

# Illness trajectory of metastatic breast cancer: A qualitative narrative study

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## Research article

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# Abstract

**Purpose:** Breast cancer is accompanied with different psychological consequences. This study investigate to describe the physical, emotional, social, and spiritual characteristics of illness trajectory of metastatic breast cancer (MBC).

**Method:** This is a qualitative study, in which repeated in-depth interviews with 15 MBC patients were conducted. The interview data were transcribed verbatim and analysed as a text, using a qualitative biographic narrative approach.

**Results:** Patient's narratives about the illness trajectories revealed various physical, cognitive, emotional, social, and spiritual needs at the time of breast cancer diagnosis, and the incidence of metastasis. Positive experiences including personal growth, and negative feelings such as rejection and isolation were reported as patient's narratives about living with MBC. At the anticipatory phase, the Patient's narratives were classified into pessimistic and optimistic predictions which were affected by spiritual attitude. Similarly, spiritual as well as religious beliefs were highlighted in psychological reactions and patient's point of view about death.

**Conclusions:** The MBC trajectory is complicated and each phase of the MBC trajectory includes characteristic tasks and focal points. To move away from the predominant traditional approach towards a more comprehensive and better-targeted service, an increased understanding of the complexities of the MBC trajectory is necessary.

## 1. Introduction

### 1.1. Problem formulation

Breast cancer is the second most common cancer worldwide, and the most frequently diagnosed malignancy in women [1]. According to the last report of the world health organization (WHO) 2.09 million cases of breast cancer identified in 2018 [2].

Despite increasing incidence rates, breast cancer is the most prevalent cancer five years after diagnosis, due to the improvement of screening and effective treatments [3, 4]. Besides, the recent meta-analysis indicated the change in survival in metastatic breast cancer (MBC) with treatment advances [5]. However, the diagnosis and treatments of breast cancer are a painful and traumatic experience [6]. Moreover, the side effects resulting from invasive cancer treatments put the enormous emotional burden on affected women during treatment and/or remission periods [7, 8]. Indeed, breast cancer patients experience continuous physical, emotional, and social changes as the disease progress [9]. However, little is known about the trajectory of the abovementioned experiences over time among MBC women. To understanding and managing of MBC as a chronic disease, Reed. et al introduced a five trajectory model [10]. This longitudinal mixed-methods study, according to the general illness trajectory model [11], identified five

trajectory phases (pre trajectory, trajectory onset, living with progressive disease, downward phase, and dying phase) were experienced by MBC women [10].

Thinking in terms of these trajectories provides a broad timeframe and patterns of associated needs and challenges of the illness process. The understanding of illness trajectories can give rise to the better adjustment of the patient and their caregivers to illness and its demands. This insight helps them feel a sense of control and empowerment [12]. In other words, the knowledge of change is bound to be important for a better understanding of how MBC patients cope with this stressful encounter.

Previous studies pay attention to the various psychosocial trajectories of breast cancer, such as trajectories of psychological distress [7, 13, 14], psychosocial coping along disease trajectory [9], psychological and physical adjustment [15], quality of life trajectories [8], trajectories of distress, anxiety, and depression [16, 17], or acute stress trajectories after breast cancer diagnosis [18].

## **1.2. Purpose of the research question**

Although the abovementioned studies provided information considering the changes of psychological characteristics in a different phase of breast cancer, there is no investigation to encompass the comprehensive range of MBC characteristics, including the physical, emotional, social, and spiritual aspects of illness trajectory.

Therefore, the present study attempts to fill this gap by examining the trajectory of MBC in light of retrospective qualitative study. The current study aims to map MBC patients' psychosocial change along the illness trajectory via a narrative approach. Indeed, the finding of this investigation can help to the enhanced understanding of the dynamic process of adaptation to MBC.

## **2. Methods**

### **2.1. Qualitative approach and research paradigm**

To explore the women's experience of living with MBC, all participants were interviewed using a qualitative biographic narrative approach [19].

Reed and Corner illness trajectory of MBC utilized as a research paradigm. As noted earlier, these five trajectory phases have been identified according to the Corbin and Strauss chronic illness trajectory framework [11]. All interviews were conducted by a clinical health psychologist (MM), using a structured interview based on the framework of MBC trajectory [10]. About the framework of a narrative interview, it is notable that the participant, rather than the interviewer determines the narrative form.

### **2.2. Data collection**

Any interview includes five opening questions, begins with a question about the breast cancer diagnosis '*tell me about the onset point of breast cancer diagnoses*'. Subsequent questions include the incidence of metastasis, living with MBC, anticipatory of future, respectively. Finally, the last question includes the

participants' point of view about death. All in-depth interviews were performed in the breast disease clinic of the breast cancer research center (BCRC), each lasted, on average, 60 min. For more accuracy, all conversations were recorded by audio recorders.

Medical evidence for MBC has been considered as inclusion criteria. Then, eligible patients have identified according to the demographic and medical information registered in the database of BCRC. Initially, 101 MBC patients meet medical inclusion criteria. 66 MBC patients were excluded from the study because of missing contact information. In the next step, invitation, and information about the research process presented to each of the eligible MBC patients ( $n = 69$ ), through the phone conversation. Finally, by attainable sampling method, fifteen MBC women represented their satisfaction for the study participation, and completed informed consent.

In terms of the confidentiality principle, all interviews were kept confidential and anonymized. Also, data protection was performed at all stages of the research process. Furthermore, we clarified that the information of participants was unavailable for others.

## **2.3. Data analysis**

All data collected via in-depth narrative interviews were triangulated to map in detail the illness trajectory of each MBC women. In other words, the Interviews were transcribed verbatim and analyzed in their entirety. Standards for Reporting Qualitative Research (SRQR) Checklist was used to improve the communication of research methods and findings [20].

### **Ethics approval**

for this study received from the ethic committee of Academic Center for Education, Culture and Research (Ethic Code: IR.ACECR.BCRC.REC.1396.8).

## **3. Results**

The mean age of the participants ( $n = 15$ ) was 47.6 years (range = 33–80 years), most women were married (93.33%), and some of them currently working. The mean time since diagnosis, and the time since metastasis incidence was 55.06 months, and 25.21 months respectively. The time of metastasis of one participant was not assigned. The frequent metastatic organs were lung ( $n = 3$ ), and brain ( $n = 3$ ), followed by skin ( $n = 2$ ) and liver ( $n = 2$ ). Moreover, 5 participants reported two metastatic organ, such as lung & colon ( $n = 1$ ), lung & brain ( $n = 1$ ), lung & skin ( $n = 2$ ), and bone & brain ( $n = 1$ ). All participants' characteristics are presented in table 1.

Analysis of the participant's narratives revealed five phases of MBC trajectory which includes 10 categories (each phase consisted of two categories). According to secondary coding, 21 subcategories were extracted from participants' narratives (Table 2).

Table 2

Participant code	Age (year)	Marital status	Time since diagnosis (month)	Time since metastasis (month)	Metastatic organ
Participant 1	50	Married	21	14	Brain
Participant 2	33	Married	12	6	Skin
Participant 3	44	Married	92	72	Liver
Participant 4	55	Married	30	Ns	Brain & Lung
Participant 5	53	Married	31	7	Skin & Lung
Participant 6	73	Married	205	84	Lung
Participant 7	52	Married	72	32	Colon & Lung
Participant 8	52	Married	72	12	Lung
Participant 9	33	Married	23	11	Brain
Participant 10	45	Married	15	7	Skin
Participant 11	34	Married	25	20	Liver
Participant 12	38	Married	36	29	Brain & Bone
Participant 13	33	Married	24	23	Lung
Participant 14	39	Married	32	12	Skin & Lung
Participant 15	80	Widow	136	24	Brain
<i>Participant's narratives about metastatic breast cancer trajectory</i>					

### Narratives about the past

## 3.1. Participant's narratives in phase I: Diagnosis & Treatment

Women's narratives in the first trajectory, divided into two categories which include a timeline from breast cancer diagnosis to pre metastasis incidence. Each category referred to cognitive, emotional, physical, and social reactions of participants to illness circumstances.

### **3.1.1. Time since diagnosis to pre treatment**

#### **3.1.1.1. Cognitive and emotional reactions**

The majority of participants have mentioned stressful life events as the probable cause of their illness.

My mother died two months before my cancer diagnoses

They postponed the medical procedures, due to the fear of cancer diagnosis and its treatment. In some cases, the participants represented an intensive anger feeling resulted from medical negligence, and malpractice, consequently give rise to delay in starting treatment. Notably, the denial of cancer diagnosis, crying were the frequent reactions to the breast cancer diagnosis. Moreover, some participants point out the concealment of a cancer diagnosis from others.

#### **3.1.1.2. Physical and social reactions**

The participants were designated to the experience of pain and deformity of the breast as a trigger for the medical attempt.

I refused to see a doctor, as long as the pain was endurable

Moreover, some of them mentioned the reference to non-specialist persons rather than cancer specialists.

### **3.1.2. Treatment onset to pre metastasis**

#### **3.1.2.1. Cognitive and emotional reactions**

Many participants noticed the promptitude from diagnosis to initial treatment, in their narratives.

There was no gap between the diagnosis and the time point of surgery. My doctor immediately gave me an appointment for breast surgery

Moreover, they reported the emotional states such as hopefulness in treatment effectiveness which help them tolerance of side effect of cancer treatment.

#### **3.1.2.2. Physical and social reactions**

Some women reported side effects such as fatigue due to cancer treatment, particularly chemotherapy and radiotherapy.

Despite the abovementioned problems, family and friends play an important role in the acceleration of treatment attempts. They provided adequate social support in the treatment phase of the illness.

My husband helps me to cope with breast cancer treatment

## **3.2. Participant's narratives in phase II: The occurrence of metastasis**

The second phase of trajectory includes the timeline from the incidence of metastasis to renewed treatment for MBC. The narratives in this phase encompass the cognitive and emotional characteristics and their consequences.

### **3.2.1. Metastasis incidence to decision making about treatment**

#### **3.2.1.1. Cognitive and emotional reactions**

There are two considerable narratives in this subcategory, which point out the emotional state of patient and physician. The majority of patients reported the experience of intense emotional burden at the moment of breaking bad news about the metastasis incidence.

I faint when I strike the metastases

Likewise, they mentioned the physician's reaction to the metastasis.

My doctor appeared to be worry, while look at my test answer

Moreover, some patients have been attributed to the incidence of metastasis to the physician's negligence.

If my doctor was careful, the metastasis did not occur

While others considered the role of psychological factors in the incidence of metastasis.

I was free for symptoms for several years until my sister received a cancer diagnosis. Then, my unpleasant emotional state gives rise to the recurrence of cancer

#### **3.2.1.2. Consequences**

It appears that the incidence of metastasis can disappoint the patient for continuing the treatment.

If the treatment was effective, the illness would not recurrent

### **3.2.2. Renewed treatment for metastasis**

#### **3.2.2.1. Cognitive and emotional reactions**

In this subcategory of MBC trajectory, the majority of participants emphasize the severity of physical and emotional pain as well as the side effect of treatment.

I started the chemotherapy again, however, I have not any energy rather than two years ago at the time of primary incidence of breast cancer

It is considered that despite the previous category, the participants point out the perceived social support from their physician.

I started crying when my doctor says about metastasis to the liver. Then Dr tell me: don't worry, it is curable

## **3.2.2.2. Consequences**

One of the consequences of illness recurrence was the financial problems for treatment cost:

I spent all my savings on illness

Narratives about the present

## **3.3. Participant's narratives in phase III: Living with MBC**

Participant's narratives about living with MBC encompass two categories namely intrapersonal and interpersonal. Each of these components concentrated on the positive and negative experiences of patients through illness trajectory.

### **3.3.1. Intrapersonal**

#### **3.3.1.1. Positive experiences**

The narratives indicated that living with MBC can accompany numerous positive experiences such as moral elevation, psychological hardiness and resiliency, acceptance of illness, independence, and the change of worldview.

A 33 years MBC women told about his psychological and spiritual growth through illness trajectory:

I was depended on my son, in such a way that could not stay away from him even for a moment. Whereas, trough chemotherapy I learn to manage my feeling and uncontrollable dependency

#### **3.3.1.2. Negative experience**

The incidence of MBC and the experience of unpleasant treatment and its physical and economic consequences can give rise to numerous negative experiences represented in several narratives of MBC women.

Three MBC women broach to the isolation and resignation from others due to their compassionate behaviors:

I don't like to see anyone, I don't want to anyone notice my illness

Several MBC women reported the decreased mood, irritability, and low level of energy as a consequence of illness:

I am no longer that woman; I don't have the patience of my child; it is embarrassing; I'm not a good mother

Sexual and body image problems were other negative experiences of living with MBC. Three of the participants reported marital dissatisfaction after sexual problems caused by breast cancer and its treatments particularly mastectomy, and hormone therapy.

One month after mastectomy, I decided to live apart from my husband, this is better for both of us

Economic burden and helplessness due to the disturbance of future programs were another priority of living with a progressive illness. The expensive cost of treatment disrupts all plans. A retired teacher who had spent all his savings on cancer treatment said:

I had great plans for the future, the money I had set aside for my interest, I had to spend on treatment

## **3.3.2. Interpersonal**

### **3.3.2.1. Positive experiences**

The enhancement of perceived social support from family, as well as physician, was the prominent positive interpersonal feature of living with MBC. The majority of participants affirmed the supportive role of their family in the illness trajectory. For example:

In the illness process, I become aware that my family loves me very much, I realize that I'm not alone

The increased interest in outdoor activity was another offspring of living with MBS. Five participants state that such activities help them to cope with circumstances of living with progressive illness, and resulted in the capability feeling, rather than disability associated with the illness. An employee woman who had quit her job due to MBC was referred to the outdoors activities as an enjoyable activity:

I am entertained by these things, and enjoy from them; if I stay at home all the time, I get frustrated

### **3.3.2.2. Negative experiences**

According to participants' narratives, there are two negative interpersonal experiences: rejection, and pitiful reactions of associates. An employee woman who undergoing chemotherapy said sadly about his colleagues' reactions:

She looks at my face (hair loss due to chemotherapy) and said: what you have done that God has done to you

Another woman referred to the pitiful reactions of associates as the main cause of concealment of a cancer diagnosis from others:

I make the right decision; I hid breast cancer diagnosis from anyone, except my husbands. I hate pity

Narratives about the future

## **3.4. Participant's narratives in phase IV: Anticipatory of future**

Participant's predictions about the future with MBC can be divided into optimistic and pessimistic predictions, which includes several aspects such as psychological, spiritual, and physical characteristics.

### **3.4.1. Optimistic prediction**

#### **3.4.1.1. Spiritual**

Invocation, and reliance on God, were the spiritual aspect of optimistic prediction for the remission of illness in the future. Three of the participants have believed that invocation as well as religious ritual have healing power:

I believe that God heals me; I only hope in God. I live only in this hope

I drank healing water and I believe that it heals me

#### **3.4.1.2. Psychological**

In some cases, the downward comparison is the last refuge of MBC women, which help them to cope with the unpleasant impact of illness on their life. In other words, they compare themselves with patients who are in a worse condition. In half of the cases, they hoped for remission in the future.

My diagnosis is breast cancer; physicians say the breast cancer is controllable, rather than other types of cancer

Metastasis to my brain is restricted; it is curable

It is important to mention the mothering role as a motivation for optimism toward the future. It is obvious in MBC women with very young children. A young MBC woman who had a 4-year-old son said about the prediction about the future:

I'm a mother; this is adequate motivation to conquer cancer and attain remission

### **3.4.2. Pessimistic prediction**

#### **3.4.2.1. Psychological**

A frequent reaction to the prediction of the future was avoidance from thinking about it. It appears that some patients are afraid to think about the future. Moreover, in some cases, they referred to the ambiguity about the future. A young woman who lost her fertility due to cancer, state that:

I do not like to think about it. Because when I think about it, I get nothing

Another pessimistic prediction includes the fear of metastasis to other sites of the body. One of the participants remember the worse condition of a patient with various metastasis in the chemotherapy ward and said:

I saw patients whose different organs of their body were affected; I'm afraid other parts of my body will be involved

### **3.4.2.2. Physical**

It should be noted that the physical condition of patients has a direct effect on their opinion about the future. The severity of pain can give rise to a pessimistic perspective.

When I feel good, I think that the future is good; but when I am at the peak of pain, I cannot even think about two months later; I'm afraid I'll be disabled in the future

### **3.4.2.3. Financial**

Another aspect of pessimistic prediction is related to financial problems. The cost of treatment causes many financial problems that affected the future itself.

I plan for the future, but I'm scared when I think about the cost of my treatment

## **3.5. Participant's narratives in phase V: Point of view about death**

Participant's narratives about death encompass two approaches; religious beliefs about death, and psychological reactions to this issue.

### **3.5.1. Religious beliefs**

#### **3.5.1.1. Attitude toward the afterlife**

Expressing disgust with religious stereotypes, was evident in some of the narratives:

I do not pay any attention to what the clerics say; I do not believe in the torment after death

Moreover, there was an association between illness perception and patients' attitudes toward death. In some cases, they considered the illness as a pathway toward comfort in the afterlife, even so, the approximation to God.

If I die, I am happy because I am going to see God

My place will be better there. There is better than this world. It is better than the worry and anxiety of this world. There is peace there

### **3.5.1.2. Attitude toward the worldly life**

Despite the prognosis of MBC, some of the patients presented an intense longing for life. They draw on their religious beliefs to be saved from death.

God is my protector and refuge, who should fear

God willing, I will survive

### **3.5.2. Psychological reactions**

#### **3.5.2.1. Fear of death**

As mentioned earlier, women with young children, were worried about their children in their absence. These patients attributed their fear of death to these worries.

What will happen to my child if I die?

Albeit, from a positive point of view, the illness can give rise to the reduction of fear of death.

During this time, the fear of death has become much less

#### **3.5.2.2. Avoidance and refraining**

Some of the participants avoided thinking or speaking about death. Their narratives include the statements about bargaining with God for more lifetime.

I suffered a lot in life; my mother died very soon. I say to God: You must give me my mother's lost life. I want to live a long life

## **4. Discussion And Conclusion**

### **4.1. Discussion**

This study was performed to explore the illness trajectory of MBC women from breast cancer diagnosis to metastasis. Meanwhile, the perspective of patients toward the future has been evaluated through their narrative in the framework of a qualitative study.

There are several differences between the two phase of breast cancer diagnosis, and incidence of metastasis. Despite the feelings such as shock and denial in the diagnosis phase, the hope and energy are higher rather than the metastasis phase. It addresses the despairing nature of metastasis which resulted in the disappointment of MBC women.

An interesting finding is a variation in perceived social support particularly from the physician. Almost, the metastasis occurrence is accompanied by losing trust in the physician, such as away some of the patients in metastasis onset category, attributed the illness recurrence to the medical malpractice, and they start blaming the doctor. While, simultaneously with treatment resuming, they decide to trust their physician. At this time, they disclose the supportive role of the physician for facilitating the decision making about the future therapeutic attempts and encouraging them to remission. This finding suggests the educational and supportive program for improvement of the relationship between patient and physician, in a different phase of illness and treatment. Being aware of these trajectories may help clinicians plan care to meet their patient's multidimensional needs better, and help them to cope with their situation [12].

The diversity and complexity of the problems resulting from the disease and its treatments could affect the physical, emotional, and social domains of MBC patients' life [8].

According to the study finding, a frequent complaint of MBC especially in the metastasis phase was the physical and emotional pain caused by remembrance of chemotherapy and its side effect. This suffering in some cases can give rise to the avoidance from medical attempts, or treatment postpone. It can be attributed to recent findings emphasizing the physical and cognitive dysfunction caused by chemotherapy which leading to increased psychological distress [21].

This study revealed that living with MBC as a progressive illness can consist of both positive and negative experiences at intrapersonal and extra personal levels. Positive experiences such as hardiness and resiliency have consisted of previous research and theoretical foundation which referred to the post-traumatic growth [22], and psychological hardiness theory [23]. These positive psychological changes occur as a result of the struggle with MBC as challenging life circumstances.

On the contrary, some of the adverse consequences of the MBC, such as isolation, rejection, hopelessness, and other experiences due to side effect of treatment (for instance, sexual, hot flashes, and body image problems), can consider as common negative experiences leading to the annoying memories, even after treatment complement. These findings highlight the importance of monitoring MBC challenges during the illness trajectory and reinforce the necessity of management of physical, psychological, social, and spiritual needs of MBC women.

Moreover, patients' narratives about the future of illness, revealed an interesting result. In predicting the future, the spiritual theme is visible. For examination of this finding, this is crucial to highlight the religious and spiritual nature of Iranian culture. Religious beliefs play an important role in coping strategies for the management of illness trajectory. Consistent to McLaughlin et al. deferring control to God leads to lower levels of breast cancer concerns but also more passive coping styles [24].

Similar to anticipatory narratives, the MBC patients' perspective about death, includes spiritual, as well as religious concepts in terms of revision from illness and attaining to long-time life. This matter is evident

in their psychological reactions, especially avoidance from speaking about death, and bargaining with God for a lifetime.

As noted by Lam et al. distress trajectories over the first 8 months post-operatively predicted psychosocial outcomes 6 years later [25]. Then, screening for distress at the initial phase of breast cancer may help to identify patients with more unmet needs, and higher use of maladaptive coping styles who are at risk of experiencing non-resilient trajectories for further management of these symptoms [26].

This study can be considered with several limitations. Some of the confounding demographic and medical variables such as the age of patients, time since diagnosis, time since metastasis occurrence, stage of illness, and physical condition and mental status of patients at the moment of the interview can be contributed to their narratives. All of the abovementioned factors can tarnish patient's narratives about past experiences, and/or affected their perspective about living with MBC and their overview about the future. Also, further information about the important others associated with patients, such as caregivers, family members, as well clinician and, medical professionals during illness trajectory, is required to organize the interventions tailored to their actual needs or aimed to prevent later difficulties [27]. Finally, more research is needed to understand the heterogeneity of individual trajectories within these major patterns of variation [8].

## **4.2. Conclusion**

As each phase presents a new set of challenges, the identification of the cognitive problem and emotional distress associated with each phase of illness trajectory such as hopelessness, avoidance, fear of death, and so on, is helpful to improve QOL of MBC women both in the short and long term. In sum, physical, social, psychological, and spiritual challenges of MBC patients are likely to vary according to the trajectory they are following [12]. Therefore, they should be monitored over time to detect and treat women with alarming levels on them [27].

## **4.3. Practice Implications**

To move away from the predominant traditional approach towards a more comprehensive and better-targeted service, an increased understanding of the complexities of the MBC trajectory is necessary.

## **Declarations**

## **Conflict of interest**

All authors have no conflicts of interest to declare

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## Table 1

### Table 1

*Participant's characteristics*

<b>Participant code</b>	<b>Age (year)</b>	<b>Marital status</b>	<b>Time since diagnosis (month)</b>	<b>Time since metastasis (month)</b>	<b>Metastatic organ</b>
<b>Participant 1</b>	50	Married	21	14	Brain
<b>Participant 2</b>	33	Married	12	6	Skin
<b>Participant 3</b>	44	Married	92	72	Liver
<b>Participant 4</b>	55	Married	30	Ns	Brain & Lung
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<b>Participant 7</b>	52	Married	72	32	Colon & Lung
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<b>Participant 13</b>	33	Married	24	23	Lung
<b>Participant 14</b>	39	Married	32	12	Skin & Lung
<b>Participant 15</b>	80	Widow	136	24	Brain

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