

Original Article

Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy



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Abstract

Context. Women with metastatic breast cancer often receive many lines of palliative chemotherapy, which might be beneficial but also harmful. Still, little is known about the patients' perception of the patient-doctor communication regarding late lines of noncurative treatment.

Objectives. Our aim was to explore breast cancer patients' preferences and perceptions of patient-doctor communication regarding continuous late lines of palliative chemotherapy.

Patients and Methods. A qualitative study was conducted with semiguided face-to-face interviews with 20 women, 40–80 years old, on at least their second line of palliative chemotherapy (second to eighth line). We used a qualitative conventional content analysis.

Results. All women knew they had incurable breast cancer but expressed hope for cure. Patients' definition of a good compassionate doctor was one who gives positive news and leaves room for hope. Ongoing chemotherapy, positive news from the doctors, and support from relatives encouraged hope. The women often expressed they accepted chemotherapy to please their doctor and relatives. The informants appreciated the doctor to be honest, but within positive limits. Over time, they stopped asking questions afraid of getting bad news, and left more and more treatment decisions to the doctor.

Conclusions. The women's preferences for truth versus hope in patient-doctor communication changed over time, which increase the risk for continuous late lines of palliative chemotherapy by common collusion. Doctors need to individualize information, help patients make sense of their life, and allow hope to endure without further chemotherapy. *J Pain Symptom Manage* 2019;57:746–752. © 2019 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words

Communication, breast cancer, palliative chemotherapy, decision making, psycho-oncology

Introduction

Patients with metastatic breast cancer receive in general many lines of palliative chemotherapy before treatment is stopped. Still, little is known about how the patients experience the patient-doctor's communication about continuing noncurative treatment. Patients often receive their tumor-specific treatment at the hospital, meanwhile their palliative care needs (e.g., symptom control) are taken care of by palliative home-care services. There is a thin line between

benefits and risks with late lines of palliative chemotherapy, and it is well known that a lot of patients with incurable cancer have unrealistic expectations and believe they will be cured.¹ For those with incorrectly optimistic views, there are reports of increased risk for death at hospital and less chance of receiving end-of-life care according to their wishes.^{2,3}

To be informed is not always the same as understanding one's disease prognosis.⁴ Furthermore, not only patients but also doctors tend to exaggerate

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when it comes to prognosticate the survival of a patient.^{5,6} In addition, the doctors very seldom recognize the patients' misunderstanding of treatment goals.⁷ There are studies reporting that approximately 20%–30% of patients and caregivers had realistic expectations, which proves that accurate understanding of prognosis and goals of palliative oncologic treatment can be accomplished, at least in some cases.^{1,8} However, denial is a strong coping strategy and/or defense mechanism for many people facing unacceptable truths, why we probably never will achieve completely and fully aware patients and family members. Furthermore, the awareness of understanding with realistic expectations has been described to be a dynamic process for patients and caregivers, changing over time.⁸

The amount and pace of information have to be individually adjusted.⁹ Different desires for information, as well as of understanding, have been reported for different types of cancers.^{10,11} In general, breast cancer patients seek more information than patients with prostate cancer; however, gender is a possible confounding factor, as men request less information than women.¹² Patients' awareness of disease and prognosis has been related to quality of life, although with diverging results. According to one study, a more accurate understanding of one's terminal illness and prognosis was associated with worse quality of life,¹⁰ while others did not find any impaired QoL association with end-of-life care discussions.^{3,13} Interestingly, physicians who deliver more optimistic views are perceived as more trustworthy and compassionate by the patients.¹⁴

In light of these conflicting views, our aim was to explore breast cancer patients' preferences and perceptions of patient-doctor communication regarding continuous late lines of palliative chemotherapy, in a Swedish context.

Patients and Methods

We included 20 women with metastatic breast cancer at the Karolinska University Hospital Solna. Inclusion criteria were as follows: ≥ 18 years old, Swedish speaking, patients with ongoing (at least second-line) palliative oncologic treatment. Patients who were cognitively impaired or non-Swedish speaking were not included. Patients received written information of the study by a nurse when they came for palliative chemotherapy and were interviewed after given consent at the outpatient clinic for chemotherapy treatment. The author J. B. performed the interviews alone with the patient in a room at the clinic and it was made clear to the patient that none of their doctors and or nurses would get any knowledge of what they answered to our questions. Two women declined

Table 1
Sociodemographic and Disease Characteristics of the 20 Women With Metastatic Breast Cancer Interviewed According to a Semistructured Interview Guide

Characteristics	Number of Patients, <i>n</i> = 20 (%)
Age	
Range	40–80
Median	65.5
Mean	64
Married or living with partner	
Yes	8 (40)
No	12 (60)
Economic situation	
Good	12 (60)
Good enough	7 (35)
Bad	1 (5)
Education level	
University	13 (65)
High school	2 (10)
Vocational school	5 (25)
Years since primary diagnosis	
Range	1–35
Median	8
Mean	10.3
Years with metastatic disease	
Range	1–15
Median	4
Mean	4.5
Lines of palliative treatment	
Range	2–8
Median	3

to participate when asked, based on tiredness and not enough time to stay for the interview.

We aimed at a maximum variation sampling with concern to years lived with metastatic disease, received lines of palliative chemotherapy, age, education, and socioeconomic status. Patient characteristics are outlined in Table 1.

We used a semistructured interview guide, constructed by the two authors, in face-to-face interviews according to a qualitative study design. The guide gave a general structure to the interview, but the interviewer was free to use follow-up questions whenever needed for validation and further exploration of the answers. The 30- to 46-minute long interviews were tape-recorded and transcribed verbatim before they were analyzed by the two authors. We used a qualitative conventional content analysis, as described by Hsieh et al.,¹⁵ based on coding categories derived directly from the text. In brief, the two authors reread the interviews several times to identify meaning units, text segments, or words of potential interest with reference to the research question, i.e., how the patients perceived and preferred the information in relation to continuation of palliative chemotherapy. For example, statements explicitly stressed or repeated several times were selected. Preliminary codes were then chosen for the texts or words identified as meaning units. Next step was to group similar preliminary codes into preliminary categories. The content of

Table 2
Categories and Subcategories From the Face-to-Face Interviews With Women on Their Second to Eighth Line of Palliative Chemotherapy for Treatment of Metastatic Breast Cancer

Category	Subcategory
Communication	Partial/selective truths Patients' will to please
Hope	Patient-doctor communication Patient-family interaction
The doctor	The expert Positive characteristics Negative characteristics

each category was to be limited, without too wide variations and without obvious overlapping between the categories, and we tried to find possible relationships or hierarchies between them. The Stockholm Ethical Committee approved the study.

Results

The informants described that their need for information changed over time and became more selective for positive news, not necessary the “whole” truth. Other common themes in the interviews were descriptions of how the patients experienced their doctors as experts, exemplified with good and bad characteristics. The women expressed they wanted to please the doctors and hoped for cure. A summary of categories and subcategories is displayed in [Table 2](#).

Communication

The informants expressed different needs in how much or little details they thought were accurate, which sometimes changed over time.

Partial/Selective Truths. Some of the informants said they looked for positive information only, and when they found such information, they did not ask for more, afraid of getting bad news. However, the need for information and the way the patients wanted to communicate with their doctors changed over time. At the beginning of their palliative treatment, some of them had asked about their prognosis, and detailed information about the tumor size, but now they asked for less and less information as time went by and the disease progressed.

“She (the doctor) often says that it looks like everything is under control, not changing much, and then I settle with that” and later on the same woman says “I am easily satisfied (laughing)!”

A sixty-three-year-old woman with metastases since four years, on her second line of palliative chemotherapy.

To begin with you asked about it (the prognosis), but now I have stopped.

A sixty-three-year-old woman with metastases since four years, and on her second line of palliative chemotherapy.

Instead of asking their doctor and getting an answer about their specific condition, they sometimes googled on the Internet. They found these data not necessarily applicable to their own situation and, therefore, less frightening. Some informants said they preferred to read about isolated symptoms rather than about the disease and prognosis. If they found information about their symptoms linked to bad prognosis by accident, they often referred to it as old or not relevant information.

Sometimes you can end up on a webpage telling you that survival with skeletal metastases is maximum 2 years. Then you look at the date and see that it was published in 2002, and feel relieved. Because such information gives you the hiccups, so I try to avoid such obscure information.

A fifty-nine-year-old woman with metastases since one year ago, on her second line of palliative chemotherapy.

Patients' Will to Please the Doctor. The women expressed a wish to make things easier for their doctors and said they focused on symptoms and treatment but left their feelings and inner thoughts out of the consultation. The informants felt guilty for their long notes with questions and said they did their best to hide frustration and anger when the health care system failed them in terms of late appointments, another new doctor, and so on. They even excused their doctor when he or she had provided too optimistic information.

I think it would be hard to say such things [bad prognosis] to a person, like one year // He (the doctor) cannot be sure ... and it would be hard to say it. Don't you think so too? Would you like to say to someone—Well you might make it another year ([but you probably won't)”?

A seventy-eight-year-old woman with metastases since 15 years, on her sixth line of palliative oncologic treatment.

Hope

The women explained that both patient-doctor communication about treatment and patient-family interaction were sources of hope. With ongoing treatment, they explained their hope grew stronger, especially when they were able to take part in everyday life and talk about other things than the disease with

family and friends. Maintained relations and life in itself were important sources of meaning.

Patient-Doctor Communication. Patients said that information reassuring continuous treatment was essential for their feeling of hope, whereas withheld treatment was associated with thoughts of death.

When the patients had raised questions about their impending death, they expressed they were relieved when the doctor dismissed it, as such responses fostered hope and meaning. When life was no longer a self-evident fact, it was valued so much more.

I once said: Well I'd better go home and tidy up then before death. Then he (the doctor) said: Oh no, I will not listen to such nonsense.

A seventy-seven-year-old woman with metastases since three years, on her third line of palliative chemotherapy.

Patient-Family Interaction. The women expressed that family and friends were highly appreciated support but mainly served as a much needed distraction from the disease, not as partners to discuss treatment options and fear of death with. In a broad sense, however, close relationships were increasingly important: reciprocal affection, love, support, and consideration were narrated as important sources of meaning in their exposed situation.

They also told how their friends and family put great faith in the treatment and expected them to continue with treatment to keep death at a distance. The women gave many examples of situations when they had refrained from telling family members about how they really felt, to protect their loved ones from worries.

So I said—But you know I have to do this?—Yes, answered my 10-year-old son, because if you don't get your treatment you will die.”

A forty-four-year-old woman with metastases since four years, on her fifth line of palliative chemotherapy.

No I have not([discussed treatment with family members). They take it for granted that I will continue with anticancer therapy. What will happen if I don't?”

A seventy-seven-year-old woman with metastases since three years, on her third line of palliative chemotherapy.

The Doctor

The Expert. The patients expressed that they put their faith and hope to the expertise, the doctor. They did not want the responsibility themselves to decide what to do next. All the women said they trusted their doctors and wanted him or her to decide about treatment,

as the doctor was the “expert.” They outlined they wanted the doctor to take care of their cancer, while they wished to focus on their everyday life themselves.

If my doctor suggests a treatment, then I trust her. She is the expert and takes care of my disease, while I take care of my well-being.

A fifty-year-old woman with metastases since nine years, on her eighth line of palliative chemotherapy and antibody therapy.

The women did not want to disappoint their doctor, and if he or she recommended new treatment, the women expressed they felt it was their mission to endure the side effects, because the doctors were the experts. Some women said they had begun to fear they would not be able to cope with more treatments as they felt so tired all the time. But when they had mentioned this to their doctors, they had been reassured that they were fine and treatment could continue.

I have asked (the doctors), lots of times—How much treatment can the body manage? And the answer I got is that—The body can cope much longer than you think!

A sixty-three-year-old woman with metastases since four years, on her second line of palliative chemotherapy.

Positive Characteristics. The women described a good doctor as one who delivered good news and left you still able to hope for a future. They said a good doctor paid attention to them and knew what to do next. The majority said they looked for positive things in their patient-doctor communication. If there were bad news delivered, the women said they tried to focus on something positive to talk about with the doctor or with family members after the consultation. The informants said they appreciated the doctor to be honest, but in the next sentence, they would state that they wished for honesty within positive limits, as they did not want bad news.

The doctor tells me I do not look ill. He is a senior consultant and he has said many times that I do not look ill.

A seventy-eight-year-old woman with metastases since 2 years, on her second line of palliative chemotherapy.

Negative Characteristics. The informants expressed that being late and stressed out, in addition to giving too much and too detailed information, was considered characteristic for a bad doctor. To present negative information was also associated with bad doctors, especially if it was provided too frankly. One informant

described the doctor associated with delivering bad news to her as brutal.

But she said there are metastases here and in the lung and I thought if I may say so, that she was brutal Should you hand it out like that?"

A seventy-eight-year-old woman with metastases since two years and on her second line of palliative chemotherapy.

Discussion

All women described that their need for "all" information at the beginning of their disease changed to a wish for "useful" information, to maintain hope and meaning. They asked less and less questions over time, afraid of receiving bad news. Such a dynamic process of awareness of treatment goals among patients receiving noncurative cancer treatment has been previously published by Burns et al.⁸ Our study also confirms that when the desire for information and participation in treatment decision diminish over time, the patient may want to put someone else, doctor or family, to be in charge of the situation.¹²

A limitation with this study is that we only interviewed patients on palliative chemotherapy, whereas the experience of those who refrained treatment might be different. Furthermore, patients were 40–80 years old, and patients of other ages may be of different perceptions. However, during analysis, we met saturation in data after six interviews and have additional 14, that is, 20 interviews in total, why we think it is a representative set of data. As information strategies and truth telling in most cases are described from the doctor's point of view, a strength is that this study sheds light over the patients preferred mode of truth, that not necessarily are congruent with those of the doctor.

Our study, in line with previous research, identifies hope^{16–19} and meaning^{20–23} to be crucial parts of common coping strategies, to reduce depression and anxiety associated with fear of progressive disease and death. Being on palliative chemotherapy with a structured schedule according to this has been suggested to facilitate for patients to live in the present, instead of having to deal with anxious thoughts about end of life.²⁴

Discussions regarding treatment can protect both patient and doctor from discussing existential issues like death threat. Such a strategy is called the "common collusion" according to The et al.²⁵ In our study, many women even expressed they continued with treatment to not disappoint their doctor.

Our informants associated treatment discontinuation to ineligibility for new treatments that could

represent cure or longer life. Continuous chemotherapy helped women to hope for new "miracle" treatments, in line with coping strategies and defense mechanisms as described by Yalom, who focuses on the concepts of "specialness" and "ultimate rescuer."²³ These mechanisms imply that the actual patient should be the one that miraculously cheats death and is cured against all odds, also identified by other researchers.^{11,23,26}

In today's health care system, "truth" is often acknowledged to be the most important issue in patient-doctor communication. However, we must bear in mind that truth is complex, relative, and dynamic, not neutral. Terminally ill patients may adjust the definition of "truth" with regard to information of prognosis to their needs, to be able to take action and be in control of their lives with maintained hope.²⁷

Like Salander et al. 1998 presented the concept of a "creative illusion,"²⁸ we found that the patients wished for different quality and quantity of truth over time. The doctor's formalized duty to inform is obviously in conflict with these data. Friedrichsen et al.²⁷ described that terminally ill cancer patients used three different truths: 1) The absolute truth was unquestionable and included detailed information about what to expect from the future. 2) Partial truth was a patient-preferred half-truth, less detailed than the absolute truth, and included for the patient useful and/or positive information. 3) Desirable truth was more or less unrealistic and made it possible to believe in miraculous cure of their late stage of cancer. These strategies counterbalance death with manifestations of life, accepting and denying death at the same time.²⁹

According to our informants, there was seldom a shared decision making of continuing with palliative chemotherapy. To accomplish shared decision making, doctors have to present both pros and cons with further chemotherapy and allow no further chemotherapy to be an option when applicable. At times, we have to let the patient use their coping strategy, n.b. not mistake it for pure denial, and let them rest from thoughts about an imminent death when they find it necessary, to let patients hope consist even without further chemotherapy.

Interestingly, Weeks et al. reported that patients who by misunderstanding thought they had a curable disease were more content with their doctors, compared to those who understood they had an incurable disease.¹ In line with these data, we found that women associated a good doctor with one who delivered good news. Furthermore, our data confirm recently published data by Tanco et al. showing that patients found doctors delivering more optimistic messages, more compassionate, and trustworthy.¹⁴

According to our present data, patients would probably acknowledge their doctor as a bad doctor, if presented with an option to stop treatment, in a new situation with progressive disease. This underlines the importance of communication. Back et al.³⁰ have presented some general advice of how to discuss treatment or no treatment in this context and still give room for hope. To begin with, physicians should clarify to the patient that there is “a new situation” and no point in continuing ongoing treatment and accept their patients’ possible feelings of anxiety.

Second and third, doctors should exemplify what can be done now and focus on the future life.

In conclusion, hope gives energy in end of life when, in fact, energy is scarce. Both the doctor and the treatment serve as factors increasing patients hope. Oncologists must bear in mind that important decisions regarding continuous treatment with late lines of palliative chemotherapy are seldom autonomous, but affected by family and doctors.

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