloperidol and other neuroleptics - discontinuation of opioids, corticosteroids or benzodiazepines
	Symptom analysis	• Routinely assess anxiety using appropriate instruments h and discuss the results of the instruments with the patient and their loved ones - For early recognition: Lastmeter or Utrecht Symptom Diary (USD) - For monitoring: Utrecht Symptom Diary - To deepen anxiety and screen for anxiety disorder: Hospital Anxiety and Depression Scale (HADS) • Observe non-verbal expressions and physical signs that could be related to anxiety and/or delirium • Use suitable wording and synonyms of anxiety like worried, scared, tense • Ask about: - the severity, pattern and the course of anxiety over time - possible causes, influencing factors and sources of anxiety and their fluctuation over time in all domains (physical, psychological, social and spiritual/existential) - organization of care - poor communication, lack of information, feelings of loss of control and unsafety - the impact of anxiety on quality of life and on psychological and social functioning - his or her way of coping with anxiety and how he or she wants to be approached in this respect by caregivers - the perceived effect of previous interventions (both non-pharmacological and pharmacological

Table 1: continued

Phases	General aspects	Anxiety related aspects
	Priorities and wishes of the patient	• Assess whether the patient is motivated to address his anxiety and if so, how? • Explore and document the priority and whishes of the patient
Attune to the patient and loved ones and use measurement instruments		
Phase 2: Summarize the problem and formulate a proactive care plan	Name the problems and formulate a working hypothesis	• Include the sources of anxiety (if present) • Specify underlying causes and influencing factors of anxiety
	Treat the cause	• Treat uncontrolled symptoms, in particular depressed mood, dyspnea, insomnia, drowsiness, pain, nausea, anorexia and fatigue. • Change medication causing anxiety • Treat underlying medical conditions (e.g. delirium, hypercalcemia, hyperthyroidism, fever, infections)
	Non-pharmacological treatment	• Basic non-pharmacological support may consist of: - Psycho education with regard to anxiety and related symptoms (dyspnea, suffocation) - Structural attention on a regular basis - Information about the underlying disease - Enhancing feelings of control and safety - Enhancement of patients' coping strategies - Discussing care plans - Support of loved ones • Tailor interventions to the specific wishes and coping mechanism of the patient. • Actively involve the loved ones • Assess whether referral to a psychiatrist, psychologist or a chaplain is required, consider the use of the HADS to screen for an anxiety disorder and referral to a psychiatrist
	Pharmacological treatment	• Consider the use of: - Benzodiazepines - Selective Serotonin Reuptake Inhibitors (SSRI's) - Other drugs (e.g. mirtazapine, trazodone, quetiapine, olanzapine)
Attune to the patient and loved ones and use measurement instruments		
Phase 3: Evaluate	• Plan how the effect of the care plan is measured, by whom and when • Measure the effect by symptom severity and experience and patient functioning and well-being • Document the outcome measures and the process evaluation in the patients records	• Involve the loved ones in the evaluation of the effect of interventions on patients' anxiety
Attune to the patient and loved ones and use measurement instruments		
Phase 4: Adapt the care plan and constant evaluation	• If the effect is positive: continue treatment and continue evaluation • If the effect is limited or absent: - Adapt the care plan (go back to phase 2) - Re-analyze the problem (go back to phase - Accept the situation	• Be aware that the underling cause of anxiety can change over time • Keep in mind that anxiety cannot be fully taken away

Attune to the patient and loved ones and use measurement instruments

Samenvatting

Angst wordt ervaren door 20 tot 50% van de patiënten met kanker in de palliatieve fase. Vroegtijdige herkenning en behandeling van angst zijn essentieel om optimale palliatieve zorg te kunnen verlenen. Zorg voor patiënten met angst in de palliatieve fase is echter een ware uitdaging vanwege de verschillende manieren waarop angst wordt geuit, de verschillende onderliggende oorzaken en de vaak korte periode die patiënten nog te leven hebben.

In de zorg betrokken verpleegkundigen kennen de patiënt en zijn naasten in die laatste levensfase vaak van dag tot dag waardoor zij in de optimale positie zijn om angst te herkennen, bespreekbaar te maken, te analyseren en in afstemming met andere professionals te behandelen. Er is echter sprake van een tekort aan kennis bij verpleegkundigen als het gaat om angst bij patiënten met kanker in de palliatieve fase. Een veel voorkomende misvatting onder zorgverleners is dat angst een invoelbare reactie is op hetgeen de patiënt overkomt en "erbij hoort". Een deel van deze aanname is wellicht correct, maar het is te makkelijk om daarmee af te zien van een verdere analyse van die angst en van de mogelijkheden om de patiënt gericht te ondersteunen. Vroegtijdige herkenning en ondersteuning blijkt in de zorgpraktijk nog veelal afhankelijk van de motivatie en competenties van de individuele verpleegkundige waardoor risico van onderhandeling.
Om passende zorg te verlenen zullen de beïnvloedende factoren van angst in kaart moeten worden gebracht. Zorg voor patiënten met angst is vaak complexe zorg vanwege de verschillende beïnvloedende factoren, de gedragsvariatie van patiënten alsook van de verpleegkundige en de gevraagde flexibiliteit om zorg op maat te leveren. Er is behoefte aan een systematische benadering om de kwaliteit van zorg voor patiënten met angst te verbeteren.

Dit proefschrift heeft daarom als doel om het inzicht te vergroten in enerzijds de huidige praktijk van de behandeling van angst en de evidentie ervan en anderzijds de behoefte van patiënten met kanker in de palliatieve fase vanuit hun eigen perspectief alsook dat van hun naasten, om daarmee zorgverleners, en in het bijzonder verpleegkundigen en multidisciplinaire teams te ondersteunen bij de vroegtijdige herkenning en behandeling van angst.

Het proefschrift is onderverdeeld in drie delen. Voor deel I en II zijn de volgende onderzoeksvragen geformuleerd:
Deel I

- Welke niet-medicamenteuze verpleegkundige interventies zijn beschikbaar en wat is het effect van deze interventies op angst bij patiënten met kanker in de palliatieve fase?
- Welke meetinstrumenten worden ingezet door verpleegkundigen om angst te meten bij patiënten met kanker in de palliatieve fase opgenomen in een hospice of een ziekenhuis

en welke overwegingen spelen daarbij een rol?

Deel II

- Wat zijn de behoeftes van patiënten met ongeneeslijke kanker, opgenomen in een hospice, met betrekking tot zorg ten aanzien van angst?
- Wat zijn de ervaringen van naasten met betrekking tot angst ervaren door de patiënt met ongeneeslijke kanker, opgenomen in een hospice?
- Zijn vermoeidheid, misselijkheid, pijn, kortademigheid, somberheid, slapeloosheid en welbevinden voorspellers voor angst voor patiënten met kanker in de palliatieve fase, opgenomen in een hospice?
- Wat weten, doen en hebben verpleegkundigen nodig om patiënten met kanker, opgenomen in een hospice te ondersteunen bij angst?

In deel III beschrijven we aanbevelingen en brengen we mogelijkheden voor verbetering van de zorg voor angstige patiënten met kanker in de palliatieve fase samen. We doen dat door gebruik te maken van een systematische benadering voor de zorgpraktijk en onderzoek.

De basis voor dit proces wordt gevormd door het raamwerk van de Medical Research Council (MRC), een kader dat veelvuldig wordt gebruikt als leidraad voor het ontwikkelen van complexe interventies in de (verpleegkundige) zorg.

Deel I

Niet-medicamenteuze interventies gericht op angst

Hoofdstuk 2 beschrijft een systematisch review van de literatuur over het effect van niet-medicamenteuze verpleegkundige interventies ingezet om angst bij patiënten met kanker in de palliatieve fase te voorkomen en verminderen. Vier databases (MEDLINE, CINAHL, PsycINFO and Cochrane) werden doorzocht naar gerandomiseerde en gecontroleerde studies met behulp van tevoren geformuleerde zoekvragen. Zeven studies werden geïncludeerd. De interventies werden ondergebracht in vijf categorieën: educatie van patiënten, telemonitoring, psychotherapie, complementaire zorg of een combinatie hiervan. Twee studies lieten een significante verbetering van de ervaren angst zien bij patiënten die psycho-educatie ondergingen en bij patiënten die deelnamen aan een telemonitoringsprogramma. Beide studies werden als ‘hoog risico op vertekening’ beoordeeld, vanwege uitval van patiënten gedurende de studie en het ontbreken van een gedetailleerde beschrijving van de randomisering en blindering. Ondanks het gebrek aan stevig bewijs lieten deze twee studies wel zien dat verpleegkundigen een belangrijke rol kunnen spelen bij de behandeling van angst door middel van psycho-educatie alsook bij de vroegtijdige herkenning van angst door gebruik van een telemonitoringsprogramma. Een opvallende tekortkoming was dat in geen van de studies rekening is gehouden met de onderliggende oorzaken van angst.

Het gebruik van meetinstrumenten door verpleegkundigen om angst te meten

In hoofdstuk 3 wordt een analyse beschreven van meetinstrumenten die verpleegkundigen gebruiken om angst bij patiënten te meten als op zichzelf staand symptoom of als onderdeel van de analyse van meer symptomen met bijvoorbeeld een symtpoomdagboek. Data werden verzameld door dossieronderzoek (n=154) en interviews met verpleegkundigen (n=12) in een universitair ziekenhuis, een perifeer ziekenhuis en een hospice. Bij 67% van de patiënten in het academisch ziekenhuis werd tenminste één instrument gebruikt, in het hospice was dit voor alle patiënten (100%) het geval. In het perifere ziekenhuis werden geen meetinstrumenten gebruikt om angst te meten.

In de situaties waarin een instrument werd gebruikt betrof dat het Utrecht Symptoom Dagboek, een korte vragenlijst met numerieke schalen (0=geen angst; 10= ergst denkbare angst) dat door de patiënt zelf wordt ingevuld. Soms werd aanvullend het Utrecht Symptoom Dagboek Zorgverlener (ingevuld door de zorgverlener) gebruikt. Dit gecombineerde gebruik vonden we alleen in het hospice. Zowel in ziekenhuis als hospice werden incidenteel de Lastmeter en de Hospital Anxiety en Depression Scale gebruikt.

De gemiddelde angstscore van patiënten, opgenomen in het hospice was significant lager dan de gemiddelde angstscore van patiënten opgenomen in het academische ziekenhuis (1.8 vs. 1.1, p=0.019).

Gebrek aan kennis werd door verpleegkundigen in het perifere ziekenhuis het meest genoemd als reden om geen meetinstrument te gebruiken. Verpleegkundigen die bekend waren met het gebruik van meetinstrumenten gaven aan dat zij zich ondersteund voelden in het herkennen en monitoren van angst, om het gesprek hierover aan te gaan, om te voorkomen dat patiënten overrompeld werden door ongerichte vragen over angst, om inzicht te krijgen in de mogelijke oorzaken van angst en uiteindelijk om het effect van de ingezette interventies te evalueren. Verpleegkundigen gaven aan dat het Utrecht Symptoom Dagboek een passend en waardevol instrument was voor het meten van angst. Belemmerende factoren bij het gebruik van meetinstrumenten waren patiënt gerelateerde factoren zoals de patiënt die te ziek of te druk was en/of problemen met de Nederlandse taal had. Daarnaast speelden omgevingsfactoren zoals werkdruk van verpleegkundigenen gebrek aan privacy om de uitkomsten te bespreken.

Deel II

Behoefte patiënten met kanker opgenomen in een hospice

In hoofdstuk 4 beschrijven we een kwalitatieve studie waarin de behoeftes van de patiënt met kanker opgenomen in een hospice ten aanzien van angst werd geëxploreerd met gebruik van semigestructureerde interviews. Veertien patiënten werden geïncludeerd (mediane leeftijd 71), waarvan twaalf patiënten binnen tien weken voor hun overlijden werden geïnterviewd. Patiënten gaven aan dat zij zichzelf niet altijd konden identificeren met het woord "angst". Zij gebruikten liever ander woorden zoals bang, gespannen of bezorgd zijn. Er werden vijf belangrijke behoeftes genoemd: informatie en gevoel van controle, veiligheid, adequate symptoom controle, bespreken van angst (of niet) en respect voor de manier waarop de patient met angst om gaat. De meest op de voorgrond staande behoefte was informatie. Dit betrof informatie over alle aspecten van zorg. Onvolledige communicatie genereerde een gevoel van wantrouwen dat de angst versterkte. Het gevoel van controle hebben over de situatie was geassocieerd met minder angst en dat hing weer samen met het gevoel van veiligheid en vertrouwen in het professionele team. Veiligheid werd ervaren door de 24/7 aanwezigheid, zich niet alleen voelen en de expertise van professionals. Het verkennen van de betekenis vanveiligheid en controle voor de individuele patiënt hebben we daarmee geduid als van groot belang. Adequaat symptoommanagement werd genoemd als een belangrijk aspect van zorg in het verminderen van angst. Lichamelijke symptomen zoals pijn of dyspnoe werden in veel gevallen genoemd als een directe oorzaak van de angst. Een goede nachtrust droeg er aan bij om 1) 's nachts niet angstig te zijn en 2) om voldoende energie te hebben om overdag met de angst om te kunnen gaan.

Respect voor de manier waarop iemand individueel met angst omgaat werd eveneens uitgesproken als een belangrijke behoefte. Patiënten zouden gesteund moeten worden in de wijze waarop ze op dat moment met hun angst om gingen, hetgeen kan variëren van alleen gelaten willen worden tot afleiding of juist het gesprek aan willen gaan over angst. Het was belangrijk voor patiënten dat de keuze voor het wel al dan niet in gesprek gaan werd gerespecteerd. Patiënten gaven aan dat ze de vragen over angst niet als vervelend ervaarden ongeacht hun manier van omgaan met de angst. Er werd door patiënten nooit een oplossing verwacht, zij waren zich ervan bewust dat de angst niet altijd verminderd kon worden. Patiënten verwachten van zorgprofessionals wel aandacht, vriendelijkheid en het gevoel serieus genomen te worden.

Inzicht in de behoeftes van de patiënt heeft belangrijke aangrijpingspunten opgeleverd rondom de vraag hoe zorgprofessionals een verschil kunnen maken ofwel hoe vorm te geven aan een effectieve en persoonlijke benadering. Optimale herkenning en behandeling van angst moet bestaan uit het proactief bevragen van patiënten waarbij synonieme begrippen van angst gebruikt moeten worden, adequate informatie en educatie gegeven moet worden, zorgen voor veiligheid en controle vorm moet krijgen, adequaat symptoommanagement moet worden uitgevoerd en er vorm moet worden gegeven aan herkenning en stimulering van de individuele wijze waarop de patiënt omgaat met zijn angst.

Het perspectief van de naaste

In hoofdstuk 5 hebben we de behoeftes van de patiënt vanuit het perspectief van de naaste geëxploreerd met gebruik van semi-gestructureerde interviews. Veertien naasten van patiënten, opgenomen in het hospice werden geïncludeerd. Naasten gaven een hoge score voor de angst van de patiënt (mediane score 6,5, range 3-8) en gaven aan dat de angst een hoge impact had op alle dimensies: fysiek, psychisch, sociaal en existentieel. Naasten noemden een verscheidenheid van bronnen van angst: angst voor fysieke en mentale achteruitgang en angst voor het onbekende werden met name genoemd, maar ook angst voor verlies van controle over lichaam en geest, afhankelijkheid van anderen en verlies van waardigheid. Volgens de naasten hadden de patiënten behoefte aan een veilige omgeving, eerlijke informatie, de aanwezigheid van mensen om hen heen en zorg op maat, gebaseerd op de voorkeuren en wensen van de patiënt. Naasten vertelden over een verscheidenheid aan verbale en non-verbale uitingen van angst van de patiënt zoals onrust, rusteloosheid, vijandigheid, onaardig reageren, vermijden, terugtrekken en afwezig in gedachten zijn. Ook kleine gebaren zoals het rond draaien van een ring om een vinger, de hand op het voorhoofd leggen of het vastklampen aan bepaalde mensen of dingen werden genoemd als uitingen van angst.

De naasten bleken in staat om belangrijke informatie te geven op basis van hun lange relatie met de patiënt. Omdat de naaste de patiënt goed kent, kunnen zij waardevolle informatie verstrekken over het herkennen van angst, maar ook over persoonlijke ondersteuning, vooral wanneer de patiënt niet meer in staat is om te communiceren over wat hem bezig houdt. Naasten zouden daarom meer moeten worden betrokken bij het in kaart brengen van angst en bij gerichte ondersteuning van patiënten met angst.

Symptomen die angst voorspellen

In **hoofdstuk 6** wordt onderzocht of er voorspellende symptomen zijn voor angst. Vermoeidheid, misselijkheid, pijn, kortademigheid, somberheid en slapeloosheid en het algemeen welbevinden werden gemeten met het Utrecht Symptoom Dagboek bij patiënten met kanker, opgenomen in een hospice. De keuze voor deze symptomen is gebaseerd op eerder onderzoek in onze groep waarbij een verband met angst werd gevonden. Multivariate lineaire regressie-analyses werden gedaan om de voorspellende waarde te analyseren.

De prevalentie van angst in de hospice populatie was opvallend laag. Dit roept de hypothese opdat angst mogelijk meer wordt ervaren in eerdere fases van de ziekte. Er zou mogelijk sprake kunnen zijn van onderrapportage als gevolg van het feit dat patiënten het soms lastig vinden om hun beleefde angst in een score weer te geven, mede vanwege het feit dat zij zich niet altijd herkennen in het woord angst. Woorden als 'bang', 'gespannen' of 'bezorgd' waren meer gebruikte woorden voor angst in de interviews. Somberheid en benauwdheid bleken onafhankelijke voorspellers voor angst na correctie voor leeftijd, geslacht en burgerlijke staat. Somberheid, benauwdheid samen met leeftijd, geslacht en burgerlijke staat verklaarde 22,8% van de variantie. Concluderend kunnen we zeggen dat de behandeling van angst specifieke aandacht vereist voor somberheid en dyspnoe.

De rol van de verpleegkundige

In hoofdstuk 7 is onderzocht wat verpleegkundigen, werkzaam in een hospice, weten, doen en nodig hebben bij het ondersteunen van angstige patiënten met kanker. We hebben het onderzoek vorm gegeven door middel van een online vragenlijst en focusgroep interviews.

Verpleegkundigen, werkzaam in hospices die zijn aangesloten bij de Associatie Hospicezorg Nederland werden gevraagd deel te nemen. De vragenlijst werd ingevuld door 265 verpleegkundigen (79%) en er werden vijf focusgroep interviews gehouden (n=25). 134 van de 213 (63%) verpleegkundigen vroegen patiënten regelmatig of zij zich angstig voelen. 16% van de verpleegkundigen besprak angst alleen als de patiënt dit zelf als gespreksonderwerp aangaf. Meetinstrumenten voor het identificeren, monitoren en analyseren van angst werden gebruikt door 37% van de verpleegkundigen. Sommige verpleegkundigen kozen er bewust voor om geen meetinstrumenten te gebruiken omdat het invullen van een vragenlijst als last voor de patiënt werd gezien. Andere verpleegkundigen waren zich niet bewust van het feit dat er meetinstrumenten bestaan om angst te meten. Verpleegkundigen ervoeren problemen bij het herkennen van angst als gevolg van de verscheidenheid aan uitingen van angst: emotioneel, cognitief en gedragsmatig. Uitingen van angst door de patient werden meer waargenomen gedurende de avond en de nacht. Om angstige patiënten te ondersteunen ervoer 50% van de verpleegkundigeneen tekort aan tijd en 31% van de verpleegkundigen een tekort aan kennis.

In de focusgroep interviews kwam naar voren dat interventies meestal werden geselecteerd op basis van intuïtie. Een andere opvallende uitkomst was dat verpleegkundigen in de avond en nachtdienst een grote verantwoordelijkheid ervaren om de zorg voor patiënten met paniekaanvallen vorm te geven door keuzes die op acute momenten gemaakt moeten worden.

De resultaten van deze studie benadrukken de worsteling van verpleegkundigen bij de zorg voor angstige patiënten met kanker die zijn opgenomen in een hospice. Verpleegkundigen in een hospice hebben behoefte aan richtlijnen om meetinstrumenten toe te passen, effectieve communicatiestrategieën en besluitvormingsmodellen alsook inzicht in voorspellende factoren om angst te identificeren en gerichte interventies in te kunnen zetten. Die behoefte is het grootst tijdens de avond- en nachturen.

Deel III

In **hoofdstuk 8** beschrijven we een samenvatting van de resultaten, reflecteren we op de gebruikte methodologie en staan we stil bij de implicaties voor vervolg onderzoek en voor de dagelijkse zorgpraktijk.

Gebaseerd op de eerder genoemde bevindingen hebben we een systematische benadering ontwikkeld voor de zorg voor patiënten met angst en deze uitgewerkt volgensde veelvuldig gebruikte methode in de dagelijkse zorg voor patiënten in de palliatieve fase in Nederland, de methodiek ‘besluitvorming in de palliatieve fase’.

Deze systematische benadering is gebaseerd op het principe van ‘palliatief redeneren’ en start met een systematische analyse van de symptomen en problemen van de patiënt in de individuele context (fase 1); gevolgd door het formuleren van een werkhypothese, een behandelplan en het doel hiervan (fase 2); een evaluatie van het effect van de behandeling (fase 3); en het zo nodig en waar mogelijk het aanpassen van het beleid (fase 4). De betrokkenheid van patiënten en naasten met betrekking tot hun wensen en prioriteiten is essentieel gedurende het cyclisch proces. Met deze methode zou de communicatie met patient en naasten moeten verbeteren, mits gebruikt in de multidisciplinaire samenwerking tussen alle betrokken zorgverleners.

Deze systematische benadering is samengevat in de tabel aan het einde van deze samenvatting. Of de hier door ons voorgestelde benadering daadwerkelijk zullen leiden tot de gewenste betere uitkomsten op patiënt niveau zullen we in de toekomst gaan evalueren.

Conclusie

Zorg voor patiënten die angst ervaren is een ware uitdaging vanwege het beperkte levensperspectief van patiënten, de verscheidenheid aan expressies van angst, communicatie stijlen, oorzaken en bronnen van angst, beïnvloedende factoren, coping strategieën en individuele behoeftes van patiënt en zijn naasten aan de ene kant en het gebrek aan effectieve interventies aan de andere kant. Dit proefschrift heeft belangrijke aangrijpingspunten zichtbaar gemaakt die zorgverleners helpen om een verschil te maken in de zorg voor patiënten met angst in de laatste fase van hun leven en zo de kwaliteit van leven en uiteindelijk de kwaliteit van sterven te optimaliseren.

Tabel. Systematische benadering van zorg rondom angst uitgewerkt volgensde methode ‘palliatieve besluitvorming’

Fases	Algemene aspecten	Angst gerelateerde aspecten
Fase 1: Breng problematiek in kaart	Medische voorgeschiedenis: diagnose, huidige en eerdere behandelingen, c morbiditeit	• Vraag of de patiënt een angststoornis, depressie of andere psychiatrische stoornissen in het verleden heeft gehad • Check in hoeverre de patiënt is geïnformeerd over zijn situatie en hoeverre hij deze begrijpt

	• Multidimensionele analyse van de patiënt in de huidige situatie:
	• Gebruik een en persoonlijk patiëntenprofiel
	• Lichamelijk: performance status, ADL
	• Psychologisch:
	  • Algemene psychologische status: cognitieve functies, communicatiemogelijkheden, vermogen om informatie te verwerken
	  • Stemming: bezorgdheid, , spanning, boosheid, somberheid.
	  • Wijze van omgaan met de situatie
	• Sociaal
	• Existentieel
		• Psychologischedimensie: Hoe wil de patiënt worden benaderd door de professional(of niet), welke behoefte aan informatie heeft de patiënt en wat is de betekenis van veiligheid en controle voor de patiënt?
		• Sociale dimensie: Wat is de rol van de naaste in het algemeen en in het omgaan met angst, en welke aspecten van de sociale rol van de patiënt levert problemen op en/of veroorzaakt een gevoel van incompetentie en/ofincompleetheid?
		• Existentiële dimensie: Welke spirituele en/of existentiële rituelen zijn gerelateerd aan angst? Welke existentiële factoren beïnvloeden angst?

	Geschatte levensverwachting	De duur van het resterende leven bepaalt de scope van interventies en de gerelateerde continuïteit van de zorg

	Medicatie	• Check de huidige en eerdere farmacologische behandelingen voor angst
		• Check of medicatie(-verandering) een oorzaak kan zijn vande angst:
		  - Gebruik van corticosteroïden, sympathicomimetica, anti-emetica, benzodiazepines, dopaminerge medicatie, ketamine, methylfenidaat, haloperidol en andere neuroleptica
		  - Het abrupt stoppen van opioïden, corticosteroïden en benzodiazepines

	Symptoomanalyse	• Gebruik routinematig passende meetinstrumenten om angst te meten en bespreek de resultaten met de patiënt en de naaste
		  - Voor vroegtijdige herkenning: Lastmeter en/of Utrecht Symptoom Dagboek (USD)
		  - Voor monitoring: USD
		  - Voor meer inzicht in de angst en screening voor een potentiele angststoornis: Hospital Anxiety and Depression Scale (HADS)
		• Observeer non-verbale uitingen en lichamelijke signalen dat gerelateerd aan angst of een delier zou kunnen zijn
		• Gebruik synonieme begrippen van angst zoals: zorgen maken om, gespannen voelen, bang zijn; beklemd gevoel hebben
		• Vraag naar:
		  - de mate waarin het voorkomt, de ernst of intensiteit, of er een patroon herkenbaar is en het verloop van angst over de tijd
		  - mogelijke oorzaken, beïnvloedendefactoren, bronnen van angst en hun fluctuatie over de tijd voor alle dimensies:lichamelijk, psychisch, sociaal en spiritueel/existentieel
		  - zijn of haar manier om met angst om te gaan en hoe hij of zij benaderd wil worden door zorgprofessionals

Tabel vervolg

Fases	Algemene aspecten	Angst gerelateerde aspecten
		- de organisatie van zorg; wordt deze als voldoende en passend ervaren, is er sprake van vertrouwensrelaties en continuïteit - de manier van communicatie, gebrek aan informatie, gevoel van verlies van controle en veiligheid - de impact van angst op kwaliteit van leven en op psychisch en sociaal functioneren - het effect van eerdere interventies zowel(niet-farmacologisch en farmacologisch)
	Prioriteit en wensen van patiënt	• Ga na of de patiënt gemotiveerd is om iets aan de angst te willen doen en zo ja, hoe hij of zij zich voor zich ziet • Exploreer en documenteer de prioriteit en wensen van patiënt en naasten
Stem af met patiënt en naaste en gebruik meetinstrumenten		
Fase 2: Vat problematiek en beleid samen	Benoem de problemen en formuleer een werkhypothese	• Geef aan waar de patiënt bang voor is • Specificeer de onderliggende oorzaken en beïnvloedende factoren van angst
	Behandel de oorzaak	• Behandel ongecontroleerde symptomen, met specifieke aandacht voor somberheid, kortademigheid, slaapproblemen, sufheid, pijn, misselijkheid, anorexie en vermoeidheid • Zoek naar alternatieve mogelijkheden voor medicatie die angst veroorzaakt • Behandel onderliggende medische condities zoals bijv. een delier, hypercalciëmie, hyperthyroïdie, koorts, infecties)
	Niet-medicamenteuze behandeling	• Basale niet-medicamenteuze interventies kunnen bestaan uit: - Psycho-educatie met betrekking tot angst en gerelateerde symptomen zoals kortademigheid en de angst om te stikken - Structurele en regelmatige aandacht en gesprek - Informatie over de onderliggende ziekte en het toetsten van begrip ervan - Versterken van het gevoel van controle en veiligheid door aan te sluiten bij de persoonlijke wensen hieromtrent - Ondersteunen van de manier waarop de patiënt met zijn angst omgaat, rekening houdend met wisselende intensiteit en wisselende momenten van voorkomen - Bespreken van het zorgplan met een cyclische regelmaat - Ondersteuning van de naasten t.a.v. hun eigen rol • Stem interventies af op de specifieke wensen en manier waarop de patiënt met zijn angst omgaat en de verschillen hierin in het verloop van de dag, avond en nacht • Stem met patient en naasten af omde naasten actief te betrekken in de ondersteuning • Ga na of verwijzing naarpsycholoog ofgeestelijk verzorger gewenst is. Overweeg het gebruik van de Hospital Anxiety and Depression Scale (HADS) om te screenen op eenangststoornis envoor verwijzing naar een psychiater
	Farmacologische behandeling	• Overweeg het gebruik van: - Benzodiazepines - Selectieve Serotonine Reuptake Inhibitors (SSRI's) - Overige medicatie (bijv. mirtazapine, trazadone, quetiapine, olanzapine).

Tabel vervolg

Fases	Algemene aspecten	Angst gerelateerde aspecten
Stem af met patiënt en naaste en gebruik meetinstrumenten		
Fase 3: Maak afspraken over evaluatie van het beleid	• Plan hoe het effect van het zorgplan wordt gemeten, door wie en wanneer • Meet het effect aan de hand van klachten en problemen en de beleving daarvan, functioneren en welbevinden van de patiënt • Documenteer de uitkomsten ten aanzien van resultaat en proces in het patiëntendossier	Betrek de naaste bij de evaluatie van het effect van de interventie in relatie tot eerder samen bepaalde doelstellingen
Stem af met patiënt en naaste en gebruik meetinstrumenten		
Fase 4: Stel het beleid zo nodig bij	• Als het effect positief is: blijf periodiek evalueren (ga terug naar fase 3) • Als het effect afwezig is of beperkt: - Stel beleid bij (ga terug naar fase 2) - Breng situatie opnieuw in kaar en stel werkhypothese bij (ga terug naar fase 1) - Accepteer de situatie	• Wees ervan bewust dat: - de onderliggende oorzaak van angst kan veranderen in de loop van de palliatieve fase - angst niet altijd volledig weggenomen kan worden

Stem af met patiënt en naaste en gebruik meetinstrumenten

Appendices

Appendix A: Interview guide - Patients

Topic	Questions
Introduction	• Introducement of researcher • Verify if the patient does know what includes participating • Verify if the patient agrees with the audio recording • Verify if the patient is able and willing to talk about anxiety on this moment • Explain that the maximal duration of the interview will be 30 minutes • Check or sign the informed consent • Introduce subject ○ Anxiety is a common symptom ○ To help healthcare professionals in order to early identify anxiety and to let the care less independent of the individual professional ○ Insight into the needs of patients ○ It is all about your experiences according anxiety management ○ Can you tell us something about that?
Additional questions	Reflection on patients anxiety score: Patients with anxiety score >0 • What do you feel? / What are the expressions? • Level of anxiety • What kind of support helped you to control anxiety? • What did/do you need? • What was (not) supportive? • What are the sources of your anxiety? Patietns with anxiety score=0 • How do you reflect on this? • What was supportive for you? • What was not supportive? • Reflect on previous outcomes of the interviews • Do you think you will experience anxiety in the future and why? • What do you think you will need?
General	• Reflect on previous outcomes of the interviews • What should we take with us in order to develop an intervention regarding anxiety management?
Closure	Thank patients fort heir openness and time, If patients need aftercare by a professional it is possible to address this by their nurse.
Field notes	*Make notes directly after the interview took place (atmosphere, how was the interview, what was my role, surroundings, striking expressions, etc.)*

Appendix B: Themes and codes

Preconceived framework interview guide	Themes	Codes
Anxiety	Level, impact and course of anxiety	Present daily Not continuously No anxiety Decrease in relation to hope Decrease in relation to acceptation No influence on daily life
	Synonyms of anxiety	More sadness then anxiety Cannot identify themselves with the word anxiety Worried Tense Scared Insecure Not so high then you can speak of anxiety
Needs	Influencing factors regarding needs	Discussion with nurse Proximity of nurses Change of needs Depending on level anxiety Depending on source of anxiety
	Information and sense of control	Open communication Honest information about nearing death Honest information about life expectancy Honest information about treatment options Honest information about progression of the cancer Honest information about medication Involvement in daily schedule Involvement in decision making Check of information in medical file Information connected to be less overwhelmed No information need No details Wait and see No information about what might will happen
	Safety	Safe environment Continuous availability of nurses Not being alone Competent professionals Knowledge of professionals about personal situation Knowledge of professionals about care plan Bedside transferal between shifts Safety connected to the need to be in control
	Adequate symptom management	Treatment of pain Treatment of dyspnea Symptoms should be taken seriously Competent professionals Education of patient about symptoms Good night of sleep
	Talking about anxiety (or not)	Discussing anxiety with nurse Discussing anxiety with doctor Discussing anxiety at anxious moments

Appendix B: continued

Preconceived framework interview guide	Themes	Codes
	Talking about anxiety (or not)	Reflecting after an anxious moment Trust in professional Safety Reluctant to call for a nurse to talk about anxiety Inviting behaviour by professionals No expectation of a solution Listening by professional Attention of professionals Kindness of professionals Compassion of professionals Encouragement to discuss anxiety Difficulty for the patient to discuss anxiety Preference to speak to professionals instead of loved ones Dealing with emotions of loved ones Balance between positive and negative conversation topics Conversation about positive aspects of life No wish to talk about anxiety Preference to deal on their own Reflecting on thoughts on their own
	Respecting for coping strategies by professionals	Not bothered by questions Respect Tailored to the situation of the patient Distraction Discuss anxiety Not feeling respected Support Facilitating Not being forced
Causes and sources		Information too worse to share Lack of information Lack of control Information about what might will happen Feeling unsafe Lack of competence of professional Pain Dyspnoea Suffocation Thoughts of increased pain or dyspnea in the future Lack of sleep Physical decline Mental decline Uncertainty Uncertainty about life expectancy Care of children Leaving their home
Expressions		Sleeping problems Worrying at night Blocking behaviour Anger Irritation towards others Tense during the night Crying

Appendix C: Interview guide - Loved Ones

Topic	Questions
Introductory sentence and question	Anxiety is common in patients with an incurable disease, but not always recognized, talked about or acted upon. To make sure we are on the same page with regard to the concept of anxiety, what do you see as anxiety? *(think about the words: fear, anxiety, tension, insecurity, afraid, worrying, nervous, panic, cramped)*
Presence	Can you tell me if you ever experience or experienced anxiety in the patient?
Sources	What do you think is the source of the anxiety the patient experiences? *What is the underlying source?* *No fear of death? Was it present before? Why not? What changed?* *Does religion play a part?* *Anxiety about the way of dying? What is he scared of exactly?* *No anxieties present? Anxieties in the past? How come there is no anxiety at the moment?* *(think about: anxiety of upcoming suffering, dependency, losing control, losing dignity, losing autonomy, saying goodbye, dying and death, choking, pain)*
Signal	How do you know/feel that the patient is feeling anxious? *What do you see/feel/hear?* *What does he say?* *How does he call/name the anxiety?* *How does he feel when he is anxious?* *What makes him restless?* *What does it look like?* *Can you/he talk about it?* *(Think about: verbal expressions, insomnia, nightmares, restless, worrying, dyspnoea, nausea, irritable, gastro-intestinal complaints, sweating, pain, crying, feeling sad)*
Severity	How frequently do you experience anxiety in the patient? To what extent do you think the patient is feeling anxious? *(per day/week, continuously or ups en downs)* How severe/intense would you describe the anxiety in your loved one? *Mild-moderate-severe / 1-10* *Why do you choose that? On what basis?*
Influencing factors	What are factors that influence the anxiety in the patient? *(Consider: place of stay, who, time of day, progression of the disease, death drawing near, before and after diagnosis, alone or not, darkness etc.)*
Impact	What consequences does this anxiety have for the patient? *On social level, psychological level, spiritual level, physical functioning, on daily life?* What consequences does the anxiety of the patient have for you as loved one? *On social level, psychological level, spiritual level, physical functioning, on daily life?* *What is it like for you to see him anxious?* *To what extent does it affect you?* *To what extent can you face his fears?* *Did you find it harder to see his anxiety before? What changed?*
Needs	What do you think the patient needs to prevent/reduce/stabilize his anxiety? *What, how, who, when?* *(Think about: talk about anxieties/worries, provide information, prepare for the coming end, distraction)* Did the patient do/try anything to reduce anxiety? What helped and what did not? What did the patient greatly appreciate about preventing/reducing/ stabilizing anxiety? Dos *(examples?)* What should not be done to prevent/reduce/stabilize anxiety in the patient? Don’ts *(examples?)* What do you think that nurses can do to prevent/reduce/stabilize anxiety in the patient?
Conclusion	Reflection on the interview
Field notes	*Make notes directly after the interview took place (atmosphere, how was the interview, what was my role, surroundings, striking expressions, etc.)*

Appendix D: Coding scheme –anxiety from the perspective of the loved ones

Themes	Subthemes	Codes
1.Presence and severity of anxiety	1. Presence	• Daily • Not continuously • Frequency decreases • Anxiety increases during active treatment of the illness • No anxiety
	2.Severity	• Fluctuating • Anxiety does not dominate • More anxiety present than shown as a result of protection of loved one by patient
2. Influencing factors		• Physical condition • Mental condition • Age/ generation • Previous experiences • Influence of previous loss experience • Religion • Character • Attitude towards disease • Setting/surroundings • Moment of the day • Presence of people • Calmness because of contemplated scenario's • Calmness because of care plan • Confidence • Distraction by writing a book
3.Sources of anxiety		• Anxiety for diagnostics and treatment • Anxiety for deterioration • Reflected anxiety • Anxiety for having to leave the hospice • Anxiety for burden of loved ones • Anxiety for letting go • Anxiety for losing control • Anxiety for being alone • Anxiety for the unknown • Anxiety for losing autonomy • Anxiety for losing dignity • Death anxiety • Anxiety for reaction of loved ones regarding end-of-life decisions
4.Observed expressions	3.Verbal	• Verbal signal • Reading between the lines
	4.Non-verbal	• Emotions • Facial expressions • Restlessness • Small gestures • Worrying • Keeping control • Clinging behaviour • Withdrawing and avoidance behaviour • Hostile behaviour • (Almost) No expression of anxiety

Appendix D: continued

Themes	Subthemes	Codes
5.Impact	5.Impact on patient	• Minimal impact on patient • Physical: sleeping problems • Physical: losing weight • Physical: transpire • Physical: causing or worsening pain • Physical: fatigued • Psychological: difficulty in controlling their thoughts • Psychological: worrying • Spiritual: struggling in saying goodbye • Social: being overactive • Social: harsh and hostile behaviour towards loved ones • Social: avoiding behaviour causing irritations
	6.Impact anxiety patient on loved one	• Minimal to moderate impact on loved one • Impact dependent on severity of anxiety • Psychological: hard to see the patient anxious • Psychological: feeling powerless • Spiritual: more conversations concerning disease, anxiety and death • Social: feeling claimed / own life on hold
6.Needs		• Distraction and relaxation • Having a talk • Presence of people • Safe environment • Expertise • Control • Tailored care

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Curriculum vitae

Over de auteur

Daniëlle Zweers werd geboren op 14 oktober 1986 in het Overijsselse Hardenberg.
In 2003 rondde ze haar middelbare school af aan het Vechtdal College in Hardenberg. In 2007 voltooide zij de HBO- Verpleegkunde opleiding aan de Christelijke Hogeschool Windesheim te Zwolle. In het laatste jaar van de HBO-V behaalde zij eveneens de premaster Verplegingswetenschap. Haar interesse voor wetenschappelijk onderzoek was gewekt. Zij startte haar loopbaan als verpleegkundige op de afdeling interne geneeskunde en dagbehandeling oncologie van het Röpcke Zweers Ziekenhuis te Hardenberg. In 2009 behaalde ze haar Master Verplegingswetenschappen aan de Universiteit van Utrecht en begon zij als klinisch verpleegkundige op de afdeling Medische Oncologie van het Universitair Medisch Centrum Utrecht. Deze afdeling maakte het in samenwerking met academisch hospice Demeter mogelijk om haar afstudeerproject " Angst bij patiënten met kanker in de palliatieve fase" een vervolg te geven. In 2011 behaalde ze de opleiding tot oncologie verpleegkundige. In 2014 startte ze haar promotietraject waarvan dit proefschrift het resultaat is. Praktijk en onderzoekstaken werden gecombineerd vanuit een gecombineerde aanstelling bij de afdeling Medische Oncologie en het Expertisecentrum Palliatieve Zorg Utrecht. Tijdens haar onderzoek begeleidde zij twee studenten verplegingswetenschap bij hun onderzoeksstage/masterthesis. Sinds 2016 is zij ook als consulent verbonden aan het Consultatieteam voor Ondersteunende en Palliatieve Zorg UMCU (COPZU). In 2018 behaalde zij cum laude de verkorte opleiding tot Verpleegkundig Specialist aan de Hogeschool Utrecht en sindsdien begeleidt ze, naast haar consulentschap, patiënten met kiemceltumoren en jongeren met kanker (AYA: adolescents and young adults with cancer).
Haar ambitie is een brug te slaan tussen wetenschap en de verpleegkundige praktijk in de zorg voor patiënten met kanker. De zorg inspireert, het onderzoek leert en de combinatie daarvan creëert!
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