

Section 1

Patient Care Perspectives



Introduction

// Balance, in the world of breast cancer metastasis for a woman who is going through the experience of the recurring disease, is essential for her survival. She must find the inner and outer resources to meet the challenges of her situation, to regain control, to harness her fears, to cope, to strive for normality and create stability and continuity. //

Evi Papadopoulos, Vice President of Europa Donna, 2015

Early breast cancer (eBC) has benefited significantly from advances in care over the past decade. (American Cancer Society Facts and Figures, 2014) While there have been efforts to advance the approach to management of metastatic breast cancer (mBC), there remains considerable room for improving patient care and support to patients and their families and caregivers. The mBC patient care needs evolve along the disease continuum, from the time of diagnosis to end-of-life care.

The course of mBC can be varied; some patients may live for several years with mBC, some may have a shorter continuum. Consequently, a patient's needs and experiences with the disease are diverse and very personal to each individual. However, there are some commonalities, which are highlighted throughout this section.

Throughout the disease continuum, patients tend to face highs and lows associated with both the disease and its treatment (Figure 1.1). The diagnosis of mBC represents a time of shock, crisis, and anxiety for patients and their families, and as such, they require sensitivity, as well as emotional and physical support. (Secondary Breast Cancer Taskforce, 2008)



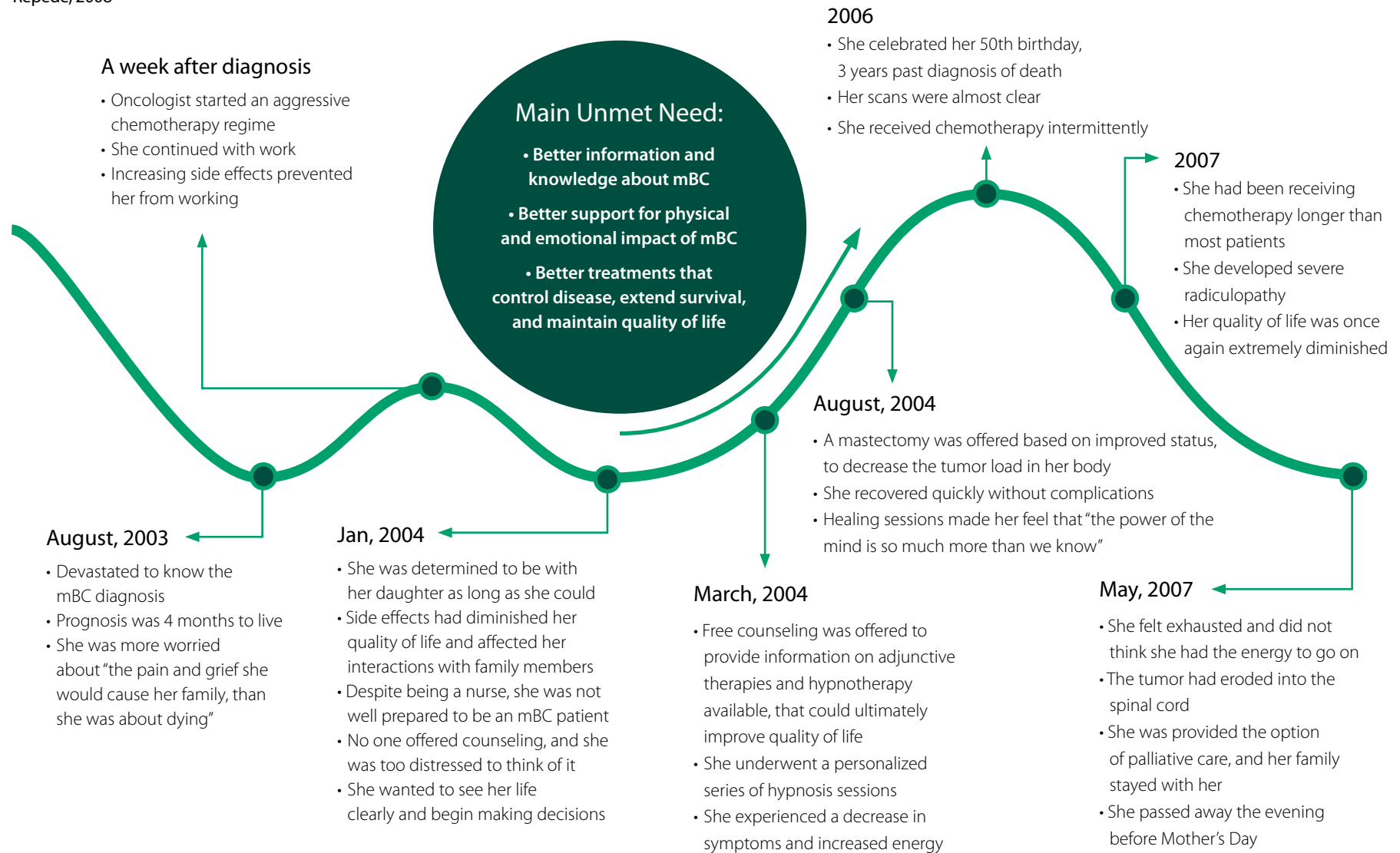
Cece Curry, mBC patient. Deceased June 2013



Figure 1.1

Highs and Lows of the mBC Patient Experience

Based on personal journal notes from a 47-year-old female, US, nurse with mBC
Repede, 2008



To better understand the current landscape and identify areas of focus moving forward, this section outlines the mBC patient's care needs along the disease continuum and the extent to which they have been addressed over the past decade.

Research has been conducted to better understand patient care perspectives in mBC. Reports generated from that research, such as the mBC Alliance Report (2014), highlight some existing fundamental gaps that were uncovered previously in the BRIDGE survey (2009). A multitude of factors were noted as important considerations for patients with mBC, these include: psychosocial well-being, quality of life, patient/caregiver needs and support requirements, and the overall burden that mBC places on patients and their families. The majority of documented strategies for the management of mBC are the result of efforts in the developed world; unfortunately, there is a scarcity of research from the developing world in mBC. However, globally, it is noted that there is both a lack of evidence at particular stages across the disease continuum and an inconsistency in the reporting of supportive care in mBC.

Methodology: To assess the complete body of evidence in relation to patient care perspectives after a diagnosis of mBC, a systematic literature review was conducted in EMBASE. One hundred and thirty two articles published from 2004-2015 were identified and reviewed. Details of key terms and search strategies are included in Section 1 Appendices and References. In addition to the systematic literature review, industry-sponsored or public studies not published in journals (ie, as surveys, reports, or white papers) were included in this review.

Also, a survey was conducted to understand insights related to management and support of mBC patients and healthcare professional perceptions of mBC patients' needs and perspectives. A total of 582 specialists were surveyed, respondents were those who treat breast cancer in cancer centers including: oncologists, gynecologists (Germany),

oncology nurses, and Breast Cancer Center leaders (C-Level, administrator, medical director of oncology). The 9 participating countries were: US, Sweden, Germany, UK, Italy, Portugal, Brazil, Mexico, and Australia. In all countries respondents were invited to complete a 30 minute self-administered internet survey. Because of the small sample in Sweden (n=14), results were analyzed separately and included in open-end reporting only.

Finally, in-depth interviews were conducted with 6 breast cancer centers from France, Argentina, Lebanon, India, and the United States to highlight diverse and unique approaches to managing and supporting mBC patients. These are included as breast cancer center profiles in this section.

A series of themes related to patient care perspectives were identified as a result of the literature search and primary research. These themes form the chapters of this section:

- **Information and Communication Needs**
- **Decision Making**
- **Quality of Life and Daily Living**
- **Supportive Care along the mBC Continuum**
- **End-of-Life Care**
- **Approaches to Delivering mBC Care: Cancer Center Profiles**

Quality of Life is a common theme discussed within this section.

While quality of life is most often described as a patient reported metric, captured using validated questionnaires and report data at a group level, this section refers to quality of life and daily living qualitatively for patients with mBC. It considers all aspects that could impact quality of life qualitatively and could apply at an individual patient level or represent general opinions.



Chapter 1: Information and Communication Needs

- Patients recognize the quality of information provided at an initial diagnosis of eBC but do not feel that this is matched at the point of diagnosis of mBC
- The breast cancer community has identified the need for holistic, individualized communication about mBC
 - Patients report inadequate communication and understanding about prognosis, treatment risks vs benefits, and future options
 - There remains a need for greater sensitivity and transparency from healthcare professionals
- There is a need for better information and proactive communication to patients about clinical trial options
 - Current information provided about clinical trials in mBC is variable and may either confuse or overwhelm patients
 - There is a need to address patient misperceptions about clinical trials
- Appropriate management of patients with mBC must be cognizant of cultural sensitivities

// The mental demands facing metastatic patients are significant. Our need for support and encouragement never ends because we will always be in treatment. //

Shirley Mertz, President, Metastatic Breast Cancer Network, 2015



A Patients have highlighted the need for greater mBC focused information

In a report exploring the individual experiences of women with mBC, it was highlighted that the information and support provided to them is inadequate compared to the services available at the time of an initial diagnosis of eBC. (Johnston, 2010)

Generationally, in a UK study, younger women were found to be less satisfied with the information and advice they received. Overall, these women highlighted dissatisfaction with the provision of information and support from healthcare professionals when compared with their experience of being diagnosed with early stage disease. (Reed, J Pain Symptom, 2012) Similar unmet needs were identified by women in Hong Kong with mBC (53% were diagnosed with mBC and the remainder with stage III disease) in a study conducted between 2008 and 2010. (Au, 2013) These examples highlight that within some areas of the world, there is a need for greater emphasis on provision of information for patients whose disease has progressed from eBC to mBC.

Healthcare providers also experience difficulties in providing patients with appropriate mBC-focused information. In a 2015 primary research survey conducted among specialists who treat breast cancer, 7 mBC-specific, patient-directed resources were considered helpful in greater than 62% of respondents. These resources included: identification of currently available resources for mBC patients and guiding patients to these resources; goal setting and potential questions for mBC patients and families/caregivers to ask their physician; referral to peer support and/or specific consumer organizations to support mBC patients; a patient/caregiver empowering guide outlining expectations for their mBC experiences; a conversation guide that patients can share with

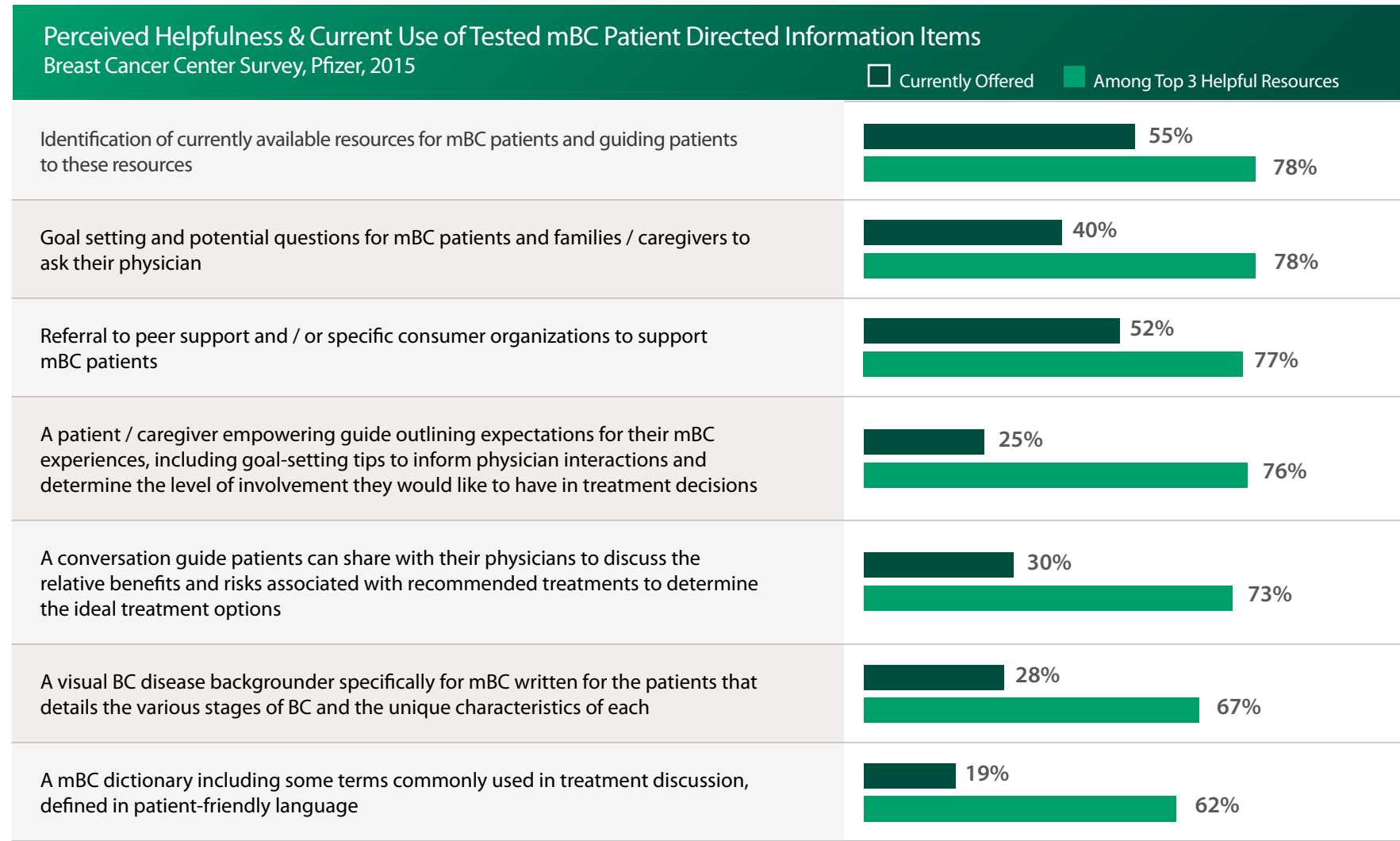
their physicians to discuss the relative benefits and risks associated with recommended treatments to determine the ideal treatment options; a visual BC disease backgrounder specifically for mBC written for the patient that details the various stages of BC and the unique characteristics of each; and an mBC dictionary including some terms commonly used in treatment discussions, defined in patient-friendly language. However, the same specialists frequently did not have these resources available to offer to their patients, as illustrated in Figure 1.2. (Breast Cancer Center Survey, Pfizer, 2015) Comparably, in an Austrian survey, physicians knowledgeable in metastatic cancers recognized that information about diagnosis and treatment may not be uniformly provided to patients at time of diagnosis. (Kierner, 2010)

Apart from information from their healthcare providers, there also needs to be adequate mBC focused information available for patients through patient support groups as well as internet based resources. In a study across 13 countries surveying 1,342 women with mBC, 46% identified patient support groups as an information resource; however, only 13% considered this the most useful source of information other than healthcare professionals, with 23% choosing a website or internet resources as the most useful sources of information. (Mayer, 2010)

Despite seeking information on a variety of topics about treatment and care from multiple sources, patients have difficulty finding the information they needed. Patients have specifically expressed a need for more information about future medical treatments, research and information on the balance between the benefits of treatment and the risks. (Harding, 2013) Despite the numerous channels through which information is disseminated, many breast cancer patients reported that they could not find ongoing community or internet-based educational programs. (LBBC, 2015; Nahleh, 2013)



Figure 1.2



BCC Quant July 21-Aug 12, 2015

Q41, Q42 Base = Total Respondents (n=568)

Q41, How helpful to your *mBC patients and their families / caregivers would each of the following be? 1 = Not Helpful at All, 7 = Very Helpful

Q42 Please indicate if you currently offer each.

*Stage IV / Unresectable Advanced BC

Respondents were from US, UK, Germany, Italy, Portugal, Brazil, Mexico, and Australia



B Women with mBC have identified the need for holistic, individualized, and compassionate communication about mBC from their healthcare professionals

Honest communication about prognosis and anticipated treatment benefits, which is delivered with empathy and compassion by healthcare professionals, is anticipated to allow a patient to maintain hope while also being realistic about the likely outcome. (Grunfeld, 2006). In a study performed with 126 patients in Australia with metastatic diseases, it was found that a majority of patients preferred realistic, individualized approaches from the healthcare professional, including details about prognosis and progression. (Hagerty, 2005) When communicated sensitively to the patient, it empowers them to participate fully in decision making for their care. (Cleary, 2013) Further, patients then have the option to access a spectrum of supportive, palliative, end-of-life, and survivorship care services, where these services exist.

Misperceptions about mBC exist and the incurable nature of mBC may not be recognized by patients. According to nurses and physicians interviewed for the 2015 Global Cancer Center Survey, the most common misconceptions that patients with mBC experience are that pain is inevitable and uncontrollable, no effective treatments are available, and a cure is still possible. (Breast Cancer Center Survey, Pfizer, 2015) Patients should be informed that there may be multiple treatment options remaining, support is available, the disease is treatable even though incurable, treatment can maintain quality of life, and they will continue to receive the best care. (Breast Cancer Center Survey, Pfizer, 2015)

However, an in-office ethnographic survey conducted in 2014 observing the interactions between 22 US mBC patients and their oncologists uncovered that the severity of metastatic disease tends to be minimized by physicians. In conversations studied, metastatic disease was conveyed as a chronic, livable disease, which minimized the actual severity of mBC.

As a result, prognostic information was unclear, and patients were not being provided the maximum opportunity to plan accordingly. (A Story Half Told, Pfizer, 2014)

While providing adequate information to patients about their illness and care is important, healthcare professionals must also remain sensitive to the patient's individual preferences. While some patients with mBC may want full disclosure of prognosis information, others may prefer less information on their prognosis in order to try to maintain feelings of hope. As such, comprehensive standardized support packages may not be optimal for all patients with mBC, suggesting the need for a more tailored approach. (Grunfeld, 2006) A customized approach to information provision was implemented in patients in Hungary with both eBC and mBC, resulting in a meaningful decrease in reported anxiety levels. Distress levels were decreased by providing patients with as much information and involvement in decision-making regarding therapy as they were comfortable doing. (Kahán, 2006)

Quality of life issues should also be discussed, along with tools for communicating and sharing their experiences more successfully, with family, friends, and their community. (Mayer, 2010; Nahleh, 2013) Half of patients/caregivers also felt care could be enhanced if healthcare professionals listened more to patients, ensured continuity of care with the same doctors, nurses, and specialists (55%), and guaranteed the availability of counseling, if needed (55%). (Harding, 2013)

In one study, nearly 40% of patients expressed a need for greater sympathy and/or empathy from healthcare professionals.

(Harding, 2013)



Only 43% of healthcare professionals report having received training on how to bring bad news to patients and families.

(Breast Cancer Center Survey, Pfizer, 2015)

An open and honest discussion about mBC prognosis needs to incorporate greater sensitivity and empathy. In one study, nearly 40% of patients also expressed a need for greater sympathy and/or empathy from healthcare professionals. (Harding, 2013)

Feelings of blame and regret experienced by women with mBC, along with questioning if their disease was being managed correctly, can complicate the intricate and sensitive nature of the disease. As a result, increased communication difficulties were experienced between the patient and physician. (Danesh, 2014) Healthcare professionals find talking about prognosis difficult and feel that their training could be improved to allow effective communication about end-of-life issues. (Cleary, 2013) Access to physician training and information on how to conduct discussions and respond to questions about prognosis and end-of-life matters, may be beneficial to help address some of these challenges. (Danesh, 2014) However, evidence from a 2015 primary research survey,

commissioned by Pfizer, suggests that healthcare-professional training and information is often unavailable. Although 83% of respondents identified “learning how to bring bad news to patients and families” as a key training need, only 43% had received this level of training. (Breast Cancer Center Survey, Pfizer, 2015)

Healthcare professionals should be educated about effective patient communication through training programs, should be culturally sensitive, and recognize that patient educational needs may differ based on age, ethnic background, religion, and nationality.

🕒 There is a need for better information and proactive communication to patients about clinical trial options

Clinical trials are an important component to both treatment and maintenance of hope for patients with mBC. Women who seek out information about their disease have been found to be more likely to be actively involved in their therapy decisions and to participate in clinical trials. (Mayer, 2010) In order to support healthcare professionals and patients with the delivery of evidence-based medicine in oncology, a sufficient number of clinical trials must be ongoing to continually generate new data and treatment modalities. (Cardoso, 2011) Poor recruitment into clinical trials for mBC is an issue, (Nahleh, 2013) which underscores the importance of appropriate communication between

“ Even the way researchers and healthcare providers sometimes say, “The patient failed treatment X” suggests that the patient somehow fell short. But it is really the therapy that failed the patient. ”

Kimberly Sabelko, PhD, Managing Director, Strategic Partnerships and Programs, Susan G. Komen, 2015



patients and healthcare professionals about the availability of clinical trials and the benefit of participation. In fact, a 2015 US study found an association between clinical trial participation and increased overall survival (OS), particularly with certain subsets of mBC. (Kim, 2015) These results suggest there is a need to change the perception, for both healthcare professionals and patients, that clinical trials are a “last resort.” In a 2015 call to empower patients as the driving force behind drug development, Richard Pazdur, Director of Office of Hematology and Oncology Products at the FDA, highlighted the need to look again at eligibility criteria and the informed consent process in clinical trials. (Sutter, 2015)

One misconception is that clinical trials in oncology provide an option of “last hope”; instead they should be perceived as a potential augmentation to the standard of care for mBC. (Nahleh, 2013) Of those patients participating in a clinical trial, the main reason identified for doing so was encouragement by a healthcare professional. (StatBite, 2009) However, 78% of patients with mBC report they had never participated in a clinical trial and cite never having been invited or receiving a recommendation from the healthcare provider as the reasons. (Statbite, 2009)

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There are a number of potential explanations for this lack of communication by healthcare providers. Financial disincentives exist for

clinicians in non-trial centers to refer patients to another treatment center offering access to trials. Furthermore, exclusion criteria may reduce the eligible population by prohibiting the enrollment of an individual due to factors such as age, stage of disease, treatments already received or presence of concurrent illness, which may prevent discussion about the opportunity. (Institute of Medicine US Forum on Drug Development, 2010)

When clinical trial information is presented, its content may vary greatly and can confuse or overwhelm even well-educated patients. Where knowledge about the opportunity for clinical trial entry exists, oncology patients fear being entered into a placebo arm, despite there being an ethical requirement that patients in cancer trials must at least receive standard of care. In their minds, the placebo arm would be the same as receiving no treatment. Effective communication by healthcare professionals is necessary to correct this point or challenge the perception that entry into clinical trials is a last resort. (Institute of Medicine US Forum on Drug Development, 2010)

To address this, a number of clinical trials now utilize new approaches (such as interactive DVDs, web-based approaches, short informational decision aids) that may aid patients in better understanding the trial's objectives. (Nahleh, 2013) In addition to online resources, it is also important to have paper-based clinical trial information available for patients with mBC who have no internet access. (Harding, 2013; Boonzaier, 2010)

Beyond the need for improved communication, increasing education of healthcare professionals would help ensure they can thoughtfully encourage patients to enter into trials. Education and engagement should not be limited to physicians but should also include nurses and other healthcare providers who play a vital role in treatment and are an invaluable source of information. Defining the roles of physicians and nurses in clinical trial discussions may also facilitate greater healthcare professional and patient discussion. (Nahleh, 2013) Resources to assist



patients in identifying all available clinical trials outside of the traditional healthcare setting may also facilitate future discussions regarding clinical trials between patients and their healthcare providers.

D Appropriate management of patients with mBC must take into account cultural sensitivities

All approaches to improving the patient care pathway for women with mBC should take into consideration cultural and religious influences on patient behavior. Cultural differences may alter information preferences of patients with mBC. While many cancer patients in Western countries (up to 85%) state that they want all information, positive or negative, a minority prefer to receive minimal information only. Across the world, religious differences may influence how much information the patient would like to know vs leaving decisions to a higher power. (Butow, 1997; Banning, 2014) In many developing countries, the majority of patients are initially diagnosed with mBC (rather than eBC), which often leads to poor outcomes and its associated burdens. (Pakseresht, 2014; Anderson, 2006; Bhatt, 2011)

Furthermore, ethnic and language diversities can bring additional challenges. For instance, in some indigenous African languages there is often no adequate synonym for the word “cancer”. (Maree, 2010) In such cases, translation of health promotion materials to ensure correct interpretation by the target audience becomes more difficult.

Around the world, breast cancer nurses already perform a key role in educating women with mBC and providing support for patients and their families. It is therefore vital that all healthcare professionals are adequately trained, supervised, and coached to be able to provide patient support in a multitude of different societies and cultures. Holistic care is particularly important in cultures where patients rely on religion as a coping mechanism. (Banning, 2012) It is important that nurses and healthcare professionals, whether members of those cultures or not, are aware of the cultural needs and sensitivities of their patients with mBC to ensure optimal care for all cultural backgrounds. This may require the recognition of a family-centered model of decision making, rather than an individual-autonomy model, within some cultural groups. It is critical that healthcare professionals and other support staff acknowledge and are sensitive to cultural beliefs of women with mBC and their families.



Chapter 2: Decision Making

- Patients with mBC face more complex decisions regarding their care as they live longer and have more treatment choices
 - There is a need to recognize the increasing complexities in balancing multiple goals of managing mBC
 - A sound relationship between physicians and patients is needed to facilitate joint decision making
- Some progress has been made in joint decision-making between patients and their physicians, but much more needs to be done
 - Some countries offer guidelines and information on advanced care planning
 - There is a need for greater emphasis on finding opportunities for patients to share their treatment goals with their physicians
 - Treatment decision making should avoid discrimination against older patients with mBC

A Women with mBC face increasingly complex decisions regarding their care, including treatment goals and preferences

In the past decade, there have been modest improvements in median survival of patients with mBC, caused primarily by increased understanding of the disease and advances in mBC treatments. (Ruiterkamp, 2011; Barinoff, 2013; Rossi, 2013) As women live longer with mBC, they now face more complex decisions regarding their care because of this change. These decisions are often time-sensitive and must balance personal therapeutic goals, drug toxicities, quality of life, and the reality of uncertain outcomes. Women with mBC can experience feelings of confusion and conflict when facing treatment decisions. (Danesh, 2014) Ultimately, the final decision regarding treatment should be a joint decision made by the patient and the physician. This relies on establishing a sound relationship between the physician and the patient from the beginning. (Filleron, 2015) However, the extent to which patients are involved in the decision-making process should

be in line with their actual desire for participation. (Grunfeld, 2006) The MBCAlliance is undertaking a program of research to identify and design tools that remove the communication barriers between patients and their healthcare providers. This will allow patients to easily access information that will support their informed decision-making. (MBCAlliance, Communication Tool, 2015) Separately, work has been done which shows that the use of apps can be an acceptable and effective approach to patient education about treatments. (Younus, 2015)

Understanding patient preferences and goals are vital in making treatment decisions, comparing therapies that have different side-effect profiles, determining the aggressiveness of the treatment strategy and deciding when to switch from active treatment to palliative care. (Sepucha, 2009; mBC in Canada, 2013) In order to play an active role in decision making, patients need to be accurately informed about their diagnosis, prognosis, and treatment options. (Chiew, 2008) Use of simple calculations based on median overall survival to create best case, worst case and typical scenarios have been shown to help patients with mBC understand



survival data. (Vasista, 2015) Adjustment and acceptance of a diagnosis of mBC takes time, and so discussions about treatment goals should be revisited along the continuum of the disease course. As treatment options change, patients should continually be asked about their treatment goals so that their healthcare providers are clear about their wishes. It can be emotionally challenging for both patients and healthcare professionals alike to stop active treatment and acknowledge there may be little chance of prolonging life or palliating symptoms with further anticancer therapy. (Sepucha, 2009)

As more mBC treatments have been approved over the last decade, and as additional treatments may become available in the future, the complexity of making treatment choices will continue to increase. When making treatment decisions, a US survey found that the likelihood of treatment benefit was more important than toxicity when considering common treatment options for mBC (patients would opt to undergo a treatment with 27%-33% likelihood of benefit regardless of the toxicity scenario presented). (Smith, 2014) Patients indicated a willingness to endure side effects and delay or eliminate aspects of their life for a treatment that “is working” (ie, one that extends overall survival or progression free survival).

In evaluating treatments, the majority of patients (63%) from a study of 282 US mBC patients indicated they preferred treatments with longer disease control. Longer disease control was also associated with better emotional well-being (58%), higher overall quality of life (41%), and better physical functioning (31%). (Hurvitz, 2013) In a European study of patients with metastatic or locally advanced breast cancer, survival was indicated as the priority for the majority of women, with patients being willing to “trade-off” drug side effects in order to prolong their life (6% of respondents were caregivers). (Harding, 2013)

In evaluating treatments, the majority of patients (63%) from a study of 282 US mBC patients indicated they preferred treatments with a longer disease control. Longer disease control was also associated with better emotional well-being (58%), higher overall quality of life (41%), and better physical functioning (31%). (Hurvitz, 2013)

B Progress has been made in joint decision-making between patients and their physicians, but much more needs to be done

In the United States, the Centers for Disease Control and Prevention (CDC) offers guidelines and information on advanced care planning for all patients. The goal of these guidelines is to ensure patients understand their choices in care decisions both before and during illness, and even at end-of-life. Ultimately, it is important the patients decide what they want based on their definition of quality of life. (Tangum and Benson, 2012)

After a 3-month use of decision aids, agreement between patients and providers on the main goal of treatment (ie, lengthen life vs relieve symptoms) improved from 50%-74%. (Sepucha, 2009)



In a US survey, the use of decision aids was found to be beneficial for patients and did not increase patient distress. The majority of patients desired to share decision making with their doctor, however only 38% achieved their desired level of participation. After a 3 month use of decision aids, agreement between patients and providers on the main goal of treatment (ie, lengthen life vs relieve symptoms) improved from 50%-74%. (Sepucha, 2009)

Approximately half (56%) of patients will always or usually voice their treatment aims, whether unprompted or in response to a direct question from their doctor.

(Breast Cancer Center Survey, Pfizer, 2015)

In an ongoing US study, the use of a continuing medical education tool by health care providers and patients is being assessed to show its impact on adherence to nationally recognised treatment guidelines to improve supportive care. (Hathaway, 2015)

In a survey of 582 physicians, nurses, and breast cancer center leaders, it was found that it takes, on average, 3 discussions with their oncologists before patients with mBC have a clear understanding of the goals of their therapy. However, only about half (56%) of patients are likely to voice their treatment goals, whether unprompted or in response to a direct question from their doctor. This data shows that there needs to be a greater emphasis on finding opportunities for patients to communicate their treatment goals with their healthcare providers and for clinicians to ask more probing questions. (Breast Cancer Center Survey, Pfizer, 2015)

According to healthcare professionals, on average, it takes 3 discussions with their oncologists before patients with mBC have a clear understanding of the goals of therapy.

(Breast Cancer Center Survey, Pfizer, 2015)

Treatment decision making should avoid discrimination against older patients with mBC.

In order to increase collective decision making between physicians and older patients, and to ensure treatment decisions are not defined by patient age alone, treatment options need to be tailored for older patients with mBC. (Freyer, 2006) Age has been found to be a discriminating factor in treatment decisions, with patients older than 76.5 years old being treated in a different way in comparison to younger patients. Elderly patients are often treated with weaker doses of chemotherapy, which is often based on a subjective evaluation of the patient's general health status. Available data indicates that a different approach in older patients with mBC is justified. (Hamberg, 2007) Physicians treating mBC may benefit from collaboration with a geriatrician or, alternatively, specific training of all physicians in the field of geronto-oncology. (Freyer, 2006)

Treatment decision making should avoid discrimination against older patients with mBC.

(Freyer, 2006)



Chapter 3: Quality of Life and Daily Living

- Women with mBC experience a decline in their quality of life and daily living
 - A desire for maintaining quality of life is often expressed by patients and physicians
 - Evidence suggests patient quality of life scores, after a diagnosis of mBC, may not always improve
 - There is a need to improve how we assess quality of life in patients with mBC
- Being diagnosed, then living with mBC greatly impacts patients' emotional and physical well-being
 - Distress, depression, and anxiety weigh heavily on mBC patients' emotional state
 - Patients also experience social isolation, feelings of reduced self-worth, pain, and sexual dysfunction
- Caregivers and healthcare professionals are directly affected by the impact of caring for a patient with mBC, but do not receive adequate support
 - Family-focused interventions may help patients and caregivers to cope with cancer together

“ Living with mBC is like walking on a tight rope, a balancing act using all resources, to hold on and reach the other end. ”

Evi Papadopoulos, Vice President of Europa Donna, 2015



The burden of mBC is significant and can be felt particularly around the time of diagnosis and as patients near the end of their lives. A patient's overall well-being is impacted by a number of factors associated with their disease, such as physical burden, psychosocial burden, caregiver burden, and financial burden. A patient's overall well-being, sometimes referred to as quality of life (QoL), is often impacted by both internal and external factors. Further, each of these factors can be additionally complicated by cultural sensitivities. Here, quality of life has been defined through instruments used in clinical studies as well as from multiple patient research and primary surveys conducted.

There are a multitude of factors related to the burden associated with mBC, from the physical and psychosocial impact on the patient to the burden on both caregivers, and healthcare professionals.

A Women with mBC experience a decline in their quality of life and activities of daily living

The overall burden facing women with mBC can be reliably assessed using quality of life analyses. As mentioned previously, patient quality of life is impacted by a number of factors that include, but are not limited to, physical burden, psychosocial burden, caregiver burden, and financial burden. It is important to note that each individual patient's values will directly impact their assessment of quality of life.

Eight out of ten women feel that quality of life is the biggest area in need of improvement in mBC care. (Here & Now, Novartis, 2013) Fatigue, insomnia, concentration, neuropathy, and pain are consistently mentioned by patients as having the greatest effects on their quality of life. (mBC in Canada, 2013; Danesh, 2014) While quality of life is being frequently touched upon in consultations, it is often quickly and vaguely discussed, therefore leaving women feeling as though their needs have not been met. (Danesh, 2014)

Patient quality of life is impacted by a number of factors that include, but are not limited to, physical burden, psychosocial burden, caregiver burden, and financial burden.

(Here & Now, Novartis, 2013)

The ability to accurately quantify changes in quality of life amongst patients with mBC remains challenging. Quality of life is referred to in many quantitative and qualitative patient care perspective surveys. However, there is no standard definition of quality of life in clinical practice at the individual patient level, and variation exists in how surveys/studies report on this measure across the general patient population. Patients and physicians often express the explicit hope to maintain "quality of life" without further explanation or definition of its meaning. (Danesh, 2014) Standardized and validated instruments for measuring quality of life in clinical trials exist, but are not used in clinical practice. (FACIT.org; EORTC.org; Osoba, 2011) Without better understanding of what quality of life should mean as both a standard and at the individual level, it is nearly impossible to ensure that patients' unmet needs regarding quality of life are being addressed in real world clinical practice. A more structured definition of quality of life is needed, both for patients to verbalize their needs and also to support the broader community.

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(Here & Now, Novartis, 2013)



Methodology: A review of mBC related quality of life studies/surveys was conducted and established that data published on QoL instruments are commonly used in clinical studies, but the same does not seem to be true of the real world clinical practice setting. A description of the approach taken is provided in Section 1: Appendix 1.3.

In some cases, general noncancer-specific QoL instruments are being utilized, such as the EQ-5D, 12-Item Short Form Health Survey (SF-12), and 36-Item Short Form Health Survey (SF-36). These instruments are patient-reported surveys of general health status. (Perrillon, 2015) Some cancer-specific QoL instruments were also used, with the EORTC core QoL questionnaire (QLQ-C30) and Functional Assessment of Cancer Therapy Questionnaire (FACT-G) being examples. For both instruments, a breast cancer-specific questionnaire does exist, ie, the EORTC breast cancer-specific QoL questionnaire (EORTC QLQ-BR23) and FACT-B (for patients with breast cancer).

Questionnaires to assess the value of delaying progression in mBC need to be developed. (Perry, 2007) However, pilot studies have begun evaluating mBC-specific questionnaires. (Hurvitz, 2013)

Questionnaires to assess the value of delaying progression in mBC need to be developed, suggesting that current methods to capture this measure are not fully capturing patient experience. (Perry, 2007) However, pilot studies have begun evaluating mBC-specific questionnaires, for example mBC-P. (Hurvitz, 2013)



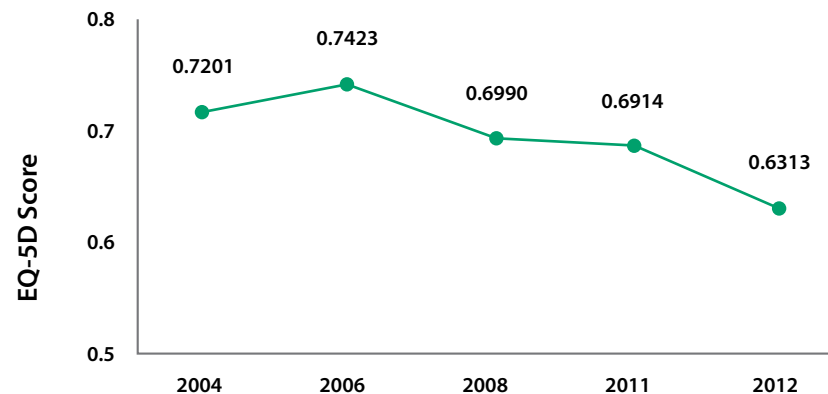
Methodology: Due to different quality of life measures used in clinical studies, it is difficult to assess how quality of life has changed over the past 10 years. As such, an analysis was conducted to convert quality of life measures to EQ-5D in order for us to understand trends in quality of life over the past 10 years. Please see Section 1: Appendix 1.3 for detailed methodology.

Quality of life for patients with mBC has not improved in the last decade. A review of the trends in quality of life for mBC within this analysis indicates that there has not been a significant improvement in patients' quality of life since 2004 (see Appendix 1.3 for methodology). In fact, there has been a slight drop in measured quality of life over these years (see Figure 1.3).

Figure 1.3

Quality of Life in Patients with mBC as Assessed by EQ-5D, 2004-2012, Generic (non-Cancer Specific) Health Utility Score

Research from Appendix 1.3



Analysis was based on a review of 132 articles, of which a quantitative analysis was conducted of 14 studies reporting QoL measure values for mBC. Values are weighted based on sample size.

This analysis indicates a numerical decrease over time. It does not intend to demonstrate statistical significance.

Why has there been a reduction in overall quality of life in patients with mBC since 2004, despite advancements in treatment during that time? What if treatments reduce quality of life? The lack of improvement observed in quality of life for patients with mBC may be underscored by a failure to address remaining unmet needs. More research is required to determine what approaches create the greatest benefit in resolving their quality of life concerns, for example access to referral services. (Mosher, 2013) While there are numerous treatments available for mBC and more in development, they may not be able to address the myriad of factors that potentially impact a patient's quality of life, including physical side effects and emotional well-being in patients with mBC. Lastly, as mentioned previously, these results may not accurately reflect quality of life due to the use of nonspecific instruments.

Further development of mBC-specific QoL instruments, for both clinical trial and community use, is essential to improve our understanding of this measure in patients with mBC and assess quality of life in association with any new intervention, as well as for flagging potential unmet needs in this specific group of patients. There is clearly an opportunity to improve quality of life for these patients, and more accurate assessments will allow for targeted solutions.

B Being diagnosed and living with mBC greatly impacts patients' emotional and physical well-being

Emotional functioning is a key indicator of quality of life for patients with mBC. Patients report feeling bad-tempered, down, depressed, and less tolerant. Some feel bitter and find it very difficult to accept their fate,

while others describe anger as the most predominant feeling. Physical and emotional functioning are intertwined where days without pain, fatigue, insomnia, or vomiting can be indicative of a positive mood. Patients closely associate their emotional functioning with the ability to enjoy life, giving them the strength to commit themselves to treatment. Often patients' coping methods rely on denial and avoiding thinking about their illness in order to sustain their emotional functioning and live a somewhat normal life. (Luoma, 2004; Danesh, 2014; Aranda, 2005) For most women, their disease strengthened their religious beliefs, and through their religion, they became emotionally stronger. This reinforced faith provided a personal coping strategy which enabled women to manage their illness and improved their overall sense of well-being. (Banning, 2014)

In a US-based study, women reported struggling to accept a diagnosis of mBC, which manifested into feelings of blame or regret. (Danesh, 2014) Feeling scared, confused, depressed, angry, and alone at the time of diagnosis was observed in 55%-80% of women in a survey of patients with mBC between 2008 and 2009, across 13 countries. (Mayer, 2010) Physicians suggest disappointment or distress at progression to mBC was associated with a number of feelings. (Wardley, 2008)

In a study of 282 women with mBC, patient's emotional well-being after a diagnosis of mBC (new to breast cancer, or progression from earlier stage disease) was found to be worse than in those given a diagnosis of eBC. Younger (< 50 years) and newly diagnosed women indicated their emotional well-being was more negatively impacted than women who were either older or had lived with mBC for some time. (Hurvitz, 2013)



This highlights a greater emotional need for patients at initial diagnosis of mBC, which may require a more intensive level of support. Further, women at a younger age may also require more intensive supportive services given their stage of life and the perception of greater life expectancy generally.

Figure 1.4

Common Words Signifying Patient Experiences Throughout mBC Diagnosis and Treatment

Wardley, 2008; Danesh, 2014; Luoma, 2004; Aranda, 2005



In many countries, patient groups exist to help women discuss their diagnoses, share their experiences and seek support from one another. While this type of psychosocial support does not have any effect on disease outcome, it does improve mood and the perception of pain, particularly

// I did everything right, I did everything the doctor told me to do, and look what happened anyway... It's the same thing that makes people fear metastasis and recurrence. You don't know what causes it, and you know it could happen to you. Your logical brain knows, but you still feel that somehow your body betrayed you. I've heard it over and over again. Many times people have been told they've been cured, and then become metastatic—and that's a horrible thing. //

*North American Respondent,
mBC PSO Survey, Pfizer, 2015*

in women who are initially more distressed. (Goodwin, 2001) A pilot study has indicated that provision of preparatory information at the time of diagnosis may enhance patients' coping ability and also assist in managing expectations around the disease; such tools require further investigation to validate their usefulness in relieving burden at diagnosis. (Rosenzweig, 2010)



If not addressed early, manageable emotional burdens can quickly escalate; 61% of women in one study were identified as distressed and one week later, they reported clinically significant anxiety or depressive symptoms. (Mosher, 2012)

Distress, depression, and anxiety weigh heavily on mBC patients' emotional well-being. Depressed mood may interfere with a patient's coping mechanisms, or even compliance with treatment regimens, (Kissane, 2004) making it an important area for clinicians to address with patients. In 2008, a study among patients with mBC in the Czech Republic found the incidence of depression to be 61%. 20% of the 25 patients diagnosed with mBC had severe depression, 40% were moderately depressed, and 40% had mild depression. Overall, there was found to be an association between mBC, depression, and the low level of global quality of life. (Slovacek, 2010)

If not addressed early, manageable emotional burdens can quickly escalate; 61% of women in one study were identified as distressed (using a screening instrument) and one week later, they reported clinically significant anxiety or depressive symptoms. The majority of patients (70%) also suffered from sleep disturbances indicating that emotional burden can also impact sleep. (Mosher, 2012)

Women with mBC frequently experience a lack of self-identity and disruption to their family life. In a study of 25 women with mBC, it was found that those who work outside the home or have active professional lives were unable to continue their employment, were on prolonged sick leave, or forced to retire. Many women described themselves as feeling useless in society when they had to stay away from work (ie, on sick leave or disability pension).

A few patients who were still employed, emphasized how important it was to them to continue working to ensure that their lifestyle was altered as little as possible. Women who served important roles within their families also found themselves limited, as their ability to perform domestic work was also diminished. These limitations prevent women from maintaining their previous roles, and this change (from being needed, to needing someone) is difficult to accept, leading to a decreased sense of autonomy. (Luoma, 2004)

The consequences of an mBC diagnosis on family life have a significant impact on a woman's self-identity as mother and partner, particularly in families that include younger children.

// Although I stay as positive as possible, there is always the horrible doubt of "what if" and "when". //

mBC Patient, from Secondary Breast Cancer Research, BCNA, 2014

For example, detrimental effects on patient well-being occur when cancer affects social functioning, such as children choosing not to invite their friends over if their mother is experiencing side effects of treatment. Additionally, worries and concerns can arise about how a spouse or partner will cope with their disease or possible death. (Luoma, 2004; Mosher, 2013; Badr, 2010) This impact on self-identity might be a particular problem in cultures where women have the predominant responsibility for caring and bringing up children and can add considerable emotional burden at an already challenging time. (Banning, 2014)



Metastatic disease often results in social isolation. Social functioning in patients with mBC can deteriorate, along with confidence and comfort levels, with appearance changes due to treatment-related side effects (ie, alopecia). Patients may modify their behavior by staying at home to limit opportunities for socializing in their community, with friends, or in the workplace despite recognizing that they miss normal social interactions. Patients are concerned that wearing a wig makes their diagnosis obvious to strangers and symbolizes the loss of personal control over their cancer experience. (Luoma, 2004) For more information on caregivers and social relationships, please see Section 2, Chapter 6: *The Impact of mBC on Patient Social Relationships and Caregivers*.

Maintaining normal interpersonal relationships and being able to control the illness experience are crucial to patients' maintaining healthy emotional well-being. Activities that enable patients to lead a near normal life are helpful, particularly those that patients enjoyed before their diagnosis. Patients have observed that learning to live for the moment and learning new ways of enjoying things helped them to grow personally and in turn reduce their emotional burden. (Luoma, 2004)

Patients have observed that learning to live for the moment and learning new ways of enjoying things helped them to grow personally and in turn reduce their emotional burden. (Luoma, 2004)

Pain, fatigue, and weakness impacts patients' daily lives. A survey in Europe of 158 women with mBC and 146 caregivers, found that half of women experienced pain that interfered with their daily life and half suffered from discomfort and anxiety. (Here & Now, Novartis, 2013) Quality of sleep has also been found to be significantly decreased in patients with mBC; this may be due to increased pain. (Mystakidou, 2007)

mBC treatment can also result in fatigue and weakness, which limits the ability to conduct daily activities. That is not to say that all physical side effects related to treatment have a negative effect, some patients with treatment response experienced improvement in their physical condition as a result and thus felt joy. (Luoma, 2004)

// Family and friends find it extremely hard to understand the concept of Stage IV cancer, being incurable, and meaning that you have to be on treatment for the rest of your life. If you are on a treatment with no visible side effects, even the most intelligent and loving friends and family members don't really remember that you have cancer. //

mBC Patient, from Secondary Breast Cancer Research, BCNA, 2014



Deterioration in sexual function has far reaching physical and emotional impact. Sexual function is an area that receives very little attention and investigation in many diseases, including mBC. Despite a 2014 US study finding decreased sexual interest as one of the most severe symptoms of mBC, (Cleeland, 2014) limited research has been completed to study its impact. (Milbury 2013) Links between sexual problems, depressive symptoms, and types of spousal communication patterns have been identified, indicating that reduced sexual function may have broader implications. (Milbury, 2013) Sexual problems were associated with depressive symptoms in both patients and their partners. (Milbury, 2013)

Deterioration of sexual function has far greater consequences than physical function alone, as patients' emotional and social well-being are also impacted. Couple-based interventions that address patients' and partners' sexual concerns are beneficial to help alleviate depressive symptoms for both members of the couple. Teaching effective

Despite a 2014 US study finding decreased sexual interest as one of the most severe symptoms of mBC (Cleeland, 2014), limited research has been completed to study its impact. (Milbury 2013)

communication patterns, such as mutual engagement and joint problem-solving, is key to support improved emotional intimacy and sexual satisfaction. The role of communication is important in identifying and alleviating burden associated with sexual function. It may however require some nuances to be effective for both partners. (Milbury, 2013) Enhanced communication about sexuality may also help to support

broader improvements in psychological adjustment for patients with metastatic disease. (Au, 2013)

The lack of attention to sexual dysfunction in mBC patients is further compounded by cultural sensitivities around sexual function. In some cultures, discussing sexual concerns and satisfactions is highly sensitive; however, despite these sensitivities, avoidance is not the best solution. Facilitation of culturally sensitive interventions that support couples of all cultures could lead to better care of sexual function burdens and overall improved quality of life in women with mBC. (Au, 2013)



Debbie Gurley, mBC patient diagnosed in March 1998. Living with the disease.



“ Uncertainty... am I going to have enough money to see me out...how does all of this affect my standard of living and therefore my relationships with family and friends? ”

mBC Patient, from Secondary Breast Cancer Research, BCNA, 2014

Younger patients with mBC face challenges different to those of older patients due to diagnosis at an earlier stage of life.

Survival rates for young women (≤ 40 years of age) with breast cancer remain lower than those for older women, particularly because young women have an increased likelihood of developing more aggressive subtypes of breast cancer and presenting with more advanced stage disease. (Rosenberg, 2015) There are a variety of differences that affect the management of breast cancer for young women, including being premenopausal at diagnosis, fertility, genetics, and social/emotional issues with being younger at the time of diagnosis. (Rosenberg, 2015) Additionally, many younger women may experience sexual dysfunction, which arises during treatment and may only partially resolve after treatment has been completed. (Kedde, 2013) All of these aspects should be considered early in the course of care.

Younger age at diagnosis is associated with greater symptom severity and interferences, worse health-related quality of life (HRQoL), and greater activity impairment than experienced by older patients. (Cleeland, 2014)

Younger age at diagnosis is associated with greater symptom severity and interference, worse health-related quality of life (HRQoL), and greater

activity impairment than experienced by older patients. (Cleeland, 2014)

An mBC diagnosis at a young age is often accompanied by the realization that there is less time to experience aspects of life that were previously taken for granted, particularly the positives experiences of growing older. Will you live to see your children graduate college? Will you celebrate your 10th wedding anniversary? Additionally, end-of-life planning requires a high level of diligence because patients are often still working to support a family who will financially struggle when they are unable to work anymore. Generally, younger patients will assume more active roles either at home or by returning to work than older patients, (Cleeland, 2014) having then to deal with the challenge of supporting their families, as well as their own lifestyles while battling mBC.

Economic and family-life factors, specific to younger women, mean that

“ [In some African countries] the literature is focused almost entirely just on treatment with little discussion of patient quality of life or standard of practice. There is no explanation that breast cancer must be diagnosed, staged and properly treated. ”

Dr. Olufunmilayo Olopade, Director of the Center for Clinical Cancer Genetics, University of Chicago, 2015



a particular research focus is required for this population. Prioritization should focus on the effects of shared decision making, balancing body image, fear of recurrence, recommended treatments and lastly, palliative care. (Fernandes-Taylor, 2015)

The financial implications of mBC on women and their families can impact quality of life. While there have been relatively few articles published detailing the economic burden of mBC on patients, it is important to recognize the expensive nature of health and social care, particularly in terminal illness. mBC is an expensive disease to manage, requiring hospital-led care, medication, close monitoring, and often additional care givers. (Sorensen, 2012; Remak, 2004) This financial burden can negatively impact the lives of women with mBC and their families, and may result in them compromising some aspects of their care to reduce healthcare related costs. (Buzaglo, 2014) For more information on the economic burden of mBC, please see Section 2, Chapter 2: *Economic Burden of mBC*.

Healthcare professionals are directly affected by the impact of caring for a patient with mBC but do not receive adequate support

Healthcare professionals treating patients with mBC have reported a significant negative psychological impact on themselves. (Count Us, Know Us, Join Us, Psychological Impact, Novartis, 2014) Although not generally a primary focus, it has also been acknowledged that healthcare professionals involved in the care of patients with mBC may also be psychologically impacted. Oncologists make important assessments evaluating life expectancy of their patients with mBC on a daily basis and must discuss options with patients. (Filleron, 2015) Even experienced healthcare professionals may experience a degree of psychological stress when delivering difficult information to patients with mBC, including discussing

eventual death. In a US survey, 42% of oncologists said that treating patients with mBC had a significant negative emotional impact on them. (Count Us, Know Us, Join Us, Novartis, 2014) This may be due to limited treatment options. Similar to women diagnosed with mBC progression, a majority of healthcare professionals (67%) exhibited increased levels of distress when their patient's disease progressed, compared with an initial diagnosis. (Wardley, 2008) Healthcare professionals internalized the inadequacy of the first treatments they prescribed, had feelings of personal failure, and a notion that they had let the patient down. (Wardley, 2008) Clinicians also recognized that the disease state had now reached an incurable stage, with fewer treatment options available, which some patients might not fully realize. Physicians identified having developed closer relationships with their patients by this stage, increasing the difficulty in telling patients that their disease had recurred. (Wardley, 2008)

These surveys highlight the importance of adequate training and psychological support for healthcare professionals treating patients with mBC to ensure they can continue to care with compassion. It has been suggested that this could prevent possible questions in the minds of clinicians and patients about treatment adequacy and efficacy, which is important because treatment dilemma has been associated with a negative emotional effect.

Similarly to women diagnosed with mBC progression, a majority of healthcare professionals (67%) exhibited increased levels of distress when their patient's disease progressed, compared with at initial diagnosis.

(Wardley, 2008)



Chapter 4: Supportive Care Along the mBC Continuum

- There have been several areas of progress during the last decade in the supportive and palliative care of patients with mBC
 - mBC guidelines recognize the need for a holistic approach to supportive care that covers the entire disease continuum
 - Some cancer centers across the world have introduced and evaluated new approaches to delivering supportive care
- Access to wider and individualized support services is important to patients with mBC along their treatment continuum
- Access to effective supportive and palliative care is not yet globally achieved
 - Improved training is required for the broader multidisciplinary healthcare team to ensure palliative care is offered at the appropriate time
 - Patient- and family-focused information on supportive and palliative care is needed
 - Despite the impact of mBC on psychosocial health, access to mental health services is limited
 - Treatment adherence remains challenging and more support is needed

Breast cancer survivors have specific supportive care needs, especially those who are long-term survivors. Continuum of care for breast cancer starts with their first diagnosis of breast cancer. For women with eBC, it continues even after primary treatment for eBC. Patient education and support is needed to help survivors of eBC move from being cared for by their cancer care providers, to monitoring their own well-being. Survivors of eBC require education on recognizing disease recurrence or metastases, management of treatment-related events, psychosocial issues, and the importance of a healthy lifestyle. Their care will continue to require screening and ongoing support for symptoms or

consequences of their cancer treatment. (Ganz, 2013) Diagnosis of mBC is an important transition in the disease continuum, where the support needs change. Women who live with mBC have specific concerns that must be addressed throughout their lives, including health needs later on in life.

Recognizing that each patient's diagnosis and treatment path is unique, the following evaluation examines supportive care from a variety of perspectives. This includes evidence for supportive interventions, palliative care measures and survivorship support.



According to the EAPC, supportive care is suitable for patients still receiving anticancer treatment and for cancer survivors. (EAPC, 2009)

Terminology in this space is often confusing. The terms “supportive care” and “palliative care” are sometimes used interchangeably adding to the complexity. However, for the purposes of this report, supportive care in mBC is defined as the prevention and management of the effects associated with the disease itself or its treatment. This includes management of physical and psychological symptoms and therapy side-effects across the continuum of breast cancer—from primary diagnosis through initial neoadjuvant /adjuvant treatment, diagnosis of mBC and its treatment through to end-of-life care. Within this broad term, enhancing rehabilitation, survivorship, and end-of-life care are being considered integral parts of mBC supportive care and the overall patient experience.

According to the European Association for Palliative Care (EAPC), supportive care is suitable for patients still receiving anticancer treatment and for cancer survivors. (EAPC, 2009) Supportive care is especially important for patients with mBC, as a significant proportion of patients will remain actively managed for a prolonged period of time. However, there are significant gaps in supportive care for patients. Based on a survey of 568 respondents across 8 countries, 57% of patients with mBC receive palliative care but less than 5% have access to emotional and psychological support. (Breast Cancer Center Survey, Pfizer, 2015) Effective supportive care allows women to lead more fulfilling lives while living with their breast cancer.

In contrast, palliative care focuses on patients with very advanced mBC after active anticancer therapies have been withdrawn. (EAPC, 2009) It is an equally important part of living with metastatic disease, ultimately preparing for the end-of-life. The National Comprehensive Cancer

Network® (NCCN®) described palliative care as “a special kind of patient- and family-centered healthcare that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures”. (NCCN Guidelines® for Palliative Care v.1.2016) At some point along the mBC disease continuum, the aim of treatment will shift from the active treatment of disease to the palliation of symptoms, with the aim of minimizing distress and the impact on the individual’s ability to perform normal daily activities.

Methodology: In order to specifically address this topic a supplemental literature search was conducted for supportive care in patients with mBC. Please see Section 1: Appendix 1.4.

A There have been several areas of progress during the last decade in the supportive and palliative care of patients with mBC

There is a general consensus across guidelines that supportive and palliative care is needed for patients with mBC globally.

Evidence-based clinical guidelines for treatment of mBC, from international organizations (including those in both high- and low-income countries), recommend supportive and palliative care as part of mBC care. (Cleary, 2013) Some organizations with guidelines to note are the Breast Health Global Initiative (BHGI), Women’s Cancer Initiative, NCCN, and National Institute for Health and Care Excellence (NICE). (Cleary, 2013; NICE, 2014; El Saghir, 2015) All encourage expanding the concept of palliative care (previously limited to end-of-life care), to include supportive care offered concurrently with curative or life-prolonging treatments, for patients with all stages of breast cancer. (Cleary, 2013; NICE, 2014; NCCN Guidelines® for Palliative Care v.1.2016) In some places, access to palliative care may now be considered a human right.



A dedicated clinical nurse specialist with skills and knowledge of managing mBC would help alleviate the discrepancy between the level of supportive care received during treatment for eBC and after a diagnosis of secondary breast cancer.

(Secondary Breast Cancer Taskforce, 2008; Watts, 2011)

The BHGI and the World Health Organization (WHO) suggest introducing the concept of palliative care at the time of diagnosis of advanced disease or the initiation of treatment for advanced disease. (Cleary, 2013) These guidelines reflect the need to be able to identify and categorize common components of treatment-related supportive care for metastatic disease and end-of-life palliative care in order to establish evidence-based criteria for implementation of supportive care programs. (Cleary, 2013)

Some cancer centers across the world have introduced and evaluated new approaches to delivering supportive care.

Research on an electronic health questionnaire system, using algorithms based on patient reported outcomes, highlighted a high need for supportive care services for patients with mBC. Of the 983 patients included in the study, 623 (63.4%) received at least one referral to a supportive care service. (Wong, 2015) Opportunities for improved supportive services exist; in one study the introduction of a new mBC nurse role was found to improve the provision and organization of supportive care for patients with metastatic disease. The majority of patients were satisfied with the overall supportive care provided by the mBC nurse and perceived that the service had contributed to their care and well-being. Duties of an mBC nurse were

seen to be the provision of emotional support and information resources (ahead of coordination of care, clinical liaison, and provision of referrals). (Watts, 2011) A dedicated clinical nurse specialist with skills and knowledge of managing mBC would help alleviate the discrepancy between the level of supportive care received during treatment for eBC and after a diagnosis of secondary breast cancer. (Secondary Breast Cancer Taskforce, 2008; Watts, 2011)

In addition to specialist roles, specialist teams for specific care services could also provide benefit for patients with mBC. Palliative care focuses on a holistic approach to the management of distressing symptoms of disease incorporating psychosocial and spiritual aspects of care. (NCCN Guidelines® for Palliative Care v.1.2016) In a study analyzing the effects of specialist palliative care teams on outcomes for cancer patients, it was found that these specialist teams helped increase the amount of time spent at home by patients, satisfaction by both patients and their caregivers, symptom control, a reduction in the number of inpatient hospital days, a reduction in overall cost, and the patients' likelihood of dying where they wished. (Hearn, 1998) These teams required a specialist nurse, as well as the general practitioner, among other support staff, such as social workers, chaplains, therapists, etc.

Several cancer centers across the world have introduced patient-centric supportive care approaches. More details on these are in Chapter 6: *Approaches to Delivering mBC Care: Cancer Center Profiles*.

Countries and regions, such as Europe, have made advancements in palliative care through greater integration into mainstream health services. (WPCA, 2014) According to policy in the EU, anyone in need of palliative care should be able to have access to it. (Van Beek, 2013) While policies and regulations differ by country, there is a universal understanding around the importance of palliative care in helping to maintain quality of life in patients with mBC, despite its varied implementation.



B Access to effective supportive and palliative care is not yet globally achieved

Implementation of supportive care has been variable and significant gaps remain. Often, this requires an interdisciplinary approach and a shared objective of creating health systems that both identify and provide supportive care resources. Unfortunately, this coordination of effort may not exist today in even resource-rich health systems. A study conducted in Canada in patients with advanced cancer, assessed the impact of discussing palliative care on quality of life (measured using the FACIT-Sp scale). Although no significant difference in quality of life was observed between those who were told about palliative care upon diagnosis and those who weren't, patients did experience an improvement in an alternative measure of quality of life (QUAL-E) and satisfaction with care. (Zimmermann, 2014)

Data guiding palliative interventions, specifically in mBC, are sparse. (Morrogh, 2010) However, guidance on palliative care is being more widely represented in the literature independent of disease state and broadly across cancers. (Cleary, 2013; Cardoso, 2013)

Advances in palliative care have not been successfully implemented in all countries. (Harding, 2011; Sepulveda, 2003; Jeremic, 2014) For example, some types of palliative care (eg, access to pain medications) still remain unavailable in some countries, such as in Africa. Additionally, a systematic appraisal of the status of palliative care in Sub-Saharan African countries found limited evidence on the problems and outcomes of patients. (Harding, 2005) Although palliative care is now advocated as a global human right, (Gwyther, 2009) the research evidence in Africa to date has focused

almost exclusively on advanced human immunodeficiency virus (HIV), and specifically on the availability of opioids to improve both cancer and acquired immunodeficiency syndrome (AIDS) pain relief. (Harding, 2010; Logie, 2005; Cherny, 2013)

C Training for healthcare professionals on all aspects of supportive and palliative care is lacking

The primary focus of education around supportive care for metastatic disease and palliative end-of-life care should be on training multidisciplinary and interdisciplinary health professional teams and improving coordination of care. Patients with mBC should have multiple care providers that actively coordinate care as a key component of supportive and palliative care programs. (Cleary, 2013; EAPC, 2009; Cardoso, 2013; NCCN Guidelines® for Palliative Care v.1.2016) Efforts have already been made in some countries, to create interdisciplinary teams and educate primary-care physicians, nurses, and other specialists, such as oncologists and surgeons, in palliative care. Training of nursing staff in palliative care is important; currently, nurses report a lack of skills training, as well as confidence and tools needed to provide adequate palliative care. (Cleary, 2013)

Patients with mBC should have multiple care providers that actively coordinate care as a key component of supportive and palliative care programs. (Cleary, 2013; EAPC, 2010; Cardoso, 2013; NCCN Guidelines® for Palliative Care v.1.2016)



“ Patients and families should prepare in advance for this and should have people who are acceptable to the patient and capable of the work decided upon and lined up. Hours sitting in the quiet beside a patient as they rest and watching to make certain they aren’t in too much pain or having trouble catching their breath, calling hospice for advice, altering and administering medications, helping them on and off the toilet, which often will cause the patient pain— this can be daunting to the person who did not realize what they were signing up for and thought they’d just have a bit of pleasant conversation as they whiled away the afternoon with a friend. ”

“CJ” (Dian) Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAvivor Research & Support, 2015

Additionally, training should ensure healthcare professionals are cognizant of relevant clinical practice guidelines for supportive care. Guidelines exist to support specific treatment-related toxicities, such as pain, nausea, vomiting and anemia. Guidelines on other supportive care topics are also available, including depression, rehabilitation, nutrition and exercise. These guidelines have been reviewed and detailed further as part of the 5th BHGI Global Summit for Supportive Care. (Cardoso, 2013)

Consideration should be given to the supportive care resources required for the management of the adverse effects of chemotherapy, radiotherapy and the complications of surgery and endocrine therapy. When resources to manage side-effects are unavailable or limited, effective treatment with limited toxicities should be considered. The optimal treatment goal is to have a full range of treatment options available and supportive care interventions to manage treatment-related side-effects. Monitoring for treatment-related side effects is considered part of routine breast cancer treatment protocols, but it is also an important part of supportive care throughout mBC disease progression. (Cardoso, 2013)

Health professional education in this domain should include the universal principles of pain management. This should include safe and effective use of strong opioids for mBC pain relief, understanding the relative differences in analgesic effects of various drugs, close and accurate clinical monitoring of patients’ pain levels and well-being, and identifying pain-related emergencies (eg, bone fracture, spinal cord compression, infection, or bowel obstruction). (Cleary, 2013) Pain control remedies should follow the WHO ladder, administered according to clinical practice guidelines. Basic nonpharmacologic pain management interventions should also be available and include management of pain-related physical symptoms. Patients’ preference for alternative and complementary pain medication should also be considered. (Cleary, 2013)



D Patients have identified a need for a wider range of support services

As patients with mBC progress through their treatment, support needs change in both intensity and type. Emotional support and quality of life improvements were identified as the top 2 needs of patients with mBC, beyond basic medical needs (Figure 1.5), in a primary research study with breast cancer centers. (Breast Cancer Center Survey, Pfizer, 2015)

In Europe, more than 40% of patients with mBC identified regular support from healthcare professionals as an area needing improvement, and more than 50% identified continuity of care and counseling specifically. (Harding, 2013) Despite differing levels of available support for patients, those with mBC may also not be aware of some of the resources available to them, such as telephone hotline access to specialist nurses and trained volunteers or access to in-person/online support communities. (Mayer, Lessons Learned, 2010)

Figure 1.5

Prioritized mBC Patient Needs

Breast Cancer Center Survey, Pfizer, 2015

Support 79%	Quality of Life 72%	mBC Management 32%	Financial Support /Cost / Insurance 31%
Emotional / Psychosocial Support	Pain Control / Management	Survival: OS, PFS	Especially US, UK, Australia
Family Support	Quality of Life	Effective / more effective treatment	
Social Support	Nutrition / Diet / Weight	Alternative / new treatment options	
Availability of caregivers / physician	Symptom Control / Management		

BCC Quant July 21-Aug 26, 2015

Q14, Q42 Base = Total Respondents (n=568);
Sweden included (n=582)

Q14, Beyond the medical needs that are focused
only on addressing the cancer itself, what do
you think are the top 5 most important needs of
*mBC patient? (Top 5)

*Stage IV / Unresectable Advanced BC

Respondents were from US, UK Germany, Italy,
Portugal, Brazil, Mexico, Australia, and Sweden

Research has identified that there are also generational differences in support needs for women with mBC. In the UK, younger women with mBC were more likely to rate the overall support they received as lower than older women; those who received formal support services felt they were beneficial, but a significant number did not know how to find these. (Reed, J Pain Symptom, 2012)

The majority of patients with mBC fail to access mental health services. Despite the impact an mBC diagnosis can have on psychosocial health, only around one-third of patients with significant anxiety or depressive symptoms access mental health services. (Mosher, 2012) This suggests an additional area of high unmet need in patients with mBC (Aranda, 2005), and a requirement for greater vigilance from healthcare professionals in detecting any alteration in mood, at early stages, to ensure patients are referred to the appropriate support services. (Kissane, 2004) Developing easily accessible interventions, such as telephone and internet-based counseling, may also assist patients who may face obstacles in accessing mental health services. (Mosher, 2012)



Use of mindfulness-based stress reduction (MBSR), a form of psychosocial support, has been shown to enable women with mBC to feel less reactive to emotional distress, while also reducing anxiety. (Eyles, 2015) Offering psychosocial intervention programs to patients with mBC, through social workers, also has demonstrated an improvement in outcomes, such as distress and despair, despite disease progression. The majority of patients found psychosocial interventions helpful with a greater than 10% decrease in prevalence of fatigue in these patients (baseline to 3 months). (Abernethy, 2010) Additional research is needed in this area to design effective interventions, that ensure women with mBC are being adequately and continually supported from a psychosocial perspective.

Support for mBC patients outside of families generally comes from adjunctive programs specializing in psychotherapy or support groups. (Abernethy, 2010) The support provided by patient support organizations (PSOs) will be covered in Section 2 of the report, *Policy, Society and Community Impact*.

Treatment adherence is another area where patients need support.

Globally, nonadherence with treatment is an issue in the management of mBC. In the United States, approximately one third of women with mBC report engaging in nonadherent treatment behaviors. Most commonly, patients in the study reported nonadherence due to forgetfulness (41%) and intolerance of side effects (37%). Nonadherent behaviors were found to be significantly associated with a decrease in functional well-being. (daCosta DiBonaventura, 2014) Nonadherence could be improved by simpler and less toxic treatment regimens that are as effective in treating mBC as more intolerable treatments. (daCosta DiBonaventura, 2014)

In a study evaluating how mBC patients value the attributes of different treatment options and how this subsequently impacts adherence, effectiveness was valued as 3 times more important than side effects.

(daCosta DiBonaventura, 2014) In this survey, patients described being willing to accept substantial additional risks from side effects for gains in overall survival. However, the severity of treatment-related symptoms or accumulation of symptoms over time significantly predicted early discontinuation or switching of treatment. This highlights how physicians may better maintain patients on planned therapy if they attend to the overall symptom burden that patients experience over time. This also reinforces the need for healthcare professionals to focus on symptom development during a patient's treatment and work to prevent and reduce symptoms as early as possible to help improve adherence. (Walker, 2014)

In some African countries, due to lack of national funding and access to adequate healthcare, poor compliance with treatment regimens is a major problem. Patients may have to bear the burden of transportation costs as well as the cost of diagnosis, overall care, chemotherapy, antibiotics, blood product support, and food and accommodation during treatment. (Adde, 2013; Abuidris, 2013; Adesunkanmi, 2006) This is also often the case for women living in rural and remote locations within more developed nations. While reasons for nonadherence differ, this is unquestionably a large problem worldwide.

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(daCosta DiBonaventura, 2014)



E Patient- and family-focused information on supportive and palliative care is limited

Improved communication about patient care and treatment options assists in understanding supportive and palliative care services available to a patient and their caregiver(s). Focus in this area should be paid to late-disease risks, complications of advanced disease, and palliative care treatments and their side-effects. In addition, patients and their families should be provided with information on pain management, skin care, and psychosocial and spiritual aspects of end-of-life care. (Cleary, 2013)

Early education of patients with mBC can help improve facilitation of future access to supportive care when needed. During active treatment, patient education should include recognition and management of treatment-specific organ-based toxicities and other treatment effects, including possible early menopausal symptoms, infertility, body image concerns, and sexual health issues. Patients should be further informed of the potential psychosocial complications related to treatment, such as anxiety and depression, and potential disruptions to their usual social roles, including employment and motherhood. (Cardoso, 2013)



Chapter 5: End-of-Life Care

- Studies have started to explore patient wishes related to end-of-life care and address challenges with delivering effective care
- Greater facilitation of doctor-patient communication about palliative and end-of-life care in a sensitive manner is needed
 - Healthcare professional may be reluctant to have such conversations or find it challenging to balance sensitivity and reality in their communication
 - Patients report that they find it difficult to talk to their healthcare provider about end-of-life care
 - Education of both patients and relatives about supportive, palliative, and end-of-life care is needed
- New collaborative approaches are needed to improve end-of life care for mBC patients
 - A disconnect remains between institutional models of care and the desire of patients for end-of-life care at home
 - An increased focus on timely hospice/palliative care referral is a crucial factor in providing high quality, individualized, end-of life care
- Better psychosocial support for women with mBC is needed to ease the end-of-life care experience

Each patient's experience is unique, but almost all reach a time where mBC leads them to face end-of-life. Based on a review for this report, no holistic reporting on the management of end-of-life care in patients with mBC has been identified, even though end-of-life care is one of the most distressing periods for patients, families, and caregivers and contributes to

a large proportion of healthcare costs for these patients. A transformation is needed to ensure that patients and families' wishes are met and ethnic and cultural sensitivities are also addressed in a patient-centric system. Policy makers, physicians, and patients must work together to improve end-of-life care for patients with mBC.



“ If the physician has been honest with the patient about prognosis, there are fewer misinterpretations about hope and extent of life. Oncologists must be able to say that the disease normally ends in death, but death can come at different times. For some, death may come within the first few years, but others live well for 5, 10, and even 20 years after diagnosis, and a few even survive the disease permanently. Oncologists should stress that no one can truly predict when the end will come and what it will be, but the best course of action is to prepare for every possible outcome. ”

“CJ” (Dian) Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAvivor Research & Support, 2015

A Greater facilitation of doctor-patient communication about palliative and end-of-life care in a sensitive manner is needed

When discussing mBC with patients, physicians must carefully balance the dialogue to ensure a fair balance of sensitivity and reality. This is not to say that realities of mBC should be ignored. Primary research carried out for this report found that physicians currently first raise end-of-life discussions after multiple changes to treatment. (Breast Cancer Center Survey, Pfizer, 2015) Conversations about end-of-life care should be initiated earlier in the mBC treatment pathway, communicated using language appropriate to the changing situation, and tailored to the patient’s needs. Having this critical discussion sooner rather than later will increase the amount of time available for effective planning, and for some, not having adequate time could inhibit death preparation activities. (Chunlestskul, 2008) In reality, research completed for this report showed that, currently, in 65% of cases end-of-life discussions are held too late - first arising after multiple changes in treatment have already occurred. (Breast Cancer Center Survey, Pfizer, 2015) Effective and planned communication surrounding preparation for end-of-life is especially important for enabling women with mBC to participate in the process in an active and supported way.

Research completed for this report identified that, currently, in 65% of cases end-of-life discussions are held too late - first arising after multiple changes in treatment have already occurred.

(Breast Cancer Center Survey, Pfizer, 2015)

Oncologists play a vital role in determining whether palliative care and hospice services will be involved at all, and at what point of disease progression this will likely be accessed. (Kierner, 2010) Although conversations about end-of-life are extremely difficult for all involved in healthcare, it is crucial for healthcare providers to clarify patient and family preferences about care, location of death, and other requests. (Irvin, 2011)



Although conversations about end-of-life are extremely difficult for all involved in healthcare, it is crucial for healthcare providers to clarify patient and family preferences about care, location of death, and other requests. (Irvin, 2011)

However, such conversations can be misinterpreted by patients to mean there is no hope left, and this is one of many reasons why oncologists may be reluctant to have such conversations in the first place, or may find them particularly difficult. (Behl, 2010; O'Connor, 2015)

The role of families in making decisions on behalf of the patient has gained prominence. (Hauke, 2011) Education of both patients and relatives about supportive, palliative and end-of-life care may also help to address reports that family members/relatives do not always accurately interpret, communicate, or act on patient preferences. Family perception of patient wishes may also differ from the physician's perception. (Cleary, 2013; Hauke, 2011)

Advanced directives, or legal documents that explain decisions to be made at the end-of-life, can assist in conveying patient preferences, thus helping patients, families, and healthcare providers communicate more

Cultural or family traditions regarding the sharing of end-of-life decisions should also be respected, as they may differ from those of healthcare professionals or others involved in care. (Cleary, 2013)

effectively about end-of-life choices, and to definitively document patient decisions. (Cleary, 2013; Ozanne, 2009) It is important for patients to have full autonomy and power to make these choices on their own, without interference from external parties or even family members. It may even fall on the hospital or medical care center to ensure patients have this ability. Cultural or family traditions regarding the sharing of end-of-life decisions should also be respected, as they may differ from those of healthcare professionals or others involved in care. (Cleary, 2013)

Patients often find difficulty in speaking to healthcare professionals about supportive, palliative, and end-of-life care, despite the fact that a majority of patients with mBC report making plans for end-of-life medical care with others. Patients are more likely to talk to family and friends about end-of-life decisions than to their providers, and very few providers report an awareness of patient-led advance directives. Patients express a desire to share treatment decision-making with their provider; however, it is difficult to gauge success in reality. (Ozanne, 2009)

Greater facilitation of doctor-patient communication about end-of-life care is needed in order to provide high-quality patient care for patients with mBC. (NCCN Guidelines(R) for Palliative Care v.1.2016)

// Most of the time, there is a misunderstanding between the specialist and patient. The specialist does not want to think about end-of-life and metastatic diseases. He does not want the patient to be depressed, so nothing is relayed to the patient about the truth of her disease. //

Breast Cancer Nurse, France (Interview), 2015



B Changes are needed to existing supportive and palliative care models in order to further ease the burden on patients with mBC

The location of end-of-life care is a primary concern for patients and their families, and many existing models of care in mBC are centered on institutional care settings. (Cleary, 2013) A 2013 systematic review in adults from 8 countries with advanced or severe malignant or nonmalignant disease found that most people expressed a preference to die at home. (Gomes, 2013) However, factors such as culture, disease, and socio-economic status influenced the ultimate preference stated for home versus institutional end-of-life care. (Murray, 2009) Accessibility of pain relief, availability of affordable care, and the amount of assistance in coping with the burden of care were influential factors in patient choice of location for end-of-life care. Patient preference for the place of death may change over time due to a variety of factors, indicating a need for flexibility in care models, including preference for home care. (Cleary, 2013; Gomes, 2013)

These considerations are important, not only in high-income countries with high levels of resources, but also in low-and middle-income countries. In one Nigerian study, only 46% of patients dying of terminal breast

A 2013 systematic review in adults from 8 countries with advanced or severe malignant or nonmalignant disease found that most people expressed a preference to die at home. (Gomes, 2013)

cancer did so under hospital care. (Gukas, 2005) Reasons for patients' preference of dying elsewhere had not been studied, but it is proposed that the cost of terminal care, religious, and traditional beliefs may play a role. (Gukas, 2005) Unfortunately, this can lead to patients leaving hospital care and losing their life at home or in native herbal homes (treatment centers operated by herbalists) without appropriate management of symptoms, which can lead to severe pain, with sepsis, depression, and feelings of isolation. (Gukas, 2005) Since over 50% of terminally ill breast cancer patients preferred to die outside of a hospital setting in this study, the authors highlight that access to ambulatory care services that can support effective symptom control is necessary during the end-of-life stage of disease. (Gukas, 2005)

“ Most people may not know what hospice care can and cannot do. Staying in a hospice facility can be very expensive for the family. Also, when under hospice care at home, the patient will have support in her home for at best 2 to 3 hours per week. When the patient can no longer be left alone, she will have to find friends and family to sit with her. ”

“CJ” (Dian) Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAvivor Research & Support, 2015



Reasons for patients' preference of dying elsewhere has not been studied, but it is proposed that the cost of terminal care, religious, and traditional beliefs may play a role. (Gukas, 2005)

The World Health Organization (WHO) state that palliative care is an urgent humanitarian need for people with cancer worldwide and recognize that it is particularly needed where a high proportion of patients have advanced disease for whom there is little chance of cure. Effective public health strategies, comprised of community and home based care, are essential to provide effective end-of-life care for patients and their families in low-resource settings. (WHO, 2015) In some countries in Africa, the absence of palliative care and hospice facilities may impair the quality of life in people with cancer. Whereas in India, hospice and palliative care services have become more widespread over the last 25 years through the notable efforts of individuals. (Khosla, 2012) The services remain early in their development and continue to face challenges including insufficient capacity in facilities, not enough trained personnel to meet population demand over a wide geographical area, and burdensome legislation that makes access to strong opioids difficult. However, a change in the mindset of healthcare professionals and national decision makers has occurred during this time giving impetus to the greater provision of palliative care. (Khosla, 2012)

The decision to refer a patient to hospice can be difficult, and many patients who enroll are referred very late in the course of their cancer,

preventing them from receiving most of the benefits of hospice care and support. (Irvin, 2011; Casarett, 2007) A survey performed in Austria indicated that Austrian oncologists contacted palliative care services later during the course of the patient's cancer and hospice services even later, even though early initiation of palliative care is recommended for patients with incurable diseases. (Kierner, 2010) An unplanned hospitalization in patients with advanced cancer may signal the time for palliative care consultation or hospice referral. (Rocque, 2013) Timely hospice referral or referral to specialist palliative care team is a crucial factor in providing high quality end-of-life care for patients with mBC. (O'Connor, 2015)

Better psychosocial support for women with mBC is needed to ease the end-of-life care experience.

Some patients with mBC experience high levels of anxiety, leading to a more negative and isolated end-of-life experience. Anxiety about death is associated with an increased rate of psychological problems. (Iverach, 2014) Many patients with mBC experience major concerns including the fear of dying and care at the end-of-life. (Mayer, 2010)

Severity of physical suffering, past history of depression/psychiatric illness, and a lack of social support can all increase the likelihood of depressive symptoms that may impact patient decision making around supportive and palliative care. (Cleary, 2013) Those involved in providing end-of-life care need to be aware that depression can be a cumulative response to progression of metastatic cancer and proximity of death.

Clear and compassionate communication between healthcare professionals, patients and families is a critical aspect of psychosocial care in any supportive or palliative care setting. Psychosocial care focuses on addressing the effects of cancer and its treatment on the mental and emotional well-being of patients and their families. (Jacobsen, 2012)



Clear and compassionate communication between healthcare professionals, patients, and families is a critical aspect of psychosocial care in any supportive or palliative care setting.

(Jacobsen, 2012)

The spiritual well-being of cancer patients is now recognized as an important consideration of care, and as a result, has been incorporated into cancer care programs. (Cleary, 2013; NCI, 2015) Attention to spiritual well-being may be helpful for patients with mBC, including faith, a sense of meaning, inner peace, and spiritual counseling, found either within or outside of religious practice.

Experiences at the end-of-life are naturally unique to each patient. A descriptive study of 5 women in Canada was conducted that sought to depict the experiences of women with mBC as they prepared for end-of-life. The women observed used a variety of methods to help themselves through this process, such as the open expression of feelings and giving themselves time and permission to grieve. Some women also did extensive cognitive work to prepare themselves for death, and they were able to identify their concerns (such as how should they be living, how could they say goodbye to their family, etc.) and valued their time in a new way by realizing that death could happen any time. They began to change their priorities and live life in a new, fully conscious way. (Chunlestskul, 2008)

Another highlighted need from patients was for healthcare professionals to be able to effectively assess their own attitude to death (as well as their patient's death attitudes) in order to rectify any emotional avoidance, superstition, or fear. Nurses in particular were identified as being able to fill the need of being conscious of death preparation and help patients to confront and manage it. (Chunlestskul, 2008)

Consideration of the range of support services available for patients, their families, and caregivers is important when initiating end-of-life discussions. Many women sought death preparation programs at different times while living with metastatic disease. Multigenerational support for family members was also an area of great need for patients with mBC, as end-of-life preparation not only impacts children of such patients, but also the parents of patients as well. (Chunlestskul, 2008) Bereavement support should be provided by the end-of-life care team to families according to assessed need and may include spiritual support in the community. (Cleary, 2013; Hudson, 2012) Women might prepare their families for their death by talking, using professional support (eg, a counselor), writing (eg, journals), and through role delegation. Part of this process could involve arranging wills, clearing out personal effects, and arranging for final preparations.

Individual counseling can enhance the ability of women to share and express their feelings about death without negative effects. It can also serve to help to clarify family problems and strengthen family well-being, so patients feel their families will function after they have gone. Regular participation in support groups can enable women to communicate with their family in a less emotional way and enable their family to start to prepare for their death. Support groups also provide a network for other women going through the same experience. (Chunlestskul, 2008)

Nurses have been identified as being able to fill the need of being conscious of death preparation and help patients to confront and manage it. (Chunlestskul, 2008)

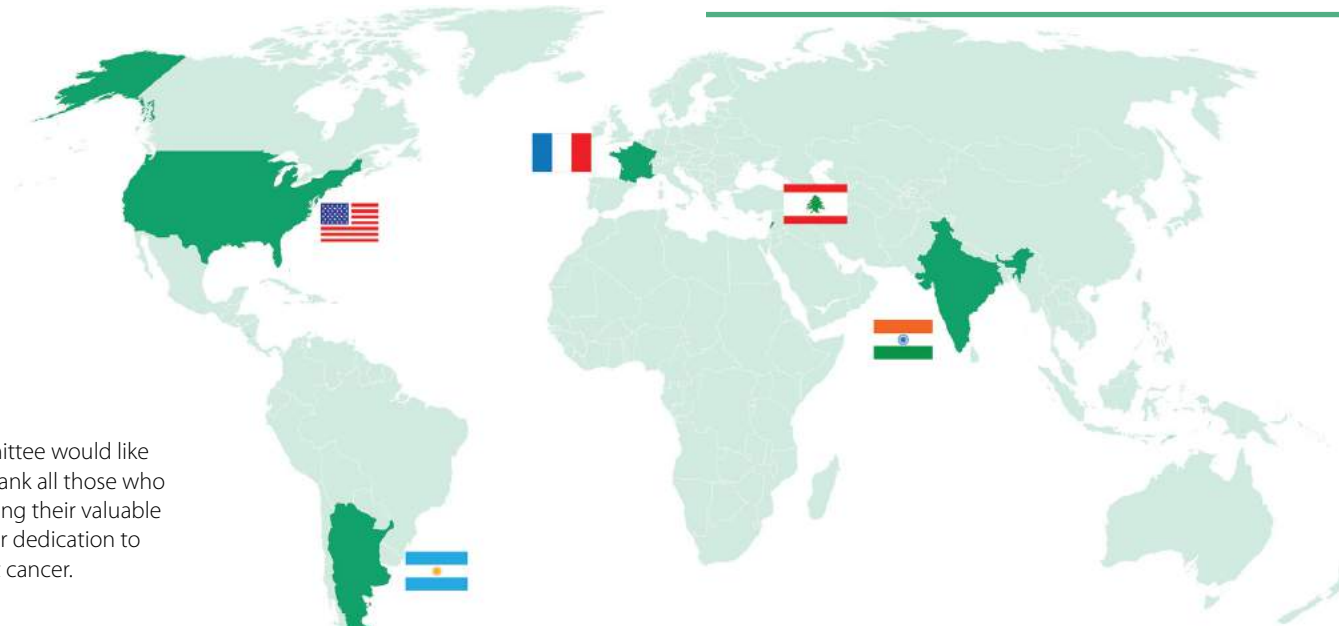


Chapter 6: Approaches to Delivering mBC Care: Cancer Center Profiles

The wealth of primary and secondary research reviewed in development of this report, provided an evidence-based approach to assessing the status of mBC. Perspectives from a vast range of stakeholders also highlighted how the findings translate into the everyday lives and experiences of patients with mBC, their healthcare professionals, families, and caregivers. Healthcare professionals play a pivotal role in treating and supporting patients throughout the continuum of their disease. Many cancer centers have developed and implemented their own approach to managing mBC patients that are tailored to local patient needs and socio-economic context.

While there are certain commonalities in approach, there are unique elements in each center's patient management and care delivery model, that provide valuable insights. Each is intended to provide a holistic and realistic view of the healthcare team's experience in caring for mBC patients, with the aim of sharing successes and challenges still to be overcome, in providing high quality cancer care.

Methodology: Interviews were conducted with 6 breast cancer centers from France, Argentina, Lebanon, India, and the US. Interviews were conducted with 2 to 3 positions working within each center to obtain a multidisciplinary view of how the centers address the needs of patients with mBC; these included: Directors, Oncologists, and Nurses.



The Steering Committee would like to recognize and thank all those who participated in sharing their valuable insights and for their dedication to patients with breast cancer.

USA:
MD Anderson Cancer Center
 • Dr. Mariana Chavez-MacGregor
 • Susan Ferguson
 • Theresa Johnson

USA:
Queens Cancer Center
 • Dr. Margaret Kemeny
 • Linda Bulone

Argentina:
Instituto de Oncologica Angel H. Roffo
 • Dr. Valeria Caceres
 • Dr. Ana Cagnoni
 • Esther Nunez

France:
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Naef K. Basile Cancer Institute
 • Dr. Nagi El Saghir
 • Rebecca El-Asmar
 • Mira Wehbe Hariri

India:
Tata Memorial Centre
 • Dr. Sudeep Gupta
 • Dr. Seema Gulia



1 The Nellie B. Connally Breast Center at MD Anderson Cancer Center, Houston, TX, USA

Participants: Dr. Mariana Chavez Mac Gregor, Assistant Professor, Department of Breast Medical Oncology; Susan Ferguson, Clinical Administrative Director; Theresa Johnson, Nurse Manager

Statistics:

Created as part of The University of Texas System, MD Anderson is one of the nation's original 3 comprehensive cancer centers designated by the National Cancer Act of 1971 and is one of 45 National Cancer Institute-designated comprehensive cancer centers today.

- Founded: 1941
- Patients per year: 40,000 of those approx. 80-100 new mBC patients

mBC Patient Population and Needs:

According to Ms. Ferguson, *"We see a whole spectrum of patients [at the Breast Center]. We see patients from around the world, as well as right in our neighborhood."*

In regards to the needs of mBC patients, Dr. Mariana Chavez Mac Gregor explained, *"The needs for each patient are different. mBC Patients are patients that have an incurable disease and are very likely to die. So throughout that journey, for some patients, support groups with patients that also have metastatic disease are very helpful. Support groups for those with early disease are much different than those with metastatic disease."* She went on to explain, *"Our [mBC] patients know what they have and they know we're not going to cure them. While difficult, this truth opens doors around discussing very clearly what we can accomplish with treatment and what we cannot."* Ms. Ferguson highlighted that mBC patients generally need a lot of psychosocial support. The center's members believe it is important to also provide support for the loved ones of mBC patients.

mBC Care Approaches:

Overall, a multi-disciplinary model is used for mBC patient care. Based on patient and disease characteristics, patients are triaged to the most appropriate department within the Breast Center. mBC patients may meet first with a medical oncologist, unlike eBC patients who might first be seen by the surgical team. As Ms. Ferguson explained, *"As far as what services for mBC patient care are provided to a new patient for their clinical care, we have algorithms and decision points. We have a very specific plan coordinated by physicians and staff for when a referral is needed for a new service."*

The multidisciplinary and holistic approach to care allows for the bundling of service appointments together which is especially beneficial for patients traveling great distance for care. All services collaborate together with the primary focus of the gain and good of patients.

Dr. Chavez Mac Gregor adds, *"We provide the best compassionate evidence-based care to our patients, especially when discussing clinical trial options and standard of care with our patients."*

"One of the greatest challenges is the discussion around palliative care and end-of-life; it's a difficult conversation for physicians to have and just as hard deciding when do you have it. Oftentimes, communication ends up happening in emergency department where patients are in pain and are now having an end-of-life discussion with a complete stranger."

Susan Ferguson



(continued)

The Nellie B. Connally Breast Center at MD Anderson Cancer Center, Houston, TX, USA

Challenges:

Ms. Ferguson explains, *“One of the greatest challenges is the discussion around palliative care and end-of-life; it’s a difficult conversation for physicians to have and just as hard deciding when do you have it. Oftentimes, communication ends up happening in emergency department where patients are in pain and are now having an end-of-life discussion with a complete stranger.”*

Despite ample resources, sometimes you cannot provide optimal treatment due to other challenges, such as patient financial constraints and physical conditions. In these cases, Dr. Chavez Mac Gregor explained, *“It’s not that we were doing something wrong. We do what needs to be done, but unfortunately it is very frustrating for everyone because the patient may not be in optimal condition.”*

Unique Features of Center:

All breast cancer nurses go through a robust nursing orientation program, which includes 4 to 6 weeks with a breast cancer center nurse mentor along with other educational aspects. As stated by Ms. Johnson, these programs *“make sure they have a foundation of breast cancer knowledge, including mBC, and signed-off before they can treat patients independently.”* All nurses at the Breast Center must be further certified in breast cancer care or oncology through a nurse educator program concluding in a certification exam. According to Johnson, *“The whole institution [at MD Anderson] has now implemented this as a best practice. What you see with certification in nurses is better patient outcomes.”*

Within the Breast Center, patients have access to nearly every service they may need. Outside of traditional oncology services, the Breast Center also has specific support professionals that are dedicated solely to breast cancer including, interpreters, social workers, pastoral services, pharmacists (PharmDs), and dieticians. Although separate from the Breast Center, MD Anderson also has several free services for mBC patients a dedicated Breast Imaging Center and a Breast Reconstruction Center.

Additionally, the Breast Center has its own beauty salon that provides several free aesthetic services. An internal store called “Appearances” is dedicated to personal items for women with breast cancer, including prosthetics, wigs, etc.

Ms. Johnson informed, *“The great thing about MD Anderson is that everyone that needs to be included to take care of your breast cancer is right here, within the same building.”*

Additionally, within MD Anderson, psychology professionals, international services (which provide support for international patients), a palliative care center, a pain center, and a survivorship center offer various services to all patients, including mBC.

“These programs make sure they have a foundation of breast cancer knowledge, including mBC, and signed-off before they can treat patients independently.”

Theresa Johnson





2 Queens Cancer Center (QCC), NYC, USA

Participants: Dr. Margaret Kemeny, MD, FACS Medical Director; Linda Bulone, Clinical Trial Manager Nurse

Statistics:

NYC has the largest public hospital system in the USA: the Health and Hospitals Corporation (HHC). QCC can be considered one of NYC's "safety net hospitals," which are hospitals that provide care to uninsured or low-income individuals.

- Founded: 2001

mBC Patient Population and Needs:

As the second largest borough in New York City, Queens has 2.3m people with 2 public hospitals taking care of all Queens patients without insurance or who are undocumented. Breast cancer is the most common cancer seen at QCC; approximately 20% of the patient population at QCC has this diagnosis. In addition, all patients have diverse needs due to cancer diagnosis and social backgrounds. Ms. Bulone notes, "In this community sometimes cancer is not the main problem the patient has... they don't have housing, jobs..." However, the director is keen to stress, "We treat patients regardless of their ability to pay." Due to the cultural and social backgrounds of the patients, many present with late-stage diseases such as mBC.

mBC Care Approaches:

QCC offers multi-modality cancer care. Patients are able to see surgical, medical, and radiation oncologists under one roof, and at the same time. Part of this interdisciplinary team is 3 social workers, one of which every new cancer patient sees, along with a nutritionist, pharmacists, and psychologist. The latter is particularly important for mBC patients as many have psychological distress as a result of their diagnosis. QCC also has its own geneticist, who may even test the families of mBC patients, while an anaesthesiologist runs a pain service within the Center.

"One of the unique features of our center is that we take time with our patients. We want to make the atmosphere as good as possible for the patients."

Linda Bulone and Dr. Margaret Kemeny

In addition to medical staff access, there are also a number of support groups for patients with general cancer and mBC, including monthly support groups run by psychologists, and often in collaboration with Patient Support Organizations (PSO). The external 'Gilda's Club' collaborates with QCC to run support groups for patients, which produce a variety of informative meetings such as nutrition and movement/dance therapy.





(continued)

Queens Cancer Center (QCC), NYC, USA

Palliative care is provided via an in-patient service only, and “Home Hospice” is engaged for patients at home; alternatively, patients enter a separate hospice facility. This may be facilitated by the pastoral or spiritual care service, another feature provided for patients by QCC. However, Dr. Kemeny emphasizes, “We really hand hold the patient through services, whether the services are on site or if they are offsite.”

QCC strongly supports access to clinical trials in a community hospital setting, providing opportunities to uninsured patients that they otherwise would not have elsewhere in the state. “It’s about getting patients access to new drugs that they didn’t have access to; everyone eligible for a trial will be screened,” says Dr. Kemeny.

Challenges:

Prior to the Cancer Center opening in 2001, a third of patients arrived at Queens with advanced or metastatic BC; this is a much higher number than the rest of the US. QCC works actively in the community to drive awareness of cancer and encourage patients to present earlier in their disease. As a result of a number of outreach programs, the number of advanced/metastatic BC patients at initial diagnosis at QCC has decreased to come in line with the rest of the country. Through the Queens public library system, QCC worked to promote mammograms by taking the “Mammo-van” to 20 branches for screenings. Ms. Bulone explains, “Education was very tailored to the communities, with community members telling us how they wanted to run the program.”

Some populations are more of a challenge due to cultural differences. “You know what you can do for them, and if they don’t let you do it, it becomes a very difficult

situation,” says Dr. Kemeny. QCC engages other tactics to help address cultural barriers; for example, enlisting local pastors, for instance, to join the consultation; however, patients ultimately make their own decision on how to proceed.

Unique Features of Center:

At QCC, 92% of patients fall into minority populations and 60% of patients are immigrants — as a result, QCC is truly multi-cultural and 105 languages are spoken by the population. QCC use a certified telephone translation service which facilitates conversation at visits.

In addition, QCC was successful in engaging an individual to act as a “Patient Navigator” through an external grant, thereby creating the Patient Navigator Program. In conjunction with the Center’s social workers, the Navigator meets with every new patient and connects them with outside resources such as meals, transportation solutions, cancer support groups, access to financial assistance during treatment, and outreach to other organizations. Both Dr. Kemeny and Ms. Bulone state, “We are not going to ever let the Navigator go, it’s too important for the patient.”

“One of the unique features of our center is that we take time with our patients. We want to make the atmosphere as good as possible for the patients. As a result this group of patients are very grateful – a ‘Book of Thoughts’ in the Center reflects this,” both Ms. Bulone and Dr. Kemeny explain.

“We really hand hold the patient through services, whether the services are on site or if they are offsite.”

Dr. Margaret Kemeny



3

Instituto de Oncología Angel H. Roffo, Buenos Aires, Argentina

Participants: Dr. Valeria Caceres, Chief of Oncology Department; Dr. Ana Cagnoni, Staff Oncologist; Esther Nunez, Nurse



Statistics:

The Instituto de Oncología Angel H. Roffo is a large teaching hospital associated with the University of Buenos Aires, specializing only in the treatment of cancers.

- Founded: 1922, the first oncology center in Latin America
- mBC Patients per year: 100
- Breast Cancer Appointments per year: 10,000



mBC Patient Population and Needs:

Of the entire breast cancer population treated at the hospital, approximately 20%-30% present at first diagnosis with metastatic disease, and a further 20%-30% are being treated for relapsed breast cancer. *"Many of our relapsed patients may have been initially treated elsewhere and are considered complex cases,"* explains Dr. Cagnoni. Often information about how patients have been previously treated is limited and this can make it more difficult to organize their ongoing care.

While holistic care for patients is available irrespective of the stage of breast cancer diagnosed, the participants noted that care of patients with mBC can be more complex than for those with earlier stage disease.

"Some patients may be seeing 10 or 15 doctors for different aspects of their mBC needs. We can deal with all of the adverse events and complications of disease that a patient with mBC could face."

Dr. Ana Cagnoni



mBC Care Approaches:

Organization of an individualized care plan is led by oncologists. Beyond providing and following up with their medical care, Dr. Cagnoni co-ordinates referrals for her mBC patients to other services and departments according to patients' personal needs.

Core to the success of this institute is the truly multidisciplinary approach to care with a team that includes a wide range of specialists, to support mBC patients holistically. This team consists of an oncologist, breast surgeon, palliative care clinician, radiation therapist, microbiologist or neurologist, and any other healthcare professionals needed. *"Some patients may be seeing 10 or 15 doctors for different aspects of their mBC needs. We can deal with all of the adverse events and complications of disease that a patient with mBC could face,"* said Dr. Cagnoni.

Psychosocial care needs can be complex, as the Instituto cares exclusively for patients who do not have health insurance. Patients may travel great distances and in some cases might not have the means to pay for transportation. Each patient is considered individually so that the most appropriate help can be offered. *"We have a social workers and psychologists that can offer 1:1 support for our mBC patients according to their assessed need. The service also aims to support families or caregivers where resource is available,"* said Dr. Cagnoni. Esther and the nursing colleagues play an important role in patient education, focusing patient education on approaches to maintain patient well-being during treatment as well as providing a point of contact and emotional support.



(continued)

Instituto de Oncología Angel H. Roffo, Buenos Aires, Argentina

Challenges:

Financial constraints prevent the center from increasing resources towards additional doctors to further meet the demands for services. Oncologists sometimes worry that they are unable to spend enough time with each patient. *“Patients with mBC need to be listened to. We need to give them time, space and attention and our first appointment can take 45 minutes or an hour,”* says Dr. Cagnoni. However, to provide additional support, volunteer doctors and “ladies in pink” come to help with patient care.

Building and infrastructure restrictions also have an impact on the services offered, but clinicians are well practiced at adapting. *“When there are no inpatient beds available, we offer very close follow-up to patients who need to be admitted. We would still like to be able to create greater access to clinical trials, currently this is very difficult in Argentina. We are also looking at service enhancements that ensure patient quality of life. This could be through exercise, meditation, or other support approaches,”* said Dr. Caceres.

A medical challenge includes changes in diagnosis. *“One of the most challenging parts of the breast cancer journey is the point at which care transitions over from active treatment to end-of-life care. There are few hospices in Argentina, as such, the palliative care team at the Instituto sets up end-of-life support at home with the help of the psychology department,”* said Dr. Caceres.

Unique Features of Center:

As well as referencing international best practice guidelines, the Instituto publishes updated cancer guidelines, that includes mBC every 2 years. The Instituto, through its links with the University of Buenos Aires, focuses heavily on the training and education of healthcare professionals. The Instituto runs an annual 3 day oncology congress which is attended by Argentinian doctors and provides a BC preceptorship program for doctors from other countries in Latin America. In addition, the Instituto has residency programs in clinical oncology and surgical oncology, which helps train healthcare professionals as part of this multidisciplinary team.

While the palliative care department is separate from the oncology team, its clinicians are integrated into treatment plan right from the start. *“All of our patients with an mBC diagnosis are offered an initial assessment appointment and about 80% will receive ongoing support. Help is focused on the management of any cancer symptoms that cannot be adequately treated in the clinic,”* Dr. Cagnoni explained. *“Within the palliative care center, we also offer non-traditional therapies such as acupuncture, massage and music therapy. Our specialist acupuncturist offers support to patients with pain that has been difficult to manage with more traditional therapeutic measures,”* said Dr. Caceres.

“Patients with mBC need to be listened to. We need to give them time, space and attention and our first appointment can take 45 minutes or an hour.”

Dr. Ana Cagnoni



4

Institut Curie, Paris, France

Participants: **Dr. Véronique Diéras**, Head of the Clinical Investigation Unit; **Dr. Paul Cottu**, Head of Service at the Day Hospital; **Sylvie Carrie**, Head Nurse, Medical Oncology Department



Statistics:

The Institut Curie exists in 2 locations: Paris/Orsay and the René-Huguenin Hospital in Saint-Cloud, all in the Paris region.

- Founded: 1921
- mBC Patients per year: 200-250 (new patients)



mBC Patient Population and Needs:

At the Institut, 50%-80% of the patients seen by oncologists have mBC, with 25-30 mBC patients seen per physician per week outside of clinical trials. One third of patients travel from up to an hour away, and a quarter come from a great distance, which is *"a big issue in the continuing care of these patients,"* according to Dr. Diéras. The Curie center was rated #1 for breast cancer treatment in France this year, so many patients are referred there for treatment.

According to Dr. Cottu, *"The biggest need of the mBC patient is to have some reassurance, some comforting words from the physician. Telling her that her life is not in danger in the short term, and she is going to be able to continue her normal life... they need to know that we will help them."*



mBC Care Approaches:

60% of a doctor's time during the week may be dedicated to the clinic. Breast nurses focus on organization of care and coordination with all the practitioners, which may include calls with the patient weekly to get updated information

"The biggest need of the mBC patient is to have some reassurance, some comforting words from the physician. Telling her that her life is not in danger in the short term, and she is going to be able to continue her normal life they need to know that we will help them."

Dr. Paul Cottu

and making referrals. The nurse keeps in contact with the patients' healthcare providers and any of the nursing teams that look after the patient at home, while coordinating with all teams in the Institut regarding patient care and treatment.



(continued)

Institut Curie, Paris, France

Challenges:

Caring for mBC outpatients in their hometowns is challenging. General practitioner care can be suboptimal, as the patients often may not get the systematic care they deserve, and it is difficult to take charge of that patient from a distance. A communication network is needed among all providers as there is a lack of information at the local level, and patients also need more supportive care service coordination including additional focus on care dedicated to the quality of life of the patient. There is no dedicated place for these support services in social systems, and *“women are sometimes alone,”* says Ms. Carrie. While government does provide some funding for these services, shortfalls exist that are through oncology networks funded by resources such as the mayor or administrative regions (government organizations).

Despite having all the tools required for effectively treating the patient in theory, in fact, resources cannot be applied to everyone. Some patients may not receive care due to personal choices or condition upon arrival. For example, Dr. Diéras feels that it would be advantageous for every patient to have a psychological review earlier in the treatment pathway: *“In mBC, at the beginning of their story if they could all see a psychologist to make sure everything is OK, and not wait for the 3rd or 4th line of therapy to be in the psychologists care.”*

Financial and space constraints are also evident in supportive care; more team members are needed, time spent with patients, education about the disease and treatment side effects, and translating what the specialist has told them, is not paid. Some people feel *“there is no value placed on taking care of the patient outside the prescription, no financial interest in taking care of the patient,”* Ms. Carrie commented. There is a need for someone in the hospital to link the patient between specialists, other doctors, the pharmacist, etc. *“to be there from the beginning to the end to help patients progress along their journey,”* continues Ms. Carrie.

A medical challenge in the treatment of mBC is the lack of accurate, specific prognostic data and predictive data that allow determination of the diagnosis and a choice of individualized therapy. *“Even if we won’t have a definitive answer for every patient, research will generate knowledge, and what we currently lack is knowledge. This is the next big step we have to go through in the coming years,”* says Dr. Cottu.

Unique Features of Center:

The role of the Nurse Specialist in mBC is being enhanced. Through a dedicated clinical nurse facility for mBC patients who have oral chemotherapy, 14 nurses on rotation specialize in caring for and educating patients on oral treatments and targeted therapy. The team undergoes continuous medical education regarding new oral therapies in cancer. Activities at the facility include patient counselling, and managing side effects and toxicities of treatment. Nurses can prescribe some basic treatments and refer back to the oncologist when required. There is a drop-in center staffed by 2 nurses that sees 10-20 mBC patients per day. Other hospitals have sent nurses to be educated at the center over last 2 years.

The Curie Institut also recently implemented a patient forum. mBC patients talk about their experiences, describe their disease course, what to expect from care, and details of their treatment to inform other patients. An outreach program is also in place to coordinate mBC patient care outside the institute.



5

Mamdouha El-Sayed Bobst Breast Unit, The Naef K. Basile Cancer Institute (NKBCI) at The American University of Beirut Medical Center, Beirut, Lebanon

Participants: **Nagi El Saghir**, MD, FACP, Professor of Clinical Medicine; **Rebecca El-Asmar**, Clinical Nurse Specialist (CNS), Breast Cancer; **Mira Wehbe Hariri**, Clinical Department Administrator



Statistics:

- Founded: 2007
- mBC Patients per week: 20 to 25, weekly or bi-weekly
- Patient Population: 50% under age of 50



mBC Patient Population and Needs:

Of the entire breast cancer population treated at the hospital, approximately 30%-40% present at first diagnosis with metastatic disease. They generally used to treat 60%-70% mBC patients, but this number has dropped considerably because of earlier diagnosis of BC due to awareness campaigns.



mBC Care Approaches:

The Breast Cancer Center is not a stand-alone, but rather a Center of Excellence within the Cancer Institute. This academic center offers service, teaching, and research, while caring for patients with all stages of breast cancer, and home care services are provided for many of their terminally ill mBC patients through non-government organization and palliative care teams. The multidisciplinary team includes radiologists, surgeons, pathologists, oncologists, nurses, residents, and interns, social workers and palliative care nurses. The center offers a full range of mammography and breast care services, using advanced technology. Patients can participate in global mBC clinical trials. Ms. Mira Hariri adds, *"In particular, a Data Management and Clinical Research Unit exists for researchers to collaborate and combine basic, translational, and clinical research to explore ways to prevent, control, and treat cancer, including mBC."*

At the institute, there has been movement into sub-specialization in clinical practice, research, and education programs for different disease sites. Dr. El Saghir focuses heavily on mBC patient education within his practice, as

well as highlighting its importance generally; *"The more the women know, the better their surgeon has to be. When they have more information they force the surgeon to do a proper treatment up front, because you know very often the upfront treatment is very important."* In affiliation with an NGO (The Lebanese Breast Cancer Foundation), The NKBCI Breast Center of Excellence runs breast cancer awareness campaigns, creates and distributes educational booklets, and organizes meetings in Beirut, other major cities, and in the countryside with local women's groups and charity organizations. Dr. El Saghir discusses breast cancer awareness, causes, detection, screening, and proper treatment. Dr. El Saghir focuses highly on mBC in particular. He states, *"We always make sure that when we talk about awareness we don't only talk early breast cancer, we make sure we talk about metastatic as well."*

"We like to involve the patients and be truthful with them; however, with advanced disease, is it important to tell the patients everything about it? Also, in this part of the world it is not easy to talk to patients very explicitly about their prognosis...For example, patients do not come alone to the clinic; there can be several relatives that fill up the room. The husband or sister may be behind the patients making signs to tell us 'please don't say everything to her', you learn how to manage between telling the truth and saying it step by step. You don't have to say everything on the occasion of the first clinic visit."

Dr. Nagi El Saghir

When choosing regimens, the patient is involved in the choice of treatment; but with advanced disease, the team tread carefully. *"We like to involve the patients and be truthful with them; however, with advanced disease, is it important to tell*



(continued)

Mamdouha El-Sayed Bobst Breast Unit, The Naef K. Basile Cancer Institute (NKBCI) at The American University of Beirut Medical Center, Beirut, Lebanon

the patients everything about it? Also, in this part of the world it is not easy to talk to patients very explicitly about their prognosis... For example, patients do not come alone to the clinic; there can be several relatives that fill up the room. The husband or sister may be behind the patients making signs to tell us 'please don't say everything to her', you learn how to manage between telling the truth and saying it step by step. You don't have to say everything on the occasion of the first clinic visit," says Dr. El Saghir.

As well as providing the best treatment possible, the center also focuses on the non-medical needs of mBC patients. Patient support groups are held weekly. They include survivors and family members, joined by breast cancer nurses and psychology nurses. The support group includes patients, regardless of their disease status, who not only attend the meeting but also participate in outside activities together. Ms. El-Asmar explains, *"The patients who have been through treatment give support to new patients, and are the most positive."*

Challenges:

Financial constraint creates the biggest challenge for care of patients with mBC in Lebanon. *"In this part of the world, lots of patients are uninsured and it's a big burden for them to pay for chemotherapy or drugs,"* says Dr. El Saghir. For many patients, their economic situation forces them to stop treatment, and they often prioritize the financial needs of their family over their health. Fundraisers are held to provide partial financial support for patients. Financial issues, palliative care and counselling in advanced breast cancer are major concerns the center tries to address. Ms. El-Asmar notes that the mBC patients and their families have the greatest need for these services.

Unique Features of Center:

The center employs a Clinical Nurse Specialist for BC, Rebecca El-Asmar, a very valuable resource to provide treatment continuity and patient support. Ms. El-Asmar states, *"Doctors may have tight schedules, so it is reassuring for the patients*

to have a Nurse Specialist who is there all the time... with recurrent patients, after 5 years some of these would ask for me, as we have a relationship, trust and a bond." Dr. El Saghir is a strong advocate for nurses in the breast cancer setting, *"It's really important to let the patients talk – very often they don't express themselves fully when they are in the doctor's office so we try to make sure the nurses take the time to do that. We need more specific breast cancer nurses in general, to spend more time with patients, and we need to pay better income for those nurses and support them personally, financially and psychologically as well. We also provide educational programs to help them advance their careers."*

An "emergency step-down" ambulatory unit to manage symptoms will allow patients to drop in without appointments, avoiding the emergency room where they have a long wait time and can be exposed to infections. Ms. El-Asmar notes that the mBC patients and their families have the greatest need for these services.

In addition, the center collaborates with other organizations around the world. Ms. Hariri adds, *"Internationally, we have established affiliations with sister institutions where we hold regular videoconferences and tumor boards for teaching, training, and management of cases. Regionally, we have established affiliations where meetings are held regularly to discuss research activities. Nationally, we are expanding our local medical services through affiliations with hospitals in different regions."*

"It's really important to let the patients talk – very often they don't express themselves fully when they are in the doctor's office so we try to make sure the nurses take the time to do that. We need more specific breast cancer nurses in general, to spend more time with patients, and we need to pay the income for those nurses and support them personally, financially, and psychologically. We also provide educational programs to help them advance their careers."

Dr. Nagi El Saghir





6 Tata Memorial Centre, Mumbai, India

Participants: Dr. Sudeep Gupta, Deputy Director; Dr. Seema Gulia, Medical Oncologist

Statistics:

This cancer center is a very high-volume hospital and is one of India's leading healthcare organizations.

- Founded: 1941
- mBC Patients per year: 4000 new patients, approx 400 have mBC

mBC Patient Population and Needs:

About 50% of mBC patients choose to receive their care near their home rather than at the center, usually due to geographic reasons or personal preference. Depending on their location and preferences, some patients may stay in proximity to the center while 40%-45% of patients return home after the initial phase of treatment. They will return for the response assessments, but most of the treatments will be conducted in local treatment centers, according to the original treatment plan provided by this center's team.

The participants noted that mBC patients require a greater level of supportive care compared to those with eBC. Additionally, there is a different level of counseling that is provided to these patients, as mBC patients require a more frequent assessment of disease progressions and have variable prognosis.

mBC Care Approaches:

Prior to coming into the breast cancer center, patients register online to streamline the process. Upon arrival, patients, including mBC patients, will be evaluated by a resident doctor within one to 2 hours. After this initial meeting, patients will also have the chance to speak with a faculty member and counselor, as well as have any additional tests and screening that may be required. With all of these steps, within 4-6 working days total, patients can have a full work-up completed to inform the care team, which includes all relevant healthcare professionals for the patient's condition, and focus on the extent of disease status and burden. During this time, patients will meet with a medical oncologist, surgical oncologist, radiation oncologist, and nurse who will help with treatment navigation. In these meetings, the care team will sit with the patient and

“We need to increase communications with other [cancer] centers.”

Dr. Sudeep Gupta

counsel them about the potential treatments, anticipated outcomes, and costs. According to Dr. Gulia, *“Starting at the point of registration at the center, patients can usually start chemotherapy within 7 to 10 days.”*

A big component to care within the center is a multidisciplinary approach. During the first week of a patient being registered at a center, a multidisciplinary team will meet in a “joint clinic” to discuss the patient. This group may consist of professionals such as surgeons, medical oncologists, radiation oncologists, radiologists, pathologists, nurses, or counselors. As mentioned by Dr. Gulia, *“These multidisciplinary teams are geographically located in the same location to ensure that patients can receive all of the care they require in one place.”*



(continued)

Tata Memorial Centre, Mumbai, India

Within the center, there are a multitude of services that are available for mBC patients such as medical oncology, counseling, genetic counseling, systemic therapy/radiation therapy, supportive care services, longitudinal care, and follow-up. Dr. Gupta noted, *"We provide high-quality pathology testing which is not a universal feature in a country like India."* A major difference to mBC treatment compared to eBC is in the provision of palliative care. The center has a full palliative care unit; with mBC patients, the center involves the palliative care team at the start of the treatment plan. By doing so, the center tries to "avoid abrupt situations," such as starting palliative care too late.

Because center is large academic cancer center, this provides opportunities for patients to be included in clinical trials for mBC.

Challenges:

Financial barriers are one of the biggest challenges for mBC patients at the cancer center and across India as a whole. *"Financial barriers may prevent patients from getting the best possible care in India,"* stated Dr. Gulia. She continued, *"A large fraction of the Indian population does not have access to formal health insurance,"* and therefore, they often need to provide their own financing for treatment. While the center is a public institution and will provide care to all patients regardless of the ability to pay, some therapies for mBC patients, like expensive targeted drugs, are not accessible to them due to lack of funding. While some NGO assistance is available, many of these therapies cannot be covered by these limited funders. The social work department will help link patients to philanthropic organizations and donors, but this is not always enough for mBC patients.

Additionally, there is an enormous shortage of medically trained personnel to care for mBC patients in India. As one physician stated, *"For every 50-60,000 patients in general, there is one trained medical oncologist. There is gross disproportion between persons who are trained for such patients versus the number of patients who need treatment."* Thus, services are stretched within the center and others.



"[mBC patients] need to know that they should be reporting as early as possible to the hospital to gain treatment. People are not aware and still think that cancer is a social taboo."

Dr. Sudeep Gupta

Lack of awareness and education among patients drives misconceptions and fear. As Dr. Gupta advised, *"They need to know that they should be reporting as early as possible to the hospital to gain treatment. People are not aware and still think that cancer is a social taboo."*

Unique Features of Center:

The center focuses on connectivity with other centers and institutions. Patients often come from far distances to receive treatment at the center and receiving follow-up care near their home can improve comfort and feasibility of care. In order to do this, the multidisciplinary care team develops a plan for treatment and communicates this plan with a local institution, even providing training if needed. Throughout the treatment process, the center stays in close contact with the local treatment team to follow-up regularly on patient progress. The center aims to send patients to remote institutions that they trust will provide good care to patients through following international guidelines.

There is a distinct understanding of the need for communication with local regions to better coordinate mBC care. As stated by Dr. Gupta, *"We need to increase communications with other [cancer] centers."* Many institutions do not currently have the capability to treat mBC patients adequately, but stronger development between cancer centers through training and increasing communication may improve care overall in India. This center is working towards this goal. *"Some basic care should be present at each center in India,"* as Dr. Gupta stated.



Emerging Recommendations

In review of the broad and complex needs and perspectives of patients with mBC, it remains clear that there are a number of unmet needs globally for patients, caregivers, and their families. Improvements in these areas will require the attention and action of a multistakeholder group, including mBC patients, healthcare professionals, policy makers, patient support and advocacy organizations and beyond, to truly drive change and better support patients living with mBC.

Education, Information, and Knowledge

A common theme identified within our analysis is centered on gaps in mBC-specific information and its communication between physicians and patients. Some key recommendations are outlined below:

- mBC specific training should be implemented for healthcare professionals and staff on how to better communicate with patients regarding mBC
 - National strategies are required to guarantee training needs are sustainably addressed
 - Communication skills should be an integral part of the oncology residency training and curriculum
 - Cultural sensitivity needs to be integrated into training
 - Provide psychological support for HCPs treating mBC patients
- Clinical trial information should be proactively discussed with patients in context of overall treatment
 - Discussion should address specific misperceptions
 - New communication and training approaches should be utilized



Jonny Salveron, mBC patient diagnosed in 2008, living with the disease

- Information and knowledge expansion for patients and caregivers regarding their disease and treatment options
 - Increased availability and comprehensiveness of guides to patients on diagnosis, treatment, and advanced planning
- Shared decision making between physicians and patients
 - Upfront discussions on multiple goals of managing mBC and patient priorities and preferences are needed
 - New approaches, such as decision aids, are needed to enhance patient participation and satisfaction in joint decision making
 - Treatment decision making should take into account the unique needs of older patients with mBC and avoid discrimination



Patient Care and Support Services

- Patients need multidisciplinary, holistic, and individualized approaches to mBC patient care
 - Improved understanding and training is needed for the broader multidisciplinary team to ensure individualized supportive care offered at the appropriate time in a patient's mBC continuum
 - Patient- and family-focused resources and services are needed that address physical and emotional aspects of care, especially for younger women
 - Greater focus on roles other than that of oncologist in providing holistic support – eg, the role of the specialist mBC nurse
 - Novel and patient-centric approaches to care implemented in several cancer centers around the world could provide valuable learnings and examples for other centers
- The role and impact of Patient Support Organizations (PSOs) is discussed in detail within Section 2
- Sensitive and realistic discussions about end-of-life matters should be initiated earlier in the mBC treatment pathway
 - Comprehensive psychosocial support involving patients, families, and caregivers is needed to ease the end-of-life experience
 - Communication training is key to ensuring all of these sensitive, yet critical, issues can be addressed with patients effectively by healthcare professionals
 - Patients, clinicians, and policymakers need to work together to improve end-of-life care for mBC patients

Quality of Life Research

- Greater focus and research into the factors that impact quality of life and effective psychosocial interventions to maximize this measure in mBC patients
 - There is a need for the development of validated clinical practice tools that can assess quality of life in real time at the patient level and help play a significant role in patient management in clinical practice
 - Research into psychosocial interventions should consider the emotional needs of caregivers and families



Appendices and References

Section 1: Appendix 1.1

Patient Perspectives Systematic Literature Search (2/27/2015)

Purpose: The purpose of this search was to better understand patient perspectives in mBC space, particularly regarding patient quality of life, psychological associations, unmet needs in supportive care, and patient treatment preferences and decisions.

Method: For this search, we used a systematic search methodology in order to mitigate the risk of missing relevant content by incorporating all perspectives and by including content from trusted and revered sources.

Sources: In order to gain an understanding of the patient experience, a qualitative literature review was conducted using secondary source data. The search was restricted to the years 2005-2015 in the EMBASE database.

Search Terms: Key search terms were selected with the goal of understanding the patient experience, from diagnosis with mBC to the end-of-life stage. These terms were categorized into 5 topics: disease, subjects, study type, study focus, and exclusion terms. See below for the search strategy.



Database: EMBASE Publication time period 2005-2015			
Index	Description	Search terms	Hits
1	Disease area	"metastatic breast cancer" OR ("stage iv" AND "breast cancer") OR "advanced breast cancer" OR "secondary breast cancer"	15104
2	Study subject	"patient"	3800675
3		("physician" OR "doctor" OR "oncologist" OR "surgeon" OR "provider") OR "healthcare professional" OR ("nurse")	963222
4		("caregiver" OR "care-giver" OR "care giver" OR "carer") OR ("family" OR "spouse") OR ("colleague")	1066369
5		#2 OR #3 OR #4	5080912
6		#1 AND #5	9117
7		Study type	"survey" OR "questionnaire" OR "perspective" OR "attitude" OR "perception" OR "satisfaction" OR "opinion"
8	Study focus	#6 AND #7	752
9		"unmet need" OR "support" OR "gap" OR "burden" OR "psychosocial" OR "physical" OR "quality of life" OR "treatment preference" OR "information" OR "decision" OR "treatment satisfaction" OR "communication"	4139327
10		#8 AND #9	491
11	Exclusion terms	("randomize controlled trial" OR "randomized controlled study")	435392
12		"non metastatic breast cancer" OR "non-metastatic breast cancer" OR "non-metastatic breast cancer" or "early stage"	481
13		#10 NOT #11	454
14		#13 NOT #12	407
15		#14 AND "article"/it	132



Section 1: Appendix 1.2

Company-Sponsored Study /Public Study Reports

Index	Year	Study title	Sponsor
1	2013	Pan-European Here & Now patient and carer survey	Novartis
2	2013	Patient Perspectives: Communicating With HCPs About Metastatic Breast Cancer	Astra Zeneca
3	2013	Metastatic Breast Cancer in Canada: The lived experience of patients and caregivers	CBCN and RETHINK
4	2014	mBC Alliance Landscape Analysis: Research Report	mBC Alliance
5	2014	Breast Cancer: A Story Half Told	Pfizer
6	2014	Count Us, Know Us, Join Us; Make Your Dialogue Count, (Harris Interactive)	Novartis

Section 1: Appendix 1.3

Quality-of-Life Instrument Conversion Methodology

Purpose: The purpose of this search was to better understand how quality of life has been measured and reported over time through a systematic literature search.

Method: For this search, we used articles from the systematic search conducted for patient perspectives (see Appendix 1). To better understand how quality of life has been measured and reported over time, 132 studies were reviewed through the literature review. Of these studies, a qualitative analysis was conducted on 14 studies reporting QoL measure values for mBC.

Comparison of QoL in patients with mBC over time required the conversion of all QoL measures to 1 uniform QoL measure using accepted conversion schemes based on published literature (outlined below). EQ-5D was selected as the uniform measure, due to the widespread acceptability. (EuroQol Group, 2004)

After conversion, the following studies were included in the final QoL trend analysis:



Converted Quality of Life Survey Comparison 2004 - 2012

Study Year	Sample Size	Region	Converted EQ-5D Value	Original QoL Instrument	Method of QoL measurement
2004	105	Australia	0.7201	EORTC	Cross-sectional survey
2006	168	UK and US	0.7413	FACT-B	At baseline of intervention
2006	168	UK and US	0.7433	FACT-B	At baseline of intervention
2008	36	US	0.6990	FACT-B	At baseline of intervention
2011	235	UK	0.6914	FACT-B	Cross-sectional survey
2012	21	Greece	0.8187	EORTC	At baseline of intervention
2012	21	Greece	0.7850	EORTC	At baseline of intervention
2012	169	US and EU	0.6367	FACT-B	Cross-sectional survey
2012	191	US and EU	0.5890	FACT-B	Cross-sectional survey

3 schemes of conversions

1. Convert from EORTC QLQ-C30 to EQ-5D: the conversion from EORTC QLQ-C30 to EQ-5D is based on the study (Kontodimopoulos et al, 2009), this study was selected because the conversion is estimated based on a cohort of Greek population, and the 2 studies that reported EORTC QLQ-C30 values were conducted in Greek and Australia, respectively.
2. Convert from FACT to EQ-5D: the conversion is based on the study (Cheung et al, 2014). There is currently limited study focusing within the breast cancer population and this study was selected because it is the only study focused on breast cancer patients. The conversion scheme based on the "ordinary least square" algorithm is used, as it has the best performance.
3. Convert from SF-12 to EQ-5D: the conversion is based on the study (Lawrence et al, 2004). This study is based on a cohort of the US population, and the conversion scheme with the best performance was selected. Based on data availability in order to convert to EQ-5D values, within all studies that were conducted since 2004, 2 studies are included for EORTC conversion, 4 studies are included for FACT conversion, and 1 study is included for the SF-12 conversion. Values of EQ-5D from studies conducted in the same year were averaged with the sample size as the weight.



Sources: For this review, 14 articles from the Patient Perspectives review were analyzed qualitatively (see Appendix 1.1). Of these articles, 6 were eligible for the quantitative analysis.

Search Terms: See Appendix 1.1 for search terms used.

Results: Of the 14 studies, a variety of quality-of-life measures were utilized: 7 studies reported FACT3 studies reported EQ-5D, 2 studies reported EORTC and 1 study reported SF-12 and hrQoL. Most of the studies that reported QoL values were conducted in developed countries, eg, the US, UK, or, Australia. Recently, studies have also been conducted in Asian, Latin American and African regions; however, adequate QoL values were not reported in the studies reviewed, which limited their inclusion.

Limitations: There are several limitations of the results reported: (1) The patient care literature search is not tailored only for QoL trend analysis, and thus it is possible that the studies that reported QoL are not exhaustive in the analysis; (2) Studies included in the trend analysis are from various countries with different mBC populations. It has been discussed in several studies that the same QoL instrument can have different levels reported in different countries; (3) In addition, the conversion of each instrument to EQ-5D can also potentially introduce bias in the analysis. This is because each conversion scheme is estimated based on a certain population cohort. For example, the FACT to EQ-5D conversion is based on 1 Asian study (Cheung et al, 2014); however, the studies in the literature review are all conducted in the US or the EU. In addition, almost all regression algorithms have estimation errors. These uncertainties should be taken into consideration when interpreting the trend.

General	Clinical
Aranda S, et al. Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. <i>Eur J Cancer Care</i> . 2005;14(3):211-222.	Zhou X, et al. Lapatinib plus capecitabine versus capecitabine alone for HER2+ (ErbB2+)metastatic breast cancer: quality-of-life assessment. <i>Breast Cancer Res Treat</i> . 2009;117(3):577-589.
Reed, Elizabeth, et al. Quality of life and experience of care in women with metastatic breast cancer: a cross-sectional survey. <i>J Pain Symptom Manage</i> . 2012;43:747-758.	Abernethy AP, et al. Phase 2 pilot study of Pathfinders: a psychosocial intervention for cancer patients. <i>Support Care Cancer</i> . 2010;18(7):893-898.
Gupta S, Zhang J, and Jerusalem, G. The association of chemotherapy versus hormonal therapy and health outcomes among patients with hormone receptor-positive, HER2-negative metastatic breast cancer: experience from the patient perspective. <i>Expert Review of Pharmacoeconomics & Outcomes Research</i> . 2014;14(6):929-940.	Kyrgidis A, et al. Quality of life in breast cancer patients with bisphosphonate-related osteonecrosis of the jaws and patients with head and neck cancer: a comparative study using the EORTC QLQ-C30 and QLQ-HN35 questionnaires. <i>Anticancer Res</i> . 32(8): 3527-3534.



Section 1: Appendix 1.4

Appropriate Supportive Care while Living with Metastatic Disease Systematic Literature Review

Purpose: The purpose of this search was to better understand the perspectives of patients, physicians, caregivers, and families from patient diagnosis with mBC to final stages of life through a systematic literature search.

Method: For this search, we used a systematic search methodology in order to mitigate the risk of missing relevant content by incorporating all perspectives and by including content from trusted and revered sources.

Source: In order to gain an understanding of patient experience, a qualitative literature review was conducted using secondary source data. The search was restricted to the years 2005-2015, from 3 main databases: EMBASE, Medline, and Cochrane Library.

Search Terms: Search terms were selected with the intent to ascertain all essential articles to understand the patient experience. These terms described types of care or therapies other than standard medical care that may be used from diagnosis of mBC to final stages. A complete list of search terms are provided in the table below.

NB: The terms 'advanced breast cancer' and 'stage IV breast cancer' are not specifically recognized in EMBASE.

Database: EMBASE Publication time period 2005-2015			
Index	Description	Search terms	Hits
1	Disease area	mBC/exp OR "mBC" OR "advanced breast cancer" OR "stage IV breast cancer" OR "secondary breast cancer"	27,823
2		"breast metastasis"	9,194
3	End-of-life care	#1 OR #2	27,928
4		"palliative therapy" OR "palliative care"	85,916
5		"terminal care"	36,080
6		"supportive care"	24,878
7		#4 OR #5 OR #6	128,585
8		#3 AND #7	743



Database: MEDLINE Publication time period 2005-2015

Index	Description	Search terms	Hits
1		mBC.mp	22,131
2	Disease area	metastatic OR metastasi. mp breast cancer OR tumor OR malignant OR oncology OR carcinoma OR neoplasm OR mas OR growth OR cyst).mp	32
3		#1 OR #2	22,139
4		"advanced breast cancer" or "stage IV breast cancer" or "secondary breast cancer" AND #7	284
5		#8 OR #9	495
6	End-of-life care	"end-of-life" OR "palliative" OR "terminal" OR "supportive" AND "care"	46,374
7		#3 AND #4	489
8		"Palliative Care" OR "Terminal Care" OR "Supportive Care"	76,565
9		#3 AND #6	302
10		#6 OR #7	743

Database: COCHRANE Publication time period 2005-2015

Index	Description	Search terms	Hits
1		MeSH descriptor: (Breast Neoplasms) explode all trees	8,963
2	Disease area	(metastatic or metastasis). mp	478
3		#1 and #2	138
4		MeSH descriptor: (Palliative Care) explode all trees	1,449
5		MeSH descriptor: (Terminal Care) explode all trees	378
6	End-of-life care	MeSH descriptor: (Supportive Care) explode all trees	0
7		#4 OR #5 OR #6	1,662
8		#3 AND #6 Publication Year from 2005 to 2015	0



Database: COCHRANE Publication time period 2005-2015			
Index	Description	Search terms	Hits
1	Disease area	breast (cancer or tumour OR malignant OR oncology OR carcinoma OR neoplas OR mass OR growth OR cyst).mp	415
2		(metastatic OR metastasis).mp	476
3		#1 OR #2	188
6	End-of-life care	(palliative OR end-of-life or terminal OR supportive).mp AND (care).mp	12,939
7		#3 AND #4	112

Source: A total of 1,350 abstracts from these 3 databases were systematically recorded in an Excel document, including relevant source information and abstract text. Of these, 38 abstracts were identified for full review based on relevant themes and content. These articles were fully reviewed and relevant content was highlighted as evidence in this section. Other articles were excluded based on limited access, content being irrelevant to supportive care for mBC patients, or duplication in search results. As this section was not meant to be a systematic literature review report, only the most relevant articles were included. Thorough examination of all abstracts allowed for the best selection of articles relevant to supportive care for patients living with mBC.

Limitations: Despite this systematic approach, limitations to this search methodology exist. Specifically, articles irrelevant for this section might have appeared in the search through selected search terms being used in different contexts. For example, if the search term was “mBC,” non-“mBC” could also appear. To account for this challenge, each abstract was reviewed to determine relevance and inclusion criteria. In addition, there is a potential risk of missing articles if the databases failed to capture all relevant articles in the space based on the search terms used. However, based on the credibility and number of databases, this limitation is unlikely to significantly impact the findings.



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