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Quality of life and care needs in women with estrogen positive metastatic breast cancer: a qualitative study

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ABSTRACT
Background: In recent years, the prognosis of metastatic breast cancer (MBC) has improved with more effective therapies applicable to a wider range of patients. To many patients, a MBC diagnosis thus initiates a prolonged course of illness and treatment. This qualitative study aimed to explore the long-term health-related quality of life (HRQoL) and support needs in MBC patients of all ages in the Danish context.

Material and methods: Eighteen MBC patients participated in five qualitative focus group interviews that were analyzed using content analysis and a constructivist approach.

Results: The participants described how MBC severely reduced their physical and psychosocial functioning and required a constant adaptation of their quality of life (QoL) standards in relation to their changing life situation and disease progression. Overall, they felt medically well-treated but lacked a multidisciplinary approach to care including psychological support, in particular, but also manual physiotherapy, health care coordination and social counseling. The participants called for continuity of care with the same health care professionals as this facilitated communication and flexibility in planning treatment and controls. They requested a reduction of precious time spend on treatment to enable them to focus on their most meaningful relations and activities.

Conclusion: With the MBC diagnosis, the focus of treatment switches from disease eradication to prolonging survival, alleviating symptoms and improving QoL. To patients, MBC marks a shift in expectations from quantity to quality of life and a perpetual adaptation of their QoL standards. To sustain patients’ HRQoL, it is important that along with improvements in life-prolonging treatment, comprehensive care also supports their main psycho-social needs. These patients needed support in maintaining normality and role functioning enabling them to focus on living, not merely surviving, through this prolonged disease phase.

Introduction

Breast cancer (BC) is the most common cancer in women worldwide. In developing countries it is the second cause of death after lung cancer. The prevalence of distant metastasis is high in patients with locally advanced cancer (LBC) including those with large tumors (>5 cm) and noticeable nodal disease (>3 cm), even if asymptomatic [1]. About 5% of BC patients in Western countries are diagnosed with LBC or metastatic breast cancer (MBC) while around 30% of the patients with early breast cancer (EBC) eventually develop MBC [2-4]. While breast cancer mortality overall has decreased as a result of earlier detection and adjuvant treatment, only minor survival gains have been achieved in MBC though individual patients may obtain prolonged survival, predominantly following endocrine or HER2 targeted treatment. With no cure yet available for MBC, palliation and prolongation of survival are the main treatment goals. Median survival is 2-3 years but as long as 15 years in indolent disease [2,5] implying that a diagnosis with MBC often initiates a prolonged course of illness and treatment rather than immediate end-of-life care [6]. This augments the importance of examining MBC patients’ health-related quality of life (HRQoL), i.e. the disease’s impact on their physical and psycho-social well-being and everyday lives, and needs to provide optimal care and support in this phase of disease.

The complex nature of metastatic disease including the patient’s subtype of BC, menopausal status, age, comorbidity and previous treatment experiences must be taken into account when discussing treatment options [3,7-9]. Emphasis will predominately be on molecular targets such as estrogen receptor (ER) and human epidermal growth factor receptor 2 (HER2). Common side effects of treatment (targeted treatment, chemo- and radiotherapy) are fatigue, nauseae, vomiting, hair loss, diarrhea, peripheral neuropathy, menopausal symptoms, poor sleep and skin toxicity [3,10-15]. Palliation may also include bone modifying agents, pain medication, antidepressants or anti-emetics, for instance [7,10].
MBC patients’ quality of life (QoL) has been shown to be severely reduced with symptoms and side effects having a detrimental impact on psychosocial and physical functioning, working ability, family life and couple relations [2,6,10–13,16–19]. Fatigue is dominant but depending on the extension and localization of metastasis, physical symptoms such as pain, dyspnea, and lymphedema are frequent. Emotionally, MBC patients are much affected by treatment response and recurrences, and uncertainty, grief, lack of control, fear of death and loss of identity and future life often lead to depression and anxiety [2,10,11,16,20]. Physical and psychological symptoms tend to exacerbate one another [10,11,21]. It has been suggested that younger women and mothers may have lower HRQoL and functioning as compared to older women [6,12]. Despite such serious QoL impairment, MBC patients often have an unmet need for information about treatment options and prognosis, as well as management of symptoms, side effects and psychological problems [2,5,6,10,12,14,22].

While quantitative studies have described factors reducing QoL in MBC, studies exploring the relations between these issues, i.e. providing explanations of why certain symptoms are important to patients and how they affect their QoL and support needs, are lacking. This is particularly the case in the present context of improved treatment options and prolonged life expectancy. As most QoL studies have been linked to clinical trials, there is also shortage of studies examining HRQoL and care needs in MBC patients >60 years of age albeit the median age at BC diagnosis is above that [3,9]. To our knowledge, studies of Danish MBC patient perspectives are absent. The present qualitative study therefore aimed to explore in depth the HRQoL of Danish MBC patients of all ages and how this might be related to their support needs.

Material and methods

An initial search for literature was carried out in PubMed, Embase, Psychinfo and Artikelbasen yielding 635 abstracts of articles published in English 2010–2015 of which 74 were selected for full-text analysis. The literature study informed the qualitative study design including a question guide used in focus group interviews with 18 MBC patients. Focus groups were chosen to elicit a broad variety of patient perspectives on the women’s experiences and needs. Participants were invited by The Danish Breast Cancer Organization (DBO) encouraging interested patients to contact the researchers directly for further information and screening. Eligible patients were diagnosed with estrogen receptor-positive MBC, i.e. the most common type of BC, to enhance comparability. Due to the focus on subjective patient perspectives and experiences, no medical records were collected. Informed written consent was obtained, participation was anonymous and ethical committee approval was therefore not required. Five small focus groups – representing all regions of Denmark – were held with 3–4 participants in each, to create confidential settings for discussions among peers about their HRQoL and supporting care needs.

The focus groups were set in regional health centers or conference rooms and lasted two hours. They were moderated by G Lee Mortensen, assisted by IB Madsen. When introducing the focus group discussions, the participants were told of the aim to explore all experiences and encouraged to voice converging as well as diverging perspectives, provide examples and elaborate on their own and others’ experiences and expressed needs. The questions in the semi-structured interview guide were open-ended [23,24] and began with questions to the participants’ disease trajectory: time of first diagnosis with BC, time of diagnosis with MBC, subsequent disease development and current disease status. The women then described their reactions to the MBC diagnosis followed by its physical, cognitive, psychosocial and professional impact on their QoL and functioning. They then described their treatment experiences, and finally, their medical and non-medical care needs (Supplementary file: Question guide).

The interviews were transcribed verbatim and analyzed using Nvivo 8 software (QSR International) and a combination of inductive content analysis and a constructivist approach, i.e. focusing on how the language used in the focus groups unveiled how patterns of meaning were created in social interaction among peers and in relation to each patients’ personal situation [25,26]. First, the transcripts were read through numerous times (independently, by three researchers) to get familiar with the data. Second, the data was coded (categorized) into moderator- and participant-generated topics that were raised during the discussions. Third, main themes within each topic were identified, and finally, recurrent connections between topics and themes were analyzed. This generated a pattern of the relative significance that the topics and themes had for the participants, i.e. the main QoL impact of MBC and the participants’ most important care needs. All methodological and analytical steps were discussed among GLM, IBM and an independent qualitative researcher (SLM) until agreement was reached.

Results

The participants resided in 17 different towns and attended 11 hospitals across Denmark; they were aged between 41 and 72 years old, and had been diagnosed with MBC for 1–11 years. At the time of MBC diagnosis they were aged between 35 and 65 years reflecting great variation of life situations with respect to family, e.g. age of children, and work status. 16 participants had been well for 2–16 years following treatment of EBC; two had MBC at diagnosis (Supplementary file: Table 1).

Two main topics were discussed in the focus groups: The quality of life impact of living with MBC and patient needs for treatment and care, both including a number of subthemes to be described below (Supplementary file: Figure 1).

Quality of life impact of metastatic breast cancer

The first main topic included several subthemes: (a) reactions to the MBC diagnosis, (b) cognitive, (c) physical, (d) psychological, and (e) social/relational QoL aspects of MBC, and (f) strategies to cope with MBC.
(a) The participants described reacting to the MBC diagnosis with shock and fear of imminent death. This was aggravated by hearing that only ‘life-prolonging treatment’ remained which they interpreted as implying very short life expectancy. Once new treatments were initiated, the women’s anxiety was somewhat reduced by learning that they might have more treatment options and time than expected. Still, the MBC diagnosis was depicted as marking an end to ‘ordinary everyday life’ with family life, work, social and leisure activities.

(b) Many participants described cognitive problems with memory and concentration but none felt this significantly reduced their QoL. (c) More importantly, their physical QoL and functioning was severely impaired by symptoms such as pain, gastrointestinal upsets, flu symptoms, nausea, cardiovascular dysfunction, edema, stomatitis, neuropathy, stiffness of muscles and joints, dyspnea, dizziness, problems with sleep and gait, hair loss and menopausal symptoms. Fatigue was particularly limiting the women’s role functioning and participation in activities bringing meaning and joy to life. (d) Yet the main hardship of MBC was said to be emotional. Most participants had recurrent spurs of depression and anxiety, especially when feeling particularly poorly and with the occurrence of new metastases. Metastasis to vital organs and the brain were the most dreaded sites. Living on borrowed time was stressful and included alertness to possible symptoms of relapse, hypersensitivity or propensity to anger in some.

When I relapsed, I just sat down in my couch for half a year and thought “this is the end” because he said it was life-prolonging treatment now. It was extremely stressful. You never know how long “life-prolonging” is, they cannot tell you that. But just when you hear it, you think it’s half a year… It is so stressful not knowing if you’re here in a half a year. For instance, when my daughter said she was getting married in a year. In one year?! If only she had said “next week”? As it turns out, that’s a year ago now, but you don’t know that (FG2B).

That’s right, you always feel the guillotine hanging above your neck (FG2A).

(e) Regarding the women’s relational QoL, children’s welfare was the main concern, especially to mothers of young children. Some had written letters or speeches for children. Some had time was stressful and included alertness to possible symptoms of relapse, hypersensitivity or propensity to anger in some.

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(f) Finally, the participants described their strategies to cope with living with MBC. Although distressing, many found that ‘getting things sorted’ – e.g. making arrangements for the funeral – enabled a feeling of control and to focus on living: ‘It allowed me to put the disease on a separate shelf and then live life on the other shelves’ (FG2B). Coping with MBC required a constant adaptation of individual QoL standards and changed roles vis-à-vis the patients’ self-perceptions and social relations. For instance, ‘while you have children at home it is either sink or swim; when they are fledged and move out, you have to adapt to a new situation’ (FG4D). Maintaining normality – especially upholding one’s role functioning as a mother, grandmother, partner or professional – was of major importance. Half of the women found that even a few hours of work per week allowed them to feel useful, to get out of the house and keep their minds busy ‘to stay sane’. Others felt that stopping work had been a great loss. Setting milestones like turning 40 years old or attending a baptism, was described as a crucial means to stay strong. Fortunately, many milestones were reached and new ones set along the way. Many expressed surprise at how long they had survived with MBC and that the disease course had not merely been downhill.

Treatment and support needs

The second major topic concerning the participants’ treatment and supporting care needs included the subthemes: (a) treatment needs, (b) worries related to treatment and controls, (c) minimizing time spend on treatment, (d) socio-economical clarification, (e) psychological counseling, and (f) information needs.

(a) The women mostly felt they received adequate symptom treatment but some called for improved options of receiving manual physiotherapy to alleviate the physical pain and discomfort. Although dealing with symptoms and treatments was challenging, they ‘grew with the task’ and would accept almost any medication that might keep them alive.

(b) Controls and waiting for test results tended to reactivate concerns about whether the cancer had spread, about running out of treatment options and the QoL impact of the next treatment.

The main concern is whether the treatment you are receiving continues to work and if the side effects are getting worse. The worries arise: ‘what if you have to stop this, what will you then have to go through? Do they have more options in store – and for how long do they have more? And will the side effects be worse than the ones I have now?’ (FG1A).

(c) The limited time perspective was closely related to the women’s care needs. They felt that treatment and controls were time consuming and requested short waiting times for test results at all hospitals and the assemblage of as many medical issues as possible at the specialized clinic. Acting themselves as coordinators between health professionals – some seemingly unfamiliar with MBC related issues – was challenging. All preferred seeing the same or very few oncologists as this ensured a feeling of continuity and confidence. This again facilitated flexibility in planning treatment and...
discussing test results or concerns over the telephone – all with an end to minimize the disruption of everyday life.

After the examination of my stomach – cause that's where they thought something was wrong – the doctor said 'there is some cancer going on in L2'. I asked what would happen next. 'Why, he didn't know that; he didn't even know if there was anything that could be done at all'. So I asked for my medical record so that I could see an oncologist and ask myself. Then he told me to take it easy. I became so angry and said that he shouldn't bloody hell tell me to take it easy! I have two small children. I do not have time for this nonsense! (FG2D).

Our time is important. That is the thing with all the waiting, well, 'I have a job for God’s sake, I could have worked during those hours!' … It’s like, when you’re a patient, that’s all you are, and you’re available when they have time. That needs to be turned around (FG4A).

(d) The participants called for a more comprehensive approach to MBC care including professional social support. Women with cognitive problems particularly wished for a health care coordinator helping with the various medical and social aspects of living with MBC, e.g. getting rapid clarification of their financial support options.

I really appreciate the ‘stand-by plan’ according to which they [the job centre] don’t have to follow up on you all the time … Because I just try to live my life every single day without the disease taking up too much space and that is such a struggle if social workers call you up constantly to ask how you’re doing … And then you get to sit there afterwards and think ‘God, yes, I do actually feel awful and there are all these things I can’t do’. The option of staying on sickness benefit [with a flex job in this case] rather than receiving disability pension is really good (FG4D).

I’ve tried to get that but, unfortunately, I didn’t succeed yet. It would give me some peace of mind (FG4A).

(e) Lacking psychological support was the greatest unmet need. Participants attending one hospital much appreciated being offered psychological counseling at the hospital; all strongly believed this should be offered everywhere.

When I was told there was nothing they could do, that it had spread so much, I thought to myself ‘when is a psychologist entering that door?’ It seemed absolutely insane that this doctor and nurse just sat there – and they do say things quite directly when something’s wrong. After that, you are supposed to just … go home? You are devastated. They should have offered something there … They should ask if you need to talk to someone. You can always say no. They do ask you how you’re doing and if you have any questions, so I guess you could bring it up yourself. But I’ve got the impression that it’s easier to get morphine than a psychologist (FG5B).

Yes, and a crisis can also appear later on, when you get home and it starts to dawn on you. Then too it would be nice if you could contact someone. I’ve heard of many who get a depression when they’re actually over it [the first shock], after half a year. Surely, they must know that out there … and be able to tell you (FG5D).

Participants living alone particularly needed professional psychological support to cope with MBC being ‘like a rollercoaster switching between anxiety and relief’ (FG4D).

(f) The final needs-related subtheme pertained to the participants’ information needs. One hospital was commended for offering patient education courses for new MBC patients, including information on treatment, physical and emotional disease aspects and a visit to relevant hospital departments. This too was requested at all hospitals. While most felt adequately informed about standard treatment options, a few called for early genomic testing to prepare for targeted or experimental treatment and information about treatment options abroad. Others requested independent professional advice regarding non-medical options of symptom management and fortification, issues that are much discussed in patient networks. The Danish Cancer Society and DBO organizes highly valued services such as meetings, mindfulness courses and support groups for children. An unmet need was expressed for individual counseling of spouses who were often severely troubled but uneasy with group support.

Just as importantly – and reflecting the prolonged life expectancy in MBC – some participants underlined a need to hear more ‘good stories’ about MBC patients. They had heard much about the hardships of MBC and prepared themselves for dying, but had lacked complementary help to focus on living – on ‘how to grab life’ (FG4A). Especially at the time of diagnosis, the patients needed stories about how women live with MBC and may indeed lead good lives for several years. This prospect led some to prefer coining MBC as a ‘chronic’ disease while cringing at terms like ‘incurable’ cancer and ‘life-prolonging treatment’.

Discussion

Improved treatment options imply that, today, a MBC diagnosis often marks the beginning of a prolonged course of illness and treatment with ensuring optimal QoL being a major aim. The present study explored how Danish MBC patients’ QoL was related to their main support needs during this particular disease phase.

Patient experiences with disease are related to their socio-cultural context. Our participants’ expectations, needs and priorities were based on their personal situation as well as a societal context with public health care and various financial support options. Danish MBC patients are thus not representative of MBC patients worldwide. A selection bias should also be considered as our participants were relatively high-functioning MBC patients that may not reflect the experiences or lower functioning patients. We believe, however, that the care needs expressed by our participants may well be even more pronounced in patients with poorer function and caregiver support. With these reservations, our qualitative methodology allowed for an in-depth understanding of MBC patient perspectives, i.e. analytical generalization, but they do not support statistical generalization. Our analysis, however, has the strength of representing patient perspectives unrelated to a clinical trial.

MBC severely reduced the participants’ HRQoL and functioning. This was one of the two main topics and the women’s descriptions of its various subthemes revealed that despite substantial physical symptoms, the psychological burden was the hardest and socio-relational QoL aspects of key importance. This ordering of QoL aspects is likely affected by the participants’ satisfaction with medical treatment as well
as a health care system providing financial security. The participants described a dynamic perception of their QoL as requiring constant adjustment to their changing circumstances and disease progression. For instance, the younger women focused much on their children’s present and future welfare and struggled with maternal role functioning. Many also felt a loss of feminine and professional identity. Such altered roles are well-known to challenge patients and their relations [2,6,11,13,15]. Yet while patients’ physical well-being has been shown to decrease with older age, social and functional well-being tends to increase [6]. In our analysis, this may be due to impaired physical functioning interfering relatively less with the roles, self-perception and expectations of older women. Still, they too prioritized the potential benefits of treatment over the risk of side effects and would accept almost any treatment giving them extra time – a priority that has previously been shown in younger MBC patients [3,5,18,19,27].

Others have shown that goal adjustment is indeed crucial to coping, i.e. disengaging from unattainable goals and reengaging in more attainable goals that are often more immediately rewarding and emotionally meaningful [28]. Our participants had become keenly aware of prioritizing meaningful relations and activities and set milestones for events they hoped to live to experience. They described their course of disease as fluctuating between periods of relative well-being and tougher patches – ‘a rollercoaster’ – which is in line with what Sarenmalm et al. described as a dialectal process of suffering and easing distress and constantly ‘making sense of living under the shadow of death’ [11]. Following the improved life expectancy, some of our participants preferred coining MBC as a chronic condition and called for an increased support in how to continue life rather than ending it. They especially needed support in upholding identity and normality with respect to work and role functioning as much as possible. Continuity was thus a key aspect of their QoL priorities and coping with MBC.

Following these main QoL concerns with psychosocial issues being vital, and pertaining to the second main topic, the participants requested a more comprehensive approach to the care of MBC patients. This supports that, seen from a patient perspective, cancer is a biopsychosocial illness, yet cancer care is mostly bio-medically focused [11]. Our participants lacked a multidisciplinary approach to care, primarily including ongoing management of psychological issues, possibly intensified at diagnosis, in patients living alone and with the occurrence of new metastases. Psychological support of spouses, who can be principal sources of support but are often destabilized by anxiety and depression [17], also appeared lacking. Finally, our participants requested manual physiotherapy, health care coordination and social counseling to clarify their options of financial support and perhaps maintain some professional activity, e.g. via a flexible work position. Our study supports previous findings that work and keeping busy are crucial to maintain normality and QoL [13,16].

Living a medicalised lifestyle is stressful and time consuming [19]. To MBC patients, time is sparse and precious. The less time spend on treatment related activities, the more time for meaningful activities – i.e. living. Minimising medical disruptions of everyday life, e.g. by reducing waiting times and pooling medical issues, are thus ways to maintain normality and support QoL as conveyed by the patients. Continuity of care with the same health care professionals enabled this and was thus of great importance to our participants. Overall, they felt adequately informed, but just like other MBC patients, some requested more knowledge about clinical trials, treatment options abroad and non-medical symptom alleviation and fortification [5].

With the MBC diagnosis, the focus of treatment switches from disease eradication to prolonging survival, alleviating symptoms and improving QoL [2,5]. To patients, MBC marks a shift in expectations from quantity to quality of life and a perpetual adaptation of their QoL standards. To enhance patients’ QoL, it is important that along with improvements in life-prolonging treatment, comprehensive care supports their changing physical and psycho-social support needs. Finally, we suggest that more attention should be paid to the needs of older women who also want a full life as long as possible but have received less attention despite constituting the majority of MBC patients [8].

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ORCID

Gitte Lee Mortensen  http://orcid.org/0000-0001-9750-2493

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