RESEARCH REPORT

Anxiety in patients with advanced cancer admitted to a hospice, from the perspective of their loved ones: A qualitative study

Student	J.M. Duijn
Student number	4300262
Status	Final version
Coordinating investigator	D. Zweers
Workgroup teacher	J.M. de Man
Training institution	Hospice Demeter, De Bilt
Contact training institution	S.C.C.M. Teunissen
Target journal	Palliative Medicine, European Association for Palliative Care
Total words	3781 words
Words abstract	300 words
Words Dutch resume	300 words
Reporting criteria	COREQ
Date	28th of June 2017
Education	Masterdegree Clinical Health Sciences, Nursing Science, UMC Utrecht, Utrecht University

Abstract

Title. Anxiety in patients with advanced cancer admitted to a hospice, from the perspective of their loved ones: A qualitative study

Background. Anxiety is a common symptom among patients with advanced cancer, however not always recognized in clinical practice. There is a need for interventions to support patients with anxiety, especially in this last phase of life where patients are not always able to communicate about their concerns. Here, loved ones can be a valuable source of information.

Aim. To explore the experiences and views of loved ones concerning the presence, severity, cause, expression and impact of anxiety in patients with advanced cancer admitted to a hospice and their needs regarding anxiety management.

Methods. Qualitative research by performing semi-structured interviews among loved ones of patients admitted to a hospice. Open and axial coding was performed to reduce the data into relevant concepts.

Results. Of the 14 loved ones, 64.3% was female, most were in the role of daughter and the mean age was 56 years. Loved ones identified a variety of causes and expressions of anxiety and recognized the patients' need for support. Mean score of patients' anxiety scored by loved ones was 6 (NRS 0-10). They indicate that anxiety affects both the physical, psychological, social and existential dimensions. Loved ones noted that the anxiety in the patient also affects themselves.

Conclusion. Although the perspective of the patient is the golden standard, loved ones can be a valuable source of information in the recognition and support concerning anxiety. Therefore, loved ones should be more involved in the care for patient with anxiety. Given the impact of anxiety on both patient and loved ones, interventions should be aimed at both patients and loved ones to improve quality of life and dying.

Keywords. Anxiety, neoplasms, hospice and palliative nursing, caregivers, family.

Samenvatting

Titel. Angst bij patiënten met kanker opgenomen in een hospice, vanuit het perspectief van hun naasten: een kwalitatieve studie.

Achtergrond. Angst komt veel voor bij patiënten met kanker in de palliatieve fase, al wordt dit in de praktijk niet altijd als zodanig herkend. Er is behoefte aan interventies om patiënten met angst te ondersteunen, met name in de laatste fase van het leven waarin patiënten vaak zelf niet meer aan kunnen geven wat zij nodig hebben. Het perspectief van naasten vormt hierin een waardevolle informatiebron.

Doel. Het exploreren van de ervaringen en zienswijze van naasten betreffende de aanwezigheid, ernst, oorzaak, impact en behoeften van angst bij patiënten met kanker opgenomen in het hospice.

Methode. Kwalitatief onderzoek middels semigestructureerde interviews onder naasten van patiënten met kanker opgenomen in een hospice. De interviews zijn getranscribeerd en middels codering gereduceerd tot relevante concepten.

Resultaten. Van de 14 naasten waren de meeste in de rol van dochter, 64,3% was vrouw, de gemiddelde leeftijd was 56 jaar. Naasten benoemen een diversiteit aan oorzaken en uitingen van angst bij de patiënt en herkennen diens behoefte voor ondersteuning. Naasten scoren angst van de patiënt gemiddeld met een 6 (NRS 0-10) en geven aan dat angst van invloed is op zowel de lichamelijke, psychische, sociale als existentiële dimensies. Naasten geven aan dat de angst van de patiënt ook impact heeft op hun eigen functioneren.

Conclusie. Alhoewel het perspectief van de patiënt de gouden standaard is, kunnen naasten een waardevolle informatiebron vormen bij signaleren van angst en ondersteunen van de patiënt. Naasten zouden daarom meer betrokken moeten worden in de zorg voor patiënten met angst Gezien de impact van angst voor zowel patiënt als naaste zijn interventies gericht op patiënt en naaste wenselijk om kwaliteit van leven en sterven te verbeteren.

Trefwoorden. Angst, kanker, palliatieve zorg, naaste, mantelzorger.

Introduction

Anxiety is a common symptom among patients with advanced cancer; a systematic review showed a pooled prevalence of 30%[1]. Anxiety is defined 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 be difficult to identify in clinical practice, because some signs and symptoms of anxiety can also be caused by the underlying disease or treatment[3–5]. Death anxiety, anxiety of dying, disability, disfigurement, dependency, pain, shortness of breath, separation from loved ones, being a burden to others and losing control are often causes of anxiety in this population[3,6,7]. Common expressions of anxiety are restlessness, worry, dyspnoea, gastrointestinal problems, sleeping problems, irritability, palpitations, and transpiration[3,6]. Anxiety commonly increases when treatment is not sufficient and is associated with impaired quality of life[8,9], meaning there is a clinical relevance to act upon anxiety in this population[3,6].

In the last days before death, patients can be too ill to communicate about their problems and concerns[10]. In this case, the loved ones have an important role in clarifying the preferences and needs of the patient and supporting them in this last phase of life. McPherson showed that loved ones can be a valuable source of information concerning patients' anxiety because they have knowledge regarding the patient's character and preferences before illness[10]. Further, McPherson studied the perspective of bereaved loved ones on patients' anxiety[10]. However, no prospective research is known to the authors concerning anxiety in patients in the last months of their life, from the perspective of their loved ones. Other previous research among loved ones concerned the exploration of their overall experience of caring for a patient suffering from cancer[11–14]. Therefore, the aim of this study was to explore the experiences and views of loved ones concerning the presence, severity, cause, expression, and impact of anxiety in patients with advanced cancer and their possible needs regarding anxiety management. The overall aim is to contribute to the development of an intervention set to adequately support patients with advanced cancer and anxiety, in order to improve or maintain the quality of their remaining life[1,9].

Method

Design

Given the nature of this research, the exploration of the experiences and views of loved ones concerning anxiety in patients with advanced cancer, a qualitative study with an explorative design was performed[15].

Population & domain

The population consisted of the loved ones of patients with advanced cancer with a life expectancy of less than three months. As mentioned above, loved ones play an important role in this last period of life. Loved ones are defined as ''those persons who are close to the patient, regardless of whether they are spouses, significant others, relatives, adult children or friends[16], according to the patient." Loved ones were eligible if they were >18 years and able to communicate in Dutch. Furthermore, the patient had to be alive at the moment of the interview with their loved one to avoid recall bias[17,18] and because of the possible influence of bereavement on the perception of anxiety. One or two loved ones per patient were interviewed to get maximum variation in cases. In order to approach this population we included loved ones of patients admitted to a hospice in the Netherlands.

Procedures

Loved ones were identified by the patient at admission. Convenience sampling was applied, meaning all present loved ones were informed, irrespectively whether the patient indicated to be anxious or not. Loved ones and patients were informed through oral and written information provided by the healthcare professionals. When both patient and loved one agreed verbally to participate, loved ones were contacted to provide more information and to schedule an appointment. Prior to the interview, informed consent was obtained. Loved ones received a small gift to show gratitude for their participation in the study.

Two pilot interviews were conducted to test the interview guide and reflect on the interview style. Minor changes were made in the interview guide to clarify some questions. The two pilot interviews were included in the final analysis.

Data collection

Data was collected using face-to-face interviews between January 2017 and July 2017. The interviews were semi-structured using an interview guide (appendix A), developed by the researchers (JD,DZ,ST) using clinical experience and literature[3,10,12,13,19]. The main topics of the interview were the presence, severity, cause, expression, impact, and needs concerning anxiety in patients, as experienced by their loved ones. During the interviews, the patient was not present because of their possible influence on the response of the loved one. Data was collected until saturation. The interviews were conducted by one nursing researcher student (JD), who was trained in interviewing and discussing sensitive topics such as anxiety. There was no relationship between the interviewer and the loved ones prior to the study. The interviews were recorded with a digital voice recorder and field notes were made directly after each interview. Socio-demographic characteristics such as age, gender, relationship with the patient and participation in daily care or not were collected using a form filled in by the loved ones.

Data analysis

The interviews were transcribed verbatim and read by JD and DZ. Fragments of data were coded independent of each other and initial codes were developed using open coding[20]. Thereafter, coding schemes were discussed until consensus was reached. Because of the explorative nature of this study the main topics (presence, severity, cause, expression, impact, and needs) were used as main themes while developing the coding scheme. Next, axial coding was applied to reduce the data into relevant concepts[20]. NVivo (version 11, QSR International) was used to structure the data. The data analysis was an iterative process, meaning that the researchers moved back and forth from data collection to analysis[15]. Peer debriefing and expert opinion was applied by discussing the sampling method, procedures, interview guide, the process of interviewing and coding scheme within the research group. The consolidated criteria for reporting qualitative research (COREQ) were used to report the study[21].

Ethical issues

A review committee decided that the study lies outside the scope of the Medical Research Involving Human subjects Act[22]. However, the study was executed according to the principles of the Declaration of Helsinki[23] and the Guidelines of Good Clinical Practice[24]. The hospice formally agreed to participate. The handling of the data complied with the Dutch Personal Data Protection Act[25].

Results

Of the 20 eligible loved ones 14 were interviewed (table 1). Four loved ones did not want to participate and two could not be interviewed because the patient passed away before the interview took place. In two interviews, two loved ones were present at once which means in total 12 interviews were conducted. Most interviews were conducted in the hospice, one interview at the loved ones' home and one interview at the place of work of a loved one. The mean age of the loved ones was 55.9 years and 64.3% was female. Most loved ones were not religious and of Dutch origin. Most loved ones were daughter, son or spouse of the patient and did not participate in the daily care of the patient. In total, 42.9% had contact with the patient several times a week and all patients were admitted for a last resort admission. The interviews had an average duration of 43 minutes (range 25-60 minutes). No demographic data was collected concerning the patients, however in the interviews it emerged that they were mainly >65 years. After ten interviews code saturation was reached[26] (figure 1) and the coding scheme was fixed (table 2). Two more interviews were conducted to confirm code saturation.

{Table 1}

{Figure 1}

The findings concerning the presence, severity, cause, expression, impact, and needs concerning anxiety in patients with advanced cancer, from the perspective of their loved ones, are presented below.

Presence and severity

Almost all loved ones indicated that anxiety was daily present in patients, however not predominantly. Several loved ones indicated that anxiety was more present and severe at the time of diagnosis and treatment and was less present in this last phase of life. Some stated that patients had resigned in their fate and as a result, were less anxious. They were asked about the severity of anxiety in the patient, by using a 0-10 numeric rating scale. The mean anxiety score according to the loved ones was 5.8 (range 3-8). Several loved ones thought that anxiety was more severe, than the patient was showing them. They believed that the patient did not burden them in order to protect them.

> She does not want it to be clearly present to 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 years)

Box 1

Cause

Several causes of anxiety were identified by the loved ones of patients with advanced cancer. First, anxiety of deterioration was frequently named. Patients were anxious of physical deterioration in general or of specific effects of deterioration such as choking or mental deterioration as to be not clear of mind or not being able to say goodbye consciously. According to loved ones, these anxieties were often caused by negative experiences in the past.

Second, anxiety of the unknown and the process of dying was frequently present. Patients wondered what was waiting for them and how they were going to die. In contrast, death anxiety was present in only a few patients. Third, patients were feeling anxious before end-of-life discussions or for the reactions of their family about these discussions. Fourth, patients were anxious of letting go of loved ones and did not want to leave them with grief. Fifth, anxiety of losing control over their body, mind, and life was also noted by some loved ones. Having control was also noted as an important need and expression.

Further, losing autonomy and dignity were discussed by the loved ones, however not literally referred to as anxiety. They stated that patients found it very difficult and unpleasant to lose control over their body and mind, to be dependent of others and their dignity being affected by the disease. One patient was afraid the person behind the patient and wound would be forgotten. Though, they did not have a choice, accepted their fate and their boundaries

shifted as the disease progressed. Finally, loved ones noted anxieties in earlier stages of the disease. Namely, some patients were anxious of diagnostic tests, getting the diagnosis and subsequent treatment.

Expression

Most loved ones identified anxiety in patients via verbal expressions. They heard literal statements regarding anxiety or deduced it from the words of the patient. Also, patients worried about the disease and anxieties concerning the consequences of the disease, especially at dark and lonely moments. Further, loved ones saw anxiety in emotions such as crying, being irritated or insecure and noted that anxiety was often visible by facial expressions such as a worrying or rigid expression.

Restlessness was another identified expression of anxiety in patients with advanced cancer and was recognized in patients because of tension, eyes shooting back and forth, and sometimes moments of panic. Loved ones also identified hostile, avoiding, and withdrawing behaviour as an expressions of anxiety by the patient being absent of mind, acting harsh towards others, and not want to talk about the disease and anxieties resulting from the disease. Another expressions were small gestures such as twisting the ring on a finger or a hand on the forehead. Clinging to people, objects, and past events was also identified as an expression of anxiety. For example: calling the nurse as much as possible, clinging to objects that did not have emotional value in the past, and verbally repeating memories from the past. As mentioned above, keeping control in an extreme way was another expression of anxiety in patients, such as keeping control over their medication and determining who can visit and at what time.

> She really likes to plan and control everything and by demarcating things so clearly I think she can keep anxiety out. (Loved one 8, daughter, aged 33 years)

Box 2

Impact

Loved ones stated that anxiety has impact on all dimensions of existence of patients. Physical impact such as sleeping problems was mentioned frequently. They named psychological impact such as insecurity and existential impact such as anxiety controlling the thoughts of the patient. Patients decreased the impact of anxiety by keeping control and continuing daily life as much as possible. Loved ones did not discuss the impact of anxiety on the social dimension. However, as mentioned above, they did discuss withdrawing and hostile behaviour of the patient as an expression of anxiety. Therefore, this could have had impact on the communication and the relationship between patients and their loved ones.

Loved ones mentioned that the anxiety of the patient had impact on their own life. They found it hard to see the patient anxious or felt powerless because they could not take the feelings of anxiety away. Loved ones were sometimes claimed and thence their own lives were put on hold. Logically, the impact of anxiety in patients on their loved ones was dependent of the presence and severity of anxiety in the patient.

> Yeah, well you try to do your best, but you cannot always take that tension away and I find it hard when she is so tense. When I go home and the tension stays, that is not a pleasant feeling. (Loved ones 2, daughter, aged 50 years)

Box 3

Needs

Several needs of patients regarding anxiety management were identified. First, distraction such as watching TV and relaxation such as massage were important needs. Second, talk about anxiety was another important need. Several loved ones pointed out that healthcare professionals had to initiate conversations actively, because the patient did not ask for it themselves. In addition, loved ones commented that it is important to be honest about the patients' situation while conversing. However, it depends on the patient how much detail should be discussed. Third, loved ones claimed that expertise of healthcare professionals in general was an important need, such as being familiar with the personal care plan and providing adequate information. Providing information and saying comforting words also reassured patients. Fourth, the presence of people was very important such as visits of loved ones. Sixth, a safe environment was an important need and was created by continuing daily life as much as possible and the availability of healthcare professionals at all times. Seventh, loved ones discussed the importance of meeting the needs and wishes of patients and thereby customizing care to their specific needs. As mentioned above, keeping control over their daily life, body, and mind was another important need.

> It must be a very safe environment if you want to deal with that anxiety. (Loved one 11, brother, aged 73 years)

Box 4

Character

Loved ones discussed the patients' character in relation to their coping with anxiety and the disease in general. Some patients had always had a positive attitude and this helped them in coping with anxiety. Others had always been reserved and awaiting and this behaviour

continued in their way of coping with anxiety. In addition, loved ones indicated that the needs regarding anxiety management dependents on the character of the patient. For example, a highly educated, strong opinionated patient would like to have detailed information and needed to be convinced of the necessity of medication. Some loved ones stated that the age and generation of the patient influenced their expression of and coping with anxiety. They indicated that older patients were poorly practiced in talking about emotions and avoided extreme expressions of anxiety and thence anxiety was hard to recognize in these patients.

Physical and mental state

Loved ones indicated that the physical and mental state of the patient influenced anxiety in positive and negative ways. A deteriorating physical state caused or increased anxiety, however a deteriorating mental state could have both a negative and positive influence on anxiety. For example, one patient was probably less anxious due to brain metastases which caused flattening of emotions and a more resigned state. On the other hand, another patients' anxiety increased because of feeling drowsy after medication. Further, being clear of mind sometimes calmed patients down although in some cases it increased worrying and thereby anxiety.

Surroundings

Loved ones mentioned the influence of the surroundings of the hospice on anxiety in the patient. On the one hand, the green and friendly surroundings decreases anxiety. Additionally, the pleasant and homely atmosphere and the company of other patients contributed to a decrease of anxiety. On the other hand, some loved ones indicated that being confronted with the death of other patients increased anxiety.

{Table 2}

Discussion

The aim of this qualitative study was to explore the experiences and views of loved ones concerning the presence, severity, cause, expression, and impact of anxiety in patients with advanced cancer and their possible needs regarding anxiety management. To the best of our knowledge, this is the first prospective study to explore anxiety in patients admitted to a hospice, from the perspective of their loved ones. They described a diversity of causes and expressions of anxiety in patients and formulated needs, regarding anxiety management, for the patients. Loved ones estimated the patients' anxiety as moderate to severe and identified a negative impact on physical, psychological, social, and existential dimensions for the patients as well as for the love ones themselves.

The findings regarding expressions, causes, presence, and needs are largely in line with previous research[5,6,10,27] and expert opinions[3,7]. For example, two studies among patients and bereaved loved ones found that patients may conceal their feelings so as not to upset or burden their loved ones[10,27]. Further, Zweers et al. also found the character of the patient and surroundings to be influencing factors regarding anxiety[27].

However, there are some discrepancies with existing literature. For example, Parkes describes anxiety of separation from loved ones, homes, and jobs as the number one anxiety in hospice inpatients[7]. Only four out of 12 loved ones in our study mentioned this anxiety whereas anxiety of deterioration or the unknown were mentioned by seven or eight loved ones. An explanation could be that it is too confronting for loved ones to discuss or think about this since they are part of the concerns. This could be a way of self-protection on the one hand by the loved ones themselves or on the other hand by the patient by not discussing this anxieties with their loved ones. Furthermore, some physical expressions of anxiety such as pain and palpitations, which were identified by patients themselves[27], were not identified by loved ones in our study. Probably because these expressions are not recognized as expressions of anxiety.

Loved ones in the current study identified several causes, expressions, and needs regarding anxiety as small gestures and hostile behaviour in patients that were also found in a study among bereaved loved ones[10]. However, this was not found in studies from other perspectives[3,5–7,27]. This suggests that loved ones have a unique perspective on anxiety in advanced cancer patients. Foreknowledge concerning the patients' character, coping strategies, and possibly negative experiences in the past seems to be helpful in identifying anxiety[10]. A prerequisite of having this foreknowledge is a close relationship and intensive involvement of the loved one during the disease process.

> I am a loved one who […] has been involved very intensively […]. So I can put it in the context of the whole disease process and therefore I can give these answers, but maybe not all loved ones have had or did this. So it is very subjective of who it is, who gives those answers. (Loved one 14, partner, aged 66 years)

Box 5

Our study adds to current knowledge that patients' anxiety has a psychological impact on the loved ones and impacts their daily life. Some loved ones mentioned feeling powerless regarding the patients' anxiety. This is in line with previous research that showed loved ones sometimes have difficulty with dealing with the patients' anxiety or to support and reassure the patient[28,29]. Previous research indicated that loved ones are in the unique position of both providing and needing support[30].

The results of our study seem to point out three important concepts that overarch the data; protection, control, and safety. These three concepts appear to be related to each other and influenced our findings. Protection was presented before in the context of protection of the loved one by the patient and possible self-protection by the loved ones and patients. The hostile, withdrawing, and avoiding behaviour of patients with anxiety can also be seen as a form of self-protection or coping strategy, as discussed by Traeger et al. in a fear-avoidance cycle[5]. Protection could have influenced the perception of loved ones concerning anxiety in patients. However, previous research noted that loved ones bear this in mind and use their foreknowledge to judge anxiety in patients[10]. Protection enables control which showed to be an important aspect in several aspects of the study subject (cause, expression, need). Subsequent, control enables safety which emerged as an important need and condition in the study. Protection, control, and safety could be mechanisms to maintain patients' capacity. This finding is promising, however more research is necessary to draw conclusions.

There were certain recognised strengths which will now be detailed. First, the results of this study are valid for the loved ones that participated, however the results may be generalizable for similar populations. For the patients that were discussed by their loved ones during the interviews, were mainly >65 years and the mean age of hospice care patients in the Netherlands is 74 years[31]. Second, code saturation was reached, meaning a first exploration of the subject could be made. Third, the credibility of the study was enhanced by applying researcher triangulation during data analysis and by applying peer debriefing and expert opinion within the research group. Fourth, the reliability was enhanced by recording and transcribing the interviews verbatim and by keeping an audit trail. Fifth, to increase the dependability of the data analysis, the analysis procedure was structured and the data management system NVivo (Version 11, QSR International) was used. Sixth, a fixed interview guide was used and test interviews were performed to enhance the trustworthiness of the study.

A limitation of the study was that the study sample was limited for achieving meaning saturation. Because of the lack of meaning saturation, it is unknown if there are more dimensions present within the themes that were found.

In conclusion, this study highlights the importance of the perspective of loved ones in the recognition and support regarding anxiety in patients with advanced cancer, admitted to the hospice. Therefore, loved ones should be more involved in the care for patients with anxiety, provided there is a supportive relationship. Although loved ones can add valuable information, the perspective of the patient is the golden standard and should always be involved in the management regarding anxiety, if possible.

The findings in this study can contribute to the development of interventions regarding anxiety in patients with advanced cancer. 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 development of targeted and tailored interventions to support patients and their loved ones regarding anxiety experienced by the patient. In addition, future research concerning patients with advanced cancer should involve loved ones because of their unique and valuable perspective on the patient and their important role in this last period of life. Finally, future research should focus on the exploration of the interaction and meaning of the concepts protection, control, and safety in patients with advanced cancer.

This study underscores the importance of involving loved ones in the care for anxious patients with advanced cancer, in order to improve or maintain the quality of their remaining life.

References

1. Teunissen SCCM, Wesker W, Kruitwagen C, de Haes HCJM, Voest EE, de Graeff A. Symptom Prevalence in Patients with Incurable Cancer: A Systematic Review. J Pain Symptom Manage. 2007;34(1):94–104.
2. Carpenito-Moyet L. Nursing Diagnosis: Application to Clinical Practice. 12th revis. Pennsylvania, PA: Lippincott Williams and Wilkins; 2007.
3. Vos M, Seerden P. Richtlijn Angst (Guideline anxiety). In: Palliatieve zorg: Richtlijnen voor de praktijk (Palliative care: Guidelines for daily practice). Vereniging van Integrale Kankercentra. Utrecht; 2010. p. 47–60.
4. Stiefel F, Razavi D. Common psychiatric disorders in cancer patients. II. Anxiety and acute confusional states. Support Care Cancer. 1994;2(4):233–7.
5. Traeger L, Greer JA, Fernandez-Robles C, Temel JS, Pirl WF. Evidence-based treatment of anxiety in patients with cancer. J Clin Oncol. 2012;30(11):1197–205.
6. Roth AJ, Massie MJ. Anxiety and its management in advanced cancer. Curr Opin Support Palliat Care. 2007;1(1):50–6.
7. Parkes C. Coping with loss: The dying adult. Br Med J. 1998;316(7140):1313–5.
8. Brown LF, Kroenke K, Theobald DE, Wu J, Tu W. The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain. Psychooncology. 2010;19(7):734–41.
9. Bužgová R, Jarošová D, Hajnová E. Assessing anxiety and depression with respect to the quality of life in cancer inpatients receiving palliative care. Eur J Oncol Nurs. 2015;19(6):667–72.
10. McPherson CJ, Addington-Hall JM. Evaluating palliative care: Bereaved family members' evaluations of patients' pain, anxiety and depression. J Pain Symptom Manage. 2004;28(2):104–14.
11. Grbich C, Parker D, Maddocks I. The emotions and coping strategies of caregivers of family members with a terminal cancer. J Palliat Care. 2001;17(1):30–6.
12. Mok E, Chan F, Chan V, Yeung E. Family experience caring for terminally ill patients with cancer in Hong Kong. Cancer Nurs. 2003;26(4):267–75.
13. Lopez V, Copp G, Molassiotis A. Male Caregivers of Patients With Breast and Gynecologic Cancer. Cancer Nurs. 2012;35(6):402–10.
14. Han J, Han S, Lee M, Kwon H, Choe K. Primary Caregivers' Support for Female Family Members With Breast or Gynecologic Cancer. Cancer Nurs. 2016;39(3):E49–55.
15. Holloway I, Galvin K. Qualitative research in nursing and healthcare. John Wiley & Sons;
16. Benkel I, Wijk H, Molander U. Challenging conversations with terminally ill patients and their loved ones: Strategies to improve giving information in palliative care. SAGE Open Med. 2014;2:2050312114532456.
17. Hinton J. How reliable are relatives' retrospective reports of terminal illness? Patients' and relatives' accounts compared. Soc Sci Med. 1996;43(8):1229–36.
18. Higginson I, Priest P, McCarthy M. Are bereaved family members a valid proxy for a

patient’s assessment of dying? Soc Sci Med. 1994;38(4):553–7.

19. Zweers D, de Graaf E, Teunissen S. Suitable support for anxious hospice patients: What do nurses “know”, “do” and “need”? An explanatory mixed method study. Submitted to BMJ Support Palliat Care.

20. Boeije H. Analysis in qualitative research. 2nd ed. London: SAGE Publications Ltd.; 2010. 240 p.

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32- item checklist for interviews and focus group. Int J Qual Heal Care. 2007;19(6):349–57.

22. Wet medisch-wetenschappelijk onderzoek met mensen [statute on the Internet]. 1998 [cited 2016 Dec 12]. Available from: http://wetten.overheid.nl/BWBR0009408/2016-08-01

23. World Medical Association. WMA Declaration of Helsinki - Ethical principles for medical research involving human subjects. Bull World Health Organ. 2001;79(4):373.

24. International Conference on Harmonisation Working Group. ICH harmonised tripartite guideline: guideline for good clinical practice E6 (R1). In International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use 1996 Jun 10 (Vol. 10).

25. Wet Bescherming Persoonsgegevens [statute on the Internet]. Netherlands; 2000 [cited 2016 Dec 23]. Available from: http://wetten.overheid.nl/BWBR0011468/2016-01-01

26. Hennink MM, Kaiser BN, Marconi VC. Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? Qual Health Res. 2017;27(4):591–608.

27. Zweers D, Kant R, Vrehen H, Gamel C, Teunissen SCCM. Betekenis van het symptoom “angst” voor patienten met kanker in de palliatieve fase. Ned Tijdschr voor Palliat Zorg. 2011;11(2):38–51.

28. Sabo D. Men, death anxiety, and denial: Critical feminist interpretations of adjustment to mastectomy. In: Clinical sociological perspectives on illness and loss. Philadelphia: Charles Press; 1990. p. 71–84.

29. Hawes SM, Malcarne VL, Ko CM, Sadler GR, Banthia R, Sherman SA, et al. Identifying Problems Faced by Spouses and Partners of Patients With Prostate Cancer. Oncol Nurs Forum. 2006;33(4):807–14.

30. Northouse LL, Peters-Golden H. Cancer and the family: Strategies to assist spouses. Semin Oncol Nurs. 1993;9(2):74–82. WB Saunders.

31. Graaf E de, Zweers D, Graeff A de, Daggelders G, Teunissen S. Does Age Influence Symptom Prevalence and Intensity in Hospice Patients, or Not? A Retrospective Cohort Study. J Geriatr Palliat Care. 2014;1(S):7.

Tables

Table 1. Socio-demographic data of the loved ones

Loved ones who participated in the study N = 14		
Age (years)	Mean Range SD	55,9 33-73 11,4
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)
Participate in daily care or not (at the moment of interview) N(%)	Yes No	4 (28,6) 10 (71,4)
Intensity of participation in daily care, if applicable N(%)	Multiple times a day Daily Several times a week Weekly	3 (75) 0 (0) 1 (25) 0 (0)
Frequency of contact with patient N(%)	Several times a day Daily Several times a week Weekly	5 (35,7) 3 (21,4) 6 (42,9) 0 (0)
Living with patient or not before admission N(%)	Yes No	3 (21,4) 11 (78,6)
Reason of admission of patient (at the moment of interview) N(%)	Last resort Respite	14 (100) 0 (0)

Table 2. Coding scheme

Themes	Codes
Presence and Severity	• Frequency • Frequency decreases • No anxiety • More anxiety during treatment phase • Intensity • Anxiety does not dominate • More anxiety present than shown • Protection of loved one by patient Influencing factors: • Distraction by writing a book • Overwhelmed at admission • Anxiety not applicable now • Previous experiences • Physical condition • Mental condition • Religion • Character and attitude towards disease • Moment of the day • Presence of people • Setting/surroundings • Calmness because of contemplated scenario's • Confidence • Calmness because of care plan
Cause	• Anxiety of being alone • Anxiety of having to leave the hospice • Anxiety of deterioration • Anxiety of the unknown • Anxiety of euthanasia • Anxiety of letting go • Anxiety of losing autonomy • Anxiety of losing dignity • Anxiety of diagnostics and treatment • Anxiety of losing control • Anxiety of loved ones becoming ill • Death anxiety • No anxiety • Reflected anxiety
Expression	• No expression of anxiety • Emotions • Restlessness • Worrying • Keeping control • Small gestures • Clinging behaviour • Verbal expression • Withdrawing and avoidance behaviour • Hostile behaviour
Impact	Impact anxiety on patient: • No or minimal impact • Moderate to severe impact Impact anxiety in patient on loved one: • No or minimal impact

	• Moderate to severe impact • Influence of previous loss experience
Needs	• Control • Expertise • Having a talk • Presence of people • Distraction and relaxation • Secure environment • Customized care

Figures

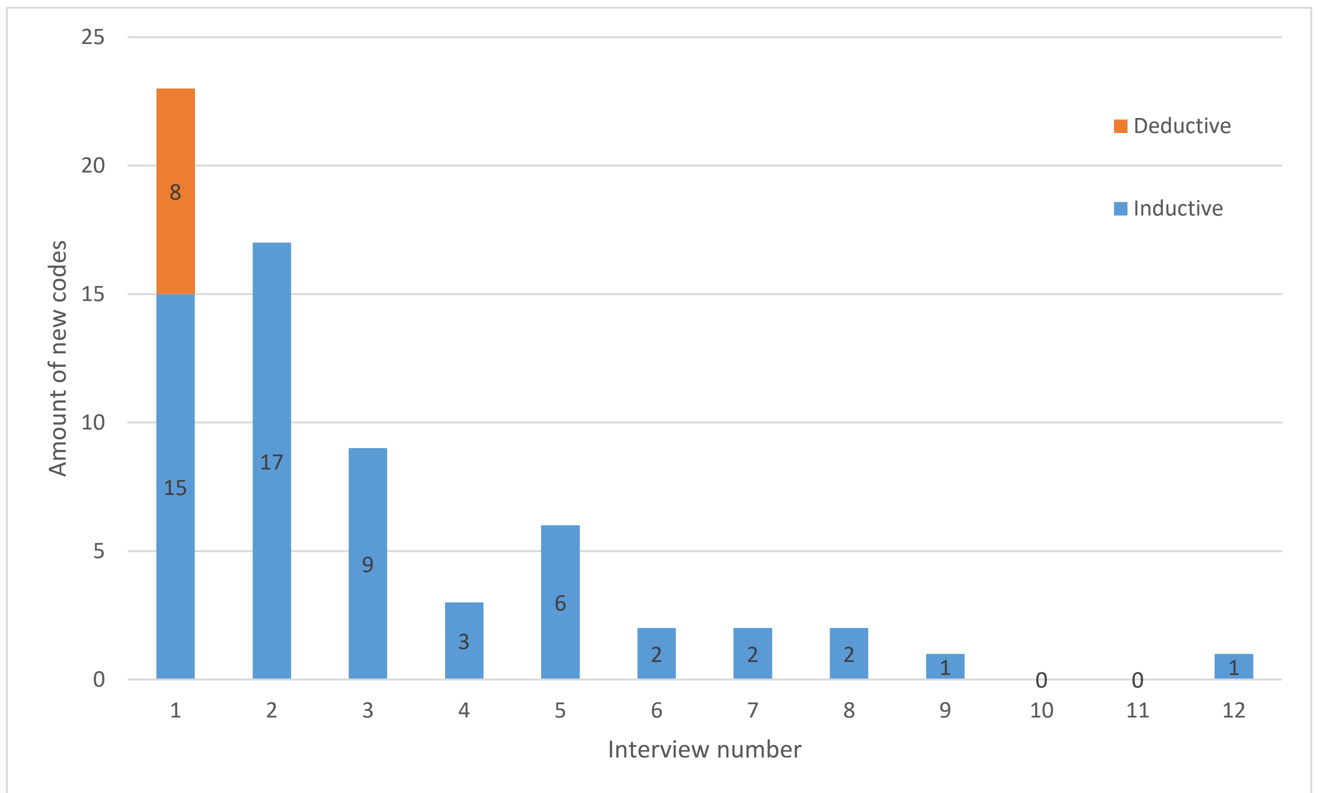

Figure 1. Timing of code development

Appendices

Appendix A. Final Interview Guide

Topic	**Questions**
Introductory sentence and question	Anxiety is common in patients with an incurable disease, however not always recognized, talked about or acted upon. To make sure we're on the same page about the concept of anxiety, what do you see as anxiety? *(think about the words: fear, anxiety, tension, insecure, afraid, worrying, nervous, panic, cramped)*
Presence	**Can you tell me if you ever experience or experienced anxiety in your loved one?**
Causes	**What do you think is the cause or root of the anxiety your loved one experiences?** *What is the underlying cause?* *No fear of death? Was it present before? Why not? What changed?* *Does religion play a part?* *Anxiety of the way of dying? What is he scared of exactly?* *No anxieties present? Anxieties in the present? 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)*
Expression	**How do you know/feel that your loved one 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 make 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, ain, crying, feeling sad)*
Severity	**How frequent do you experience anxiety in your loved one?** **To what extent do you think your loved one is feeling anxious?** *(per day/week, continuously or ups en downs)* **Hoe severe/intense would you describe the anxiety in your loved one?** *Mild-moderate-severe / 1-10* *Why do you choose that? Based on what?*
Influencing factors	**What are factors that influence the anxiety in your loved one?**

	(Think about: place of stay, who, time in the 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 your loved ones?** *On social level, psychological level, existential/spiritual level, physical functioning, on daily life?* **What consequences does the anxiety of your loved one have for you as loved one?** *On social level, psychological level, existential/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 previously find it harder to see his anxiety? What changed?*
Needs	**What do you think your loved one 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 your loved one do/tried anything to reduce anxiety? What helped and what didn't?** **What did your loved one greatly appreciate about preventing/reducing/ stabilizing anxiety? Do's** *(examples?)* **What should not be done to prevent/reduce/stabilize anxiety in your loved one? Don'ts** *(examples?)* **What do you think that can nurses do to prevent/reduce/stabilize anxiety in your loved one?**
Conclusion	**Reflection on the interview** **Express appreciation and hand over small gift**
Filed notes	*Make notes directly after the interview took place (atmosphere, how was the interview, what was my role, surroundings, striking stings etc.)*