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**Complex challenges for patients with protracted incurable cancer:
An ethnographic study in a comprehensive cancer centre**

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3 **Complex challenges for patients with protracted incurable cancer:**
4 **An ethnographic study in a comprehensive cancer centre**
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ABSTRACT

Objective

Advances in oncology increasingly result in protracted disease-trajectories for patients with incurable cancer. In this disease-phase, patients are aware that cancer is incurable but do not approach the last phase of life. We aimed to explore challenges of patients confronted with protracted incurable cancer.

Design

Ethnographic study (2015-2017) based on patient-conversations, observations at the day-care unit and a selection of medical-record information of patients who died during the study-period.

Setting

The day-care unit of a comprehensive cancer-centre in the Netherlands.

Participants

Nineteen patients with stage 4 breast-cancer (in remission \geq year after diagnosis) and 11 patients with stage 4 lung-cancer (in remission \geq 6 months after diagnosis).

Results

In patients who had died during the study-period, response to treatment often fluctuated between stable, remission and progression throughout the disease-course. Patients reported that distress of facing death (progression) and surviving (remission) different times was sometimes overwhelming. As patients grew accustomed in having long-lasting incurable cancer, associated distress that scan-results would indicate disease-progression, however slowly faded. Patients reported starting to regard cancer as part of who they were. At the day-care unit, most patients talked about their disease in an optimistic or neutral way and expressed delight-in-life. They were grateful that extra lifetime was given, expressed hope and tried to look at the bright-side of life. This was frequently enforced by optimistic doctors and nurses. Relatives, however, could downplay such optimism. Moreover, some patients acknowledged that hope was adjusted to their personal disease-challenges.

Conclusions

In situations where tumours remained in remission/stabile for extended periods, patients grew accustomed to having incurable cancer and learned more about disease-responses. At the day-care unit, medical professionals typically strengthen an attitude of being hopeful/optimistic, which could be downplayed by relatives. More research is warranted to explore this new disease-phase and this optimistic view of healthcare-professionals.

Strengths and limitations of the study

- This is the first study that qualitatively explores the impact of living with protracted incurable cancer.
- This study covered a long time-period (2015-2017) to be able to show that patient's condition indeed fluctuates over time.
- This study combined observations, short conversations with patients (and relatives), and medical record data to increase insight and context.
- A limitation of the study is that the duration of the conversations could be short and that results may be different in other (non-specialised) cancer hospitals. However, we wanted to focus on one specific disease phase that occurs very much in specialised cancer centres
- The average age of the patients was quite high and there were relatively little men, and those experiences probably differ from men.

Keywords: chronic cancer, doctor-patient communication, medical ethics, sociology, survivorship care, palliative care

INTRODUCTION

Advances in oncology have resulted in protracted disease trajectories in incurable cancer patients.⁴ Accordingly, it is sometimes argued that some forms of cancer seem to evolve in a chronic disease.⁵⁻⁷ Surprisingly, little information about the experiences of long-lasting incurable cancer are yet available.⁸ Studies focusing on the last phase of life may be assistant to achieve some ideas.⁹⁻¹⁰ Intense fear about death, fatigue, uncertainty about prognosis, and hope for recovery have been shown to be rather important.¹⁻³ Plausibly, equal topics may be applicable for patients with protracted incurable cancer. Whether and to what extent is not clear yet.

Little has been written in how these protracted disease trajectories are challenging the ability of patients to cope with the disease. In contrast, much has been written about these novel cancer therapeutics itself.¹¹⁻¹³ These prolonged trajectories were already observed in breast cancer patients, but are recently reported in subtypes of incurable lung cancer as well. An interesting finding is a study that reports that nivolumab, also in actual medical practice, shows efficacy and tolerability.¹⁴ For breast cancer patients, similar results are reported.¹⁵ In the individual (lucky) cases survival rates may be extended to more than 1-2 years. During the last couple of years new mutations have been discovered in patients with lung cancer (epidermal growth factor receptor (EGFR) mutations, BGFR mutations), breast cancer (BRCA1, BRCA2, HER2) and several other cancers, resulting in the development of new genotype-directed therapy throughout the patient's disease course. This changing landscape in treatment options will obviously evoke new (ethical) dilemmas for patients as well as healthcare professionals.

Our project started from the observation that patients living with protracted incurable cancer are inadvertently overlooked. In this specific study, we spoke with patients (and their close relatives) at the day-care unit and focused on the challenges patients are confronted with in this specific disease phase.

METHODS

Design and Setting

This study is part of a larger project that examines the experiences, needs and wishes of patients and healthcare professionals with protracted incurable cancer using a mixed methods ethnographic design. For this study, a qualitative database was used in which experiences, needs and wishes of patients with prolonged incurable cancer were collected. As of 2015, this information was gathered. All necessary items to ensure adequate qualitative research were checked with the COREQ-checklist.¹⁶

We purposefully chose this design to ensure that the results will eventually be practice driven and closely connect with medical practice.¹⁷ A specific strength of ethnography lies in its ability to communicate details plotted in experiences of illness and care.¹⁸ In the present study, we combined participant observation with (informal) conversations to build in-depth understanding about the practice of incurable cancer (explicitly and implicitly) and in how healthcare professionals and patients experience long-standing incurable cancer within the context of daily medical practice. Since this is a relatively new area to do research on, we established a definitional framework beforehand (see **Table 1**).

Recruitment & Sampling

All conversations took place at the day-care unit of a comprehensive cancer centre in the Netherlands. Such conversations were considered least disturbing for the patient (they were already there), and they were less likely to be affected by any specific event, such as receiving good/bad news after having had a consultation with their treating doctor. In the period July-October 2015, and July-September 2016, 30 patients were approached at the day-care unit by HMB, a female researcher in social sciences, with many years of interview experience. Throughout the year 2016/2017, HMB talked with 12 other patients, which were recorded in field-notes only. All patients were approached at times HMB was at the hospital and had time to talk to them. Patient-selection was therefore random. All patients were given an information sheet about the study, including background information of the researcher who carried out the interviews. Before approaching a patient, HMB checked with the nurses at the day-care unit whether it would be appropriate to do so. If nurses considered patients to be upset or not capable of having a conversation for some other reason, HMB did not approach these patients. In 3 situations, the nurses advised not to approach patients because they just had received bad news. With respect to all patients, HMB had not seen the patients before the start of the conversations at the day-care unit. Only lung cancer patients who had been diagnosed with stage 4 disease at least 6 months ago, and breast cancer patients who had been diagnosed with stage 4 disease at least 1 year ago had been selected.

The median length of the audio-recorded conversations at the day-care unit was 10 minutes (see **Table 2**). Conversations ended due to circumstances (such as the end of the chemotherapy regimen); because patients simply wanted to stop talking; or because they had nothing more to say. Patients received a short information letter with contact details about the study. None of the patients rejected to participate. In 8 cases, a close relative (often the partner) of the patient was present as well.

Table 2

	<i>n</i> patients	Mean time length (SD)	Median time length	Minimum	Maximum
Short conversations ¹	30	13 (9)	10	2	39

1. Short conversations were held at the day-care unit, while patients received their chemotherapy regimen. Conversations that were held during the observation days (n=12) are not included, and transcribed in fieldnotes only.

Short conversations and observations- Approach

Short conversations were openly framed. We purposefully chose to not use a large topic list and openly asked how patients felt while living with protracted incurable cancer. Often, the conversation started with their disease history, and about possible unmet needs. When the study progressed, we more specifically asked about patients' quality of life. We did not touch upon specific topics, such as positivity and fear, and only focused on such items if brought-up by the patient him- or herself.

Besides, many hours of participant observations had been done; combining conversations with (participant) observation is in accordance with common ethnographic research.¹⁸ At the day-care unit, HMB sat by, observed and sometimes accompanied nurses at the day-care unit. Apart from the research questions of the main study, HMB focused on the following topics during the observations: the atmosphere, emotions, mood (patient/personal reflections), language use, interaction between patients and healthcare professionals; and answers associated with the research questions. During observation-days (n=21), small conversations with patients (n=12) were not audio-recorded, but transcribed verbatim later-on, including observational field-notes. We continued

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3 conversations with patients until data-saturation with respect to the research question of this specific study was
4 reached. In some situations, we asked patients whether they were willing to continue in another interview. These
5 interviews are however not included in this study.

6 For 30 patients, the conversations were audio-recorded and transcribed verbatim (see **Table 2**). The transcripts
7 were not returned to the participants for comments. To distinguish in the text between different types of data
8 collection and technique, the following agreements were used: all data collected by observation are described in
9 the text in *italics*; all data collected by audio-recorded observations are described in the text in quotation marks,
10 also in *italics*.

11 **Medical record - Approach**

12 Of the included patients of whom their conversation was audio-recorded (n=30), and had died (n=12) by the end
13 of 2016, we collected additional medical record data. We recorded the disease status (e.g. stable, remission and
14 progression) during every consult with the treating doctor and depicted these data over time in figures for every
15 single patient (see **Figure 1**). Disease status was obtained from doctors' notes of the consults. Their conclusion
16 about disease status was mostly based on comparison of tumour markers and/or radiological findings to those in
17 the prior visit.

18 **Data Analysis**

19 All conversations/observations were coded and analysed using the programme Atlas-ti 8.2. We (MACA and HMB)
20 read apart through twelve conversations at different time intervals to seek for themes. These themes were
21 discussed to check for interpreter consensus. Subsequently, a scheme was developed to index text fragments
22 with similar content (in Atlas-ti 8.2). By analysing the themes, hypotheses emerged and were checked with the
23 data.

24 MACA subsequently developed a tabular grid to organize interview information from every individual patient about
25 the following themes: support from the patient's surroundings, physical complaints, uncertainty, an indication of
26 prognosis, how the patient seemed to deal with the last phase of life, daily life, and some space for remarkable
27 things in either content or language use. Besides, descriptive information was added to the table about date and
28 duration of the interview, gender, age, type of cancer, location of the interview and the attendees. Other members
29 of the team (OD, JAS, GSS) participated in the analysis by commenting on previous versions of the result-section.

30 A professional translator translated the quotes that we chose to illustrate our results. All authors evaluated
31 whether the final quotes were used in the right (medical) context. According to Dutch policy, the study did not
32 require a formal review by an ethics committee because the content of the interviews / observations was not
33 considered to be possibly incriminating. We however requested the committee of our medical ethical committee to
34 provide us with a declaration of no objection (In Dutch: Verklaring van geen bezwaar) to declare that our medical
35 ethical committee had seen the study and provided 'local approval' to carry out the study. Before starting a
36 conversation we provided the patient with information and asked them to audio-record this conversation to be
37 able to use unanimous quotes in the final manuscripts. We sent a lay version to the participants who were still
38 alive; the participants could contact the researcher to comment on/ask for clarification.

Table 1 / Appendix. Definitional framework**THE DISEASE**
Disease phasesChronic disease /
Chronic cancer

According to the Royal Dutch Institute of Public Health (In Dutch: RIVM), a chronic disease is a disease with irreversible prospects and with a relatively long disease course. Furthermore, a chronic disease is different from other diseases in that these patients are care-dependent for a very long time.¹⁹ Cancer is categorized as a chronic disease also.

In medical oncology, it is heavily debated as to whether cancer should be viewed as a chronic disease or not, while healthcare professionals do not want to provide unrealistic prognoses. This also holds for patients with protracted incurable cancer.

Protracted incurable cancer

We define protracted incurable cancer as a disease phase where patients receive anti-cancer treatment such as immune-therapy, hormonal treatment, or chemotherapy and in which this disease phase can be considered stable / in remission for long-standing time-periods.

During this time-period, the patient's physical condition may sometimes go up-and-down, due to treatment side-effects. In other words: although response to treatment/the patient's condition can be considered stable/in remission for long-standing time-periods, periods of progression also occur.

THE PATIENT

States of being associated with living with cancer

Deliberate optimism

Optimism is all about anticipating a positive future. To be optimistic means that we expect things to go our way.²⁰ Optimists are aware that positive outcomes are dependent on their own efforts.

It however should be noted that optimism is partly inherited, and these specific patients also more easily choose to be optimistic (e.g. deliberate optimism).

Hope

As opposed to optimism, hope generally focuses on a specific goal, such as hope for a longer life.²¹ It contrasts with hopelessness/powerlessness, and is much more about how you feel. It is however also argued that emotions go beyond the mere 'feeling' of that emotion; emotions are a way in which we interact with the world, and accordingly, hope is sometimes defined as an emotional attitude.²²

Fear

Research about cancer patient's fear is extensive. In the context of protracted incurable cancer fear of cancer recurrence (FCR) is commonly studied.²³ It is often characterized with chronic worry, excessive body checks and difficulties to make future plans.

Uncertainty

Research about uncertainty is extensive also.²⁴ In essence, uncertainty comprises the inability to attribute meaning to events.

Note:

We do not intend to explore a specific concept but want to conceptualize some definitions that often came up during conversations about these topics.

RESULTS

Quantitative findings

Of all patients, 24 were women (80%) and 6 were men (20%). In this specific study sample, 19 patients experienced some form of breast cancer (63%) and 11 patients experienced some form of lung cancer (37%). The disease trajectory of patients who died during the study period is depicted in **Figure 1**. For every patient, response to treatment often fluctuated from stable towards either remission or progression. The disease period of patients in this specific hospital varied from approximately 30 - 130 weeks.

Figure 1. Patient's response to treatment as described in their medical status during the consultations with the treating doctor. Every figure depicts 1 patient who died during the study period (n=12).

Qualitative findings

During the conversations that we held with patients at the day-care unit, three different themes immediately came up: their uncertainty about prognosis in this protracted disease trajectory, their intention to stay hopeful and the influence of others to stay hopeful and to find a new balance.

On-and-on: Facing death versus survive

Patients' and relatives' uncertainty seemed to be the overarching theme in the majority of the conversations that we held with patients at the day-care unit. The unpredictability of an effective treatment response seemed to interfere with patients' ability to attribute meaning to activities, and accordingly certainty. This was expressed either explicitly or implicitly but always depicted 2 sides of a medallion, e.g. patients seemed to be hopeful and fearful at the same time. Being aware of the incurable nature of their disease also depicted those two sides of the medallion.

R2: Sure, I think you've touched on a key aspect there [...] there is no path to full recovery, at least that's what they actually said at a certain point. [...]

R: Personally, I call it bad and stable.

I: Right.

R: Yes, stable, but we know that it's no longer 100% curable... but it could take a very long time yet.

I: Right, it could be stable for a very long time.

R2: Yeah, and then I reckon the aim is to just take the right approach to let you do as many things as possible that you want to do.

Patient 16, 2016 (breast cancer)

Sometimes, patient's fear predominated. Despite being in a stable condition, those patients experienced chronic stress in that cancer would recur. Patients seldom complained, but it could however paralyze them in doing other activities. In these patients, the frequent consultations at the hospital could be considered burdensome and enlightening at the same time.

*Yes, I think I'm someone who soon sees the gloomy side. Well, of course that's annoying. That's not good. Then you think ... then you've had a CT scan and you have to wait another week for the results and then you think: 'Oh, I can feel something here, could that be why?' And then, well, today you get the message that it hasn't grown. So you've spent a week worrying about nothing really. **Patient 5, 2016 (lung cancer)***

Often, patient's hope predominated, especially in situations where they grew accustomed in having incurable cancer. Although most patients reported to know that their disease could not be cured anymore, they often refused to focus on the incurable nature of their disease. They wanted to stay positive and attain autonomy. One patient for instance reported that she did not want to await next (scan) results, but preferably wanted to do something herself to attain some form of autonomy, also in order to stay positive. She explained that she was very conscious in what she was eating, being convinced that too much sugar could have a negative impact on tumour growth. This positive and hopeful life-stance often decreased if patients had had more than one line of treatment, and response to treatment was less convincing. Still, patients reported to cling onto hope.

I: Is it because there is less response right now, that you are more often thinking about your disease?

R: I don't know, but the heaviness... You do spend a very long time with this feeling that one day we'll win this battle, whether that's justified or not.

Patient 3, 2016 (breast cancer)

Having a seemingly short life expectancy made patients conscious in that all moments could be for the very last time, which could be distressing if this turned out not to be the case (because new treatment options were

offered). Additional time was on the one hand welcomed, but on the other hand, gave less security as future life became less clear-cut.

But then I came back, partly with the idea that this time I'll do things completely differently. We won't start making preparations any more, or more or less say goodbye or go along to every birthday party, celebrating in style because it might be your last time. But it drives you crazy if you're constantly having to say goodbye.

Patient 1, 2015 (lung cancer)

Apart from a mental challenge in itself, patients' experiences of physical discomfort sometimes resulted in uncertainty too. Patients could be extremely worried while experiencing pain somewhere in their body, immediately thinking of cancer growth or (more) metastases. Other patients explained that they did not trust their bodily sensations anymore at all while the diagnosis of cancer was something they would not have expected beforehand too. Being a stranger to your own body impacted the degree of uncertainty and, accordingly, patients' well-being.

Sure, and then you go to the hospital and you think, well, I feel good, it's all going well and ... But it turns out it's not going well and then you just lose your confidence in your body completely.

Patient 25, 2015 (breast cancer)

Staying hopeful and optimistic

In this day-care setting, where nurses ran on-and-on with chemotherapy regimen, the atmosphere could be described as positive and energetic. Nurses reported to often have no time to have deeper, time-consuming conversations. Yet, they were friendly, greeted patients they knew from previous visits and joked a lot. '*I just need to check your birth date*' (and they ran to the next patient), '*Are you cold? I'll get another blanket for you. A hot water bottle may be even better (I also use them when we are camping) but that's not working here*' [and they rushed away]. This positive and informal atmosphere seemed to impact both healthcare professionals as well as the visitors at the unit. In doing this, the atmosphere at the day-care unit seemed to give space for positive feelings/thoughts. Some patients reported that having conversations about the last phase of life, would be too burdensome at this day-care unit.

'I guess that if conversations here (at the day-care unit), would especially focus on the approaching death, conversations would be more burdensome. So no, it's OK like this.' **Patient 31 (breast cancer)**

Apart from being hopeful, patients also explained how they intended to stay optimistic, e.g. how they really tried to believe in what they hoped for. They for instance (rationally) substantiated they could start worrying by the time their prognosis got really worse. Some patients tried to look at their situation in a positive/optimistic way, for instance by perceiving every visit to the hospital as a 'day-out', or they described that walking to the city-centre was a very good way to relax and do some exercises. Instead of being hopeful, being optimistic could be viewed as a more active/rational approach. In some situations, patients for instance decided to make decisions against their doctors' advice, such as asking for a second opinion. In doing so, optimism could be viewed as a coping strategy.

No, I don't spend much time thinking about it [approaching death] because that would drive you crazy, I reckon. Still enjoy life a bit and be with the children for as long as that's still possible, and when it's no longer possible, there will still be plenty of time for sackcloth and ashes. At least that's how I see it, or want to see it [laughs], right.

Patient 24, 2015 (breast cancer)

Instead of being hopeful, being optimistic more often seemed to be a real choice. For some patients, however, this was much easier than for others. In patients for whom being optimistic was easier, accepting their fate and coping with the disease seemed easier as well. Moreover, those patients seemed to be more receptive for good news, which immediately resulted in a happy and relaxed mood and euphoric reactions.

It's great, I am just so happy that... she said it [the cancer] won't go away completely... but she can't really say anything about that. But what happened now was overwhelming.[patient just heard the excellent response of treatment] **Patient 21, 2015 (breast cancer)**

The influence of others and finding a new balance

In either staying hopeful or being optimistic, other persons could have an important role as well. Healthcare professionals could be of tremendous importance in either downplaying or increasing patient's hope as well as their optimistic life stance. Although patients appreciated doctors' commitment, they sometimes doubted whether

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3 the information they had just received was adequate. Open communication in that life expectancy could change
4 towards a longer life expectancy (instead of providing a worse prognosis) could also upset patients and make
5 them fearful.

6 *And if they say 'Well, there is a very small chance that you might*
7 *possibly recover', you find yourself actually kind of upset and*
8 *thinking 'Gosh, I was just beginning to get used to the idea that*
9 *I'm dying and now I suddenly have to start thinking about the*
10 *future and that kind of thing'. Patient 11, 2016 (breast cancer)*

11 Some patients reported to have requested psycho-social support in an earlier disease phase, right after the
12 cancer diagnosis. A majority of the patients further explicated that this protracted disease phase was different:
13 they just wanted to continue life, no psycho-social help. Most patients told us that after having had the big shock
14 of having cancer, they slowly found a new life balance with a positive focus.

15 *I remember that I was really struggling with it four years ago,*
16 *when they first diagnosed it. And then I did 'In balance', mainly*
17 *really for the social welfare, for the social support. And that helped*
18 *me a great deal to actually get a grip on it. So things like learning*
19 *to accept the fact that you'll have to learn to live with the*
20 *tiredness. And your own mortality and that kind of thing.*
21 **Patient 11, 2016 (breast cancer)**

22 Most patients explained that after a specific time-period, the situation of having protracted incurable cancer
23 eventually resulted in acceptance of the disease. In this stable disease-period (although with fluctuations in both
24 physical condition and uncertainty) patients did not seek any psycho-social help and often felt no need to talk
25 about their disease with close relatives: they regarded their disease as part of who they were. Just as healthcare
26 professionals, they seemed to downplay the situation by making comparisons like 'I've also gone grey in the
27 course of my life'.

28 *It's, I've also gone grey in the course of my life and we never*
29 *talked about that, I mean, it's just one of those things, that's really*
30 *the way it is and it's just part of who I am. Like going grey.*
31 **Patient 26, 2015 (breast cancer)**

32 Nevertheless, it sometimes seemed as if those patients were not as confident as they pretended to say, e.g.
33 some of these patients got emotional during the conversation. Accordingly, patients appreciated support from
34 friends and close relatives.

35 *One way or another, he [partner] immediately notices if something isn't*
36 *going well. But he sits in on all the appointments, he helps in asking*
37 *questions. [...] I lie here in a hospital bed sleeping part of the day and*
38 *then waking up, but he still comes along. So even if you can't see him,*
39 *you know he's waiting for you, you know he's close by.*
40 **Patient 2, 2017 (lung cancer)**

DISCUSSION

Facing death (progression of disease) and survive (remission of disease) several times could be overwhelming for patients. In these situations, support was greatly appreciated. Most patients had grown accustomed in having protracted incurable cancer if severe physical symptoms were away for quite some time. Associated fear than slowly faded. As most patients regarded cancer as part of who they were, they generally felt no need to speak about their disease. At the day-care unit, patients frequently took a hopeful and optimistic attitude, which was frequently enforced by optimistic doctors and nurses. Most patients with protracted incurable cancer talked about their disease in a positive way. Hope often dominated their uncertain life; fear was present and visible to a little extent only. Partners and close relatives, however, could downplay this optimistic stance.

Strengths and weaknesses

A previous Dutch ethnographic study focused on the phenomenon of 'false optimism about recovery'. In the waiting room, incurable lung cancer patients rarely appeared to deal with their approaching death, despite their limited life-expectancy.¹⁷ Approximately 20 years later, new cancer therapeutics have changed the landscape in cancer care. We now focused on a new phenomenon, e.g. 'Patients' challenges while having protracted incurable cancer'. A feature that increases the validity of this study is the long time-period (a 2-year study period) and the combination of observations (although not very much explicated), short conversations with patients (and close relatives), and medical record data. This long time-period is important to be able to show that patient's condition indeed fluctuates and to be able to interview over a long time period. Our study also has limitations. First, this study was performed in one cancer centre, our results may therefore not be representative for the whole cancer population. However, we particularly wanted to focus on patients' challenges and this is probably equal (although less frequent) in other hospitals. Second, the duration of conversations could be short. However, since we were particularly interested in patients' perceptions at the day-care setting, this can be considered part of ethnographic research. Third, we focused on one cancer hospital. Possibly, results may be different in primary hospitals where treatment is probably more easily ceased. However, we wanted to focus on protracted incurable cancer, which will probably increase in importance in future and then be relevant in other hospitals and settings too. Fourth, the average age of the patients was quite high and there were relatively little men (because we selected breast- and lung cancer patients). Fifth, social desirable answers of patients could be given, with close relatives in proximity, and in the absence of a private space. Sixth, HMB started her medical studies in 2015. This could have influenced her (objective) perspective. However, the presence of HMB to a certain extent shaped what happened no matter what and is in fact part of ethnographic research.

Balancing between different levels of hope and fear

All patients in our study to a certain extent experienced uncertainty in the context of their disease. This is in line with previous literature that shows that uncertainty is a common cancer experience that may be related to treatment choices, lack of information and uncertainty in coping with everyday life.^{2 24 25} Our findings however contrast with the common cancer disease trajectory, e.g. reaching an advanced stage followed by a predictable downhill course over weeks or months. Instead, the patient's disease status of patients with long-standing disease trajectories often went up-and-down (see also **Figure 1**). As a result, it is understandable that levels of fear and hope will go up-and-down too.²⁶

Apart from uncertainty due to ongoing fluctuations from stable/remission towards progression, uncertainty about the chance new treatment options will be developed on-time is new. Some patients already *gave up hope* for a longer life and had merely accepted that they would die. This could be explained by the fact that patients' wish to live decreases and their wish to die increases when nearing death, since their acceptance of death grows.²⁷ Now, this natural dying process was to a certain extent interfered. Yet, other characteristics of protracted incurable cancer *gave space for hope*. As patients grew accustomed to having incurable cancer, they learned more about their responses to their disease, and accordingly what they hoped for. Interestingly, what patients value may change or be prioritised differently, and accordingly, also what they hope for. A discussion paper of Simpson²² argues that in situations where persons can imagine poorly what their life may be like, it is difficult to hope. This is in accordance with what patients experienced that were selected in our study. Opening up the discussion about possible treatment options in future, may decrease uncertainty, and increase patient's hope.

Using optimism in the context of protracted incurable cancer

Choosing to be optimistic seemed to be an effective coping strategy according to the patients in our study. An optimistic or hopeful approach is in line with what many medical oncologists also believe is the right way to go: although an objective positive effect on disease progression has not been shown, to instil hope in patients has previously been shown to have an effect in how patients try to maintain their weight, take their medications on time, et cetera.²⁸ This discussion paper also showed that maintaining optimism is considered as one of the essences of meaningful medical practice. Although hopefulness for medical oncologists, especially in the academic/research settings, is often primarily grounded in the biomedical dimensions of their work, it is definitely worthwhile. It further suggests that the optimistic stance of nurses may be effective.

In general, the balance among feelings relates to differences in optimism, e.g. positive feelings (like being hopeful) relate to positive thinking (like being optimistic).²⁹ Some patients in our study reported that their

confidence and positive feelings grew throughout the disease course in situations where treatment appeared to have a true effect on the tumour. Carver *et al* suggests that an optimistic life stance is more changeable during times of transition and/or when outcomes become uncertain.³⁰ Our study suggests that optimism indeed changed (it increased) in uncertain situations, at least in a majority of the patients we spoke with at the day-care unit of this specific hospital.

Yet, it should be noted that optimism as a coping strategy was probably easily feasible because all patients were in relatively good physical condition. Moreover, patients might have given socially desirable answers. A previous study for instance showed that cancer patients receiving palliative care can be remarkably optimistic in the hospital or in their satisfactory relationship with the nursing staff.^{31,32} These findings are also in line with our data that shows that hardly all patients intended to be optimistic, although fear (FCR) was sometimes overriding and/or close relatives told something differently. Perhaps, optimism is frequently used as the initial coping strategy, but if fear and uncertainty predominate, other coping strategies need to be used as well.

Conclusions and implications for policy

This explorative ethnographic study can be considered a first step to discover how recent developments in cancer will shape clinical and research domains in future in the context of protracted incurable cancer /a chronic disease. It seems that the existing paradigm surrounding the curative/palliative dichotomy currently comes into play. By providing insight into the social dynamics of healthcare, our study can serve as a basis to increase awareness about ongoing care-developments, which are presently going on in patients with protracted incurable cancer.³³

Our study shows that patients with protracted incurable cancer partly have different experiences than patients with a common palliative disease trajectory.³⁴ Their physical and mental status often went up-and-down, partly because of unpredictable response rates due to new medication regimen.³⁵ Instead of slow physical deterioration, our patients at a certain moment grew accustomed to a stable situation and accepted the small physical symptoms ('like going grey').

In this protracted disease-phase, uncertainty was often noticed or discussed, and should not be interpreted as negative only. Some patients for instance clearly explained that prognostic uncertainty provided the option to look on the bright side. In line with these findings are challenges about the concept of hope for healthcare professionals as well as patients. In hoping, patients invest in their selves. In this unpredictable disease trajectory, however, patients may be hurt or disappointed if what they hoped for is not realised. This should be managed carefully by healthcare professionals. Our results provide entry-points in how this might be accomplished.

- More research is warranted to explore whether optimism as what seems is currently the common care approach by nurses, is sufficient to guarantee a good and meaningful life in these patients. If patients (and their close relatives) would be able to better manifest resilience in taking an optimistic life-stance,³⁶ this may increase well-being. Yet, it need to be taken into account that such a positive life stance may not be what everyone wishes.³⁷ Moreover, avoiding negative emotions is not always realistic or desirable.
- More research is warranted about patient's values/wishes in this protracted disease phase. It is nowadays propagated to use advanced care planning,³⁸ but it is also known that patients find it difficult to express their values and wishes for the next stage/disease period.³⁴ Yet, patients being in a stable disease phase - as is often the situation in long-standing incurable cancer - will probably be able to formulate life-goals for the present stage.^{35,39} This might be more helpful and coaching than to stimulate these patients to think about their approaching death. Such an approach may be more in line with survivorship care approaches.
- More research is warranted to explore how differences across healthcare professionals in how they relate themselves to different issues can best be embedded in actual medical practice. Patients sometimes experienced wide variety across healthcare professionals in how they relate themselves to these sometimes - existential - issues. Working with patients who are facing the frontier between life and death may be difficult. Some doctors may be more engaged in the existential issues those patients experience, while other doctors are not.

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Contributors

HMB designed the study. HMB, MvA and EPEM carried out the study. HMB, MvA, OD, GAS, GSS were involved in the interpretation of the study findings. HMB and MvA wrote the manuscript which was critically read by all the authors. HMB is guarantor of the study. All authors had full access to all the data in the study and can take responsibility for their integrity and the accuracy of their analysis.

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Competing interests

None declared

Ethics approval

The study did not require review by a medical ethical committee because the observations and short talks were not considered to be possibly incriminating for patients/relatives.

Data sharing

No additional data available

Copyright

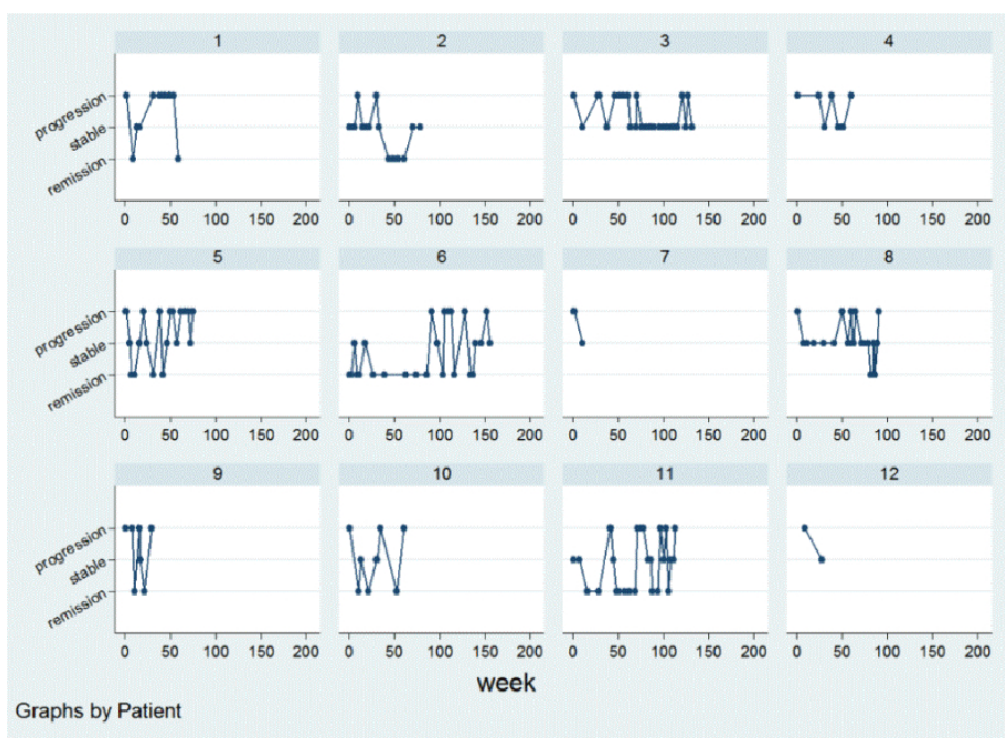
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References

1. Halkett GK, Lobb EA, Oldham L, et al. The information and support needs of patients diagnosed with High Grade Glioma. *Patient Educ Couns* 2010;79(1):112-9. doi: 10.1016/j.pec.2009.08.013 [published Online First: 2009/09/19]
2. Shaha M, Cox CL, Talman K, et al. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau* 2008;40(1):60-7. doi: 10.1111/j.1547-5069.2007.00207.x [published Online First: 2008/02/28]
3. Ashbury FD, Findlay H, Reynolds B, et al. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;16(5):298-306. [published Online First: 1998/12/10]
4. Bishop AJ, Ensor J, Moulder SL, et al. Prognosis for patients with metastatic breast cancer who achieve a no-evidence-of-disease status after systemic or local therapy. *Cancer* 2015 doi: 10.1002/cncr.29681 [published Online First: 2015/09/09]
5. Buiting HM, Linn SC, Smorenburg CH, et al. [Living with incurable cancer]. *Ned Tijdschr Geneesk* 2016;160(0):A9615. [published Online First: 2016/04/29]
6. Harley C, Pini S, Bartlett YK, et al. Defining chronic cancer: patient experiences and self-management needs. *BMJ supportive & palliative care* 2015;5(4):343-50. doi: 10.1136/bmjspcare-2012-000200rep [published Online First: 2015/11/21]
7. McCorkle R, Ercolano E, Lazenby M, et al. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011;61(1):50-62. doi: 10.3322/caac.20093 [published Online First: 2011/01/06]
8. Fadul N, Elsayem A, Palmer J, et al. Supportive versus palliative care: What's in a name. *Cancer* 2009;115:2013-21.
9. Brom L, Pasma HR, Widdershoven GA, et al. Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PLoS One* 2014;9(6):e100435. doi: 10.1371/journal.pone.0100435 [published Online First: 2014/06/26]
10. Buiting HM, Rurup ML, Wijsbek H, et al. Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ (Clinical research ed)* 2011;342:d1933. doi: 10.1136/bmj.d1933
11. Blank CU, Haanen JB, Ribas A, et al. CANCER IMMUNOLOGY. The "cancer immunogram". *Science (New York, NY)* 2016;352(6286):658-60. doi: 10.1126/science.aaf2834 [published Online First: 2016/05/07]
12. Smit EF, Wu YL, Gervais R, et al. A randomized, double-blind, phase III study comparing two doses of erlotinib for second-line treatment of current smokers with advanced non-small-cell lung cancer (CurrentS). *Lung Cancer* 2016;99:94-101. doi: 10.1016/j.lungcan.2016.06.019 [published Online First: 2016/08/28]
13. Temel JS, Gainor JF, Sullivan RJ, et al. Keeping Expectations in Check With Immune Checkpoint Inhibitors. *J Clin Oncol* 2018;Jco2017762146. doi: 10.1200/jco.2017.76.2146 [published Online First: 2018/01/26]
14. Schouten RD, Muller M, de Gooijer CJ, et al. Real life experience with nivolumab for the treatment of non-small cell lung carcinoma: Data from the expanded access program and routine clinical care in a tertiary cancer centre-The Netherlands Cancer Institute. *Lung Cancer* 2017 doi: 10.1016/j.lungcan.2017.11.012 [published Online First: 2017/11/29]
15. O'Shaughnessy J, Petrakova K, Sonke GS, et al. Ribociclib plus letrozole versus letrozole alone in patients with de novo HR+, HER2- advanced breast cancer in the randomized MONALEESA-2 trial. *Breast cancer research and treatment* 2017 doi: 10.1007/s10549-017-4518-8 [published Online First: 2017/11/23]
16. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349-57. doi: 10.1093/intqhc/mzm042 [published Online First: 2007/09/18]
17. The AM, Hak T, Koeter G, et al. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ (Clinical research ed)* 2000;321(7273):1376-81.
18. Livingstone J. Improvising medicine. An African oncology ward in an emerging cancer epidemic 2015.
19. Vonk R, Korevaar JC, van Saase L, et al. Een samenhangend beeld van kanker: ziekte, zorg, mens en maatschappij. Thema Rapportage van de Staat van Volksgezondheid en Zorg: RIVM, 2016.
20. Mendiburo-Seguel A, Paez D, Martinez-Sanchez F. Humor styles and personality: A meta-analysis of the relation between humor styles and the Big Five personality traits. *Scandinavian journal of psychology* 2015;56(3):335-40. doi: 10.1111/sjop.12209 [published Online First: 2015/03/20]
21. Olsman E, Leget C, Duggleby W, et al. A singing choir: Understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliat Support Care* 2015:1-8. doi: 10.1017/s147895151500019x [published Online First: 2015/04/29]
22. Simpson C. When hope makes us vulnerable: a discussion of patient-healthcare provider interactions in the context of hope. *Bioethics* 2004;18(5)
23. Thewes B, Husson O, Poort H, et al. Fear of Cancer Recurrence in an Era of Personalized Medicine. *J Clin Oncol* 2017;Jco2017728212. doi: 10.1200/jco.2017.72.8212 [published Online First: 2017/07/21]
24. Etkind SN, Bristowe K, Bailey K, et al. How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliat Med* 2017;31(2):171-80. doi: 10.1177/0269216316647610 [published Online First: 2016/05/01]

25. Nelson JP. Struggling to gain meaning: living with the uncertainty of breast cancer. *ANS Advances in nursing science* 1996;18(3):59-76. [published Online First: 1996/03/01]
26. Karlsson M, Friberg F, Wallengren C, et al. Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC Palliat Care* 2014;13:28. doi: 10.1186/1472-684x-13-28 [published Online First: 2014/06/18]
27. Lichtenthal WG, Nilsson M, Zhang B, et al. Do rates of mental disorders and existential distress among advanced stage cancer patients increase as death approaches? *Psychooncology* 2009;18(1):50-61. doi: 10.1002/pon.1371 [published Online First: 2008/06/05]
28. Del Vecchio M, Good B, Schaffer C, et al. American Oncology and the discourse on hope. *Culture, medicine and psychiatry* 1990;14:59-79.
29. Janssen E, van Osch L, Lechner L, et al. Thinking versus feeling: differentiating between cognitive and affective components of perceived cancer risk. *Psychology & health* 2012;27(7):767-83. doi: 10.1080/08870446.2011.580846 [published Online First: 2011/07/20]
30. Carver CS, Scheier MF, Segerstrom SC. Optimism. *Clinical psychology review* 2010;30(7):879-89. doi: 10.1016/j.cpr.2010.01.006 [published Online First: 2010/02/23]
31. Cameron J, Waterworth S. Patients' experiences of ongoing palliative chemotherapy for metastatic colorectal cancer: a qualitative study. *Int J Palliat Nurs* 2014;20(5):218-24. doi: 10.12968/ijpn.2014.20.5.218 [published Online First: 2014/05/24]
32. McCreadie M, Payne S, Froggatt K. Ensnared by positivity: a constructivist perspective on 'being positive' in cancer care. *European journal of oncology nursing : the official journal of European Oncology Nursing Society* 2010;14(4):283-90. doi: 10.1016/j.ejon.2010.03.002 [published Online First: 2010/04/27]
33. Stellmach D, Beshar I, Bedford J, et al. Anthropology in public health emergencies: what is anthropology good for? *BMJ global health* 2018;3(2):e000534. doi: 10.1136/bmjgh-2017-000534 [published Online First: 2018/04/03]
34. Buiting HM, Terpstra W, Dalhuisen F, et al. The facilitating role of chemotherapy in the palliative phase of cancer: qualitative interviews with advanced cancer patients. *PloS one* 2013;8(11):e77959. doi: 10.1371/journal.pone.0077959; 10.1371/journal.pone.0077959
35. Simpkin AL, Schwartzstein RM. Tolerating Uncertainty - The Next Medical Revolution? *N Engl J Med* 2016;375(18):1713-15. doi: 10.1056/NEJMp1606402 [published Online First: 2016/11/03]
36. Molina Y, Yi JC, Martinez-Gutierrez J, et al. Resilience among patients across the cancer continuum: diverse perspectives. *Clinical journal of oncology nursing* 2014;18(1):93-101. doi: 10.1188/14.cjon.93-101 [published Online First: 2014/01/31]
37. Den Hartogh G. Suffering and dying well: on the proper aim of palliative care. *Medicine, health care, and philosophy* 2017;DOI 10.1007/s11019-017-9764-3
38. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017;18(9):e543-e51. doi: 10.1016/s1470-2045(17)30582-x [published Online First: 2017/09/09]
39. Maas M, Beets-Tan RG, Lambregts DM, et al. Wait-and-see policy for clinical complete responders after chemoradiation for rectal cancer. *J Clin Oncol* 2011;29(35):4633-40. doi: 10.1200/jco.2011.37.7176 [published Online First: 2011/11/10]

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317x230mm (72 x 72 DPI)

Coreq checklist

Complex challenges in patients with protracted disease incurable cancer: an ethnographic study

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?
P4, recruitment and sampling
2. Credentials: What were the researcher's credentials? E.g. PhD, MD
P1
3. Occupation: What was their occupation at the time of the study?
P1
4. Gender: Was the researcher male or female?
P4
5. Experience and training: What experience or training did the researcher have?
P4

Relationship with participants

6. Relationship established: Was a relationship established prior to study commencement?
P4
7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?
P4
8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.
P4 (methods), P10 (limitations)

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?
P4 (ethnography, thematic content analysis)

Participant selection

10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball?
P4 Participants were random selected, when HB was in the hospital
11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email.
P4, face-to-face
12. Sample size: How many participants were in the study?
P5
13. Non-participation: How many people refused to participate or dropped out? Reasons?
P4 (none of the patients, in 3 situations nurses advised not to approach the patient)

Setting

14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace.
P4 (hospital)
15. Presence of non-participants: Was anyone else present besides the participants and researchers?
P4 (close relatives, n=8)
16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date

P6*Data collection*

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?

P4 (first of all openly framed)

18. Repeat interviews: Were repeat interviews carried out? If yes, how many?

P5

19. Audio/visual recording: Did the research use audio or visual recording to collect the data?

P4 (all conversations were audio-taped)

20. Field notes: Were field notes made during and/or after the interview or focus group?

P4 (observations, and some additional talks with patients)

21. Duration: What was the duration of the interviews or focus group?

P4

22. Data saturation: Was data saturation discussed?

P4, until data saturation was reached.

23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?

P5

Domain 3: Analysis and findings

24. Number of data coders: How many data coders coded the data?

P5 (2, HMB, and MACA)

25. Description of the coding tree: Did authors provide a description of the coding tree?

P5 (no explicit description of the coding tree, but we described several items)

26. Derivation of themes: Were themes identified in advance or derived from the data?

P5 (yes)

27. Software: What software, if applicable, was used to manage the data?

P5

28. Participant checking: Did participants provide feedback on the findings? No, but we sent them a lay version of the results.

Reporting

29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number.

P5-9

30. Data and findings consistent: Was there consistency between the data presented and the findings?

P5-9 (yes)

31. Clarity of major themes: Were major themes clearly presented in the findings?

P5-9 (yes)

32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?

P5-9 (yes)

BMJ Open

Complex challenges for patients with protracted incurable cancer: An ethnographic study in a comprehensive cancer centre

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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Health policy, Ethics, Qualitative research, Sociology
Keywords:	MEDICAL ETHICS, survivorshipcare, PALLIATIVE CARE, chronicity, anti-cancer treatment, medical decision-making

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Manuscripts

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3 **Complex challenges for patients with protracted incurable cancer:**
4 **An ethnographic study in a comprehensive cancer centre**
5

6 Hilde M. Buiting, Marleen A.C. van Ark, Otto Dethmers, Emma P.E. Maats, Jogien A. Stoker, Gabe S. Sonke
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ABSTRACT (max 300 words)

Objective

Advances in oncology increasingly result in protracted disease-trajectories for patients with incurable cancer. In this disease phase, patients are aware of the incurable nature of cancer although they do not approach the last phase of life yet. We aimed to explore challenges of patients confronted with protracted incurable cancer.

Design

Ethnographic study (2015-2017) based on conversations with patients, observations at the day-care unit and a selection of medical-record information of patients who died during the study-period.

Setting

The day-care unit of a comprehensive cancer centre in the Netherlands.

Participants

Nineteen patients with stage IV breast cancer (in remission, ≥ 1 year after diagnosis) and 11 patients with stage IV lung-cancer (in remission, ≥ 6 months after diagnosis).

Results

In patients who had died during the study period, the treatment response often fluctuated between stable, remission and progression throughout the course of the disease. Patients reported that this fluctuation could be overwhelming. However, as patients grew accustomed to having protracted incurable cancer, the distress associated with fluctuations (perceived in scan-results) slowly faded. Patients reported cancer became part of who they were. At the day-care unit, most patients talked about their disease in an optimistic or neutral way and expressed delight in life. They often expressed gratefulness for possible life prolongation, expressed hope and tried to stay optimistic. This was frequently enforced by optimistic doctors and nurses. Relatives, however, could downplay such optimism. Moreover, some patients acknowledged that hope was adjusted to their personal challenges regarding their disease.

Conclusions

In situations where tumours remained in remission/stable for extended periods, patients grew accustomed to having cancer. At the day-care unit, medical professionals typically strengthen an attitude of being hopeful/optimistic, which could be downplayed by relatives. More research is warranted to explore this new disease phase and this optimistic view of healthcare-professionals.

Strengths and limitations of the study

- This is the first study that qualitatively explores the impact of living with protracted incurable cancer.
- This study covered a long time-period (2015-2017) to be able to show that patient's condition fluctuates during the period in which patients are diagnosed with incurable cancer.
- This study combined observations, short conversations with patients (and relatives), and medical record data to increase in-depth insight in this relatively new disease phase.
- A limitation of the study is that the duration of the conversations was sometimes short and that results with respect to communication towards patients may be different in other (non-specialised) cancer hospitals as hospital cultures differ. However, we wanted to focus on this protracted disease phase, which occurs more often in specialised cancer centres.
- The average age of the patients was quite high and there were relatively little men. Probably, experiences with respect to protracted incurable cancer differ between men and women.

Keywords: chronic cancer, doctor-patient communication, medical ethics, sociology, survivorship care, palliative care

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For peer review only

INTRODUCTION

Advances in oncology have resulted in protracted disease trajectories in incurable cancer patients.¹ Accordingly, it is sometimes argued that some forms of cancer seem to evolve in a chronic disease.²⁻⁴ Surprisingly, little information about the experiences of long-lasting incurable cancer are yet available.⁵ However, given the extended periods of survival, patients with long-lasting incurable cancer may benefit from either survivorship interventions⁶ (e.g. the approach to address long-term needs of cancer survivors) as well as palliative or supportive care interventions.⁷ Studies focusing on the last phase of life or on advanced cancer in general may be assistant to achieve some ideas.^{8,9} Intense fear about death, fatigue, uncertainty about prognosis, and hope for recovery have been shown to be rather important.¹⁰⁻¹² Plausibly, equal topics may be applicable for patients with protracted incurable cancer. Whether and to what extent is not clear yet.

Little has been written in how these protracted disease trajectories are challenging the ability of patients to cope with the disease. Walshe and his colleagues however reported about successful coping strategies for patients living with advanced cancer, illustrating the importance of focusing on patients' personal coping strategies.¹³ Moreover, Roberts and his colleagues also reported about coping strategies in advanced cancer, focusing on either a 'problem-focused' or 'emotion-focused' therapy.¹⁴ In contrast, much has been written about these novel cancer therapeutics itself.¹⁵⁻¹⁷ During the last couple of years new mutations have been discovered in patients with lung cancer (epidermal growth factor receptor (EGFR) mutations, BGFR mutations), breast cancer (BRCA1, BRCA2, HER2) and several other cancers, resulting in the development of new genotype-directed therapy throughout the patient's disease course. Increased prognostic uncertainty on the part of clinicians however complicates prognostic communication with patients and accordingly certainty among patients.¹⁸ This changing landscape in treatment options will obviously evoke new (ethical) dilemmas for patients as well as healthcare professionals.

Our project started from the observation that patients living with protracted incurable cancer are inadvertently overlooked. In this specific study, we spoke with patients (and their close relatives) at the day-care unit and focused on the challenges in this specific disease phase.

METHODS

Design and Setting

This study is part of a larger project that examines the experiences, needs and wishes of patients and healthcare professionals with protracted incurable cancer using a mixed methods ethnographic design. For this study, a qualitative database was used in which experiences, needs and wishes of patients with prolonged incurable cancer were collected. As of 2015, this information was gathered. It contains short conversations with patients at the day-care unit and in-depth interviews in the hospital or home setting, as well as some interviews among and with bereaved family members. Over the years, topics have been added to the interviews and conversations, depending on the discussions that, at that time, were taking place. A COREQ-checklist was used to ensure adequate qualitative research.

We purposefully chose this design to ensure that the results would eventually be practice driven and closely connect to medical practice.¹⁹ A specific strength of ethnography lies in its ability to communicate details plotted in experiences of illness and care.²⁰ In the present study, we combined participant observation with (informal) conversations to build in-depth understanding about the practice of incurable cancer (explicitly and implicitly) and in how healthcare professionals and patients experience long-standing incurable cancer within the context of daily medical practice. Since this is a relatively new research area, we established a definitional framework beforehand (see **Table 1**).

Recruitment & Sampling

1. Observations

As of July 2015, observational research was started. In the *first phase*, field-notes were made in 'backstage' regions of practice (e.g. general locations such as waiting rooms) to generate knowledge about how and why patients and healthcare professionals behave as they do. HMB sat by, observed and sometimes accompanied healthcare professionals.

In the *second phase*, observation moved to the 'front stage' – that is, during doctor-patient encounters and in direct interviews with patients. In this phase, more detailed observations were done and described in observational fieldnotes. Apart from the research questions of the main study, HMB focused on the following topics during the observations: the atmosphere, emotions, mood (patient/personal reflections), language use, interaction between patients and healthcare professionals; and answers associated with the research questions.

During observation-days (n=21) observational field-notes had been made.

2. Short conversations

As of July 2015, short conversations were started at the day-care unit of a comprehensive cancer hospital in the Netherlands. These conversations were considered least disturbing for the patient because they were already there. Furthermore, they were less likely to be affected by any specific event, such as receiving good/bad news after having had a consultation with their treating doctor. Only lung cancer patients who had been diagnosed with stage IV disease at least 6 months ago, and breast cancer patients who had been diagnosed with stage IV disease at least 1 year ago have been selected.

In total, 30 patients were approached at the day-care unit by HMB, a female researcher in social sciences, with many years of interview experience. All patients were approached at times HMB was at the hospital and had time to talk to them. Patient-selection was therefore random. All patients were given an information sheet about the study, including background information of the researcher who carried out the interviews. Before approaching a patient, HMB checked with the nurses at the day-care unit whether it would be appropriate to do so. In 3 situations, the nurses advised not to approach patients because they just had received bad news. HMB had not seen any of the patients before the start of the conversations at the day-care unit.

Short conversations were openly framed. We purposefully chose to not use a large topic list and openly asked how patients felt while living with protracted incurable cancer. Often, the conversation started with their disease history, and about possible unmet needs. When the study progressed, we more specifically asked about patients' quality of life. We did not touch upon specific topics, such as positivity and fear, and only focused on such items if brought-up by the patient him- or herself.

We continued conversations with patients until data saturation with respect to the research question of this specific study was reached. In some situations, we asked patients whether they were willing to continue in another interview. These interviews are however not included in this study, although MvA participated in 5 of those interviews to attain a clearer view of the dilemmas of this specific patient group.

The median length of the audio-recorded conversations at the day-care unit was 10 minutes (see **Table 2**). Conversations ended due to circumstances (such as the end of the chemotherapy regimen); because patients simply wanted to stop talking; or because they had nothing more to say. Patients received a short information letter with contact details about the study. None of the patients rejected to participate. In 8 cases, a close relative (often the partner) of the patient was present as well. For 30 patients, the conversations were audio-recorded and transcribed verbatim (see **Table 2**). The transcripts were not returned to the participants for comments.

Table 2

	<i>n</i> patients	Mean time length (<i>SD</i>)	Median time length	Minimum	Maximum
Short conversations ¹	30	13 (9)	10	2	39

3. Short conversations were held at the day-care unit, while patients received their chemotherapy regimen. Conversations that were held during the observation days (*n*=12) are not included, and transcribed in fieldnotes only.

3. Medical record data

Of the included patients of whom their conversation was audio-recorded (*n*=30), and had died (*n*=12) by the end of 2016, we collected additional medical record data. We recorded the disease status (e.g. stable, remission and progression) during every consult with the treating doctor and depicted these data over time in figures for every single patient (see **Figure 1**). Disease status was obtained from doctors' notes of the consults. Their conclusion about disease status was mostly based on comparison of tumour markers and/or radiological findings to those in the prior visit.

Patient and public involvement

The research questions for this specific study were inspired by problems we noticed while working or observing actual medical practice. Thus, the research questions were – by definition – inspired by problems of patients themselves. We did not involve patients in the design of the study. However, during recruitment and conduct of the study we asked patients about possible suggestions to further improve the study. Finally, we intend to publish our results to all our study participants at the end of the study.

Data Analysis

All conversations/observations were coded and analysed using the programme Atlas-ti 8.2. We (MACA and HMB) read apart through twelve conversations at different time intervals to seek for themes. These themes were discussed to check for interpreter consensus. Subsequently, a scheme was developed to index text fragments with similar content (in Atlas-ti 8.2). By analysing the themes, hypotheses emerged and were checked with the data.

Although the conversations were performed by one researcher only, we assured adequate analysis of the data by at least two researchers and adequate discussions about the findings with several project members: MACA subsequently developed a tabular grid to organize interview information from every individual patient about the following themes: support from the patient's surroundings, physical complaints, uncertainty, an indication of prognosis, how the patient seemed to deal with the last phase of life, daily life, and some space for remarkable things in either content or language use. Besides, descriptive information was added to the table about date and duration of the interview, gender, age, type of cancer, location of the interview and the attendees. Other members of the team (OD, JAS, GSS) participated in the analysis by commenting on previous versions of the result-section.

All authors evaluated whether the final quotes were used in the right (medical) context. According to Dutch policy, the study did not require a formal review by an ethics committee because the content of the interviews / observations was not considered to be possibly incriminating. We however requested the committee of the medical ethical committee to provide us with a declaration of no objection (In Dutch: Verklaring van geen bezwaar) to declare that our medical ethical committee had seen the study and provided local approval to carry out the study. Before starting a conversation we provided the patient with information and asked them to audio-record this conversation to be able to use unanimous quotes in final manuscripts. We sent a lay version to the participants who were still alive; the participants could contact the researcher to comment on/ask for clarification.

To distinguish in the text between different types of data collection and technique, the following agreements were used: all data collected by observation are described in the text in *italics*; all data collected by audio-recorded observations are described in the text in quotation marks, also in *italics*.

A professional translator translated the quotes that we chose to illustrate our results.

Table 1 . Definitional framework**THE DISEASE****Disease phases**

Chronic disease /
Chronic cancer

According to the Royal Dutch Institute of Public Health (In Dutch: RIVM), a chronic disease is a disease with irreversible prospects and with a relatively long disease course. Furthermore, a chronic disease is different from other diseases in that these patients are care-dependent for a very long time.²¹ Cancer is categorized as a chronic disease also.

In medical oncology, it is heavily debated as to whether cancer should be viewed as a chronic disease or not, while healthcare professionals do not want to provide unrealistic prognoses. This also holds for patients with protracted incurable cancer.

Protracted incurable cancer

We define protracted incurable cancer as a disease phase where patients receive anti-cancer treatment such as immune-therapy, hormonal treatment, or chemotherapy and in which this disease phase can be considered stable / in remission for long-standing time-periods.

During this time-period, the patient's physical condition may sometimes go up-and-down, due to treatment side-effects. In other words: although response to treatment/the patient's condition can be considered stable/in remission for long-standing time-periods, periods of progression also occur.

THE PATIENT**States of being associated with living with cancer**

Deliberate optimism

Optimism is all about anticipating a positive future. To be optimistic means that we expect things to go our way.²² Optimists are aware that positive outcomes are dependent on their own efforts.

It however should be noted that optimism is partly inherited, and these specific patients also more easily choose to be optimistic (e.g. deliberate optimism).

Hope

As opposed to optimism, hope generally focuses on a specific goal, such as hope for a longer life.²³ It contrasts with hopelessness/powerlessness, and is much more about how you feel. It is however also argued that emotions go beyond the mere 'feeling' of that emotion; emotions are a way in which we interact with the world, and accordingly, hope is sometimes defined as an emotional attitude.²⁴

Fear

Research about cancer patient's fear is extensive. In the context of protracted incurable cancer fear of cancer recurrence (FCR) is commonly studied.²⁵ It is often characterized with chronic worry, excessive body checks and difficulties to make future plans.

Uncertainty

Research about uncertainty is extensive also.²⁶ In essence, uncertainty comprises the inability to attribute meaning to events.

Note:

We do not intend to explore a specific concept but want to conceptualize some definitions that often came up during conversations about these topics.

RESULTS

Quantitative findings

Of all patients, 24 were women (80%) and 6 were men (20%). In this specific study sample, 19 patients experienced some form of breast cancer (63%) and 11 patients experienced some form of lung cancer (37%). The disease trajectory of patients who died during the study period is depicted in **Figure 1**. For every patient, response to treatment often fluctuated from stable towards either remission or progression. The disease period of patients in this specific hospital varied from approximately 30 - 130 weeks.

Figure 1. Patient's response to treatment as described in their medical status during the consultations with the treating doctor. Every figure depicts 1 patient who died during the study period (n=12).

Qualitative findings

During the conversations that we held with patients at the day-care unit, three different themes were recorded: their uncertainty about prognosis in this protracted disease trajectory, their intention to stay hopeful and the influence of others to stay hopeful and to find a new balance.

On-and-on: Facing death versus surviving

Patients' and relatives' uncertainty seemed to be the overarching theme in the majority of the conversations that we held with patients at the day-care unit. The unpredictability of treatment response seemed to interfere with patients' ability to attribute meaning to activities, and accordingly certainty. This was expressed either explicitly or implicitly but always depicted 2 sides of a medallion, e.g. patients seemed to be hopeful and fearful at the same time. Being aware of the incurable nature of their disease also depicted those two sides of the medallion.

R2: Sure, I think you've touched on a key aspect there [...] there is no path to full recovery, at least that's what they actually said at a certain point. [...]

R: Personally, I call it bad and stable.

I: Right.

R: Yes, stable, but we know that it's no longer 100% curable... but it could take a very long time yet.

I: Right, it could be stable for a very long time.

R2: Yeah, and then I reckon the aim is to just take the right approach to let you do as many things as possible that you want to do.

Patient 16, 2016 (breast cancer)

Sometimes, patient's fear predominated. Despite being in a stable condition, those patients experienced chronic stress in that cancer would recur. Patients seldom complained, but it could however paralyze them in doing other activities. In these patients, the frequent consultations at the hospital could be considered burdensome and enlightening at the same time.

*Yes, I think I'm someone who soon sees the gloomy side. Well, of course that's annoying. That's not good. Then you think ... then you've had a CT scan and you have to wait another week for the results and then you think: 'Oh, I can feel something here, could that be why?' And then, well, today you get the message that it hasn't grown. So you've spent a week worrying about nothing really. **Patient 5, 2016 (lung cancer)***

Often, patient's hope predominated, especially in situations where they grew accustomed in having incurable cancer. Although most patients reported to know that their disease could not be cured anymore, they often refused to focus on the incurable nature of their disease. They wanted to stay positive and attain autonomy. One patient for instance reported that she did not want to await next (scan) results, but preferably wanted to do something herself to attain some form of autonomy, also in order to stay positive. She for instance explained that she was very conscious in what she was eating, being convinced that too much sugar could have a negative impact on tumour growth. This positive and hopeful attitude sometimes decreased if patients had had more than one line of anti-cancer treatment, and/or response to treatment had been disappointing. Still, patients reported to cling onto hope.

I: Is it because there is less response right now, that you are more often thinking about your disease?

R: I don't know, but the heaviness... You do spend a very long time with this feeling that one day we'll win this battle, whether that's justified or not.

Patient 3, 2016 (breast cancer)

Having a seemingly short life expectancy made patients conscious that all moments could be for the very last time, which could be distressing also if this turned out not to be the case (because new treatment options were offered). Prolongation of life was on the one hand welcomed, but gave on the other hand less security as future life was rather insecure.

But then I came back, partly with the idea that this time I'll do things completely differently. We won't start making preparations any more, or more or less say goodbye or go along to every birthday party, celebrating in style because it might be your last time. But it drives you crazy if you're constantly having to say goodbye.

Patient 1, 2015 (lung cancer)

Apart from a mental challenge, patients' experiences of physical discomfort sometimes resulted in uncertainty too. Patients could be extremely worried while experiencing pain somewhere in their body, immediately thinking of cancer growth or (more) metastases. Other patients explained that they did not trust their bodily sensations anymore at all while the diagnosis of cancer was something they would not have expected beforehand too. Being a stranger to your own body impacted the degree of uncertainty and, accordingly, patients' well-being.

Sure, and then you go to the hospital and you think, well, I feel good, it's all going well and ... But it turns out it's not going well and then you just lose your confidence in your body completely.

Patient 25, 2015 (breast cancer)

Staying hopeful and optimistic

In this day-care setting, where nurses sometimes had to rush with chemotherapy regimen, the atmosphere could be described as positive and energetic. Nurses reported to lack time for deeper, time-consuming conversations. Yet, they were friendly, greeted patients they knew from previous visits and joked a lot. 'I just need to check your birth date' (and they ran to the next patient), 'Are you cold? I'll get another blanket for you. A hot water bottle may be even better (I also use them when we are camping) but that's not working here' [and they rushed away]. This positive and informal atmosphere seemed to impact both healthcare professionals as well as the visitors at the unit. In doing this, the atmosphere at the day-care unit seemed to give space for positive feelings/thoughts. Some patients reported that having conversations about the last phase of life, would be too burdensome at this day-care unit.

'I guess that if conversations here (at the day-care unit), would especially focus on the approaching death, conversations would be more burdensome. So no, it's OK like this.' **Patient 31 (breast cancer)**

Apart from being hopeful, patients also explained how they intended to stay optimistic, e.g. how they really tried to believe in what they hoped for. They for instance (rationally) substantiated they could start worrying by the time their prognosis got really worse. Some patients tried to look at their situation in a positive/optimistic way, for instance by perceiving every visit to the hospital as a 'day-out'. Instead of being hopeful, being optimistic could be viewed as a more active/rational approach. In some situations, patients for instance decided to make decisions against their doctors' advice, such as asking for a second opinion. In doing so, optimism could be regarded as a coping strategy.

No, I don't spend much time thinking about it [approaching death] because that would drive you crazy, I reckon. Still enjoy life a bit and be with the children for as long as that's still possible, and when it's no longer possible, there will still be plenty of time for sackcloth and ashes. At least that's how I see it, or want to see it [laughs], right.

Patient 24, 2015 (breast cancer)

Instead of being hopeful, being optimistic more often seemed to be a real choice. For some patients, however, this was much easier than for others. In patients for whom being optimistic was easier, accepting their fate and coping with the disease seemed easier as well. Moreover, those patients seemed to be more receptive for good news, which immediately resulted in a happy and relaxed mood and euphoric reactions.

It's great, I am just so happy that... she said it [the cancer] won't go away completely... but she can't really say anything about that. But what happened now was overwhelming [patient just heard the excellent response of treatment] **Patient 21, 2015 (breast cancer)**

The influence of others and finding a new balance

In either staying hopeful or being optimistic, other persons could have an important role as well. Healthcare professionals could be of tremendous importance in either downplaying or increasing patient's hope as well as their optimistic life

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3 stance. Although patients appreciated doctors' commitment, they sometimes doubted whether the information they had
4 just received was adequate. Open communication in that life expectancy could change in a longer life expectancy
5 (instead of providing a worse prognosis) could also upset patients and make them fearful.

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7 *And if they say 'Well, there is a very small chance that you might*
8 *possibly recover', you find yourself actually kind of upset and thinking*
9 *'Gosh, I was just beginning to get used to the idea that I'm dying and*
10 *now I suddenly have to start thinking about the future and that kind of*
11 *thing'. Patient 11, 2016 (breast cancer)*

12 Some patients reported to have requested psycho-social support previously, right after the cancer diagnosis. A majority
13 of the patients further explicated that this protracted disease phase was different: they just wanted to continue life, no
14 psycho-social help. Most patients told us that after having had the big shock of having cancer, they slowly found a new
15 life balance with a positive focus.

16 *I remember that I was really struggling with it four years ago, when they*
17 *first diagnosed it. And then I did 'in balance', mainly really for the social*
18 *welfare, for the social support. And that helped me a great deal to*
19 *actually get a grip on it. So things like learning to accept the fact that*
20 *you'll have to learn to live with the tiredness. And your own mortality and*
21 *that kind of thing.*

22 **Patient 11, 2016 (breast cancer)**

23 Most patients explained that after a specific time-period, the situation of having protracted incurable cancer eventually
24 resulted in acceptance of the disease, which could be interpreted as positive. In this stable disease-period (although
25 with fluctuations) patients did not seek any psycho-social help and often felt no need to talk about their disease with
26 close relatives: they regarded their disease as part of who they were. Just as healthcare professionals, they seemed to
27 downplay the situation by making comparisons like 'I've also gone grey in the course of my life'.

28 *It's, I've also gone grey in the course of my life and we never talked*
29 *about that, I mean, it's just one of those things, that's really the way it is*
30 *and it's just part of who I am. Like going grey.*

31 **Patient 26, 2015 (breast cancer)**

32 Nevertheless, it sometimes seemed as if those patients were not as confident as they pretended to say, e.g. some of
33 these patients got emotional during the conversation. Moreover, patients appreciated support from friends and close
34 relatives.

35 *One way or another, he [partner] immediately notices if something isn't going*
36 *well. But he sits in on all the appointments, he helps in asking questions. [...]*
37 *I lie here in a hospital bed sleeping part of the day and then waking up, but he*
38 *still comes along. So even if you can't see him, you know he's waiting for you,*
39 *you know he's close by.*

40 **Patient 2, 2017 (lung cancer)**

DISCUSSION

Facing death (progression of disease) and surviving (remission of disease) several times could be overwhelming for patients. During these periods, support was greatly appreciated. Most patients grew accustomed to having protracted incurable cancer. Associated fear than slowly faded. As most patients regarded cancer as part of who they were, they generally felt no need to speak about their disease. At the day-care unit, patients frequently took a hopeful and optimistic attitude, which was frequently enforced by optimistic doctors and nurses. Hope often dominated their uncertain life; fear was present and visible to a little extent only. Partners and close relatives, however, could downplay this optimistic stance.

Strengths and weaknesses

A previous Dutch ethnographic study focused on the phenomenon of 'false optimism about recovery'. In the waiting room, incurable lung cancer patients rarely appeared to deal with their approaching death, despite their limited life-expectancy.¹⁹ Approximately 20 years later, new cancer therapeutics changed the landscape in cancer care. We now focused on a new phenomenon, e.g. 'Patients' challenges while having protracted incurable cancer'. A feature that increases the validity of this study is the long time-period (a 2-year study period) and the combination of observations (although not very much explicated), short conversations with patients (and close relatives), and medical record data. This long time-period is important to be able to show that patient's condition indeed fluctuates and to be able to interview over a long-time period. Our study also has limitations. First, this study was performed in one cancer centre, our results may therefore not be representative for the whole cancer population. However, we particularly wanted to focus on patients' challenges while living with protracted incurable cancer and this is probably equal (although less frequent) in other hospitals. Second, the duration of conversations could be short. However, since we were particularly interested in patients' perceptions at the day-care setting, this can be considered part of ethnographic research. Third, the average age of the patients was quite high and there were relatively little men (because we selected breast- and lung cancer patients). Fourth, social desirable answers of patients could be given, with close relatives in proximity, and in the absence of a private space. Lastly, we focused on the day-care setting only. We purposefully chose to focus on this setting since we were interested in how patients in relatively good condition experienced their disease. Moreover, we were interested as to whether the approach towards patients at the day-care unit could be used in other settings or situations also. We however realize that patients and close relatives can be rather different in for instance the home-setting.

Balancing between different levels of hope and fear

All patients in our study to a certain extent experienced uncertainty in the context of their disease. This is in line with previous literature that shows that uncertainty is a common cancer experience that may be related to treatment choices, lack of information and uncertainty in coping with everyday life.^{11 26 27} Our findings however contrast with the common cancer disease trajectory, e.g. reaching an advanced stage followed by a predictable downhill course over weeks or months. Instead, the patient's disease status of patients with long-standing disease trajectories often went up-and-down (see also **Figure 1**). As a result, it is understandable that levels of fear and hope will go up-and-down too.²⁸

Apart from uncertainty due to ongoing fluctuations from stable/remission towards progression, uncertainty about the chance new treatment options will be developed on-time is new. Some patients already *gave up hope* for a longer life and had merely accepted that they would die. This could be explained by the fact that patients' wish to live decreases and their wish to die increases when nearing death, since their acceptance of death grows.²⁹ Now, this natural dying process was to a certain extent interfered. Yet, other characteristics of protracted incurable cancer *gave space for hope*. As patients grew accustomed to having incurable cancer, they learned more about their responses to their disease, and accordingly what they hoped for. Interestingly, what patients value may change or be prioritised differently, and accordingly, also what they hope for. A discussion paper of Simpson²⁴ argues that in situations where persons can imagine poorly what their life may be like, it is difficult to hope. This is in accordance with what patients experienced in our study. Opening up the discussion about future treatment options, may decrease uncertainty, and increase patient's hope.

Using optimism in the context of protracted incurable cancer

Choosing to be optimistic seemed to be an effective coping strategy according to the patients in our study. An optimistic or hopeful approach is in line with what many medical oncologists also believe is the right way to go: although an objective positive effect on disease progression has not been shown, to instil hope in patients has previously been shown to have an effect in how patients try to maintain their weight, take their medications on time, et cetera.³⁰ This discussion paper further showed that maintaining optimism is considered as one of the essences of meaningful medical practice. Although hopefulness for medical oncologists, especially in the academic/research settings, is often grounded in the biomedical dimensions of their work, it has been shown to be worthwhile. It further suggests that the optimistic stance of nurses in our study may be effective.

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3 In general, the balance among feelings relates to differences in optimism, e.g. positive feelings (like being hopeful)
4 relate to positive thinking (like being optimistic).³¹ Some patients in our study reported that their confidence and positive
5 feelings grew throughout the disease course in situations where treatment appeared to have a true effect on the tumour.
6 Carver *et al* suggests that an optimistic life stance is more changeable during times of transition and/or when outcomes
7 become uncertain.³² Our study suggests that optimism indeed changed (it increased) in uncertain situations, at least in
8 a majority of the patients we spoke with at the day-care unit of this specific hospital.

9 Yet, it should be noted that optimism as a coping strategy was probably easily feasible because all patients were in
10 relatively good physical condition. Moreover, patients might have given socially desirable answers. A previous study for
11 instance showed that cancer patients receiving palliative care can be remarkably optimistic in the hospital or in their
12 satisfactory relationship with the nursing staff.^{33 34} These findings are also in line with our data that shows that hardly all
13 patients intended to be optimistic, although fear (FCR) was sometimes overriding and/or close relatives told something
14 differently. Perhaps, optimism is frequently used as the initial coping strategy, but if fear and uncertainty predominate,
15 other coping strategies need to be used as well.

16 **Conclusions and implications for policy**

17 This explorative ethnographic study can be considered a first step to discover how recent developments in cancer will
18 shape clinical and research domains in the context of protracted incurable cancer / chronic disease management,
19 including definitions regarding the curative/palliative dichotomy. By providing insight into the social dynamics of
20 healthcare, our study may increase awareness about care-developments, which are presently going on in patients with
21 protracted incurable cancer.³⁵

22 Our study shows that patients with protracted incurable cancer partly have different experiences than patients with a
23 common palliative trajectory.³⁶ Their physical and mental status often fluctuated, partly because of unpredictable
24 responses to anti-cancer treatment.³⁷ Instead of slow physical deterioration, our patients at a certain moment grew
25 accustomed to a stable situation and accepted the small physical symptoms ('like going grey').

26 Our results provide entry-points in how patients with protracted incurable cancer can be assisted and cared for, taking
27 into account their personal coping strategies as well as possible interventions those patients might benefit.

- 28
- 29 - More research is warranted to explore whether optimism as a common care approach by nurses, is sufficient to
30 guarantee a good and meaningful life in these patients. If patients (and their close relatives) would be able to better
31 manifest resilience,³⁸ this may increase their well-being. Yet, it need to be taken into account that such a positive
32 life stance may not be what everyone wishes.³⁹ Moreover, avoiding negative emotions is not always realistic or
33 desirable.
 - 34 - More research is warranted about patient's values/wishes in this protracted disease phase. It is nowadays
35 propagated to use advanced care planning,⁴⁰ but it is also known that expressing values and wishes for the next
36 stage/disease period can be difficult.³⁶ Yet, patients in a stable disease phase - as is often the situation in long-
37 standing incurable cancer - will probably be able to formulate life-goals for the present stage.^{37 41} This might be
38 more helpful and coaching than to stimulate these patients to think about their approaching death only, although
39 this aspect should not be neglected. Such an approach is probably also more in line with survivorship care
40 approaches, such as light-therapy against cancer related fatigue⁴², or long-term cognitive effects of some forms of
41 anti-cancer treatment.⁴³
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Contributors

HMB designed the study. HMB, MvA and EPEM carried out the study. HMB, MvA, OD, EPEM, JAS, and GSS were involved in the interpretation of the study findings. HMB and MvA wrote the manuscript which was critically read by all the authors. HMB is guarantor of the study. All authors had full access to all the data in the study and can take responsibility for their integrity and the accuracy of their analysis.

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Competing interests

None declared

Ethics approval

The study did not require review by a medical ethical committee because the observations and short talks were not considered to be possibly incriminating for patients/relatives.

Data sharing

No additional data available

Copyright

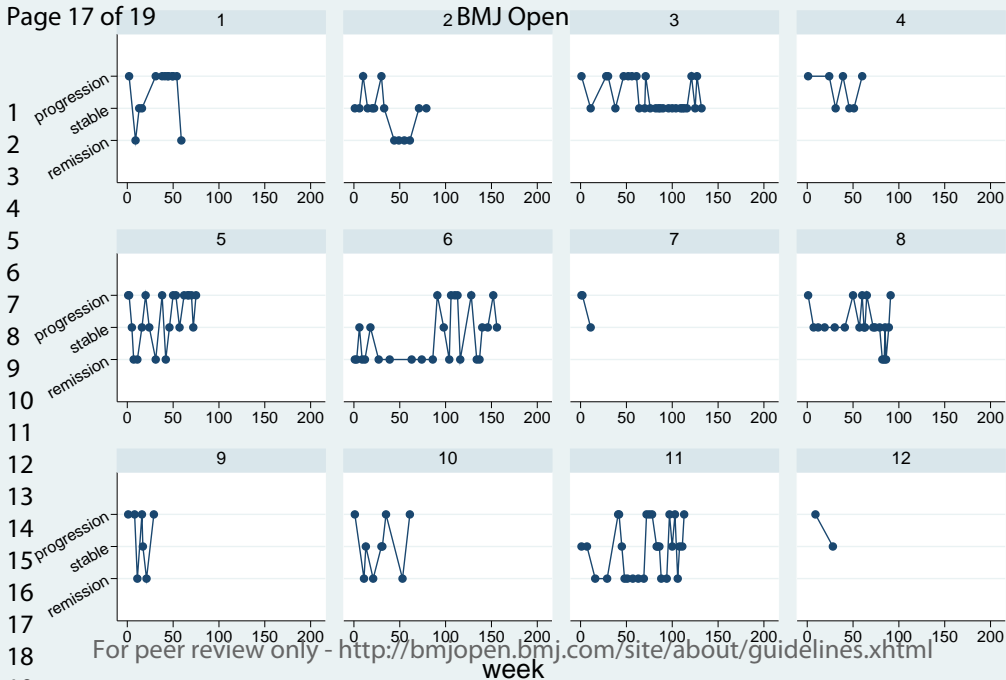
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References

1. Bishop AJ, Ensor J, Moulder SL, et al. Prognosis for patients with metastatic breast cancer who achieve a no-evidence-of-disease status after systemic or local therapy. *Cancer* 2015 doi: 10.1002/cncr.29681 [published Online First: 2015/09/09]
2. Buiting HM, Linn SC, Smorenburg CH, et al. [Living with incurable cancer]. *Ned Tijdschr Geneesk* 2016;160(0):A9615. [published Online First: 2016/04/29]
3. Harley C, Pini S, Bartlett YK, et al. Defining chronic cancer: patient experiences and self-management needs. *BMJ supportive & palliative care* 2015;5(4):343-50. doi: 10.1136/bmjspcare-2012-000200rep [published Online First: 2015/11/21]
4. McCorkle R, Ercolano E, Lazenby M, et al. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011;61(1):50-62. doi: 10.3322/caac.20093 [published Online First: 2011/01/06]
5. Fadul N, Elsayem A, Palmer J, et al. Supportive versus palliative care: What's in a name. *Cancer* 2009;115:2013-21.
6. Aaronson NK, Mattioli V, Minton O, et al. Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice. *EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]* 2014;12(1):54-64. doi: 10.1016/j.ejcsup.2014.03.005 [published Online First: 2015/07/29]
7. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA : the journal of the American Medical Association* 2009;302(7):741-49. doi: 10.1001/jama.2009.1198 [doi]
8. Brom L, Pasma HR, Widdershoven GA, et al. Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PLoS One* 2014;9(6):e100435. doi: 10.1371/journal.pone.0100435 [published Online First: 2014/06/26]
9. Buiting HM, Rurup ML, Wijsbek H, et al. Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ (Clinical research ed)* 2011;342:d1933. doi: 10.1136/bmj.d1933
10. Halkett GK, Lobb EA, Oldham L, et al. The information and support needs of patients diagnosed with High Grade Glioma. *Patient Educ Couns* 2010;79(1):112-9. doi: 10.1016/j.pec.2009.08.013 [published Online First: 2009/09/19]
11. Shaha M, Cox CL, Talman K, et al. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau* 2008;40(1):60-7. doi: 10.1111/j.1547-5069.2007.00207.x [published Online First: 2008/02/28]
12. Ashbury FD, Findlay H, Reynolds B, et al. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;16(5):298-306. [published Online First: 1998/12/10]
13. Walshe C, Roberts D, Appleton L, et al. Coping Well with Advanced Cancer: A Serial Qualitative Interview Study with Patients and Family Carers. *PLoS One* 2017;12(1):e0169071. doi: 10.1371/journal.pone.0169071 [published Online First: 2017/01/21]
14. Roberts D, Calman L, Large P, et al. A revised model for coping with advanced cancer. Mapping concepts from a longitudinal qualitative study of patients and carers coping with advanced cancer onto Folkman and Greer's theoretical model of appraisal and coping. *Psychooncology* 2018;27(1):229-35. doi: 10.1002/pon.4497 [published Online First: 2017/07/12]

15. Blank CU, Haanen JB, Ribas A, et al. CANCER IMMUNOLOGY. The "cancer immunogram". *Science (New York, NY)* 2016;352(6286):658-60. doi: 10.1126/science.aaf2834 [published Online First: 2016/05/07]
16. Smit EF, Wu YL, Gervais R, et al. A randomized, double-blind, phase III study comparing two doses of erlotinib for second-line treatment of current smokers with advanced non-small-cell lung cancer (CurrentS). *Lung Cancer* 2016;99:94-101. doi: 10.1016/j.lungcan.2016.06.019 [published Online First: 2016/08/28]
17. Temel JS, Gainor JF, Sullivan RJ, et al. Keeping Expectations in Check With Immune Checkpoint Inhibitors. *J Clin Oncol* 2018;Jco2017762146. doi: 10.1200/jco.2017.76.2146 [published Online First: 2018/01/26]
18. LeBlanc TW, Temel JS, Helft PR. "How Much Time Do I Have?": Communicating Prognosis in the Era of Exceptional Responders. *American Society of Clinical Oncology educational book American Society of Clinical Oncology Annual Meeting 2018*(38):787-94. doi: 10.1200/edbk_201211 [published Online First: 2018/09/21]
19. The AM, Hak T, Koeter G, et al. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ (Clinical research ed)* 2000;321(7273):1376-81.
20. Livingstone J. Improvising medicine. An African oncology ward in an emerging cancer epidemic 2015.
21. Vonk R, Korevaar JC, van Saase L, et al. Een samenhangend beeld van kanker: ziekte, zorg, mens en maatschappij. Thema Rapportage van de Staat van Volksgezondheid en Zorg: RIVM, 2016.
22. Mendiburo-Seguel A, Paez D, Martinez-Sanchez F. Humor styles and personality: A meta-analysis of the relation between humor styles and the Big Five personality traits. *Scandinavian journal of psychology* 2015;56(3):335-40. doi: 10.1111/sjop.12209 [published Online First: 2015/03/20]
23. Olsman E, Leget C, Duggleby W, et al. A singing choir: Understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliat Support Care* 2015:1-8. doi: 10.1017/s147895151500019x [published Online First: 2015/04/29]
24. Simpson C. When hope makes us vulnerable: a discussion of patient-healthcare provider interactions in the context of hope. *Bioethics* 2004;18(5)
25. Thewes B, Husson O, Poort H, et al. Fear of Cancer Recurrence in an Era of Personalized Medicine. *J Clin Oncol* 2017;Jco2017728212. doi: 10.1200/jco.2017.72.8212 [published Online First: 2017/07/21]
26. Etkind SN, Bristowe K, Bailey K, et al. How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliat Med* 2017;31(2):171-80. doi: 10.1177/0269216316647610 [published Online First: 2016/05/01]
27. Nelson JP. Struggling to gain meaning: living with the uncertainty of breast cancer. *ANS Advances in nursing science* 1996;18(3):59-76. [published Online First: 1996/03/01]
28. Karlsson M, Friberg F, Wallengren C, et al. Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC Palliat Care* 2014;13:28. doi: 10.1186/1472-684x-13-28 [published Online First: 2014/06/18]
29. Lichtenthal WG, Nilsson M, Zhang B, et al. Do rates of mental disorders and existential distress among advanced stage cancer patients increase as death approaches? *Psychooncology* 2009;18(1):50-61. doi: 10.1002/pon.1371 [published Online First: 2008/06/05]
30. Del Vecchio M, Good B, Schaffer C, et al. American Oncology and the discourse on hope. *Culture, medicine and psychiatry* 1990;14:59-79.
31. Janssen E, van Osch L, Lechner L, et al. Thinking versus feeling: differentiating between cognitive and affective components of perceived cancer risk. *Psychology & health* 2012;27(7):767-83. doi: 10.1080/08870446.2011.580846 [published Online First: 2011/07/20]

- 1
2
3 32. Carver CS, Scheier MF, Segerstrom SC. Optimism. *Clinical psychology review* 2010;30(7):879-89. doi:
4 10.1016/j.cpr.2010.01.006 [published Online First: 2010/02/23]
5
6 33. Cameron J, Waterworth S. Patients' experiences of ongoing palliative chemotherapy for metastatic
7 colorectal cancer: a qualitative study. *Int J Palliat Nurs* 2014;20(5):218-24. doi:
8 10.12968/ijpn.2014.20.5.218 [published Online First: 2014/05/24]
9
10 34. McCreaddie M, Payne S, Froggatt K. Ensnared by positivity: a constructivist perspective on 'being
11 positive' in cancer care. *European journal of oncology nursing : the official journal of European*
12 *Oncology Nursing Society* 2010;14(4):283-90. doi: 10.1016/j.ejon.2010.03.002 [published Online
13 First: 2010/04/27]
14
15 35. Stellmach D, Beshar I, Bedford J, et al. Anthropology in public health emergencies: what is
16 anthropology good for? *BMJ global health* 2018;3(2):e000534. doi: 10.1136/bmjgh-2017-000534
17 [published Online First: 2018/04/03]
18
19 36. Buiting HM, Terpstra W, Dalhuisen F, et al. The facilitating role of chemotherapy in the palliative
20 phase of cancer: qualitative interviews with advanced cancer patients. *PloS one*
21 2013;8(11):e77959. doi: 10.1371/journal.pone.0077959; 10.1371/journal.pone.0077959
22
23 37. Simpkin AL, Schwartzstein RM. Tolerating Uncertainty - The Next Medical Revolution? *N Engl J Med*
24 2016;375(18):1713-15. doi: 10.1056/NEJMp1606402 [published Online First: 2016/11/03]
25
26 38. Molina Y, Yi JC, Martinez-Gutierrez J, et al. Resilience among patients across the cancer continuum:
27 diverse perspectives. *Clinical journal of oncology nursing* 2014;18(1):93-101. doi:
28 10.1188/14.cjon.93-101 [published Online First: 2014/01/31]
29
30 39. Den Hartogh G. Suffering and dying well: on the proper aim of palliative care. *Medicine, health care,*
31 *and philosophy* 2017;DOI 10.1007/s11019-017-9764-3
32
33 40. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care
34 planning: an international consensus supported by the European Association for Palliative Care.
35 *Lancet Oncol* 2017;18(9):e543-e51. doi: 10.1016/s1470-2045(17)30582-x [published Online First:
36 2017/09/09]
37
38 41. Maas M, Beets-Tan RG, Lambregts DM, et al. Wait-and-see policy for clinical complete responders
39 after chemoradiation for rectal cancer. *J Clin Oncol* 2011;29(35):4633-40. doi:
40 10.1200/jco.2011.37.7176 [published Online First: 2011/11/10]
41
42 42. Starreveld DEJ, Daniels LA, Valdimarsdottir HB, et al. Light therapy as a treatment of cancer-related
43 fatigue in (non-)Hodgkin lymphoma survivors (SPARKLE trial): study protocol of a multicenter
44 randomized controlled trial. *BMC Cancer* 2018;18(1):880. doi: 10.1186/s12885-018-4746-2
45 [published Online First: 2018/09/12]
46
47 43. Menning S, de Ruyter MB, Veltman DJ, et al. Changes in brain white matter integrity after systemic
48 treatment for breast cancer: a prospective longitudinal study. *Brain imaging and behavior*
49 2018;12(2):324-34. doi: 10.1007/s11682-017-9695-x [published Online First: 2017/03/16]
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week

Graphs by Patient

Coreq checklist

Complex challenges in patients with protracted disease incurable cancer: an ethnographic study

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?
P4, recruitment and sampling
2. Credentials: What were the researcher's credentials? E.g. PhD, MD
P1
3. Occupation: What was their occupation at the time of the study?
P1
4. Gender: Was the researcher male or female?
P4
5. Experience and training: What experience or training did the researcher have?
P4

Relationship with participants

6. Relationship established: Was a relationship established prior to study commencement?
P4
7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?
P4
8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.
P4 (methods), P10 (limitations)

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?
P4 (ethnography, thematic content analysis)

Participant selection

10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball?
P4 Participants were random selected, when HB was in the hospital
11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email.
P4, face-to-face
12. Sample size: How many participants were in the study?
P5
13. Non-participation: How many people refused to participate or dropped out? Reasons?
P4 (none of the patients, in 3 situations nurses advised not to approach the patient)

Setting

14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace.
P4 (hospital)
15. Presence of non-participants: Was anyone else present besides the participants and researchers?
P4 (close relatives, n=8)
16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date

P6*Data collection*

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?

P4 (first of all openly framed)

18. Repeat interviews: Were repeat interviews carried out? If yes, how many?

P5

19. Audio/visual recording: Did the research use audio or visual recording to collect the data?

P4 (all conversations were audio-taped)

20. Field notes: Were field notes made during and/or after the interview or focus group?

P4 (observations, and some additional talks with patients)

21. Duration: What was the duration of the interviews or focus group?

P4

22. Data saturation: Was data saturation discussed?

P4, until data saturation was reached.

23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?

P5

Domain 3: Analysis and findings

24. Number of data coders: How many data coders coded the data?

P5 (2, HMB, and MACA)

25. Description of the coding tree: Did authors provide a description of the coding tree?

P5 (no explicit description of the coding tree, but we described several items)

26. Derivation of themes: Were themes identified in advance or derived from the data?

P5 (yes)

27. Software: What software, if applicable, was used to manage the data?

P5

28. Participant checking: Did participants provide feedback on the findings? No, but we sent them a lay version of the results.

Reporting

29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number.

P5-9

30. Data and findings consistent: Was there consistency between the data presented and the findings?

P5-9 (yes)

31. Clarity of major themes: Were major themes clearly presented in the findings?

P5-9 (yes)

32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?

P5-9 (yes)

BMJ Open

**Complex challenges for patients with protracted incurable cancer:
An ethnographic study in a comprehensive cancer centre in the Netherlands**

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3 **Complex challenges for patients with protracted incurable cancer:**
4 **An ethnographic study in a comprehensive cancer centre in the Netherlands**
5

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ABSTRACT (max 300 words)

Objective

Advances in oncology increasingly result in protracted disease trajectories for patients with incurable cancer. In this disease phase, patients are aware of the incurable nature of cancer although they are not yet approaching the last phase of life. We explored the challenges for patients confronted with protracted incurable cancer.

Design

Ethnographic study (2015-2017) based on conversations with patients, observations at a day-care unit and a selection of information from the medical records of patients who died during the study period.

Setting

The day-care unit of a comprehensive cancer centre in the Netherlands.

Participants

Nineteen patients with stage IV breast cancer (in remission, ≥ 1 year after diagnosis) and 11 patients with stage IV lung-cancer (in remission, ≥ 6 months after diagnosis).

Results

In patients who had died during the study period, the treatment response often fluctuated between stable, remission and progression throughout the course of the disease. Patients reported that this fluctuation could be overwhelming. However, as patients grew accustomed to having protracted incurable cancer, the distress associated with fluctuations (perceived in scan results) slowly faded. Patients reported that cancer became part of who they were. At the day-care unit, most patients talked about their disease in an optimistic or neutral way and expressed delight in life. They often expressed gratefulness for the possible prolongation of life, expressed hope and tried to stay optimistic. This was frequently reinforced by optimistic doctors and nurses. Relatives, however, could downplay such optimism. Moreover, some patients acknowledged that hope was qualified by their personal challenges regarding their disease.

Conclusions

In situations where tumours remained in remission or were stable for extended periods, patients grew accustomed to having cancer. At the day-care unit, medical professionals typically encouraged an attitude of being hopeful and optimistic, which could be downplayed by relatives. More research is warranted to explore this new disease phase and this optimistic view among healthcare professionals.

Strengths and limitations of the study

- This is the first study that qualitatively explores the impact of living with protracted incurable cancer.
- This study covered a long time period (2015-2017) and could therefore show that the patient's condition fluctuates during the period in which patients are diagnosed with incurable cancer.
- This study combined observations, short conversations with patients (and relatives), and medical record data to gain in-depth insight into this relatively new disease phase.
- A limitation of the study is that the conversations were sometimes brief and that results with respect to communication with patients may be different in other (non-specialised) cancer hospitals as hospital cultures differ.
- The average age of the patients was quite high and there were relatively few men, probably reflecting different experiences with respect to protracted incurable cancer between men and women.

Keywords: chronic cancer, doctor-patient communication, medical ethics, sociology, survivorship care, palliative care

INTRODUCTION

Advances in oncology have resulted in protracted disease trajectories in incurable cancer patients.¹ Accordingly, it is sometimes argued that some forms of cancer seem to be turning into a chronic disease.²⁻⁴ Surprisingly, little information is available as yet about experiences with long-lasting incurable cancer.⁵ However, given the extended periods of survival, patients with long-lasting incurable cancer may benefit from either survivorship interventions⁶ (i.e. the approach for addressing long-term needs of cancer survivors) or palliative or supportive care interventions.⁷ Studies focusing on the last phase of life or on advanced cancer in general may help provide some ideas.⁸⁻⁹ Intense fear about death, fatigue, uncertainty about the prognosis, and hope for recovery have been shown to be rather important.¹⁰⁻¹² Plausibly, the same topics may be relevant for patients with protracted incurable cancer. Whether and to what extent is not yet clear.

Little has been written on how these protracted disease trajectories are challenging the ability of patients to cope with the disease. Walshe et al, however, have reported on successful coping strategies for patients living with advanced cancer, illustrating the importance of focusing on patients' personal coping strategies.¹³ Moreover, Roberts and his colleagues also discussed coping strategies in advanced cancer, focusing on either a 'problem-focused' or 'emotion-focused' therapy.¹⁴ In contrast, much has been written about the novel cancer therapeutics themselves.¹⁵⁻¹⁷ During the last couple of years, new mutations have been discovered in patients with lung cancer (epidermal growth factor receptor (EGFR) mutations and BGFR mutations), breast cancer (BRCA1, BRCA2 and HER2) and several other cancers, resulting in the development of new genotype-directed therapy throughout the patient's disease course. Increased prognostic uncertainty on the part of clinicians, however, complicates prognostic communication with patients, and accordingly certainty among patients.¹⁸ This changing landscape in treatment options will obviously raise new (ethical) dilemmas for patients as well as healthcare professionals.

Our project started from the observation that patients living with protracted incurable cancer are inadvertently overlooked. In this specific study, we spoke with patients (and their close relatives) at the day-care unit and focused on the challenges in this specific disease phase.

METHODS

Design and Setting

This study is part of a larger project that examines the experiences, needs and wishes of patients with protracted incurable cancer and their healthcare professionals, using a mixed methods ethnographic design. For this study, a qualitative database was used in which the experiences, needs and wishes of patients with prolonged incurable cancer were collected. Data collection started in 2015. It consisted of short conversations with patients at the day-care unit and in-depth interviews in the hospital or home setting, as well as some interviews with bereaved family members. Over the years, topics were added to the interviews and conversations, depending on the discussions that were taking place at that time. A COREQ checklist was used to make sure the qualitative research was of an appropriate standard.

We purposefully chose this design to ensure that the results would ultimately be practice driven and connect closely to medical practice.¹⁹ A specific strength of ethnography lies in its ability to communicate details plotted in experiences of illness and care.²⁰ In the present study, we combined participant observation with (informal) conversations to build in-depth understanding about the practice of incurable cancer (explicitly and implicitly) and how healthcare professionals and patients experience long-standing incurable cancer within the context of daily medical practice. Since this is a relatively new research area, we established a definitional framework beforehand (see **Table 1**).

Recruitment and Sampling

1. Observations

Observational research started in July 2015. In the *first phase*, field notes were made in the 'backstage' regions of practice (e.g. general locations such as waiting rooms) to generate knowledge about how and why patients and healthcare professionals behave as they do. HMB sat with, observed and sometimes accompanied healthcare professionals.

In the *second phase*, observation moved to the 'front stage' – that is, doctor-patient encounters and direct interviews with patients. In this phase, more detailed observations were made and described in observational field notes. Apart from the research questions for the main study, HMB focused on the following topics during the observations: the atmosphere, emotions, mood (patient/personal reflections), language use, interaction between patients and healthcare professionals; and answers associated with the research questions.

Observational field notes were compiled on the observation days (n=21).

2. Short conversations

From July 2015 onwards, short conversations were held at the day-care unit of a comprehensive cancer hospital in the Netherlands. These conversations were considered least disturbing for the patient because they were already at the location anyway. Furthermore, they were less likely to be affected by any specific event, such as receiving good/bad news after a consultation with their treating doctor. Only lung-cancer patients who had been diagnosed with stage IV disease at least six months previously and breast-cancer patients who had been diagnosed with stage IV disease at least one year previously were selected.

In total, 30 patients were approached at the day-care unit by HMB, a female researcher in social sciences with many years of interview experience. All patients were approached at times when HMB was at the hospital and had time to talk to them. Patient selection was therefore random. All patients were given an information sheet about the study, including background information on the researcher who carried out the interviews. Before approaching a patient, HMB checked with the nurses at the day-care unit whether it would be appropriate to do so. In three cases, the nurses advised her not to approach patients because they had just received bad news. HMB had not seen any of the patients before the start of the conversations at the day-care unit.

The short conversations had an open frame. We purposefully chose not to use a large topic list, and we openly asked how patients felt about living with protracted incurable cancer. Often, the conversation started with their disease history and possible unmet needs. As the study progressed, we asked more specifically about patients' quality of life. We did not initiate specific topics, such as positivity and fear, and only focused on such items if they were brought up by the patient himself or herself.

We continued conversations with patients until data saturation was reached with respect to the research questions of this specific study. In some cases, we asked patients whether they would be willing to continue in another interview. These interviews are, however, not included in this study, although MvA participated in five of those interviews to attain a clearer view of the dilemmas of this specific patient group.

The median length of the audio-recorded conversations at the day-care unit was 10 minutes (see **Table 2**). Conversations ended due to circumstances (such as the end of the chemotherapy regimen); because patients simply wanted to stop talking; or because they had nothing more to say. Patients received a short information

letter with contact details about the study before a conversation was started. None of the patients refused to participate. In eight cases, a close relative of the patient (often the partner) was present as well. The conversations of the 30 patients were audio-recorded and transcribed verbatim (see **Table 2**). The transcripts were not returned to the participants for comments.

Table 2

	<i>n</i> patients	Mean time length (<i>SD</i>)	Median time length	Minimum	Maximum
Short conversations ¹	30	13 (9)	10	2	39

3. Short conversations were held at the day-care unit, while patients received their chemotherapy regimen. Conversations that were held during the observation days (*n*=12) are not included, and they were recorded in field notes only.

3. Medical record data

We collected additional medical record data of 12 patients the study patients whose conversation was audio-recorded (*n*=30), and who had died (*n*=12) by the end of 2016. We recorded the disease status (e.g. stable, remission and progression) at the time of each appointment with the treating doctor and plotted these data over time in figures for every single patient (see **Figure 1**). The disease status was obtained from the doctors' notes of the consultations. Their conclusion about the disease status was mostly based on a comparison of tumour markers and/or radiological findings with those in the previous visit.

Patient and public involvement

The research questions for this specific study were inspired by problems we noticed while working in or observing actual medical practice. Thus the research questions were – by definition – inspired by problems experienced by the patients themselves. We did not involve patients in the design of the study. However, during recruitment and the execution of the study we did ask patients about possible suggestions to further improve the study. Finally, we intend to send our study participants a publication with our results at the end of the study.

Data analysis

All conversations and observations were coded and analysed using the programme Atlas-ti 8.2. We (MACA and HMB) read through 12 conversations separately at different times to search for themes. These themes were discussed to check for interpreter consensus. Subsequently, a scheme was developed to index text fragments with similar content (in Atlas-ti 8.2). In analysing the themes, hypotheses emerged and were checked against the data.

Although the conversations were performed by one researcher only, we ensured appropriate analysis of the data by involving at least two researchers and holding proper discussions about the findings with several project members. MACA subsequently developed a tabular grid to organise interview information from each individual patient regarding the following themes: support from the patient's surroundings, physical complaints, uncertainty, an indication of the prognosis, how the patient seemed to deal with the final phase of life, daily life, and some space for notable aspects in either content or language use. Furthermore, descriptive information was added to the table concerning the date and duration of the interview, sex, age, type of cancer, location of the interview and the attendees. Other members of the team (OD, JAS, GSS) participated in the analysis by commenting on previous versions of the Results section.

All the authors evaluated whether the final quotes were used in the right (medical) context. According to Dutch policy, the study did not require a formal review by an ethics committee because the content of the interviews and observations was not considered to be potentially incriminating. However, we asked the the medical ethics committee of our hospital to provide us with a declaration of no objection (In Dutch: *Verklaring van geen bezwaar*) confirming that our medical ethics committee had seen the study and had provided local approval to carry out the study, a process in accordance with local ethics regulations. Before starting a conversation, we provided the patient with information and asked them for permission to audio-record this conversation so as to be able to use accurate quotes in the final manuscripts. We sent a lay version of our results to the participants who were still alive; the participants could contact the researcher to comment on this or ask for clarification.

The following conventions are used to distinguish in the text between different types of data collection and technique: all data collected by observation are presented in the text in *italics*; all data collected from audio-recordings are presented in the text in quotation marks and in *italics*.

A professional translator translated the quotes that we chose to illustrate our results.

Table 1. Definitional framework

THE DISEASE	
Disease phases	
Chronic disease / Chronic cancer	<p>According to the National Institute for Public Health and the Environment (In Dutch: RIVM), a chronic disease is a disease with irreversible prospects and with a relatively long disease course. Chronic diseases are different from other diseases in that these patients are care-dependent for a very long time.²¹ Cancer is also categorised as a chronic disease.</p> <p>In medical oncology, there is a major debate as to whether cancer should be viewed as a chronic disease or not, while healthcare professionals do not want to provide unrealistic prognoses. This also holds for patients with protracted incurable cancer.</p>
Protracted incurable cancer	<p>We define protracted incurable cancer as a disease phase where patients receive cancer treatment such as immune therapy, hormonal treatment or chemotherapy, and whereby the disease can be considered stable or in remission for long periods of time.</p> <p>During this period, the patient's physical condition may sometimes go up and down due to treatment side-effects. In other words, although the response to treatment/the patient's condition can be considered stable or in remission for long periods, briefer periods of progression also occur.</p>
THE PATIENT	
States associated with living with cancer	
Deliberate optimism	<p>Optimism is all about anticipating a positive future. To be optimistic means that we expect things to go our way.²² Optimists are aware that positive outcomes are dependent on their own efforts.</p> <p>It should however be noted that optimism is partly inherited, and certain patients are more easily able to choose to be optimistic (e.g. deliberate optimism).</p>
Hope	<p>As opposed to optimism, hope generally focuses on a specific goal, such as hope for a longer life.²³ It contrasts with hopelessness/powerlessness, and is much more about how you feel. It is also argued that emotions go beyond the mere 'feeling' of that emotion; emotions are a way in which we interact with the world, and accordingly, hope is sometimes defined as an emotional attitude.²⁴</p>
Fear	<p>Research about cancer patients' fear is extensive. In the context of protracted incurable cancer, fear of cancer recurrence (FCR) is commonly studied.²⁵ It is often characterised by chronic worry, excessive body checks and difficulties with making future plans.</p>
Uncertainty	<p>There has also been a great deal of research on uncertainty.²⁶ In essence, uncertainty involves the inability to attribute meaning to events.</p>
<p>Note: Our aim is not to explore a specific concept but to conceptualise some definitions of terms that often came up during conversations about these topics.</p>	

RESULTS

Quantitative findings

Of the 30 patients, 24 were women (80%) and 6 were men (20%). In this specific study sample, 19 patients experienced some form of breast cancer (63%) and 11 patients experienced some form of lung cancer (37%). The disease trajectory of patients who died during the study period is depicted in **Figure 1**. The patient's response to treatment often fluctuated between stable and either remission or progression. The disease period of patients in this specific hospital varied from approximately 30 to 130 weeks.

Figure 1. Patients' response to treatment as described in their medical status during the consultations with the treating doctor. Each graph depicts one patient who died during the study period (n=12).

Qualitative findings

In the conversations that we held with patients at the day-care unit, three different themes were identified: their uncertainty about the prognosis in this protracted disease trajectory, their intention to stay hopeful, and the influence of others in staying hopeful and finding a new balance.

On and on: Facing death versus surviving

Patients' and relatives' uncertainty seemed to be the overarching theme in the majority of the conversations that we held with patients at the day-care unit. The unpredictability of treatment response seemed to interfere with patients' ability to attribute meaning to activities, and accordingly achieve certainty. This was expressed either explicitly or implicitly but always revealed two sides of the same coin, i.e. patients seemed to be hopeful and fearful at the same time. Being aware of the incurable nature of their disease also brought out those two sides of the same coin.

R2: Sure, I think you've touched on a key aspect there [...] there is no path to full recovery, at least that's what they actually said at a certain point. [...]

R: Personally, I call it bad and stable.

I: Right.

R: Yes, stable, but we know that it's no longer 100% curable... but it could take a very long time yet.

I: Right, it could be stable for a very long time.

R2: Yeah, and then I reckon the aim is to just take the right approach to let you do as many things as possible that you want to do.

Patient 16, 2016 (breast cancer)

Sometimes, the patient's fear predominated. Despite being in a stable condition, those patients experienced chronic stress from the fear that cancer would recur. Patients seldom complained, but it could however paralyse them and prevent them from doing other activities. For these patients, the frequent consultations at the hospital could be both burdensome and enlightening at the same time.

*Yes, I think I'm someone who soon sees the gloomy side. Well, of course that's annoying. That's not good. Then you think ... then you've had a CT scan and you have to wait another week for the results and then you think: 'Oh, I can feel something here, could that be why?' And then, well, today you get the message that it hasn't grown. So you've spent a week worrying about nothing really. **Patient 5, 2016 (lung cancer)***

Often, the patient's hope predominated, especially in situations where they had grown accustomed to having incurable cancer. Although most patients said they knew that their disease could not be cured any more, they often refused to focus on the incurable nature of their disease. They wanted to stay positive and retain autonomy. One patient, for instance, reported that she did not want to wait for the next scan results, but preferred to do something herself to retain some form of autonomy, partly in order to stay positive. She explained, for instance, that she was very conscious about what she ate, as she was convinced that too much sugar could have a negative impact on tumour growth. This positive and hopeful attitude sometimes decreased if patients had undergone multiple forms of oncological treatment, and/or the response to treatment had been disappointing. Still, patients said that they were clinging onto hope.

I: Is it because there is less response right now, that you are more often thinking about your disease?

R: I don't know, but the heaviness... You do spend a very long time with this feeling that one day we'll win this battle, whether that's justified or not.

Patient 3, 2016 (breast cancer)

Having a seemingly short life expectancy made patients conscious that all occasions could be for the last time, which could be distressing even if this turned out not to be the case (because new treatment options were offered). Prolongation of life was welcomed on the one hand, but on the other hand it gave them less security as their future life was rather uncertain.

But then I came back, partly with the idea that this time I'll do things completely differently. We won't start making preparations any more, or more or less say goodbye or go along to every birthday party, celebrating in style because it might be your last time. But it drives you crazy if you're constantly having to say goodbye.

Patient 1, 2015 (lung cancer)

Apart from the mental challenge, patients' experiences of physical discomfort sometimes resulted in uncertainty too. Patients could become extremely worried if they felt pain somewhere in their body, immediately thinking of cancer growth or (more) metastases. Other patients explained that they no longer trusted their bodily sensations at all as the diagnosis of cancer was something they would not have expected beforehand either. Being a stranger to your own body increased the sense of uncertainty and, accordingly, negatively affected patients' well-being.

Sure, and then you go to the hospital and you think, well, I feel good, it's all going well and ... But it turns out it's not going well and then you just lose your confidence in your body completely.

Patient 25, 2015 (breast cancer)

Staying hopeful and optimistic

In this day-care setting, where nurses sometimes had to rush through the chemotherapy regimen, the atmosphere could be described as positive and energetic. Nurses said that they lacked time for deeper, time-consuming conversations. Yet they were friendly, greeted patients they knew from previous visits and joked a lot. "I just need to check your birth date" (and they ran to the next patient), "Are you cold? I'll get another blanket for you. A hot water bottle may be even better (I use them too when we go camping) but that's not working here" (and they rushed away). This positive and informal atmosphere seemed to impact both healthcare professionals and the visitors at the unit. In this way, the atmosphere at the day-care unit seemed to encourage positive feelings and thoughts. Some patients reported that having conversations about the last phase of life would be too burdensome at this day-care unit.

'I guess that if conversations here (at the day-care unit) were to particularly focus on the approaching death, conversations would be more burdensome. So no, it's OK like this.' **Patient 31 (breast cancer)**

Apart from being hopeful, patients also explained how they intended to stay optimistic, e.g. how they really tried to believe in what they hoped for. For instance, they (rationally) argued that they could start worrying once their prognosis got much worse. Some patients tried to look at their situation in a positive/optimistic way, for instance by viewing every visit to the hospital as a 'day out'. Compared with being hopeful, being optimistic could be viewed as a more active/rational approach. In some situations, patients decided to make decisions against their doctors' advice, such as asking for a second opinion. In doing this, their optimism could be regarded as a coping strategy.

No, I don't spend much time thinking about it [approaching death] because that would drive you crazy, I reckon. Still enjoy life a bit and be with the children for as long as that's still possible, and when it's no longer possible, there will still be plenty of time for sackcloth and ashes. At least that's how I see it, or want to see it [laughs], right.

Patient 24, 2015 (breast cancer)

Compared with being hopeful, being optimistic more often seemed to be a real choice. However, this was much easier for some patients than for others. Patients who found being optimistic easier also found it easier to accept their fate and cope with the disease. Moreover, those patients seemed to be more receptive to good news, which immediately resulted in a happy and relaxed mood and euphoric reactions.

It's great, I am just so happy that... she said it [the cancer] won't go away completely... but she can't really say anything about that. But what happened now was overwhelming.[patient just heard about their excellent response to treatment] **Patient 21, 2015 (breast cancer)**

The influence of others and finding a new balance

Other people could have an important role as well in whether patients were either hopeful or optimistic. Healthcare professionals could be of tremendous importance in either downplaying or increasing patient's hope as well as their optimistic attitude to life. Although patients appreciated doctors' commitment, they sometimes doubted whether the information they had just received was adequate. Open communication about the fact that life expectancy could increase (rather than providing a worse prognosis) could also upset patients and make them fearful.

And if they say 'Well, there is a very small chance that you might possibly recover', you find yourself actually kind of upset and thinking 'Gosh, I was just beginning to get used to the idea that I'm dying and now I suddenly have to start thinking about the future and that kind of thing'. Patient 11, 2016 (breast cancer)

Some patients said that they had previously requested psycho-social support, right after the cancer diagnosis. A majority of the patients further explained that this protracted disease phase was different: they just wanted to continue life, without psycho-social help. Most patients told us that after the big shock of discovering they had cancer, they had slowly found a new life balance with a positive focus.

I remember that I was really struggling with it four years ago, when they first diagnosed it. And then I did 'In balance', mainly really for the social welfare, for the social support. And that helped me a great deal to actually get a grip on it. So things like learning to accept the fact that you'll have to learn to live with the tiredness. And your own mortality and that kind of thing. Patient 11, 2016 (breast cancer)

Most patients explained that after a certain time, the situation of having protracted incurable cancer eventually resulted in acceptance of the disease, which could be interpreted as positive. In this stable disease period (albeit with fluctuations) patients did not seek any psycho-social help and often felt no need to talk about their disease with close relatives: they regarded their disease as part of who they were. Like the healthcare professionals, they seemed to downplay the situation by making comparisons like "I've also gone grey in the course of my life".

It's, I've also gone grey in the course of my life and we never talked about that, I mean, it's just one of those things, that's really the way it is and it's just part of who I am. Like going grey. Patient 26, 2015 (breast cancer)

Nevertheless, it sometimes seemed as if those patients were not as confident as they claimed, e.g. some of these patients became emotional during the conversation. Moreover, patients appreciated support from friends and close relatives.

One way or another, he [partner] immediately notices if something isn't going well. But he sits in on all the appointments, he helps in asking questions. [...] I lie here in a hospital bed sleeping part of the day and then waking up, but he still comes along. So even if you can't see him, you know he's waiting for you, you know he's close by. Patient 2, 2017 (lung cancer)

DISCUSSION

Facing death (progression of the disease) and surviving (remission of the disease) several times could be overwhelming for patients. During these periods, support was greatly appreciated. Most patients grew accustomed to having protracted incurable cancer. The associated fear then slowly faded. As most patients regarded cancer as part of who they were, they generally felt no need to talk about their disease. At the day-care unit, patients frequently adopted a hopeful and optimistic attitude, which was frequently reinforced by optimistic doctors and nurses. Hope often dominated their uncertain lives; fear was present and visible to only a small extent. Partners and close relatives, however, could downplay this optimistic stance.

Strengths and weaknesses

A previous Dutch ethnographic study focused on the phenomenon of 'false optimism about recovery'. In the waiting room, incurable lung cancer patients rarely appeared to deal with their approaching death, despite their limited life expectancy.¹⁹ Approximately 20 years later, new cancer therapeutics have changed the landscape in cancer care. We now focused on a new phenomenon, i.e. 'Patients' challenges while having protracted incurable cancer'. A feature that increases the validity of this study is the long time period (a two-year study period) and the combination of observations (although not covered in detail here), short conversations with patients (and close relatives), and medical record data. This long time period is important to be able to show that the patient's condition does indeed fluctuate and to be able to conduct interviews over a long time period. Our study also has limitations. First, this study was performed at one cancer centre, and our results may therefore not be representative for the whole cancer population. However, we particularly wanted to focus on patients' challenges while living with protracted incurable cancer and these challenges are probably comparable in other hospitals. Second, the conversations could be very brief. However, since we were particularly interested in patients' perceptions in the day-care setting, this can be considered an inherent part of the ethnographic research. Third, the average age of the patients was quite high and there were relatively few men (because we selected breast-cancer and lung-cancer patients). Fourth, the patients may have given socially desirable answers, because they had close relatives in proximity, and given the absence of a private space. Lastly, we focused on the day-care setting only. We purposefully chose to focus on this setting since we were interested in how patients in relatively good condition experienced their disease. Moreover, we were interested as to whether the approach towards patients at the day-care unit could be used in other settings or situations also. We realise however that patients and close relatives may respond rather differently in the home setting, for instance.

Balancing between different degrees of hope and fear

All the patients in our study experienced uncertainty to some extent in the context of their disease. This is in line with previous literature that shows that uncertainty is a common cancer experience that may be related to treatment choices, lack of information and uncertainty in coping with everyday life.^{11 26 27} Our findings, however, contrast with the common cancer disease trajectory, i.e. reaching an advanced stage followed by a predictable downhill course over weeks or months. Instead, the disease status of patients with long-standing disease trajectories often went up and down (see also **Figure 1**). As a result, it is understandable that levels of fear and hope will go up and down too.²⁸

Apart from uncertainty due to ongoing fluctuations between stable status, remission and progression, a new element is uncertainty about the possibility that new treatment options will be developed in time. Some patients had already *given up hope* for a longer life and had merely accepted that they would die. This could be explained by the fact that patients' wish to live decreases and their wish to die increases when nearing death, since their acceptance of death grows.²⁹ Now, this natural dying process was to a certain extent disrupted. Yet other characteristics of protracted incurable cancer *gave room for hope*. As patients grew accustomed to having incurable cancer, they learned more about their responses to their disease, and accordingly what they hoped for. Interestingly, what patients value may change or come to be prioritised differently, and accordingly, also what they hope for. A discussion paper by Simpson²⁴ argues that in situations where people find it hard to imagine what their life could be like, it is difficult to hope. This is in accordance with what patients experienced in our study. Opening up the discussion about future treatment options may decrease uncertainty, and increase the patient's hope.

Using optimism in the context of protracted incurable cancer

Choosing to be optimistic seemed to be an effective coping strategy, according to the patients in our study. An optimistic or hopeful approach is in line with what many medical oncologists also believe is the right way to go: although an objective positive effect on disease progression has not been shown, instilling hope in patients has previously been shown to have an effect on how patients try to maintain their weight, take their medications on time, et cetera.³⁰ This discussion paper further showed that maintaining optimism is considered one of the essential elements of meaningful medical practice. Although hopefulness for medical oncologists, especially in the academic/research settings, is often grounded in the biomedical dimensions of their work, it has been shown to be worthwhile. The paper further suggests that the optimistic stance of the nurses in our study may be effective.

In general, the balance among feelings relates to differences in optimism, i.e. positive feelings (like being hopeful) relate to positive thinking (like being optimistic).³¹ Some patients in our study reported that their confidence and

1
2
3 positive feelings grew throughout the disease course in situations where treatment appeared to have a real effect
4 on the tumour. Carver *et al.* suggests that an optimistic life stance is more susceptible to change during times of
5 transition and/or when outcomes become uncertain.³² Our study suggests that optimism did indeed change in
6 uncertain situations, at least in most of the patients we spoke with at the day-care unit of this specific hospital.

7
8 Yet it should be noted that optimism as a coping strategy was probably relatively easy because all patients were
9 in relatively good physical condition. Moreover, patients might have given socially desirable answers. A previous
10 study, for instance, showed that cancer patients receiving palliative care can be remarkably optimistic in the
11 hospital or in their satisfactory relationship with the nursing staff.^{33 34} These findings are also in line with our data
12 that show that nearly all patients wanted to be optimistic, although fear (FCR) was sometimes overriding and/or
13 close relatives said something different. Perhaps optimism is frequently used as the initial coping strategy, but if
14 fear and uncertainty predominate, other coping strategies need to be used as well.

14 **Conclusions and implications for policy**

15 This explorative ethnographic study can be considered a first step towards discovering how recent developments
16 in cancer will shape clinical and research domains in the context of protracted incurable cancer and chronic
17 disease management, including definitions regarding the curative/palliative dichotomy. By providing insight into
18 the social dynamics of healthcare, our study may increase awareness about the current developments in the care
19 of patients with protracted incurable cancer.³⁵

20
21 Our study shows that patients with protracted incurable cancer have different experiences to some extent to
22 patients with a common palliative trajectory.³⁶ Their physical and mental status often fluctuated, partly because of
23 unpredictable responses to cancer treatment.³⁷ Instead of slow physical deterioration, our patients at a certain
24 point grew accustomed to a stable situation and accepted the minor physical symptoms (“like going grey”).

25
26 Our results provide entry points in how patients with protracted incurable cancer could be assisted and cared for,
27 taking into account their personal coping strategies as well as possible interventions that might benefit those
28 patients.

- 29 - More research is warranted to explore whether optimism, as a common care approach by nurses, is sufficient
30 to guarantee a good and meaningful life in these patients. If patients (and their close relatives) were better
31 able to show resilience,³⁸ this could increase their well-being. Yet account needs to be taken of the fact that
32 such a positive life stance may not be what everyone wishes.³⁹ Moreover, avoiding negative emotions is not
33 always realistic or desirable.
 - 34 - More research is warranted about patients’ values and wishes in this protracted disease phase. The use of
35 advanced care planning is recommended these days,⁴⁰ but it is also known that expressing values and
36 wishes for the next stage/disease period can be difficult.³⁶ Yet patients in a stable disease phase — as is
37 often the situation in long-standing incurable cancer — will probably be able to formulate life goals for the
38 present stage.^{37 41} This might be more helpful than encouraging these patients to think about their
39 approaching death only, although this aspect should not be neglected. Such an approach is probably also
40 more in line with survivorship care approaches, such as light therapy against cancer-related fatigue⁴², or the
41 long-term cognitive effects of some forms of cancer treatment.⁴³
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Contributors

HMB designed the study. HMB, MvA and EPEM carried out the study. HMB, MvA, OD, EPEM, JAS, and GSS were involved in the interpretation of the study findings. HMB and MvA wrote the manuscript, which was critically read by all the authors. HMB is the guarantor of the study. All authors had full access to all the data in the study and can take responsibility for their integrity and the accuracy of their analysis.

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Competing interests

None declared.

Ethics approval

The study did not require review by a medical ethical committee because the observations and short talks were not considered to be possibly incriminating for patients/relatives.

Data sharing

All data relevant to the study are included in the article or uploaded as supplementary information.

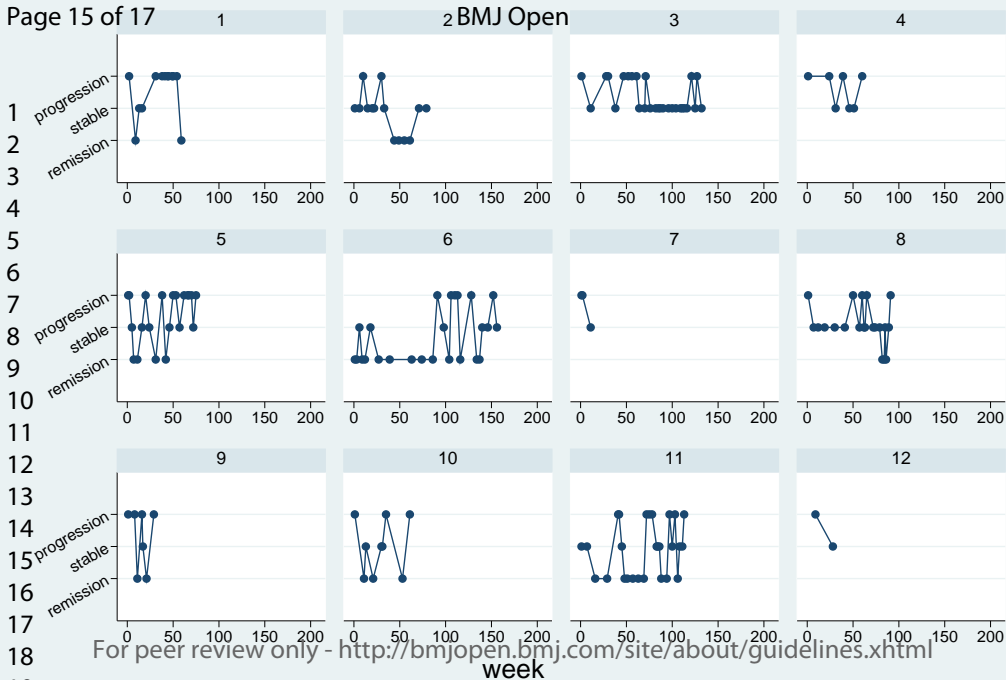
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References

1. Bishop AJ, Ensor J, Moulder SL, et al. Prognosis for patients with metastatic breast cancer who achieve a no-evidence-of-disease status after systemic or local therapy. *Cancer* 2015 doi: 10.1002/cncr.29681 [published Online First: 2015/09/09]
2. Buiting HM, Linn SC, Smorenburg CH, et al. [Living with incurable cancer]. *Ned Tijdschr Geneesk* 2016;160(0):A9615. [published Online First: 2016/04/29]
3. Harley C, Pini S, Bartlett YK, et al. Defining chronic cancer: patient experiences and self-management needs. *BMJ supportive & palliative care* 2015;5(4):343-50. doi: 10.1136/bmjspcare-2012-000200rep [published Online First: 2015/11/21]
4. McCorkle R, Ercolano E, Lazenby M, et al. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011;61(1):50-62. doi: 10.3322/caac.20093 [published Online First: 2011/01/06]
5. Fadul N, Elsayem A, Palmer J, et al. Supportive versus palliative care: What's in a name. *Cancer* 2009;115:2013-21.
6. Aaronson NK, Mattioli V, Minton O, et al. Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice. *EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]* 2014;12(1):54-64. doi: 10.1016/j.ejcsup.2014.03.005 [published Online First: 2015/07/29]
7. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA : the journal of the American Medical Association* 2009;302(7):741-49. doi: 10.1001/jama.2009.1198 [doi]
8. Brom L, Pasman HR, Widdershoven GA, et al. Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PLoS One* 2014;9(6):e100435. doi: 10.1371/journal.pone.0100435 [published Online First: 2014/06/26]
9. Buiting HM, Rurup ML, Wijsbek H, et al. Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ (Clinical research ed)* 2011;342:d1933. doi: 10.1136/bmj.d1933
10. Halkett GK, Lobb EA, Oldham L, et al. The information and support needs of patients diagnosed with High Grade Glioma. *Patient Educ Couns* 2010;79(1):112-9. doi: 10.1016/j.pec.2009.08.013 [published Online First: 2009/09/19]
11. Shaha M, Cox CL, Talman K, et al. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau* 2008;40(1):60-7. doi: 10.1111/j.1547-5069.2007.00207.x [published Online First: 2008/02/28]
12. Ashbury FD, Findlay H, Reynolds B, et al. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;16(5):298-306. [published Online First: 1998/12/10]
13. Walshe C, Roberts D, Appleton L, et al. Coping Well with Advanced Cancer: A Serial Qualitative Interview Study with Patients and Family Carers. *PLoS One* 2017;12(1):e0169071. doi: 10.1371/journal.pone.0169071 [published Online First: 2017/01/21]
14. Roberts D, Calman L, Large P, et al. A revised model for coping with advanced cancer. Mapping concepts from a longitudinal qualitative study of patients and carers coping with advanced cancer onto Folkman and Greer's theoretical model of appraisal and coping. *Psychooncology* 2018;27(1):229-35. doi: 10.1002/pon.4497 [published Online First: 2017/07/12]
15. Blank CU, Haanen JB, Ribas A, et al. CANCER IMMUNOLOGY. The "cancer immunogram". *Science (New York, NY)* 2016;352(6286):658-60. doi: 10.1126/science.aaf2834 [published Online First: 2016/05/07]
16. Smit EF, Wu YL, Gervais R, et al. A randomized, double-blind, phase III study comparing two doses of erlotinib for second-line treatment of current smokers with advanced non-small-cell lung cancer (CurrentS). *Lung Cancer* 2016;99:94-101. doi: 10.1016/j.lungcan.2016.06.019 [published Online First: 2016/08/28]
17. Temel JS, Gainor JF, Sullivan RJ, et al. Keeping Expectations in Check With Immune Checkpoint Inhibitors. *J Clin Oncol* 2018;Jco2017762146. doi: 10.1200/jco.2017.76.2146 [published Online First: 2018/01/26]
18. LeBlanc TW, Temel JS, Helft PR. "How Much Time Do I Have?": Communicating Prognosis in the Era of Exceptional Responders. *American Society of Clinical Oncology educational book American Society of Clinical Oncology Annual Meeting* 2018(38):787-94. doi: 10.1200/edbk_201211 [published Online First: 2018/09/21]
19. The AM, Hak T, Koeter G, et al. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ (Clinical research ed)* 2000;321(7273):1376-81.
20. Livingstone J. Improvising medicine. An African oncology ward in an emerging cancer epidemic 2015.
21. Vonk R, Korevaar JC, van Saase L, et al. Een samenhangend beeld van kanker: ziekte, zorg, mens en maatschappij. Thema Rapportage van de Staat van Volksgezondheid en Zorg: RIVM, 2016.
22. Mendiburo-Seguel A, Paez D, Martinez-Sanchez F. Humor styles and personality: A meta-analysis of the relation between humor styles and the Big Five personality traits. *Scandinavian journal of psychology* 2015;56(3):335-40. doi: 10.1111/sjop.12209 [published Online First: 2015/03/20]
23. Olsman E, Leget C, Duggleby W, et al. A singing choir: Understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliat Support Care* 2015:1-8. doi: 10.1017/s147895151500019x [published Online First: 2015/04/29]

- 1
2
3 24. Simpson C. When hope makes us vulnerable: a discussion of patient-healthcare provider interactions in the
4 context of hope. *Bioethics* 2004;18(5)
- 5 25. Thewes B, Husson O, Poort H, et al. Fear of Cancer Recurrence in an Era of Personalized Medicine. *J Clin*
6 *Oncol* 2017;Jco2017728212. doi: 10.1200/jco.2017.72.8212 [published Online First: 2017/07/21]
- 7 26. Etkind SN, Bristowe K, Bailey K, et al. How does uncertainty shape patient experience in advanced illness? A
8 secondary analysis of qualitative data. *Palliat Med* 2017;31(2):171-80. doi: 10.1177/0269216316647610
9 [published Online First: 2016/05/01]
- 10 27. Nelson JP. Struggling to gain meaning: living with the uncertainty of breast cancer. *ANS Advances in nursing*
11 *science* 1996;18(3):59-76. [published Online First: 1996/03/01]
- 12 28. Karlsson M, Friberg F, Wallengren C, et al. Meanings of existential uncertainty and certainty for people
13 diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC*
14 *Palliat Care* 2014;13:28. doi: 10.1186/1472-684x-13-28 [published Online First: 2014/06/18]
- 15 29. Lichtenthal WG, Nilsson M, Zhang B, et al. Do rates of mental disorders and existential distress among
16 advanced stage cancer patients increase as death approaches? *Psychooncology* 2009;18(1):50-61. doi:
17 10.1002/pon.1371 [published Online First: 2008/06/05]
- 18 30. Del Vecchio M, Good B, Schaffer C, et al. American Oncology and the discourse on hope. *Culture, medicine*
19 *and psychiatry* 1990;14:59-79.
- 20 31. Janssen E, van Osch L, Lechner L, et al. Thinking versus feeling: differentiating between cognitive and
21 affective components of perceived cancer risk. *Psychology & health* 2012;27(7):767-83. doi:
22 10.1080/08870446.2011.580846 [published Online First: 2011/07/20]
- 23 32. Carver CS, Scheier MF, Segerstrom SC. Optimism. *Clinical psychology review* 2010;30(7):879-89. doi:
24 10.1016/j.cpr.2010.01.006 [published Online First: 2010/02/23]
- 25 33. Cameron J, Waterworth S. Patients' experiences of ongoing palliative chemotherapy for metastatic colorectal
26 cancer: a qualitative study. *Int J Palliat Nurs* 2014;20(5):218-24. doi: 10.12968/ijpn.2014.20.5.218
27 [published Online First: 2014/05/24]
- 28 34. McCreddie M, Payne S, Froggatt K. Ensnared by positivity: a constructivist perspective on 'being positive' in
29 cancer care. *European journal of oncology nursing : the official journal of European Oncology Nursing*
30 *Society* 2010;14(4):283-90. doi: 10.1016/j.ejon.2010.03.002 [published Online First: 2010/04/27]
- 31 35. Stellmach D, Beshar I, Bedford J, et al. Anthropology in public health emergencies: what is anthropology good
32 for? *BMJ global health* 2018;3(2):e000534. doi: 10.1136/bmjgh-2017-000534 [published Online First:
33 2018/04/03]
- 34 36. Buiting HM, Terpstra W, Dalhuisen F, et al. The facilitating role of chemotherapy in the palliative phase of
35 cancer: qualitative interviews with advanced cancer patients. *PloS one* 2013;8(11):e77959. doi:
36 10.1371/journal.pone.0077959; 10.1371/journal.pone.0077959
- 37 37. Simpkin AL, Schwartzstein RM. Tolerating Uncertainty - The Next Medical Revolution? *N Engl J Med*
38 2016;375(18):1713-15. doi: 10.1056/NEJMp1606402 [published Online First: 2016/11/03]
- 39 38. Molina Y, Yi JC, Martinez-Gutierrez J, et al. Resilience among patients across the cancer continuum: diverse
40 perspectives. *Clinical journal of oncology nursing* 2014;18(1):93-101. doi: 10.1188/14.cjon.93-101
41 [published Online First: 2014/01/31]
- 42 39. Den Hartogh G. Suffering and dying well: on the proper aim of palliative care. *Medicine, health care, and*
43 *philosophy* 2017;DOI 10.1007/s11019-017-9764-3
- 44 40. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an
45 international consensus supported by the European Association for Palliative Care. *Lancet Oncol*
46 2017;18(9):e543-e51. doi: 10.1016/s1470-2045(17)30582-x [published Online First: 2017/09/09]
- 47 41. Maas M, Beets-Tan RG, Lambregts DM, et al. Wait-and-see policy for clinical complete responders after
48 chemoradiation for rectal cancer. *J Clin Oncol* 2011;29(35):4633-40. doi: 10.1200/jco.2011.37.7176
49 [published Online First: 2011/11/10]
- 50 42. Starreveld DEJ, Daniels LA, Valdimarsdottir HB, et al. Light therapy as a treatment of cancer-related fatigue in
51 (non-)Hodgkin lymphoma survivors (SPARKLE trial): study protocol of a multicenter randomized
52 controlled trial. *BMC Cancer* 2018;18(1):880. doi: 10.1186/s12885-018-4746-2 [published Online First:
53 2018/09/12]
- 54 43. Menning S, de Ruiter MB, Veltman DJ, et al. Changes in brain white matter integrity after systemic treatment
55 for breast cancer: a prospective longitudinal study. *Brain imaging and behavior* 2018;12(2):324-34. doi:
56 10.1007/s11682-017-9695-x [published Online First: 2017/03/16]
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Coreq checklist

Complex challenges in patients with protracted disease incurable cancer: an ethnographic study

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?
P4, recruitment and sampling
2. Credentials: What were the researcher's credentials? E.g. PhD, MD
P1
3. Occupation: What was their occupation at the time of the study?
P1
4. Gender: Was the researcher male or female?
P4
5. Experience and training: What experience or training did the researcher have?
P4

Relationship with participants

6. Relationship established: Was a relationship established prior to study commencement?
P4
7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?
P4
8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.
P4 (methods), P10 (limitations)

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?
P4 (ethnography, thematic content analysis)

Participant selection

10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball?
P4 Participants were random selected, when HB was in the hospital
11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email.
P4, face-to-face
12. Sample size: How many participants were in the study?
P5
13. Non-participation: How many people refused to participate or dropped out? Reasons?
P4 (none of the patients, in 3 situations nurses advised not to approach the patient)

Setting

14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace.
P4 (hospital)
15. Presence of non-participants: Was anyone else present besides the participants and researchers?
P4 (close relatives, n=8)
16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date

P6*Data collection*

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?

P4 (first of all openly framed)

18. Repeat interviews: Were repeat interviews carried out? If yes, how many?

P5

19. Audio/visual recording: Did the research use audio or visual recording to collect the data?

P4 (all conversations were audio-taped)

20. Field notes: Were field notes made during and/or after the interview or focus group?

P4 (observations, and some additional talks with patients)

21. Duration: What was the duration of the interviews or focus group?

P4

22. Data saturation: Was data saturation discussed?

P4, until data saturation was reached.

23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?

P5

Domain 3: Analysis and findings

24. Number of data coders: How many data coders coded the data?

P5 (2, HMB, and MACA)

25. Description of the coding tree: Did authors provide a description of the coding tree?

P5 (no explicit description of the coding tree, but we described several items)

26. Derivation of themes: Were themes identified in advance or derived from the data?

P5 (yes)

27. Software: What software, if applicable, was used to manage the data?

P5

28. Participant checking: Did participants provide feedback on the findings? No, but we sent them a lay version of the results.

Reporting

29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number.

P5-9

30. Data and findings consistent: Was there consistency between the data presented and the findings?

P5-9 (yes)

31. Clarity of major themes: Were major themes clearly presented in the findings?

P5-9 (yes)

32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?

P5-9 (yes)