The Suffering in patients with Metastatic Breast Cancer

Jayoung Ahn,
RN, MSN, KOAPN
ASAN Medical Center
I. Background

II. The suffering experienced by women with MBC
   – Associated symptoms of metastasis
   – Side effects of cancer treatment
   – Psychosocial problems

III. Understanding and sympathizing with them
     (Reviewing qualitative research)
Background
Breast cancer is a fairly common cancer among women.

National Breast Cancer Foundation (NBCF), 2017
Background

[그림 1] 2012 세계 유방암 연령표준화발생률

Incidence ASR Female

- 미국: 92.9
- 영국: 95
- 중국: 22.1
- 한국: 52.1
- 일본: 51.5

Breast cancer
- 64.9+
- 45.8~64.9
- 33.9~45.8
- 24.2~33.9
- <24.2
- No Data

GLOBCAN 2012 (IARC, International Agency for Research on Cancer)

[그림 3] 2012 세계 유방암 연령표준화사망률

Mortality ASR Female

- 영국: 17.1
- 중국: 5.4
- 한국: 6.1
- 일본: 9.8

Breast cancer
- 18.1+
- 15.0~18.1
- 13.1~15.0
- 10.1~13.1
- <10.1
- No Data

GLOBCAN 2012 (IARC)
### Background

![Table 2: 5-year age-specific survival rates in major cancers* - International Comparison](image)

![Table 5: 5-year and 10-year crude survival rates (2001-2012) for colorectal cancer patients](image)

(KBCS, 2017)
Background

- Metastatic breast cancer
  - Incurable illness
  - Median survival time: 2-4 years
  - Only with bone metastasis
    - Median survival of 24-54 months
    - Overall survival of 10 years at 35%

Patients with MBC can live for many years after diagnosis.
The suffering experienced by women with MBC

– Associated symptoms of metastasis
– Side effects of cancer treatment
– Psychosocial problems
### Nursing Session: Management of Metastatic, Recurrent and Intractable Breast Cancer

<table>
<thead>
<tr>
<th>Date &amp; Time</th>
<th>Venue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apr 21 (Fri.), 13:30-15:10</td>
<td>Weolla Room</td>
</tr>
</tbody>
</table>

**Moderators**

- Prof. Mi Young Kang (Cheil General Hospital, Korea)

**Speakers**

- **Survivorship Issues of the Metastatic, Recurrent and Intractable Breast Cancer**  
  Dr. Yaelim Lee (Chung-Ang Univ., Korea)  
  [Download](#)

- **Nursing Care in Bone Metastasis**  
  Ms. Hyelin Cho (Ewha Womans Univ. Mokdong Hospital, Korea)  
  [Download](#)

- **Nursing Care in Visceral Metastasis**  
  Ms. Seung Hee Seon (Korea Univ. Guro Hospital, Korea)  
  [Download](#)

- **Specialist Nursing Roles for the Patient with Metastatic, Recurrent and Intractable Breast Cancer**  
  Ms. Su Jin Lee (Dankook Univ. Hospital, Korea)  
  [Download](#)

- **Complementary and Alternative Therapies**  
  Prof. Eun-Young Jun (Daejeon Univ., Korea)  
  [Download](#)
## Nursing Session: Current Issues for Management of Breast Cancer Treatment

### Date & Time
- Apr 29 (Fri.), 13:10-14:50

### Venue
- Weolla Room

### Moderators
- Ms. Mi Young Kang (Cheil General Hospital & Women's Healthcare Center, Korea)

### Speakers
- **Nursing Care in Endocrine Therapy**
  - Ms. Jung A Do (Cheil General Hospital & Women's Healthcare Center, Korea)
  - [Download](#)

- **Chemotherapy-Related Cognitive Function in Patients with Breast Cancer**
  - Prof. Jin-Hee Park (Ajou Univ. College of Nursing, Korea)
  - [Download](#)

- **Chemotherapy Induced Peripheral Neuropathy Breast Cancer Patients**
  - Ms. Mi Sook Han (Inha Univ. Hospital, Korea)
  - [Download](#)

- **Nursing Care in Cardiotoxicity**
  - Ms. Onam Ok (Samsung Medical Center, Korea)
  - [Download](#)

- **Nursing Management for Patients with Advanced Breast Cancer Wound**
  - Ms. Hyun Seo (Ewha Womans Univ. Mokdong Hospital, Korea)
  - [Download](#)
## Associated Symptoms of Metastasis

### Table 1. Sites of breast cancer metastases

<table>
<thead>
<tr>
<th>Site</th>
<th>% at initial presentation [5]</th>
<th>% at autopsy [6]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone</td>
<td>40–75</td>
<td>44–71</td>
</tr>
<tr>
<td>Lung</td>
<td>5–15</td>
<td>59–79</td>
</tr>
<tr>
<td>Pleura</td>
<td>5–15</td>
<td>23–51</td>
</tr>
<tr>
<td>Liver</td>
<td>3–10</td>
<td>56–65</td>
</tr>
<tr>
<td>Brain</td>
<td>All &lt;5</td>
<td>9–20</td>
</tr>
<tr>
<td>Pericardium</td>
<td>19–21</td>
<td></td>
</tr>
<tr>
<td>Intestine</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Adrenal glands</td>
<td>31–49</td>
<td></td>
</tr>
</tbody>
</table>

### Table 2. Associated symptoms of metastatic breast cancer

<table>
<thead>
<tr>
<th>Metastatic site</th>
<th>Associated symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Fatigue, difficulty sleeping, depression</td>
</tr>
<tr>
<td>Bone</td>
<td>Pain, hypercalcemia, pathologic fracture, loss of mobility</td>
</tr>
<tr>
<td>Central nervous system (brain, leptomeningeal disease, spinal cord)</td>
<td>Headache, confusion, weakness, pain, seizure, altered mentation, cranial nerve palsies, speech impairment</td>
</tr>
<tr>
<td>Skin</td>
<td>Pain, infection, bleeding</td>
</tr>
<tr>
<td>Gastrointestinal tract (liver, ascites, peritoneum, etc.)</td>
<td>Pain, nausea, vomiting, diarrhea, early satiety, loss of appetite, dyspnea (from ascites), jaundice, bleeding</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>Pain, dyspnea, hemoptyisis, cough</td>
</tr>
<tr>
<td>Lymph nodes</td>
<td>Brachial plexopathies, pain</td>
</tr>
</tbody>
</table>
Side Effects of Cancer Treatment

• Endocrine therapy related symptoms
  – Hot flushes, Urogenital atrophy, Arthralgia...

• Chemotherapy related symptoms
  – Infection, Hair loss, Nausea, Appetite loss, Stomatitis, Peripheral neuropathy, Cognitive impairment...

• Fatigue, Pain, Difficulty sleeping, Depression, Impaired sexuality...
Psychosocial Problems

- Depression
- Anxiety
- Mood disturbance
- Fears
- Anger
- Sadness, Hopelessness
- Social isolation
- Guilty feelings
- Loss of jobs
- Financial problems
Understanding and sympathizing with them
(Reviewing qualitative research)
Research Study

Living on the outside looking in: a theory of living with advanced breast cancer

Maggie Davies, Magi Sque

Abstract

Much of the literature on women's experiences of breast cancer relates to diagnosis and initial treatment. The aim of this research was to develop a theory to explain the meaning and experience of living with advanced breast cancer. A grounded theory approach was used and ten women under the care of one hospice explained their experiences during semi-structured interviews. The findings suggest that there are significant issues and difficulties facing women with advanced breast cancer, culminating in feelings of isolation and the experience of living with the fear of advancing disease. A theory, living on the outside looking in, was developed to explain the experiences of the participants. This integrates the following five categories: reconciling a different me; time bomb; media effect; professional waning; and rescuers. The category, reconciling a different me, was identified as the core variable and had an explicated relationship to the other four cate-

Literature search

In keeping with grounded theory approaches a preliminary literature search was done. Databases, including Medline and CINAHL, were searched for articles on breast cancer, advanced disease and palliative care. It was found that research concerning women's experiences of living with breast cancer has focused on the initial treatment and diagnosis. There are few accounts of women with advanced breast cancer. One of the few studies to examine the issues for patients in the palliative care setting was done by Greisinger et al (1997). This
Living on the outside looking in: 
A theory of living with advanced breast cancer

- Location: UK
- Sample: 10 women with MBC
- Setting: Hospice
- Data collection method: Semistructured interviews
The aim of this research was to develop a theory to explain the meaning and experience of living with advanced breast cancer.

A theory, living on the outside looking in, integrates the following five categories: reconciling a different me; time bomb; media effect; professional waning; and rescuers.

The category, reconciling a different me, was identified as the core variable and had an explicatory relationship to the other four categories.

The findings raise issues regarding appropriate support.

- Providing helpful media, Expert support, Supportive group
THE MEANING OF QUALITY OF LIFE IN PATIENTS BEING TREATED FOR ADVANCED BREAST CANCER: A QUALITATIVE STUDY

MINNA-LIISA LUOMA* and LIISA HAKAMIES-BLOMQVIST
Department of Psychology, University of Helsinki, P.O. Box 9, Siltavuorenpenger 20D, FIN-00014, Finland

SUMMARY

The purpose of the present study was to investigate the meaning of advanced breast cancer patients’ quality of life (QoL). A semi-structured interview was used, and the phenomenological research method chosen to analyse the data.

The findings show that limitations in physical functioning translate into dependency on others, leading to decreased autonomy. Patients tended to ensure their autonomy by participating in easier activities or changing their internal standards. Changes in appearance and decreased condition affected patients’ ability to carry out roles and responsibilities, which led to changes in lifestyle and also affected patients’ social functioning, often resulting in isolation. The meaning of being able to sustain reciprocal relationships was emphasized. Patients maintained control of to what extent their illness was recognized in social relationships, which was crucial to their feelings of autonomy. Close families were a main source of social support, but also a major source of concern. Meaning of emotional functioning was often expressed in terms of the ability to enjoy life day-by-day and of commitment to treatment. Patients’ cognitive functioning was largely intact while their difficulties in cognitive functioning were more characteristic of anxiety. Global QoL was often expressed in terms of a normal life. In addition there were 3 meta themes which emerged from the data: the patients’ ability to control the illness experience, personal growth and hope. Copyright © 2004 John Wiley & Sons, Ltd.

INTRODUCTION

et al., 2002). These instruments are multidimensional, encompassing various aspects of life:
The meaning of quality of life in patients being treated for advanced breast cancer

- Location: Finland
- Sample: 25 women with advanced breast cancer
- Setting: Recruited from clinical trial
- Data collection method: Semistructured interviews
The meaning of quality of life in patients being treated for advanced breast cancer

- **Changes** in appearance & **Limitation** in physical functioning → affected patients’ ability to carry out roles and responsibilities → changes in lifestyle → social isolation

- Women expressed desire for a normal life.

- Maintaining reciprocal social relationships was important for quality of life.

- Key themes were around controlling their illness experience; personal growth; and hope.
ORIGINAL ARTICLE

Living with Metastatic Breast Cancer: A Qualitative Analysis of Physical, Psychological, and Social Sequelae

Catherine E. Mosher, PhD,*†,a Courtney Johnson, MS,† Maura Dickler, MD,‡ Larry Norton, MD,‡ Mary Jane Massie, MD,* and Katherine DuHamel, PhD*

*Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, New York; †Department of Psychology, Indiana University-Purdue University Indianapolis, Indianapolis, Indiana; and ‡Department of Medicine, Memorial Sloan-Kettering Cancer Center, New York, New York

Abstract: Women with metastatic breast cancer face a wide range of medical, practical, and emotional challenges that impact their quality of life. Research to date, however, has not focused on the quality-of-life concerns of metastatic breast cancer patients with significant distress. The present study examined a range of concerns among distressed metastatic breast cancer patients, including physical and emotional distress, social functioning, and existential issues. Forty-four distressed women with metastatic breast cancer wrote their deepest thoughts and feelings regarding their illness. These essays were thematically analyzed for effects of the illness on quality of life. Three themes were identified in patients' essays. First, metastatic breast cancer and its treatment may result in a number of quality-of-life concerns, including physical symptom burden, emotional distress, body image disturbance, and disrupted daily activities. Second, social constraints on disclosure of cancer-related concerns may exacerbate patients' distress. Third, many women experience a heightened awareness of life's brevity and search for meaning in their cancer experience. Results highlight a range of quality-of-life concerns following a metastatic breast cancer diagnosis and suggest that addressing social constraints on cancer-related disclosure and the search for meaning may improve patients' psychological adjustment. |

Key Words: distress, health, metastatic breast cancer, quality of life, social constraints

Metastatic breast cancer is an incurable illness with a median survival time of 2–4 years follow-thereafter (12). However, this trajectory does not characterize the experience of all metastatic breast
Living with Metastatic Breast Cancer

- Location: United States
- Sample: 44 women with MBC
- Setting: Recruited from cancer center for an expressive writing intervention trial
- Data collection method: 176 essays from expressive writing sessions conducted with women
Living with Metastatic Breast Cancer

• Quality-of-Life Concerns
  – Emotional distress
  – Physical symptom burden
  – Appearance concerns
  – Changes in daily activities

• Experiencing Social Constraints
  – Denial
  – Avoidance
  – Discomfort

• Existential Issues
Quality-of-Life Concerns

• Emotional distress

“the terror and fear that gripped me was unimaginable... I couldn't move.”

“completely devastated and numb”

“sense of desperation”

“I am a person who lives in black and white and this disease has forced me into a gray area.

“I just do not know anything anymore.”

“How disabled will this make me? What are my new limitations?”

→ Loss of a sense of control over their lives and fear of future disease progression and disability were common concerns.
Quality-of-Life Concerns

- **Physical symptom burden**
  - Most frequently symptoms: **Fatigue** (55%), **Pain** (61%)
  - **Side effect of treatment or symptoms of metastasis**: hot flashes, sexual dysfunction, anemia, neuropathy, nausea, vomiting, diarrhea, weight changes, and inability to taste certain foods. breathing difficulties, imbalance
  - **Cognitive changes**: concentration, memory, and word retrieval
  - **Functional limitations** associated with pain, paralysis, and other symptoms.

  “I am frightened every time I feel a small pain or sensation in my body that I do not recognize.

  “a cripple”, “Every joint in my body ached, my brain was fogged...”
Quality-of-Life Concerns

- **Appearance Concerns (44%)**
  - Hair loss and changes in breast appearance
  - Lymphedema, scars, weight gain, and black nails
  
  “more upsetting than I thought it would be,” “biggest grief.” : hair loss

  “How can I feel attractive when on many days I feel like a Picasso painting?”

- **Changes in Daily Activities**
  - Frequent medical appointments
  - Job loss
  - Shift in their self concept
  - Impact of their illness and Death on family functioning

  “That’s a lot of time. Sitting in waiting room – isn’t anyone else fiery mad!”

  “My emotions are so affected by tests results... I find the waiting to be the most difficult part.”

  “not working created a sense of valuelessness for me.”

  “I don’t want to be a burden on my family.”
Experiencing Social Constraints

• Denial
  – Having difficulty accepting their diagnosis: family members and friends
  – Close others denied the severity of their cancer treatment
    “telling people that I was really stage three—when my initial diagnosis was stage four”
    The friend said, “Oh, you’ll be OK; you will just have mild chemotherapy!”

• Avoidance
  – Avoidance discussing their illness, prognosis and dying
    “My husband will rarely discuss my cancer let alone my death.”
    “I can’t bring up the subject with him, as he will cut me off and discuss something he plans to do for the day.”
    “people really do not want to hear about dying.”
Experiencing Social Constrain

• **Discomfort**
  
  – Difficulty discussing their diagnosis and treatment with family and friends

  “People are often fearful of me and really don’t know what to say or do.”

  “They always ask about me and are encouraging but are uncomfortable hearing the ‘real facts.’”
Existential Issues

- The most common Existential Issue
  - Eventual death
  - The impact of death on the family

“We are all here for a limited amount of time.”

“I just have so much to do with them, It feels so unfair.”

“Why me? Do we really need to torture this family with this disease? why my children?”
Living with Metastatic Breast Cancer

• These essays were thematically analyzed for effects of the illness on quality of life.
• Three themes were identified in patients’ essays.
• First, metastatic breast cancer and its treatment may result in a number of quality-of-life concerns, including physical symptom burden, emotional distress, body image disturbance, and disrupted daily activities.
• Second, social constraints on disclosure of cancer-related concerns may exacerbate patients’ distress.
• Third, many women experience a heightened awareness of life’s brevity and search for meaning in their cancer experience.

Results highlight a range of quality-of-life concerns following a metastatic breast cancer diagnosis and suggest that addressing social constraints on cancer-related disclosure and the search for meaning may improve patients’ psychological adjustment.
Summary

• The patients with MBC hope to live as normally as possible.

• They are experiencing a variety of complex quality of life problems, including physical and psychological disabilities, appearance concerns, and functional limitations.

• They are suffering from social constraints and isolation.

• They realize a short life, and they seek to constantly adapt to the meaning of their illness experiences to belong in the normal world.

• The healthcare professionals should help them in order to be able to maintain feelings of hope.
Thank you