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Information provision to older patients receiving palliative chemotherapy: a quality study

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Abstract

Objectives Cancer treatment has become increasingly successful. However, prolonging and preserving life has become an important goal of therapy since many patients generally receive palliative chemotherapy. The perception of life changes when patients are informed, that no curative treatment is possible. This raises new dilemmas for patients with incurable cancer, but only sparse information is available about the thoughts of these patients.

The aim of this study was to explore how older patients experience the information on absence of curative treatment options.

Methods Qualitative interviews were performed in eleven older patients with incurable upper gastrointestinal cancer receiving first-line palliative chemotherapy. Median age was 74 (65–76) years. We used a qualitative approach

to collect data through semi structured individual interviews conducted at the hospital or by telephone interviews by an experienced researcher. The thematic analysis was conveyed by Braun and Clarke.

Results The interview findings were grouped around three main themes: hope of being cured, hearing but not comprehending, and desired milestones to reach. Further, it was determined that patients hid their feelings and avoided talking about the disease with the health professionals due to fear of being told the truth. **Conclusions** Receiving information about their incurable cancer was an ongoing dilemma for the patients. Following the message, patients shared thoughts about reaching important milestones in life, spending time with their family or hope for a cure to be found.

Introduction

The incidence of cancer is increasing worldwide partly due to an ageing population, with age being one of the strongest risk factors.^{1 2} For most patients with non-resectable malignancy, the treatment

intent is palliation, aiming to help patients live longer with preserved quality of life and reduced symptom burden.^{3 4} Over the past decades, the development of novel palliative therapeutic options have improved overall survival considerably.⁵ However, varying and sometimes unpredictable toxicities may do more harm than benefit, and therefore, these different scenarios must be balanced, presented and discussed with the patient.^{6 7}

Prior studies report that patients with cancer are more likely to accept treatment with minimal chance of benefit, even in an older population.^{8–10} Also, a patient survey revealed that 81% of patients with metastatic colorectal cancer did not understand that the offered chemotherapy was very unlikely to cure their cancer¹¹; and in a questionnaire study, the patients' expected survival was significantly longer than the actual survival.¹²

These findings are also the experience from daily clinical practice in patients with incurable cancer receiving palliative chemotherapy where a discrepancy often exists between patients' expectations and predicted efficacy such as hope, denial, and coping.^{13–15} In addition, patients are ever

more exposed to information about cancer and treatment from social media, which may affect their perception of their cancer and the indication of treatment. This need to be supported by health professionals (HCPs). The dialogue between patients and HCPs thus becomes more crucial to achieve shared decision making and obtain the best individual treatment result. For the (HCPs) to give thorough and accurate information and guide and involve the patient in this shared decision, it is essential to reveal and understand the patients' attitude and expectations to treatment. This study was initiated after another trial where patients were asked about their attitude to chemotherapy. Here, the patient perspective of minimal survival gains to accept treatment with a range of 3–120 months was explored. The patients included stated that they were hoping for a cure.

Therefore, this study aimed to explore how the information provided by the HCPs affect and is experienced by older patients with incurable cancer receiving palliative chemotherapy.

Methods

Design

We used a qualitative method, thematic analysis, based on semi structured individual interviews chosen to explore the patients' perspectives as it allows for in-depth dialogue in the interviews to facilitate further understanding.¹⁶ Thematic analysis can be used when a straightforward phenomenon is being sought, as is the case in this study.¹⁷ In the analytical process, the researcher remains focused on the data to describe the patients' experiences in a language similar to that used by the patients themselves.¹⁷ The qualitative semi structured interview allows the researcher to modify the questions during the dialogues that occur and enables the researcher to explore other aspects than those that have not yet been revealed. The analysis of emergent themes depends on the researchers' perceptions, inclinations, sensitivities, and sensibilities.¹⁷

Setting and participants

This study was conducted in November and December 2018 at the Department of Oncology, Odense University Hospital, Denmark. Danish-speaking patients aged ≥ 65 years with incurable non-colorectal gastrointestinal cancer who received first-line palliative chemotherapy were consecutively included through non-probability sampling. All interviews were performed between the first cycle of chemotherapy and the first evaluation scan thus before knowing the initial radiological response evaluation.

Interviews

The interview guide was tested by an experienced researcher (first author CLL) in a pilot interview, which resulted in corrections of language and content (online supplemental table 1, interview guide). Following this, seven qualitative semi structured interviews were performed at the hospital and seven by phone by the

first author. The digitally recorded interviews lasted 30–40 min. Eleven participants were interviewed, and after the 10th participant, it became evident that no new information was brought forward. However, after discussing this in the author-group, one more interview was conducted.

Seven qualitative semi structured interviews were performed at the hospital and seven by phone by the first author. The digitally recorded interviews lasted 30–40 min. Eleven participants were included. One patient did not match the inclusion criteria due to age and two patients withdrew participation as their health deteriorated after the interviews.

The six stages of thematic analysis, by Braun and Clarke, were followed.¹⁷ All interviews were transcribed verbatim, the first two by the first author and the following nine by an experienced research student. The transcriptions were loaded into NVivo, a software program for qualitative analysis.¹⁸ Step 1: the first author read and reread the content to ensure accuracy and eliminate typing errors. Step 2: a record of initial impressions and the observed similarities and differences was made. Step 3: data were divided systematically into meaningful elements (codes). Step 4: the initial codes were marked and reviewed, and the final codes presented themselves. Step 5: the coded data were developed into a thematic map allowing the researchers to consider the alignment of the themes. Step 6: each theme was refined, and clear definitions were identified for each theme. The process of this analysis was data driven. To clarify the placement of a code within a theme, data coherence was sought, and non-fitted codes were being placed elsewhere. All quotations behind each of the codes were reviewed, and patterns were sought. The checklist from the Consolidated criteria for reporting qualitative research (COREQ) guidelines was followed.¹⁹ To ensure rigour and trustworthiness, the first author (CLL) independently examined transcripts to identify initial codes and then held a collaborative meeting with the coauthor (SBW) to refine the coding framework (online supplemental table 2). This framework was applied to the data by (SBW), and double coding of a subsection of the transcripts was completed to check rigour and ensure interpretation was not dominated by one researcher perspective. Where coding differed between (CLL) and (SBW), discrepancies were resolved through discussion.

From coded transcripts, CLL and SBW identified overarching themes until consensus was reached. The naming of the themes and subthemes was identified by the first author, who reviewed the interviews to gain a thorough understanding of the wider meaning. Online supplemental table 2 illustrates the naming of the themes and subthemes. Braun and Clarke emphasise that the themes

should be related to the research question in the last step.¹⁷ This is done to ensure the validity of the qualitative description and credibility of the thematic analysis. In this study, the consistency and validity of the data were enhanced by verifying the findings through discussions with the coauthors. A logbook with analytical considerations was completed throughout the process.²⁰

Results

In our study, 11 patients were interviewed (6 women and 5 men), median age 74 (range 65–76) years.

Findings

The participants conveyed opinions regarding their situation, and the analysis resulted in three themes: ‘Hope of being cured’, ‘Hearing and not hearing’, and ‘Milestones to reach’. The findings are illustrated with selected quotations and do not mean that only the participants quoting addressed the topic.

Theme 1: hope of being cured

The first theme identified was the hope of being cured. The participants did not express hope religiously or spiritually, instead it was in a more straightforward manner. The participants argued that they were mentally aware of their situation and knew they were not going to recover. The presence of hope was essential for their will and ability to go on living. The hope of being cured, or at least getting better, was fundamental to their experience. The communication with the HCPs was weighed and interpreted by the patients:

When the word chemotherapy is mentioned, it is like seeing the light in the end of the tunnel- to get well (Man 66 years)

One of the participants' expressed:

If hope disappears, you have nothing (Man, 76 years)

Hope made the participants' lives more manageable, and accordingly, the experience of hope allowed them to envision something better or make life easier. According to the participants, hope was dependent on personality, attitudes and values:

I try to keep hope as the highest possible, but I do not always manage, because there are so many factors that play a part in this, such as my mood (Man, 71 years)

This is supported by another participant who expresses how he looks on life:

In my everyday life and world—how I look on life in general—I need to move forward—to have a goal—a positive goal (Man 72 years) or

I have just retired, and this feels very very wrong— being ill and maybe.... (voice breaking and she cries) (Woman, 69 years)

However, wishing for hope was not easy. A participant continued:

Hope is many things; hope is also that one does not talk about it (end-of-life) when you come in (the hospital) (Woman, 72 years)

Theme 2: hearing and not comprehending

When the patients are informed that the cancer is incur- able by the HCPs, they may be brought in a stressful and emotional state of mind, making them unable to comprehend the information. The second theme identified was ‘hearing and not comprehending’. The participants argued that:

Normally I want a straight answer; however, it is like my system has closed down, and we might as well talk about a cookie recipe as talk about my cancer (Woman, 65 years)

The patient further articulates:

I wish I could go to the hospital and see the doctor - receive the information in small doses, every day a little bit more and a little bit more until it made sense in my head. You can sense that they need to give you all information in one go and then you lose the grip (Woman 65 years)

This is supported by another participant and exempli- fies the mental state of having just received the information given by the HCPs:

If something is being tough, I close myself down; I cannot handle it. It (cancer) does not exist. Instead, I become very practical, information to family, insurance.... it’s all about facts. In reality, that is what keeps me on my feet (Woman, 76 years)

A male patient addresses his present situation:

I come from South Jutland—right in the countryside, and here we don't talk about our feelings, particularly men my age we just get on with it—it just gets practical, next appointment—journey to hospital.... (Man 72 years)

It was further raised by most of the participants that they were affected by the reactions from partner and family—both verbally and nonverbal:

We move around the house not speaking, but when we look at each other we both know—but we cannot find the words, or start the conversation (Woman 71 years)

Theme 3: milestones to reach

The third theme identified was ‘milestones to reach’. The participants were aware of their imminent death but claimed that they had to live as long as they were alive. They could not escape from life even if they wanted to. They felt split between a will to live and the awareness of a final capitulation to death because they were also doomed to die. The experience of belonging to both life and death was something they just had to accept. Many took comfort in thinking that they still had things they wanted to achieve in life. It became evident that the participants were not realistic about their illness.

I'm becoming a great grandfather in May next year—I want to have that experience too (Man, 69 years)

Or as expressed by another participant.

It is our diamond wedding anniversary in a year, I need to be there. In reality, I don't have time for this (having incurable cancer?) (Woman, 76 years)

Milestones were further expressed as a phenomenon that suddenly became important for the participants, and there were things they wanted to experience while living.

I have to comply with the fact that I have an expiry date—it can be in 2 years or five or maybe ten. Quality of life for me is to travel with my family, in fact, it is terribly important (Woman, 67 years)

Discussion

In our study, life changed for the patients when they were informed that no curative treatment of their cancer was available and palliative chemotherapy

was offered. Through our analyses, we revealed three different essential themes concerning the situation of living with incurable cancer 'Hope of being cured', 'Hearing and not comprehending', and 'Milestones to reach'.

As part of the care of older patients, life expectancy is important to articulate regardless of diagnosis.²¹ Prior literature suggests that HCPs lack consistency in their communication about life expectancy.^{22 23} However, no single definition of 'end-of-life' exists.²⁴ In this paper, end-of-life is understood as the time the patient can expect to live after being diagnosed with incurable cancer.²⁵ The pathway for patients with incurable cancer leads to complex decisions, such as whether to receive life-sustaining treatments or not. Some HCPs make assumptions about patients' wishes based on whether they had previously chosen to pursue curative treatment. Talking about hope and end-of-life is associated with better quality of care in the palliative period and a need to clarify the actual perception of patients concerning hope in an oncology setting, with the general practitioner and with the family. Also, hope is individual, and an assessment of hope in patients with cancer can be considered one of the critical tools to enable the personalisation of care.²⁶ Another factor in relation to this are the coping defense mechanisms and the strategies each patient takes to endure this.^{27 28}

The participants in the present study all expressed their hopes for the future concerning their illness and treatment. Subsequently, not all participants could find words to address the real end-of-life. This finding is supported by Simon *et al*, who found that older people were heterogeneous in their needs to address

end-of-life issues.^{6 28} A recent study of older patients suggests that they avoid end-of-life discussions, as they prefer not to think and talk about dying and consequently left end-of-life decisions to their family members.²⁹ However, another study points out that honesty about the diagnosis and situation was pivotal as this allows the patient to adapt to the situation, articulate their

hopes and begin for preparing for end-of-life.³⁰ The experiences are multiple and individual for each patient. Involving the family in the discussion is both helping the HCPs as well as the family.²⁹

Our findings show a fine line between the perception of a dialogue between HCPs, patients and family offering treatment to a patient and the patient's perception of the offer being life-prolonging, which led to the belief of hope. Oncological HCPs may benefit from discussing how to address the patient's current situation and the treatment outcome. A study by Pfeil *et al* points out that timing is essential when addressing communications such as hope.³¹ Ethical considerations and a more proactive stance should be undertaken for the HCPs to prepare the patients for the discussion, which may enhance the quality of the decision making for the patient and their family.²⁹ Elliott and Olver state that hope as a part of well-being is often thought of as problematic, mainly when centred around being cured.³² Hope for a cure is common for patients receiving end-of-life care. Denial of death is less attractive than patients' hope as it brings value to patients, their quality of life, and their connection to other people and families.³³

The patients' realisation of having incurable cancer creates challenges for themselves and their families. We found that hope of being cured was important, and there was a tendency that patients did not comprehend the information given by the oncologist. The stress and emotional state of the situation may also be of relevance.³⁴

This perception caused the patients to feel they had many milestones to reach before they were ready to pass with life, which could be a coping mechanism for the patient and important for them.²⁸ These findings may highlight ways for HCPs working in oncological settings, palliative care, and rehabilitation to cooperate when addressing end-of-life topics such as hope. A study by Proserpio *et al* argues that hope for patients with cancer depends on the quality of the relationships they have with their family and healthcare.³³ In recent years, there has been a debate on the link between palliative care and rehabilitation, as patients with incurable cancer live considerably longer. Whereas rehabilitation can support and improve everyday activities, the palliative care approach can relieve symptoms related to physical, psychological, existential and psychosocial issues.

Our study indicates that the patients already developed a sense of hope when they were offered palliative treatment, and it was argued that they wished to remain

active both physically and mentally and reach milestones and having the energy to be with their family. To a certain extent, they considered chemotherapy a part of their rehabilitation. Most of the participants described they felt anxious and stressed. There was the disbelief of being terminally ill, and it was not understood. One of the patients was so distressed that he did not even believe the information.

Healthcare professionals find themselves in a complex situation as they know in advance the outcome of the disease when they forward the information to the patient and family. The HCPs

discuss the situation as life-prolonging, yet the patient and family are hoping for a cure.²⁹ Best practices in the situation should depend on the individual patient, by following a plan, building a partnership with the patient and their relatives, discussing the situation, presenting the options honestly and compassionately and end the conversation with a mutual summary. Thus, the conversation may be experienced by both patient, relatives and HCPs as successful²⁷ addressing end-of-life is a contextual, personal, relational, conditional and flexible process that should not be restricted to a single conversation— and it requires interdisciplinary collaboration.^{29 35}

The participants in this study all expressed their hopes for the future concerning their disease and treatment. However, as reported by Simon *et al* some of the participants could not find the words to address the actual end-of-life.⁶ In our study, we also found that the patients were further troubled when the partner or family could not address the end-of-life issue. This lack of communication may lead the patient to express mainly hope instead of fear and worries, which may leave both the patient, partner and family isolated. According to Brashear, nobody wishes to eliminate hope, which is an important coping mechanism for both patients and their families; however, this may interfere with further dialogue.³⁶ Subsequently, Brashear supports the need for more extended and more frequent conversations between HCPs and patient/family, too, as this may help all involved to articulate the fear.³⁶ This is described by some of our participants, highlighting factors such as timing, location and relationship with the HCPs as important when speaking about end-of-life and related treatment. Further, the participants argued that the real conversation was vital as the verbal and non-verbal signs from the HCPs indicated whether it felt 'safe' to speak about the end-of-life. Patients described how they felt they did not listen properly when informed about the treatment plan as the timing or the HCPs were rushed.

The participants addressed how important it was to reach milestones in their personal life, which led to their hope of a cure. They described a balance between the 'small talk' and the 'serious' talk about the current health

situation. Furthermore, there was a cultural and age-related boundary as the participants found it difficult to talk about their thoughts and feelings—as they may be afraid of the answer. Instead, they talked about positive things like seeing a new grandchild or going on holiday. The HCPs may balance between respecting the wishes and not overstepping the boundaries with the patients and their families. Thus, at the same time, offering a conversation for those patients open to talking about their feelings and hope and not limiting the conversation to superficial 'small talk'. This diversity may be a challenge for the HCPs ensuring a trusting, compassionate relationship placing an undue burden on HCPs. This balance can be described as HCPs ability to use their intuition between 'not yet' and 'just ask'.⁶

Perspectives

Attention to older persons ability to perceive information at their own pace and the timing of the communication is a vital part for HCPs when communicating treatment-related decisions and end of life.^{9 37} The patient and family perspective and HCPs trained to encounter the balance between 'small talk' conversation and crossing the boundaries during the conversation on patients' future, hopes and treatment.³⁸

A certain expectancy may precede from unclear information from HCP's as discussed in the literature³⁹ and in particular when the prognosis and treatment response is negative many HCPs find it challenging to communicate bad news. Subsequently, patients may misunderstand the HCPs about the intention of the chemotherapy treatment. Training HCPs how to facilitate communication between the patient and their relatives is crucial. Guidance about timing during the conversation is vital. Compassionate communication using motivational interviewing is a possible tool to address sensitive subjects such as end-of-life. Recent studies indicate that personal narratives can help HCPs talk about end-of-life and ease the patients' mental and physical suffering.^{39 40} The studies address the fact that HCPs need to communicate the treatment available and end-of-life realities with excellent communication skills to capture both the patient and partner/family, who may not grasp the situation and the forwarded message at the same level. Advanced care planning may be too rigid for some 'setups' but enables the HCPs to ensure that every patient is presented with the opportunity to share their thoughts and wishes for end-of-life—and hope.³² Also, communicating with older cancer patients requires sensitivity, and HCPs should pay attention to older persons ability to perceive information in their own time and speed and the timing of the communication.⁹
³⁹ Training sessions for HCPs in communication with patients and their families on end-of-life issues may be introduced, allowing the HCPs to achieve new techniques to address sensitive topics with compassion.

Strengths and limitations

This study had some limitations. We only addressed the patient perspective. A deeper understanding, including the family and the HCPs, may have completed the study further. We found no differences in the responses from the participants who were interviewed by phone versus those who participated face to face. The patients' health illiteracy was not explored.⁴¹ Knowledge about this may have added value to the study. Finally, our participants all suffered from incurable upper gastrointestinal cancer receiving first-line palliative chemotherapy and were included from a single Danish oncological department. However, substantiation of our findings could be relevant in other patient groups and healthcare systems.

CONCLUSION

Receiving information about their incurable cancer by HCPs was an ongoing dilemma for the patients. Despite this information, thoughts were

shared about reaching important milestones in life, spending time with their family and expressing hope for a cure. Hope became fundamental for the patient and may influence how the patient comprehends the meaning of the life-prolonging treatment. Our study highlights the need for awareness treating and caring for patients with incurable cancer that can embrace diversity and ensure that all patients are systematically offered the possibility to talk about their present situation. In house training of oncology healthcare professionals to embrace communication with patients and relatives is crucial.

Correction notice This article has been corrected since it was first published. One missing sentence has been added to the methods section.

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