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ORIGINAL ARTICLE

The will to live – breast cancer patients perceptions' of palliative chemotherapy

Jenny Bergqvist[a,b] and Peter Strang[a,c]

[a]Department of Oncology-Pathology, Karolinska Institutet, Stockholm, Sweden; [b]Capio St. Görans Sjukhus, Stockholm, Sweden; [c]Department of Research and Development, Stockholms Sjukhem Foundation, Stockholm, Sweden

ABSTRACT

Background: For women with metastatic breast cancer, late lines of chemotherapy might be beneficial but also harmful. Ongoing chemotherapy late in life increase the risk of late or absent discussions of palliative care and access to symptom relief by other options than chemotherapy. Our aim was, therefore, to investigate breast cancer patients' motives, perceptions, and experiences of late lines of palliative oncologic treatment.

Material and methods: A qualitative study with semi-guided face-to-face interviews with 20 women on at least their second line of palliative chemotherapy (second–eighth line). All women had breast cancer and were 40–80 years old. The interviews were analyzed by a phenomenographical approach according to seven steps, which uses a second-order perspective, i.e., how the informants experience the world.

Results: The categories that surrounded the decision to continue with palliative chemotherapy were: The decision, Personal motives and goals and The treatment. All women acknowledged that they knew they had incurable breast cancer and that the treatment goal was to slow down cancer growth. Fear of death was a strong motive for all women in addition to experience of new values of life, still they preferred the doctor to make the decision. Cancer symptoms, especially pain triggered death anxiety, whereas the patients patiently accepted similar side effects from the treatment. There were also external motives for treatment like wishes from family, friends, but also health care staff.

Conclusions: All women knew they had disseminated breast cancer, still they expressed hopes for cure, therefore, death was more of a threat than a reality of an imminent death. None of the women had perceived there was an option to stop treatment. They felt both their families and doctors expected them to continue. Death threat was their main motive for accepting treatment.

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Introduction

For each line of palliative breast cancer treatment the response rate diminishes and is around 30% for third line palliative treatment. It is well known that patients with metastatic breast cancer in general receive a lot more than three lines of palliative chemotherapy before treatment is stopped, still the patients' motives for and thoughts about the palliative treatment beyond second and third line are not that well studied.

Response to previous treatments is the major prognostic factor of benefit from third line palliative treatment [1]. According to this, those who have not responded to previous lines of palliative chemotherapy might be better off with best supportive care or, if possible, treated within a clinical trial. However, late lines of chemotherapy can be beneficial and for fourth–seventh line of palliative chemotherapy data suggest a stable time to progressive disease of approximately three months per line of treatment [2]. The same French study reported that 50% of the patients receiving fourth–seventh line of chemotherapy progressed while 33% had clinical benefit. Five percent stopped chemotherapy due to toxicity.

Patients are more willing to accept side effects from cancer treatment when they know it is meant to cure them, compared with when it can offer symptom relief only [3]. The understanding of treatment goals and prognosis is obviously crucial for increasing the patients' chance for optimal life planning according to their wishes.

A well informed patient with more realistic expectations of treatment, based on knowledge of their disease and prognosis, might make different medical choices compared with less informed patients. Patients offered end of life discussions early have a better chance of receiving end of life care according to their wishes instead of aggressive, futile cancer treatments at the end of life [4,5]. Still, surprisingly many patients wish to continue their treatments, despite a poor prognosis. According to a recently published study [6], shared decision-making (SDM) is seldom seen in daily advanced cancer care. Data suggest there is a lack of physicians presenting foregoing treatment as one option, while communicating the risk of harm and benefit for different treatment options [6]. Patients on late lines of chemotherapy risk to miss out on early referral to specialized palliative care with access to symptom relief by other options than chemotherapy. Furthermore, they risk to receive

CONTACT Jenny Bergqvist jenny.bergqvist@capiostgoran.se Kirurgkliniken, Bröstcentrum, Sankt Göransplan 1, 112 19 Stockholm, Sweden

treatment closer to death and to die in a hospital setting [7]. To improve SDM with regard to late lines of chemotherapy we need to find out more about how the decision process take place in everyday life at an Oncology Department, from the patients' perspective.

Our aim was, therefore, to explore breast cancer patients' motives, perceptions and experiences of late lines of palliative chemotherapy.

Material and methods

The study includes 20 women with metastatic breast cancer attending the oncology clinic at the Karolinska University Hospital Solna for palliative chemotherapy. We used the following inclusion criteria: ≥18 years old, Swedish speaking, patients with on-going (at least their second line) palliative chemotherapy. Those who were cognitively impaired or non-Swedish speaking could not be included.

We aimed at a maximum variation sampling and continued to interview patients until we had included women of various ages, educations, socioeconomic status, years with metastatic disease and lines of palliative chemotherapy, in order to cover different aspects of the phenomenon, Table 1.

A qualitative study design with individual face-to-face interviews was used with a semi-structured interview guide, constructed by the two authors. 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 interviews took place at the hospital. The Stockholm Ethical Committee approved the study, Dnr2014/614-31. The interviews lasted between 30 and 46 min and were tape-recorded and transcribed verbatim before they were analyzed by the two authors.

Table 1. Characteristics of sociodemographic factors for the 20 patients interviewed in the study.

Characteristics	Number of patients ($n = 20$) (%)
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)
Highest 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

We used a *phenomenographical* approach for the analysis according to Marton, and Dahlgren/Fallsberg [8,9], a method that focuses on how people experience, conceptualize, perceive and understand aspects of a phenomena (i.e., a second-order perspective) [9]. The choice of this particular method was important as we wanted to study the patients' perspective and motives when choosing further treatment, as it was obvious already in the first interviews that the patients had a different point of departure for their decisions, than their doctors. They knew that their cancer was disseminated, still they hoped for cure.

Phenomenography allows to present the informants' genuine perception (second order perspective) in the Results section, thereby avoiding the researcher's perspective or interpretation (first order perspective, which only is present in the Discussion, according to the phenomenographic method).

The analysis is to be carried out in seven specific steps in order to create categories and subcategories: 1. Familiarization. The interviews were carefully read and comments made in the margins. 2. Condensation. Statements explicitly stressed or repeated several times were selected. 3. Comparison. The statements were compared to find sources of agreement or variation by focusing on what was diverging or similar. Implicit or explicit statements were also compared. 4. Grouping. Similar statements were grouped together according to previous questioning and comparison. 5. Articulation. The statements within respective preliminary groups were compared and critically analyzed, in order to find the central content of the similarity within each groups of answers. The content of each category was to be limited, without too wide variations and without obvious overlapping between the categories. 6. Labeling. Constructing a suitable expression directly from the transcripts denoted the found categories. 7. Contrasting. The obtained categories were finally compared with each other, considering their mutual relationship.

Trustworthiness

During the interviews a dialogical validation was used [10]: similar questions were put in different situations in order to ensure that the informant's view was correctly captured. Furthermore, dialogical intersubjectivity was aimed at, meaning that the authors analyzed relevant interview segments separately and compared their findings [11]. In case of any discrepancies, these were discussed and common descriptions were formulated. The aim was not to reach consensus, but to find possible alternative interpretations.

Results

When exploring the motives, goals and experiences related to palliative chemotherapy treatment, it was obvious that most of the informants talked about three separate issues: (a) The decision process, (b) Personal motives and goals: Their perception of death as a threat, not as a reality of an imminent, impending death, new value of life, cancer symptoms and external motives, and (c) The treatment: The experience, stopping treatment is no option and treatment recovery period (Table 2).

Table 2. Categories and subcategories of statements stressed or repeated in the 20 interviews with women receiving late lines of palliative chemotherapy.

Category	Subcategory
The decision process	
Personal motives and goals	Death as a threat
	New value of life
	Cancer symptoms as triggers of death anxiety
	External motives for treatment
The treatment	The experience
	Stopping treatment is no option
	Treatment recovery period

The decision process

As regards the decision process, all the informants described a similar experience. They did not feel that they had been offered an actual choice. Instead, they pictured consultations where the oncologist had informed about primary spread or further dissemination of their cancer, but at the same time he or she had explained next treatment. The women, expressed that they appreciated this strategy and were grateful for being offered further treatment, as this was what they actually wanted. No one questioned this authoritative approach, instead they described their doctor as an expert who offered them the best cancer treatment available. In this aspect, there was no difference between younger or older female, or between patients with newly discovered spread of disease or patients with a far advanced disease since many years ago.

> 'No, I've not been asked whether I would like to carry on with my treatments. But I want to!'
>
> 61-year old woman on her third line of palliative chemotherapy.
>
> 'Actually, you can't decide yourself, the doctors are best suited for the decision … I am not an expert, the doctors have to decide and they do.'
>
> 75-years old woman on her second line of palliative chemotherapy.

Personal motives and goals

All the informants were aware of their incurable and life threatening disease, and this explicit death threat and the associated death anxiety were central motives for accepting and continuing with palliative chemotherapy. In parallel, they described their new awareness of the value of life. For certain informants, also tumor symptoms were a distinct reason for accepting treatment. Regardless of motive, they expressed their goal was to live as long as possible.

Death as a threat

Despite being well informed about their disseminated cancer – they still did not talk about an imminent or impending death, but about death as a threat, possible to delay or even escape. All the informants mentioned the death threat directly or indirectly as the main motive for accepting treatment. When being confronted with a diagnosis of a disseminated disease or tumor progression, they assumed that treatment would prolong life as a self-evident fact and that treatment would prevent them from death. They said their doctor's had vaguely described the goal as 'slowing down cancer growth and possibly make the tumor shrink'. Although they were constantly aware of their situation and the threat was always on their mind, still many of the informants secretly hoped for cure.

> 'So now I have to change treatment as the old one does not work, and well then you think about death and such things … [and you have no choice]'
>
> 61-years old woman on her third line of palliative chemotherapy.
>
> 'I hope it slows down … .at least … .and then suddenly disappears!'
>
> 50-years old woman on her eighth line of palliative chemotherapy.

New value of life

When becoming aware of the death threat and their insecure future, every moment of life became more valuable. They knew that it could be taken away from them and therefore every moment with a relative lack of symptoms was like a gift. They all pointed out that life was precious, that they wanted to live on and this had become more evident in the light of thoughts about death, as the thought of having to die scared them and was hard to accept.

> 'I know I live on borrowed time. But every second I may borrow is fantastic.'
>
> 44-years old woman on her fifth line of palliative chemotherapy.

Cancer symptoms as triggers of death anxiety

The informants said they were terrified when they experienced new symptoms, especially pain, as they associated pain with cancer progression. Therefore, episodes of pain triggered thoughts about an impending death but also anxiety that at times was difficult to handle. Pain made them tired, anxious, and depressed and these four symptoms were often mentioned together. In addition, pain was told to affect their appetite and make them nauseous. Still, many informants said they were very reluctant to, and distressed by, the idea of being addicted to painkillers. Pain triggered not only thoughts of death, but also thoughts of a very painful end of life.

> 'As soon as you are in pain, you starts thinking … … // … I thought, well now everything is over. I am screwed. It is just the way it is, every time when you feel something new.'
>
> 62-year-old woman on her second line palliative chemotherapy.

External motives for treatment

Being diagnosed with a disseminated cancer affects not only the patient, but the whole family. In general, their families wanted them to take any chance to life-prolongation and the patients felt obliged to do so as they felt a responsibility for their beloved ones. They also wanted to shield them from their own worries. E.g. when an informant experienced distressing cancer symptoms, she would explain them for her

family as 'side-effects from the treatment' as she did not want to upset them.

Another frequently mentioned motive was the expectations from their doctors. In most cases, they had had a long contact with their oncologist and when he or she suggested continued treatment, they did not want to disappoint their doctor by refraining from the offer.

> 'I am so happy there is treatment for me! They say that breast cancer is … ….that they can make you well. You have to believe in it. You cannot give up, they [the staff and their relatives] say.'
>
> 61-years old woman on her third line of palliative chemotherapy.

The treatment itself

The experience

Everybody felt treatment was their lifeline and had set their mind on continuing as long as they could, in order to postpone death. They all had previous experience from treatment and did not want stop chemotherapy. When discussing burdensome treatments, the women said they were willing to cope with side effects and would continue even if they got worse. They also stressed that symptoms from cancer progression were much more frightening that similar or worse symptoms due to side-effects from the treatment, as treatment still was something positive.

All women talked about various numbers and degrees of side effects. The most common and life disturbing adverse event was the enormous paralyzing fatigue. Hair loss was also mentioned as very hard to cope with, not recognizing themselves in the mirror. All common side effects including nausea, neuropathy, changed taste, obstipation, diarrhea, skin problems etc. were mentioned. When the side-effects were disturbing, it was still a comforting thought that the treatment was for their own good and this was the prize they had to pay. Moreover, the physicians and nurses also did their best to normalize the experience of side-effects as something almost inevitable.

> 'The nurse said to me – You say you have no appetite, no strength and no energy to do things… Well, we're not giving you candy you see…'
>
> 76-years old woman on her third line of palliative chemotherapy.

Those who experienced less side effects with the on-going treatment compared with last treatment appreciated this. They referred sometimes to the doctor having said that this was a 'kinder' treatment than the last one. If their previous treatment(s) had been beneficial for them they expressed this was motivation enough for them to go on with treatment, despite troublesome side effects. Those who had worse side effects, compared with what they had experienced on their previous treatment, wished for this to be a sign of effective treatment.

Stopping treatment is no option

The treatment was something the women said they could count on. The informants expressed they did not know what to do instead of attending treatments and that they were afraid of not being able to receive them as planned. If their treatment was postponed, they expressed great fear for tumor growth and new metastases.

Not only the women, but their families too, planned their everyday life around the treatment days, therapy evaluations etcetera and one described treatment as 'an extra family member' to consider when planning vacations etc.

> 'Well I've had it for such a long time, so I plan things according to treatment schedules. I do not know how I would act if I did not have the treatments. What would I do instead?
>
> //Well, if you stop treatment then… ….well, then it will continue to grow or I would get more metastases.'
>
> 75-years old woman on her second line of palliative chemotherapy.

The informants expressed that being without treatment was associated with great fear of an imminent death. When asked if anything would make them say no to treatment they often sat silent for a long time, and then almost all the women answered 'no'. However, the majority then continued to say that if they were completely out of energy and without control of their body and mind only then, and only then, they would say no.

Treatment recovery period

Even if the informants expressed they did not want to stop treatment they looked forward to the week just before next treatment when they regained strength and had more energy, both mentally and physically. They highly appreciated the possibility of having enough energy to participate in social life as well as to do the everyday tasks.

> 'I have felt more energy to do things when I have had some time off treatment [just before the next course of chemotherapy] but if I don't get treatment so … (laughing) … .it's pointless really.'
>
> 61-years old woman on her third line of palliative chemotherapy.

Discussion

The central theme in every interview was how the women were overwhelmed by a death threat, which served as a strong motive for treatment. They never felt they had a choice *not to* continue with palliative chemotherapy. Our results that patients perceived continuous treatment as their only way to endure, and try to decrease the threat to their existence, are well in line with others [12,13].

To be confronted with one's own mortality triggers emotional distress and death anxiety [14–17], and requires an extraordinary psychological mobilization. People develop different kinds of coping strategies and/or defense mechanisms towards a concrete death threat and the associated death anxiety. In our study, the patients' awareness of their impending death was obviously a strong motive for continuous treatment.

Furthermore, symptoms of any kind were presented as a constant reminder of their situation. Especially pain triggered death anxiety, whereas the patients accepted similar side

effects from the treatment. Other studies have also identified pain as a much feared symptom, closely associated with dying. Being able to reassure that pain will be controlled increases hope and is, therefore, important and highly appreciated information in discussion of prognosis [18].

Hope [12,19–21] and meaning [17,22–24] have been identified as fundamental parts of useful strategies when coping with one's impending death. Nierop-van Baalen et al. conclude from their study of 76 patients with cancer in the palliative phase that hope has a dual function: patients hope because they cannot forsake it and because they benefit so much from it in terms of reduced anxiety and depression [12].

From an existential point of view, hope of cure is also related to two fundamental defenses against death, namely *specialness* ('I will be the one in a million, the first person to defeat disseminated cancer … ') and the believe in an *ultimate rescuer*: When everything seems lost, there still is a place for miracles, by someone or something rescuing you in the last moment [17]. Previously, God was the obvious ultimate rescuer. In secularized societies such as Sweden, the need of a rescuer is still there, but focus is shifting from God to health care, especially to the doctor and to the hope for new miracle treatments. This was evident in our study: the doctor was perceived as a wise expert and the one who was to rescue them from dying. This is also elaborated in previous studies: Hagerty et al. showed in 2005 that offering the most up to date treatment and appearing to 'know all there is to know about cancer' [18] is the number one strategy that fosters hope.

The fact that most of the women wanted their doctor to decide about treatment, as the doctor was the expert, is interesting. It is in disconcordance with the Swedish Health Care System's advice to empower the patients to decide for themselves according to their autonomy rights. However, the finding is in line with other studies reporting the doctor to be the person with most influence for the majority of patients' treatment decisions [5].

There is an important difference as regards decision-making in everyday health care and in a palliative phase of cancer as the latter decisions may affect the length of one's remaining life. In this situation patients generally feel unqualified to make rational decisions, which also is shown by Buiting et al. [25].

Our study also confirms family members' influence on patients' treatment decisions, as previously reported [26]. Although patient autonomy is emphasized within health care, not at least in Sweden, it is obvious that important decisions are seldom autonomous. As a rule, the patient and their families make a joint decision and often, families are encouraging the patient to go on with treatments. For this reason, patients who are living in relations are more likely to receive palliative treatments even during their last month of life [4]. However, the patients also stated that they sometimes accept further treatment in order not to disappoint their doctor, which is a more problematic finding.

In good agreement with other studies [12,20,27] our patients did not lack knowledge about their prognosis, still they secretly hoped for cure and felt dependent on chemotherapy. This conflict of mind can be explained by the suggestion that awarenesses of disease status can be conceptualized into two different kinds of awareness: being informed of or understanding disease prognosis. These two may have different impact on quality of life and therapy preferences [28].

Rather than talking about cure, most of our patients talked about living as long as possible. They chose to focus on daily chores, especially on their treatment plan with regular hospital visits and they let go of thoughts about the future, which made their daily situation manageable. This way of dividing one's remaining life into much shorter time horizons, has the capability to reduce anxiety for the inevitable [29] and it has been described as a way of coping with one's impending death [16].

The importance of meaning and meaning-making were also striking findings in our study: our patients' exposed situation and their actual death threat had made them more aware of important values of life: now, when life no longer was for granted, they valued every new day and as one informant put it: 'Every second I may borrow is fantastic'. Just being alive gave them a deep sense of purposefulness and meaning. Already in 1976, such search for meaning when facing a cancer was described by Weisman and Worden as 'The existential plight in cancer' [30]. Recently this plight was defined by Virginia Lee as '… the process by which patients struggle to retain what is personally meaningful when virtually every aspect of their life will be threatened by changes imposed by the cancer and its treatment' [31]. As a result of this search for a new meaning, successful individuals emerge with a sense of renewal, greater self-awareness and personal growth, as well as a greater appreciation for life, nature, and compassion for others [16,31].

In line with findings in previous studies [25], patients accepted side-effects regardless if they were disturbing or not. Also in this respect our informants strived to make sense of their situation. Treatment with chemotherapy had substantial positive effects: The patients felt being 'under the microscope', as one of the informants put it. The regular visits and blood samples created a sense of security, as well as they helped the patient to focus on the present as they had appointments of different kind to attend. Also Buiting et al. [25] conclude that being on active treatment helps the patients to live in the present and to keep thoughts of death at a safe distance.

Methodological considerations – strengths and limitations

Among different qualitative approaches, we chose the phenomenograpic method, as we wanted to highlight the second-order perspective, i.e., how informants experience and perceive their situation and their world [9]. A phenomenographic researcher's function is to 'illuminate the ways in which others state an understanding of something' [32], irrespective of whether or not the researcher finds the perception to be correct (in this study: whether it is plausible or not

to believe that chemotherapy will substantially prolong survival in late stages).

As treatment strategies and decision-making in most cases are described from the doctor's point of view, a strength is that this study sheds light over the goals and motives of the patients, motives that not necessarily are congruent with those of the doctor. Thus, we are able to demonstrate that the message that the doctor communicates ('slowing down the cancer growth and possibly make the tumor shrink') is apprehended but not necessarily what the patient secretly hopes for.

A limitation is that we only interviewed patients on palliative chemotherapy, whereas the experience of those who refrained might be different. It is well known that a death threat constitutes an existential boundary situation which may either result in an existential awareness with a heightened gratefulness for being alive, or in anger, despair, and resignation [17,33].

Conclusions

- All women on treatment strongly expressed their new value of life and that treatment was crucial for their hope.
- The actual death threat and the associated death anxiety were directly or indirectly the main motives for accepting treatment.
- They avoided own decisions but were pleased to leave the treatment decision to their doctor.
- Effective pain control is of great value, as pain is perceived as a marker of tumor progression and functions as a trigger for death anxiety.

Disclosure statement

No potential conflict of interest was reported by the authors.

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