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Patients' Needs Regarding Anxiety Management in Palliative Cancer Care: A Qualitative Study in a Hospice Setting

Danielle Zweers, RN, MSc[1,2], Alexander de Graeff, MD, PhD[2], Jette Duijn, RN, MSc[3], Everlien de Graaf, RN, PhD[1], Petronella O. Witteveen, MD, PhD[2], and Saskia C. C. M. Teunissen, RN, PhD[1]

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 patients with cancer. Patients admitted from May 2017 till May 2018 were eligible whether or not they were anxious. Interviews were analyzed and coded within predefined topics. **Results:** Fourteen patients were included: 10 females, median age 71, and median World Health Organization 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 6 main expressed needs. **Conclusion:** Assessing patients' needs regarding anxiety provided important angles where health-care 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 health-care professionals to manage anxiety in daily care of terminal patients.

Keywords

anxiety, palliative care, advanced cancer, hospice care, symptoms, qualitative research

Introduction

Anxiety has been reported in 20% to 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 sedation,[8] 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.[9] One of the prominent unmet needs in patients with advanced cancer is the support for feelings of anxiety (eg, for physical suffering), hopelessness, and uncertainty about the future.[10]

Hospice care nurses often struggle in supporting anxious patients, especially during late and night shifts when the presentation of anxiety is more intense.[11] Timely identification, support, and treatment of anxiety are essential in patients with a limited life expectancy.

Anxiety management benefits from a multidimensional team approach.[12] The consisting evidence regarding anxiety management is mainly focused on specialized psychosocial care.[12] Although specialized psychosocial care in hospices is provided by chaplains and social workers,[13] nurses are confronted with anxious patients 24 h/d, including difficult moments at night, when chaplains and social workers are not available.[11] Anxiety management in daily practice depends on nurses' individual competencies.[11] There is hardly any evidence about anxiety management by hospice nurses and doctors.[14]

[1] Department General Practice, Center of Expertise Palliative Care, Utrecht, the Netherlands
[2] Department Medical Oncology, Cancer Center University Medical Center, Utrecht, the Netherlands
[3] GGD Hollands Noorden, Alkmaar, The Netherlands

Corresponding Author:
Danielle Zweers, RN, MSc, Department Medical Oncology, Cancer Center University Medical Center, Postbox 85500, GA Utrecht 3508, The Netherlands.
Email: d.zweers@umcutrecht.nl

It is essential to realize the best fit between patients' needs and provided support.[15] 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 or not they were anxious. 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, World Health Organization (WHO) performance score and the most recent anxiety score (a numerical rating scale ranging from 0 to 10, 0 representing "absence of anxiety" and 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,[16] 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 analyzed 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 2 researchers (DZ and JD) independently after each interview (Table 1) Data collection continued until code saturation was achieved.[17] To ensure trustworthiness, interviews were audio-recorded, transcribed verbatim, and field notes were made directly after the interview. During the analysis, theoretical and methodological memos were made. Three peer debriefing sessions with specialist palliative care nurses of the hospices were organized during the process of analysis. Member checks were carried out by a spoken summary of the interviewer and at the end of each interviews. An audit trail of those documents was kept to systematize,

Table 1. 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 than 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

(continued)

Table 1. (continued)

Preconceived framework interview guide	Themes	Codes
		– 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
		– Reflecting after an anxious moment
		– Trust in professional
		– Safety
		– Reluctant to call for a nurse to talk about anxiety
		– Inviting behavior 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
		– Dyspnea
		– 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 behavior
		– Anger
		– Irritation toward others
		– Tense during the night
		– Crying

cross-reference, and follow the data. Discrepancies were discussed in a broader research team until consensus was reached.

Results

Fourteen patients were included (Table 2): 10 female, median age 71, and median WHO performance score 3. Most patients were highly educated. Thirteen patients were interviewed within 6 months before death. One patient was transferred to a nursing home, since his medical conditions improved.

The interviews lasted 6 to 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).

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 9 patients with a score of

Table 2. 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's degree	4
Master's 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 weeks
Range	1-27 weeks

Abbreviation: WHO, World Health Organization.

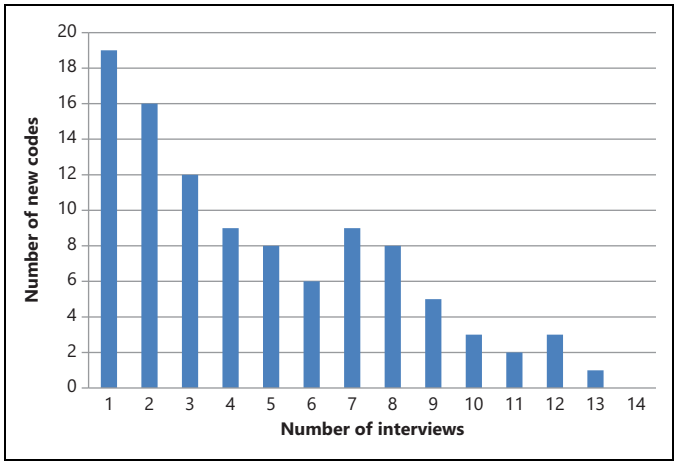

Figure 1. Number of new codes per interview.

0 came up with some type of anxiety, although not affected their daily life. These patients connected their 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.

> When there is no hope there is no anxiety. (13)

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

> Anxiety is the highest when you can lose the most. (7)

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

Once patients were asked about their needs regarding anxiety management by the professional team, they predominantly focused on nursing support and sometimes medical support. None of the 14 patients referred to the chaplain. Nurses are the most nearby according to most of the patients.

> 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. (7)

Patients talked about needs to decrease feeling anxious but also needs to prevent feeling anxious. Patients acknowledged that needs were changing over time and were dependent on the level and source of anxiety at a specific moment. Prevention of crises and panic attacks was felt as crucial because *the deeper you are in, the more difficult it is to get out* (patient 8). This patient stated that her needs depend on the severity of anxiety on that moment: *which support will work depends on how deep you are in* (8).

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 toward 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 were 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.

> 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)

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

The need for informed care mentioned above 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.

> 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)

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 influenced by several factors. 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 1 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 thoughts 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:

> 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)

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 for those patients to talk about anxiety is a relationship based on trust and safety. Some patients were reluctant to call a nurse to talk about anxiety, 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 be taken away completely. They just expected attention, compassion, and being listened to. Some patients found it difficult to discuss anxiety and liked to be encouraged to do so. Talking about anxiety and ventilating their thoughts decreases anxiety.

> Talking extensively about anxiety helps, but it cannot take all the anxiety away. (13)

> It is not easy to talk about anxiety by myself. (4)

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. Those 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 have the need to share these thoughts with others.

Respecting 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 or not 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 that focused on the needs of patient with cancer regarding anxiety in the last phase of life.

Routinely collected USD anxiety scores were relatively low. Some patients did not recognize themselves in the word "anxiety." Term like worry, feeling tense, or being scared was 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.[18]

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.[19,20] Fallowfield et al described that patients perceptions can be worse than the facts.[21] Patients do not automatically ask for further information. Since information is one of the top 3 unmet needs of patients with advanced cancer and their loved ones, addressing misconceptions and providing adequate tailored information should be a priority in clinical care.[10]

Feeling in control was connected to the needs information and safety. Control is associated with decreased anxiety.[22] 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 in anxiety. Although findings in studies are not consistent, symptoms such as pain, dyspnea, fatigue, nausea, and insomnia may be associated with increased anxiety.[5,23] 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. 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 and 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.[24] 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 toward their illness and their individual coping strategies influences their desire, for example, for information and efforts to obtain it.[25] It is therefore essential that patients' own resources are recognized and supported.[26]

This study is an essential part of a series of explorative studies[5,11,14,24,27] and contributes to the improvement in anxiety management with insight into the needs of patients themselves with 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, >58 years of age, female, and well educated. Younger, male, and less educated patients may have different needs.[18]

In conclusion, information, open communication, sense of control, safety, adequate symptom management, and respect for patients' coping strategy were the 5 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; and
- 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.

Appendix A

Interview Guide

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

Patients with an anxiety > 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 or causes of your anxiety?

Patients with an 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 for their openness and time. If patients need aftercare by a professional, it is possible to address this by their nurse.

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ORCID iD

Danielle Zweers https://orcid.org/0000-0002-9143-1759

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