Barriers to Metastatic Breast Cancer Care in California

A report to the California Breast Cancer Research Program

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By:

AJ Scheitler, EdD

Riti Shimkhada, PhD

Susan Babey, PhD

Beth A. Glenn, PhD

Ninez A. Ponce, MPP, PhD

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STUDY PURPOSE

Metastatic Breast Cancer (MBC) occurs across the United States, but differences in health care systems, health insurance products, and population characteristics create state-level differences in the experiences of patients. While there are national standards and laws governing different aspects of care that MBC patients receive, there is still significant impact from state-level policies. Yet, despite the intents of these regulations, a 2017 study by this research team at the UCLA Center for Health Policy Research found barriers to care for breast cancer patients still exist, some exposing a disconnect between what *should be happening* according to state regulations and what *actually happens* for some women in the doctor's office (Ponce et al., 2018).

The purpose of the current study was to identify barriers faced by women whose cancer has metastasized, and to propose possible solutions for system or policy changes that can improve care for MBC patients. This report is a synthesis of information collected from listening to patients, clinical and non-clinical caregivers, published research, the grey literature, and Twitter chat.

KEY FINDINGS OF THE REPORT

Based on insights from the key informant interviews, the literature review, conference proceedings, and Twitter chat, the research team identified seven typologies for categorizing barriers to care for MBC patients: financial burden, insurance, barriers, disability insurance benefits, palliative care, clinical trials, communication/information barriers, navigation and support services, and social risk factors. For each barrier typology faced by women living with MBC we proposed the following policy recommendations to improve care:

Typology of Barriers	Policy Recommendation
Financial Burden	• Provide financial assistance for cancer treatment and support services to patients that need it • Support programs to improve financial literacy and financial planning to patients, with a special attention to patients in High Deductible Health Plans (HDHP) as they face the highest out-of-pocket costs for MBC care
Insurance Barriers	• Reimbursement for retesting of receptor status and genetic changes during course of treatment.

Typology of Barriers	Policy Recommendation
	• Improve prior authorization (PA) and step therapy (ST) processes for quicker turnaround time. Consider eliminating PA and ST for metastatic cancers given the special need for timely treatment. • Connect to all support services with one application
Challenges in Accessing Disability Insurance Benefits	• Provide financial assistance for co-payments and deductibles for specifically for teachers and contract workers and other occupations that do not pay into the state disability programs who are undergoing treatment for MBC • Improve disability insurance awareness and programs to help women with MBC apply for these programs
Lack of Access and Use of Palliative Care	• Provide referral and reimbursement for care teams to take the time to make patients aware of support services • Improve quality of life (QOL) reporting so patients provide routine QOL information to their care team • Improve awareness and encourage coverage for the coordination of palliative care and special programs such as Medi-Cal's home-based palliative care program • Investment in a comprehensive study into the degree of access to patient navigation among MBC patients in California and how it differs by insurance status, race/ethnicity, and geography
Access to Clinical Trials	• Cost assistance to MBC patients in clinical trials for travel and other costs associated with participation • Investments in programs to increase participation among African American patients in clinical trials
Communication/Information Barriers	• Improve communication regarding end-of-life care, including advance care directives • Adopt measures to improve geographic access to hospice care • Train and reimburse patient navigators to support women with MBC in their decision-making for treatment, support services, palliative care and end-of-life issues • Invest in programs that focus on cultural sensitivity and breaking down barriers related to mistrust

Typology of Barriers	Policy Recommendation
Navigation and Support Services	• Provide navigation services, including hotline and remote consultations to women newly diagnosed with MBC • Ensure navigation services are accessible by language and culturally appropriate
Social Risk Factors	• Include provisions in legislative proposals for groups with high social risk factors for the barrier/issue that the intended policy aims to address

INTRODUCTION

In 2019, 30,650 individuals were diagnosed with breast cancer in California, and 4,620 died from the disease (American Cancer Society, 2020). Metastatic breast cancer (MBC), which is also called stage IV or advanced breast cancer, is the cause of nearly all these deaths. Metastasis occurs when cancer cells from the original tumor in the breast break away and travel to other parts of the body, commonly the liver, brain, bones, or lungs. While some individuals are found to have metastatic breast cancer when they are first diagnosed with breast cancer (approximately 6% of diagnoses are "*de novo*" MBC), most individuals with MBC are those who experience metastasis months or years after the original breast cancer diagnosis and treatment. It is estimated that about 30% of women diagnosed with early-stage breast cancer will go on to develop MBC. Five-year survival for MBC is only 27%, compared to 91% for breast cancer that has spread regionally and 99% for localized breast cancer (American Cancer Society, 2020). Treatment for metastatic breast cancer includes aggressive combinations of chemotherapy, radiation therapy, surgery, and immunotherapy, depending on the biology of the cancer cells, where the cancer has spread to, and prior treatments. Prognosis and treatment is highly dependent on the invasiveness of the tumor, but also the presence of hormone receptors (estrogen and progesterone) and the cancer cell's expression of the HER2 (human epidermal growth factor 2) protein (Peart, 2017). Individuals with HER2-positive breast cancer have a median survival time of over 3 years, but for individuals with metastatic triple negative disease (no estrogen or progesterone receptors and no excess HER2 protein) median survival time is only less than 1 year (Hao et al., 2015; Waks and Winer, 2019).

To understand the barriers to care that may impact quality of life for MBC patients in California, we engaged in five tasks: 1) to interview patients as well as clinical and non-clinical providers, 2) learn from key informants through MBC-specific conferences and 3) social media, and conduct a 4) literature review and 5) legislative review.

TECHNICAL APPROACH

TASKS 1 & 2: KEY INFORMANT RECRUITMENT AND INTERVIEWS

An important aspect of this project is to gain an understanding of barriers to metastatic breast cancer care in California from the perspective of patients, as well as clinical providers (i.e, physicians, nurses) and non-clinical providers (i.e. patient educators, support service providers). We conducted semi-structured to understand the experiences, perspectives, and recommendations from these key informants. The research team utilized multiple channels for participant recruitment. Drawing on existing relationships with organizations such as Susan G. Komen Foundation, Every Women Counts, and the Breast of Us, we started with a purposeful sample focused on soliciting insights from stakeholder organizations/groups. Then we relied on respondent-driven sampling (referrals) to achieve our target sample. These groups included breast health educators, on-site clinic workers, patient navigators, and individuals involved with support groups. Additionally, we attended a conference for MBC patients and providers to gain insights on the timeliest topics for this population, interact with stakeholders, share information on the study, and recruit participants for key informant interviews. The final protocol for stakeholder interviews can be found in Appendix B.

The semi-structured interviews were designed to assess barriers across the continuum of care for breast cancer that has metastasized. Patient participants were asked to share their personal experiences, and many also noted issues they were aware of that happened to other patients that they knew. Clinical and non-clinical provider respondents were asked to describe how the experience of obtaining care may differ based on insurance status – uninsured, underinsured, or privately insured. Interview transcripts (Appendix B) were initially coded in two rounds, by two separate researchers, who then consolidated codes and came to agreement on analysis.

Between January and March 2020, we interviewed 12 patients, 3 clinical providers, and 7 non-clinical providers. Among the patients, the oldest was 71 at the time of MBC diagnosis, and the youngest was 37. The number of years living with MBC ranged from 1 to 9 years. Patients were enrolled in private insurance, Medi-Cal or Medicare. Three patient participants also participated in non-clinical provider roles, leading support groups or becoming advocates (they are counted as patients only). Patients, clinical providers and non-clinical providers represented northern, central and southern California. The three clinical providers were a breast surgeon, a surgical oncologist, and an oncology nurse. One clinical provider was also an MBC patient, but categorized as a provider in this study.

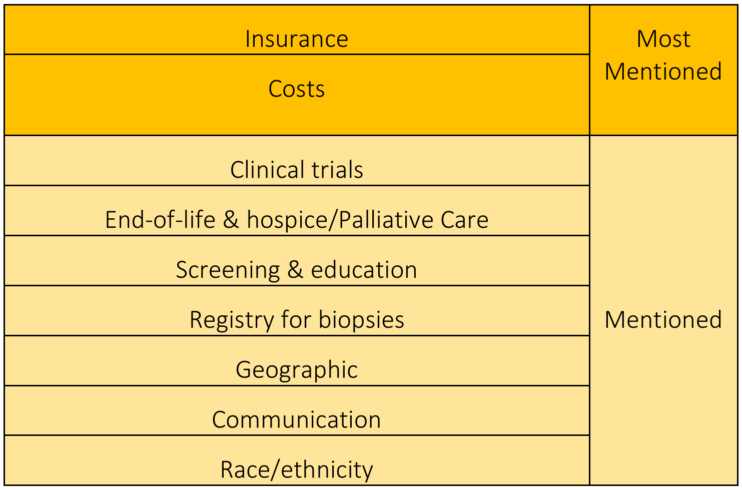
TASK 3: MBC CONFERENCE PARTICIPATION

On January 4, 2020, some members of the research team attended the 7th Annual Metastatic Breast Cancer Conference in Los Angeles, organized by the Susan G. Komen Foundation. We were invited to have a table to share information about our past research on breast cancer as well as conduct participant recruitment for this study. We attended several of the sessions, interacting with participants and gaining knowledge on the major themes that contributed to this report. We listened to a diverse group of researchers, advocates, service providers, and health care leaders discuss emerging news and issues impacting MBC patients, and share ideas for future work to improve care. We recruited some of our key informants from this event.

TASK 4: LITERATURE SYNTHESIS AND LEGISLATIVE SCAN

We conducted a narrative synthesis review of the recent evidence on the barriers to MBC and policy solutions, with a special attention to California. As part of this review, we included peer-reviewed literature and non-peer reviewed sources. For the peer-reviewed literature, we searched for articles in English and based in the U.S. published in 2015 to 2020 indexed in PubMed. We examined articles with keyword terms: metastatic breast cancer, barriers to cancer care, and breast cancer policy in the U.S. We further sought to find a subset of articles specific to barriers faced by MBC patient in California and policy solutions. For non-peer reviewed material, we examined Google News Archive for material related to MBC barriers to care. Our literature scan of the recent findings (2015-2020) on the barriers to breast cancer care and potential policy solutions yielded a set of 799 articles. From this set of articles, we looked for work specifically mentioning MBC treatment, management and care coordination, and end of life care (Appendix C), which yielded a subset of 85 articles that included any discussion of barriers to care specific to MBC In our discussion section of this report, the bulk of articles cited are from the subset of articles on MBC, but in some cases we have drawn from the larger set of articles on breast cancer barriers in general where publications on MBC specifically were not available. Only 7 articles in this timeframe were specific to a California population of patients with breast cancer, none were specific to MBC. A heat map of the topics/themes mentioned in the articles is shown in Figure 1.

Figure 1. Literature Synthesis Heat Map of Most Occurring Topics Mentioned in Articles Published 2015-2020



Insurance	Most Mentioned
Costs	
Clinical trials	Mentioned
End-of-life & hospice/Palliative Care	
Screening & education	
Registry for biopsies	
Geographic	
Communication	
Race/ethnicity	

Social Support	
Navigator	Least Mentioned
Language	
Health Literacy	

In addition to the literature review, we conducted a legislative scan (Appendix D). We searched for proposed and introduced legislation at the state level in California (using http://leginfo.legislature.ca.gov) and other states, as well as the federal level, that address barriers to breast cancer care. We recorded bills from the following California legislative sessions: 2016-17, 2017-2018, and 2018-2019. We also found older bills from other states and documented federal legislation addressing MBC.

TASK 5: TWITTER CHAT

Partnering with the Breast Cancer Social Media (#bcsm) community on Twitter, we gathered data on key barriers to care and potential policy solutions for patients with metastatic breast cancer (MBC) during a Twitter chat in November 2019. Online patient communities are a valuable source of timely and real-world data, which can be used to inform policy change. The #bcsm online community has hosted weekly Twitter chats since 2011. Topics vary each week and chats draw a diverse group of participants. Based on the literature review, and consultation with the #bcsm facilitator, a breast surgeon, we developed five questions for a chat specific to MBC care barriers and potential policy solutions for a moderated chat on November 18, 2019. These questions were:

1. What are some of the most significant healthcare communication barriers faced by patients w/metastatic breast cancer?
2. What are the palliative care barriers faced by those with metastatic breast cancer?
3. What are the financial challenges faced by patients w/metastatic breast cancer?
4. What are barriers to obtaining disability insurance benefits?
5. What health system or policy changes would you suggest to improve the care experience for patients w/metastatic breast cancer?

The five questions were posed during the course of the one-hour Twitter chat using the #bcsm hashtag. There were 41 participants on the public #bcsm Twitter chat on MBC barriers to care and policy solutions on November 18, 2019. During the course of the chat, there were 277 tweets from the 41 participants, generating 2.1 million impressions (i.e. the total number of times a Tweet appears in users' Twitter feeds, reflecting the number of Tweets using the #bcsm chat hashtag, the number of participants liking or retweeting Tweets, and the total number of followers of the moderator and participants during the chat). Participants included 23 patients/advocates, 7 doctors, 6 representatives of advocacy organizations, and 5 researchers/academics (Appendix E). We used Symplur^{TM} analytics to generate a transcript of tweets and a demographic profile of participants. We present the Tweets from the chat that were responses to each of the questions (i.e. no retweets or off-topic entries are shown in the table of results presented in this report) (Appendix E).

FINDINGS

The research team organized insights from the key informant interviews, the literature review, conference proceedings, and Twitter chat, into the following typologies:

- Financial Burden
- Insurance Barriers
- Disability Insurance Benefits
- Palliative Care
- Clinical Trials
- Communication/Information Barriers
- Navigation and Support Services
- Social Risk Factors

Below, we characterize each typology based on the literature review, key informant interviews, conference proceedings, and Twitter chat.

FINANCIAL BURDEN

The high costs of cancer drugs and the subsequent high out-of-pocket costs for patients facing cancer is a common theme in the literature (Irwin et al., 2016; Leopold et al., 2018; Prasad, 2017; Prasad et al., 2017; Reyes et al., 2019; Rosenzweig et al., 2019; Samuel et al., 2020; Trogdon et al., 2020; Williams et al., 2020). Apart from the high finincial burden of treatment, the literature docuents a high economic burden of end-of-life care (Bramley et al., 2016). Costs of treatment and the potential for financial toxicity due to treatment costs are recognized as difficult considerations in patient and provider decision making about treatment (Rocque et al., 2019; Rosenzweig et al., 2019).

At the intersection between race/ethnicity and financial burden, a recent study found women of color were more likely than their non-Hispanic White counterparts to report adverse changes in their employment status due to MBC (Samuel et al., 2020). Stopping treatment was the most commonly reported cost-management behavior among patients of color, while using savings and skipping a vacation were most commonly cited among non-Hispanic Whites. More research is needed to further elucidate associations between race/ethnicity, employment, and changes in work among MBC patients to identify strategies for addressing the disproportionate burden of work discontinuation and other adverse effects of treatment on employment among persons of color with MBC.

Young women often face more aggressive MBC and in studies examining costs of care, researchers have found young women with MBC had higher medical costs than comparable women with earlier-stage breast cancer at all ages, with the highest costs occurring during continuing and terminal phases of care (Trogdon et al., 2020). At the end of life, young women may have a higher preference and willingness-to-pay for more aggressive and additional treatments for extra months of life than for older women. However, the high financial burden of the cost of treatment and continued care may also be more problematic for young women who are often mothers of young children and may also be dealing with financial difficulties for the household due to job loss from the treatment and must make financial sacrifices (Han et al., 2020).

As such, the Centers for Disease Control and Prevention (CDC) authorized the EARLY Act to conduct research and develop initiatives to advance understanding and awareness of breast cancer among younger women. There do not appear to be any federal or state legislation or policy with an orientation to addressing the substantial financial needs of young women with breast cancer.

In our key informant interviews, MBC patients expressed significant concern over the financial implications of MBC, which involve not only issues of costs of treatment – impacted by insurance - and accessing services, but also costs for family care (if a patient needs household help during treatment), transportation to appointments, and childcare during treatment. The financial impact is also felt in their income. MBC has significant impacts on a patient’s ability to work; when employment is impacted, there are implications for insurance access and possible moves from employer-sponsored insurance to COBRA, the exchange market, or a public program. There is also confusion regarding the role of disability insurance for these patients. Additionally, given the longevity that many of these patients are now experiencing, long-term coverage and expenses add additional stress.

COSTS OF TREATMENT/MEDICINE

A major theme at the MBC conference was the cost of drugs and treatment. Costs cause significant barriers for care, and in the MBC population, it's a long-term barrier. One provider respondent summed it up:

> "I think financial barriers are across the board, but more so for patients living with stage four advanced disease because they are in treatment for longer. Treatment can be expensive, even with insurance."

Patients note cost is a top concern, but not all are lucky to have someone help them understand how to financially plan for the long term.

> "The drugs are extremely expensive. Initially with my original doctor, I was told -- because that's the first thing that comes to your mind, 'How am I going to be able to afford to have this disease?' I was reassured we have somebody in the office here whose job is to help you."

One provider not only sympathized with patients dealing with the costs of treatment, but also offered a warning that the issue interferes with care in other ways:

> "Well, if you're uninsured, you just can't afford a couple thousand dollars a month for a month's supply of pills. You just can't. Then, the treatment team, I guess, has to make the decision, 'Well, we can't go with standard of care because the patient can't afford it. Do we have to resort to our second- or third-line chemo?'"

Respondents also reaffirmed that affordability is not an issue exclusive to the uninsured or underinsured:

> "Again, even for the insured patient, if you've got -- depending on what your deductible is or your out-of-pocket maximum or maybe this isn't -- this drug may not be going towards your deductible or something like that. Maybe your copay for the meds is a couple hundred bucks or something like that. That's a problem."

Patients may try creative solutions to address what they know is an issue for themselves and others with an MBC diagnosis. One non-clinical provider shared an idea presented to her – create an exchange for unused medications to be shared with others. The respondent was well aware that would be illegal but understood the intention behind the idea.

> “I see what (she’s) saying in that. She's like, ‘We can't afford to buy our own. If people aren't using meds or if there's a way for us to have access to meds that are discounted, a repository of some sort, where is it?’”

COSTS OF INSURANCE (PREMIUMS, DEDUCTIBLES, CO-PAYS, REACHING LIFETIME MAXIMUM)

A patient’s insurance status impacts their economic outlook; however, the coverage does not equate to no expenses.

> “As far as receiving treatment, again, it goes back to financial barriers -- not being able to take time off to go get your treatment or not having the funds to provide the co-payment or co-insurance, out-of-pocket expenses. All of that has always and I think will continue to be a barrier until something can be done about it.... It always boils down to finances. I think it's one of the biggest especially in this county where it costs so much to live here.”

> “And the job I have now is the job I got it that time, and it's a full-time job. It does have a health plan, but it's very expensive because I work in nonprofit, so it's not the most, you know, robust plan, but I had to pay for the most expensive PPO. I was able to get in my plan, and it's got like -- you know, I still have to pay premiums about $83 every paycheck that's twice a month, and then, my out-of-pocket maximum is something like 5,000 or 6,000, which I need in the first two months of the year.”

Access to insurance also influences a patient’s efforts to attempt to keep working, which may not be the best decision given their treatment needs.

> “So, for many of our patients, you know, their insurance is through their job. And so, if they lose their job, they lose their insurance.”

INDIRECT COSTS (NON-MEDICAL) ALSO ADD UP

One patient respondent was very pointed about the financial outlook for MBC patients whether or not they had insurance coverage.

> “This is a very expensive disease, and some people will do the best that they can, but they're looking at financial ruin at the same time, and that's just horrible. They should not be looking at financial ruin because even if your healthcare is basically covered, there're always aspects of it that aren't right?”

We heard from all key informant groups about the associated costs of care that are not covered by insurance, including child care and transportation expenses incurred during treatment and support group participation, and other needed assistance at home. Many patients also experience lost wages from taking time off work for treatment or needing to reduce the amount of time they work.

> “It's a three-and-a-half-hour drive. That's a big, long journey going and coming or an overnight. The stress that puts on the patients -- I see them as barriers because not everybody has gas money, not everybody has a family member that could drive them and support them other while they're going for their treatment.”

> “So, transportation, and by that I'm including having to travel a long distance for treatment -- which will require not only time, but also gas money, and then also sometimes the vehicle if someone doesn't have access to their own car. Once they get to the system, parking, which for many patients is very challenging and also very expensive, and often they benefit from having valet parking, which is more expensive because they may not feel like they can walk a long distance to the parking garage. And then time. So, I would say, transportation is a big bucket, and then the other is time, and the loss -- potential loss of wages associated with having to take time to come for treatment.”

One provider respondent noted that her practice had, at times, bent some rules to help mothers, knowing that would not work in all settings:

> “All of my staff are moms and especially if you bring in a baby up to about four, they’re all over it. It’s fine, but that’s not going to work in all offices, especially we try and run it. We’re like a private practice, but you come to one of the campus clinics, it’s not going to work. The staff is not allowed to babysit the patient’s kids. I think they’re just -- staff has rules.”

Some patients and providers are aware of organizations that will assist with transportation services but note that it has limits. These are often provided by volunteers, and in areas with a lack of local providers, the distance needed to access clinics make these services prohibitive. Some suggested that the service needed to be expanded to include coverage for overnight stays in cases where patients drive themselves and cannot drive post-treatment or would need to be back at the same location the next day for additional care.

INSURANCE BARRIERS

Financial burden of MBC is intertwined with insurance coverage. Type of insurance is highly related to the out-of-pocket costs, namely insurance coverage in high-deductible health plans (HDHP) (Leopold et al., 2018; Lu et al., 2018; Wharam et al., 2018). In a study on women with MBC in HDHP plans, out-of-pocket spending was 55% higher in HDHP plans compared to employer-mandated health plans with low deductibles (Leopold et al., 2018). Modest cost differences were found in adjuvant hormonal therapy use for breast cancer in HDHP plans in another study (Lu et al., 2018) and another study found that women who switched to HDHPs experienced delays in diagnostic breast imaging, breast biopsy, early-stage breast cancer diagnosis, and chemotherapy initiation (Wharam et al., 2018). Insurance status also impacts access to chemotherapy, guideline-concordant treatment, and access to support services (Accordino et al., 2017; Charlson et al., 2017; Enguidanos et al., 2019; Han et al., 2018; Hoe et al., 2019; Leopold et al., 2016; Leopold et al., 2018; Lu et al., 2018; Mahal et al., 2020; Nattinger et al., 2017; Poorvu et al., 2018; Sabik et al., 2020; Vyas et al., 2020; Wharam et al., 2018; Williams et al., 2019; Yu et al., 2019).

In addition, research suggests type of insurance impacts survival. For example, a recent population-based cohort with over 25,000 patients diagnosed with *de novo* MBC found that insurance status and geographic region were strongly associated with death within the first month after diagnosis (Vaz-Luis et al., 2017). Odds of death at 1 month for uninsured patients was 3.24 times higher compared with insured patients, and 1.49 times higher for Medicaid patients compared to privately insured patients. Authors stressed the findings support the need for sustained efforts focused on equitable treatment in access to care, quality of care, and insurance coverage given the disparities in mortality by insurance status and geographic region of residence.

Key Informant interviews found insurance barriers across the spectrum of insurance; women with private insurance, those who are underinsured, and those on public programs all still experience issues that impact their care.

> “People who have no insurance or people who have insurance but still have barriers either to using it or affording it whether that's co-pays or premiums, location of facilities that are covered by their insurance and access to those locations, transportation, all sorts of things. It's a much broader, larger group. A lot of people tend to think when we say uninsured, underinsured, low income but it really is across all income levels that underinsured population falls into.”

> “With employer-sponsored benefits, one of the hardest things for us here to find resources and support are for patients who have been diagnosed with advanced metastatic breast cancer and don't work at companies where things like disability or the ADA and things like that come into play. Small businesses where there's seven or less employees, those kinds of things where it's not required for employers to carry those types of insurances, their coverage’s.”

For patients enrolled in Medi-Cal or Covered California, provider networks are limited, in part due to low provider reimbursement rates. One clinical provider in the study, who is also an MBC patient, shared her perspective on the ACA’s impact on providers:

> “That is part of the challenge with the Affordable Care Act is it was advertised as you get to keep your doctors. I know a lot of us doctors were like, “If you want our opinion, that’s actually a lie because we see the rates that you’re going to pay and they’re crappy and you’re just going to decide not to take those plans.”

PATIENTS NOTE DIFFERENCES BETWEEN HMO AND PPO

Respondents had a mix of insurance types, and a corresponding mix of experiences with insurers. Some patients felt their experience was better with insurance coverage through a PPO while others thought their HMO experience was better.

> “Now I'm in a PPO, so if there's a study and I don't have access to it through City of Hope, then I could go somewhere else. I'm no longer trapped in a closed system.”

> “I was blessed enough to have the PPO where I knew that it wasn’t going to cost me thousands of dollars to go to a second opinion. Those kinds of things would have been horrific for somebody who’s not just older, but also doesn’t have a PPO, then you’re really in a waiting game and letting it grow.”

> “I honestly think that I had a little bit -- I'm not sure I think I had a better experience through Kaiser because with Kaiser there's not the fight between the hospital and the insurance provider. With Kaiser, if your doctor says you need it Kaiser pays for it. Over here if the doctor says you need it, Blue Cross wants to ask questions.”

LACK OF COVERAGE FOR ORAL CHEMOTHERAPY

Depending on the type of MBC, oral chemotherapy can be an option instead of intravenous chemotherapy. Oral chemotherapy provides patients with more convenience, less time in the clinic, and allows physicians to more easily tailor therapy dosing if needed compared to IV chemotherapy (Martin et al., 2017).

A number of states in the US have enacted oral chemotherapy parity laws to limit out-of-pocket costs in line with IV administered drugs. In 2018, California Assembly Bill 1860 capped patients' out-of-pocket costs for oral chemotherapy to $250/month per drug. However, some recent research suggests that despite these types of state mandates, oral chemotherapy this study finds that oral oncology parity laws may not have consistently reduced out-of-pocket spending for all types of endocrine therapy (Chin et al., 2019; Dusetzina et al., 2018; Winn and Dusetzina, 2019). Research by the American Cancer Society's Cancer Action Network also suggests coverage for newer oral chemotherapy agents may be limited (American Cancer Society. Cancer Action Network, 2014).

It is unclear if access to oral chemotherapy for individuals with MBC in California remains a problem, thus warrants further investigation. It is also unclear if side effects and careful dosing required for oral chemotherapy is adequately communicated to patients considering oral chemotherapy.

However, clinical providers and advocates noted that oral chemotherapy is sometimes not recognized as chemotherapy by insurers and as a result may not be covered to the same degree as traditional chemotherapy.

> "Insurance is still an issue, so part of the challenge is insurance companies don't always recognize oral chemotherapy as chemo. A lot of times, there's coverage issues for oral agents…. These are all new agents, so the costs are just obscene."

According to our key informant interviews, advocates are working to change coverage rules for oral chemotherapy, which is not always currently covered at the same level as traditional chemotherapy. One advocate working on this issue at a federal level noted that there are inconsistencies between state and federal policy that need to be addressed:

> "We are lucky in California to have already passed all parity, but on the same token, since it's not at the federal level, anybody who has ERISA-regulated insurance…[that is] anyone who works for the federal government or has federally-regulated insurance, that is not a requirement."

One clinical provider emphasized the need to expand on this type of coverage as treatments advance: “Again, because I’m not the one dealing with this on a day-to-day basis, but the whole issue of oral chemotherapy agents being recognized differently than IV chemo by insurance and a different authorization process and a different copay structure and all of that, that’s huge because the trend of oncology is towards a more targeted therapy, more biologics, and more oral agents.”

“Policy changes could make oral chemo caps that are more encompassing to all insurance coverage and all plans versus. I’m fortunate the American Cancer Society on oral chemo cap legislation at the state level has passed, but again, does not cover all insurance. Any cost containment for the metastatic patient is, I think, a welcome lease for those who are struggling with barriers to finance [treatment].”

INCONSISTENT SOCIAL SUPPORT AND MENTAL HEALTH BENEFITS

Respondents noted differences in covered services, and therefore experiences and expenses, among different plans.

> “There are some insurance companies that will offer some support services like limited transportation or different discount programs and things like that. Even things like mental health coverage, someone could be fully insured for their oncology care but mental health services or psychology, counseling, therapy, those types of things wouldn't be covered.”

One non-clinical provider respondent amplified the importance of mental health services, noting that financial concerns were second to emotional concerns among MBC patients her organization served. A respondent engaged in non-clinical services felt that mental health care was often seen as “fluff” and not covered for patients.

Another provider also acknowledged the need for mental health care:

> “I think it starts with the metastatic patient and their doctor whether it's the oncologist or general practitioner or both saying what things can not only help me stay alive but will help decrease this ongoing anxiety that I have because there is no metastatic patient that has not experienced anxiety, that’s 100% guaranteed. Nobody faces a death diagnosis and says, “Oh, that’s really great. Let’s go have lunch.”

> “Yes, social services, first and foremost, psychosocial support, because every single metastatic patient has anxiety of some level and concerns about death and life and treatment and everything that goes around the diagnosis. This is something that is hugely ignored whether it’s depression in some patients.”

DESIRE FOR ACCESS TO HOLISTIC THERAPIES

Some respondents expressed frustration that holistic treatments are not always respected by providers and support services, and many are not covered by insurance.

> “Then when I went recently back to the holistic treatment, cancer went inactive again. So, I don’t want to stop these treatments, so I’ve been working on decreasing them by a little now, but there is a big question on finances considering insurance not covering everything and being costly over time.”

This issue may also factor into a patient’s decisions regarding employment. They may not want to lose coverage that would cover these services; and if the services are not covered, they may need increased income to afford paying out of pocket.

> “Some of them have to look at things like early retirement and permanent disability versus temporary disability and leave from work. That affects their overall income and their ability to afford not only their treatment but a lot of the complementary treatment or alternative therapies that really help sustain them and allow them to continue their treatments.”

TRANSITION TO MEDICARE

As MBC patients approach retirement age or need to leave the workforce, they transition to Medicare. Among our respondents, many women have done this, or anticipate doing this, although feedback from respondents suggests it can be challenging to accomplish without disrupting care.

> “There is a wait time right now for Social Security and Medicare, six and 24 months,” noted one respondent. “Again, MBC patients in particular don't have time to wait during that wait period for those benefits to kick in.”

> “For transitioning to Medicare, one thing I never even knew that I would be qualified for Medicare. Nobody told me until -- one thing is my disability is not for social security disability, but I was a teacher, so I am under the California Teacher’s Retirement Disability System. But then, when my husband was about to turn 65, we attended a seminar considering Medicare.”

PRE-EXISTING CONDITIONS NEED TO BE COVERED

Some patients and providers mentioned the importance of insurance plans continuing to cover pre-existing conditions. They noted that if insurance plans don't have to cover pre-existing conditions, many other barriers are exacerbated, particularly cost-related barriers.

> "…oh my gosh, pre-existing conditions -- I'm sorry -- because that's a huge fear for a lot of people after they've been diagnosed and if they are not able to work anymore and they need to go on COBRA or get their own insurance separately. That's always a giant fear. If those protections aren't available, then they would be susceptible to higher premiums and all these other things we talked about that are already barriers. It would just heighten those. The ACA is really great in those protections."

> "I'm watching so many political ads now and they keep talking about pre-existing conditions and it has to be that you could have a pre-existing condition and get good insurance. There should be no barrier to that. Actually, the first time around and then I went off on my own as a consultant. My insurance, first they wanted to double it for what everybody else was paying. Even though at that time, I've been, I think, 10 years cancer-free. I talked them out of it, but I talked them down until I'm 50% more instead of doubling it, but the fact that I have to do that is crazy."

PREAUTHORIZATION REQUIREMENTS, APPROVALS AND REJECTIONS

Patients overwhelmingly expressed frustration with the insurance system, particularly the need for pre-authorizations and the time to appeal some decisions. Much of the literature and responses from our Twitter chat and interviews focused on the barrier prior authorization poses in timely access to treatment (Agarwal et al., 2017; Lin et al., 2018; Wallace et al., 2019). Not only do these processes cause delays, but the process is very time consuming and anxiety-inducing.

> "It makes it very difficult to fight for your life and be well. I trust that if a drug has been approved for Stage 4 cancer, and an oncologist wants to use it on me, we should just get it, but that's not how our world works. Oncologists have to go through hoops to get the drugs they want on me, and doctors didn't go to medical school to sit around doing prior auths (authorizations)."

> "And it's because the whole process of when the physicians give you that notice that you need this test or you need this treatment, it could be basically on that

> spot or immediately, and there is no way that that paperwork, and that whole process would be able to allow the insurance company to give you "immediate authorization" that they'll cover it. And these are the things where I think that is a huge barrier for us who are already under such stress trying to get treatment to be well, and from the financial point of view because of this whole entire process takes so long, you're uncertain for that time, and perhaps you'd be denied treatment.”

There’s also a feeling among patients that insurance companies are predisposed to decline authorizations. Patients highly recommend to others that they take a strong self-advocacy position and be ready to stay on top of providers to move schedules along, as well as be prepared to fight with insurance companies over authorizations and payments.

> “I would encourage everyone when something is rejected to contact their insurance company.”

DISABILITY INSURANCE BENEFITS

Disability insurance can be an important source of financial assistance for individuals undergoing cancer treatment. In 2019, at the federal level, The Metastatic Breast Cancer Access to Care Act was proposed to waive the five-month wait before someone with breast cancer could access Social Security Disability Insurance (SSDI). The bill has not moved forward as yet but could be a step forward for those who pay into the SSDI.

In our review of news articles related to breast cancer barriers, we found an article from 2019 in which public news station KQED reported on a teacher at the San Francisco Unified elementary school who was on extended sick leave for treatment of breast cancer and had to pay out-of-pocket the full cost of her own substitute, which was nearly half of her paycheck (McEvoy, 2019).

Our patient respondents spanned a spectrum of insurance status, including women who had already made a transition to Medicare or knew that they would have to make the move at some point during their care. There was expressed frustration on the process of that transition and the requirements for Medicare qualification. There is a sentiment that patients should not have to already be in poverty before you can get assistance.

> “We know that at some point in the future, I'm going to end up not able to work and needing to go on Medicare. What else we know is that when you lose your employer's health coverage, you have to figure out how you're going to pay for two years of coverage before Medicare will pay. First and foremost, I think it's a problem that Medicare requires you to be the one to figure out how to pay for

> your health insurance for two years before you can qualify. That is not okay that they're just like, ‘Too bad, so sad. You still have to pay two years of medical insurance before you qualify.’ I think a metastatic diagnosis should immediately qualify you for Medicare.”

> “When diagnosed, I had my work insurance, and then it went under my husband. I quit my job immediately and went on disability and was on my husband’s insurance until a year ago.”

One non-clinical provider noted that her organization struggled to assist women who were not in a position to take advantage of some protections.

> “With employer-sponsored benefits, one of the hardest things for us here to find resources and support are for patients who have been diagnosed with advanced metastatic breast cancer and don't work at companies where things like disability or the ADA and things like that come into play. I can think of three individuals here in San Diego that we know of at least who have employment and have benefits to their employment but cannot enroll in disability because of their diagnosis through their employer because they don't have to comply with ADA and things like that. Social Security, disability and SSI and all those things aren't always available even if you do have employment.”

Twitter participants respondents noted:

> “Big barrier to getting disability is the patient doesn’t know the process of applying if employed, small companies don’t know what to do.”

> “[Regarding] disability I've also seen some tweets from patients that if they apply for medication financial assistance program that can limit their disability... doesn't seem right”

> “There are lots of people who are contract workers (especially in high tech). They don’t have disability insurance as aren’t aware of state disability.”

PALLIATIVE CARE

A critical area affecting women with MBC and where there appears to be lack of awareness, is in palliative care (Enguidanos et al., 2019). Palliative care, which includes pain management, psycho-oncology, social support, nutrition, legal support, functional rehabilitation, and end-of-life care, addresses many of the needs of metastatic breast cancer patients (Bergqvist and Strang, 2017; Cherny et al., 2018; Enguidanos et al., 2019; MacDonald et al., 2019; Thrift-Perry et al., 2018).

In 2018, California enacted SB 1004, which required Medi-Cal managed care providers to offer home-based palliative care to seriously-ill patients. However, enrollment in the program has been lower than projected. In a study of clinician-perceived barriers to access to palliative care by Medi-Cal patients, researchers found lack of physician knowledge, challenges in providing education about palliative care to patients, cultural and language barriers, lack of time, and competing demands of physicians (Enguidanos et al., 2019). Providers also identified patient-related barriers, including cultural barriers, mistrust regarding the health-care system, lack of social services meeting needs, such as adequate and safe housing. Based on these findings, Enguidanos et al (2019), call for an increase in physician education and awareness of palliative care and the home-based program available to Medi-Cal beneficiaries. They further note the need for culturally appropriate services and a need to develop programs that improve health literacy.

Misconceptions around palliative care were also discussed extensively at the MBC conference, and revealed in the key informant interviews. Conference attendees felt education programs should promote palliative care among providers, insurers, and patients as a valuable part of treatment to help management of pain and symptoms associated with MBC.

Palliative care was also discussed by interview participants. The first issue noted with palliative care was the lack of understanding about what it entails. Several respondents either equated it to hospice or end-of-life care or noted that providers and insurers treated it as such. Some patients viewed palliative care as equivalent to hospice/end-of-life care:

> “Well, I heard palliative and I thought this is the next thing to hospice where I'm going to die.”

One non-clinical provider sees wide-spread misunderstanding among the patients she works with:

> "Again, it goes back to lack of knowledge and fear. People, when they hear palliative or even hospice care, they're freaking out already. Your brain automatically goes to end of life and that's scary for people. I don't know what the solution is to remove the stigma around it. I think it goes back to storytelling again and just being proactive agents and hospitals being proactive and sharing stories of success around palliative care and what that means or even sharing the information early on as part of the toolkit for oncology, of informing patients and what their resources are, even if they're not faced with that at the moment, at least planting the seed of what could be potential resources for folks if things progress and get worse."

MBC patients often have to deal with nausea, pain, fatigue, so they should have access to the palliative services that can address these problems. Among those who understood that palliative care was intended as a way to help manage symptoms and pain associated with MBC, their experience being connected to such services was inconsistent. One respondent noted that while she was on private insurance the company contacted her about getting coordinated palliative care. Yet when she transitioned to Medicare she did not receive any such outreach.

And patients who actually had palliative care integrated into their treatment reported positive experiences:

> "I have a palliative care team … and I had a really rough chemo for my Stage 2 chemo, and they were amazing. Not just because they were helpful with the symptoms, but they were helpful for me thinking about quality of life."
>
> "So Palliative Care is super, super important. I know they're trying to play with the language calling it "supportive care", whatever, because palliative feels too close to hospice, and then people get nuts about it. They just get nuts about it, and that I think is another challenge with all of this."
>
> "First and foremost, the physician and patient both understanding that palliative care is not hospice only, that palliative care can be pain management and should be pain management, physical movement, relaxation, quality of life, anxiety reduction, all kinds of things aside from hospice."
>
> "And so, I would say the biggest barrier is honestly physician referral. And I say that from the bias of a surgical oncologist who -- in my training, I often had experiences where I was called to come and see a patient who -- I am called to see a patient who is at the end of their life. They're on some type of systemic therapy for metastatic treatments. And they end up being called -- we're called to

> see them because they have some new surgical emergency whether it's free air from a bowel perforation or what have you. And so, we find ourselves as a surgical consultant team having to say, 'actually, this is the end. It is not appropriate to offer surgery in this situation.' And we're engaging in conversations that I wish had been done much earlier in the process. And that is done by doctors who knew them, and instead I'm doing as someone who doesn't know them very well as meeting them up for the first time. So, I would say that the biggest barrier I've observed patients getting palliative care and hospice is often related to clinicians not making referral, you know."

CLINICAL TRIALS

Significant discussions at the MBC conference involved participation in clinical trials. The message was that there needs to be improved connections between patients and clinical trials. A first step is simplifying the main database for identifying trials (clinicaltrials.gov.com). A second step is encouraging study leaders to include more MBC patients. There are calls to improve research on survivorship as well. These same themes were echoed in the literature and from key informants in the social media conversation and the one-on-one interviews.

CLINICAL TRIAL PARTICIPATION

The expanded treatment options that are available through clinical trials are crucial for patients with MBC as clinical trials have become part of modern oncology practice (Santa-Maria and Gradishar, 2015). We heard from all respondent groups that there is significant interest in trials, but there are many barriers to actually getting connected with appropriate opportunities for participation.

EXISTING RESOURCES IMPEDE ACCESS

Of the number of barriers to clinical trial participation faced by patients, awareness may be an important one and one where health care providers can play an important role (American Cancer Society. Cancer Action Network, 2018). Most patients expect their providers to be knowledgeable regarding clinical trial opportunities and expect them to provide guidance and serve as their primary source of information with respect to eligibility criteria and other clinical trial information. Most (66%) cancer patients who have participated in clinical trials report having initially learned of their trial through one of their providers or via the research staff compared to only 6% who learned of their trial through a patient advocacy group (American Cancer Society, Cancer Action Network, 2018). The American Cancer Society, Cancer Action Network (2018) report also found women advised by their provider to participate in breast cancer clinical trial were 13 times more likely to participate compared to those advised to not participate.

Respondents in all categories expressed significant frustration in connecting with appropriate trials that may help them. If a patient attempts to seek out trials on their own, a lack of health literacy is a barrier. But even those who felt they have a good knowledge of what to look for in a trail relayed that the main portal for identifying trials is not user friendly and requires too much time to navigate. Said one respondent: "Services that are available for clinicaltrials.gov.com and all those types of things can be really hard to navigate for a patient."

To emphasize the point that there is a lack of a reliable, central resource to assist MBC patients and their caregivers, the Susan B. Komen Foundation has a helpline to assist with this very issue. However, only one respondent to this study was aware of its existence.

NOT ACCESSIBLE

Trials are also not wide-spread, and therefore unavailable to those who live outside a service area and lack the resources to travel. One respondent, who acknowledged that she was lucky to have the resources to travel, literally flies from California to Boston to access an appropriate trial.

> "For someone, if they have exhausted their treatment options and haven't had good success with standard of care, right now clinical trials are always a great option but they're not always local. Being able to access those, whether it's traveling just to a different county or whether it's a different state or even across the nation, that is a huge barrier and that's something especially for people living with advanced breast cancer who've been told they're terminal and these are their only options."

CONFUSION ABOUT PARTICIPATION AND THE INTERSECTION WITH INSURANCE (WHO PAYS FOR WHAT?)

One major step forward in encouraging clinical trial participation was the Affordable Care Act's (ACA) mandate requiring most private health insurers to cover routine patient care costs for cancer clinical trial participation. A study of cancer research centers and community based treatment centers found that despite the ACA's mandate, insurance denials for clinical trial coverage persisted after the enactment of the ACA (Mackay et al., 2017) In spite of this legislation, respondents who had participated in clinical trials reported experiencing confusion regarding whether care would be covered by the clinical trial, their insurance, or out of pocket. One patient shared “You know, I was charged for my hospital visits. I was charged for the hospital. I mean, it's okay, I can afford it, but it's not okay, right? It's like, we're doing something for someone, and those costs would be absorbed, and I don't know what they are upfront. I think it really depends on each trial, so there's nothing that's really standardized.”

As one respondent who spoke multiple languages posited about making connection in-language:

> “Where would there be information for me to seek resources related to somebody that I want to talk to with a similar disease as me?”

COMMUNICATION/INFORMATION BARRIERS

Based on the findings across the tasks of this study, patients reported challenges in communication with their health care providers. The literature suggests a lack of available tools for shared decision making might be a key barrier that is potentially addressable by wider use of decision tools that could be accessed by patients before visiting the physician as they have been shown to help patients understand their treatment choices. Spronk et al (2018) note that for curative breast cancer and other tumor types decision tools are more readily available than for MBC despite the fact that MBC requires more complex decision making and a more careful consideration of patient preferences. Physician’s lack of time may limit the provision of patient-centered communication and shared decision making. Some studies suggest the health care system fails to adequately financially compensate clinicians for the time it takes to facilitate patient-centered care (Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population; Board on Health Care Services; Institute of Medicine; Levit L, 2013; Smith and Hillner, 2011; Spronk et al., 2018). Sometimes referred to as “cognitive care,” which includes discussions with patients about prognosis, treatment, enrollment in clinical trials, and the development of advanced medical directives, is simply not reimbursed as well as the administration of chemotherapy, thus the financial incentives are not favorable for shared decision making and could potentially be addressed with system/policy change (Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population; Board on Health Care Services; Institute of Medicine; Levit L, 2013; Spronk et al., 2018).

Treatment decision-making requires a high degree of communication between physician and patient. Decision-making regarding the treatment plan for MBC ideally is done via a shared decision-making (SDM) framework as recommended by the Institute of Medicine's landmark report on delivery of high quality cancer care in 2014 (Ganz, 2014). SDM occurs when patients provided information regarding the risks and benefits associated with treatment options and work with their physicians to incorporate personal preferences and values into the treatment decision-making process, which is especially important for MBC given the complexity of the disease (Niranjan et al., 2020; Rocque et al., 2019; Spronk et al., 2018).

MBC treatment is highly dependent on patient characteristics and disease biology, as such MBC treatment has the largest number of available treatment options than any of the other metastatic cancers (Gradishar et al., 2020). Treatments, especially those that are beyond first-line, have often widely different toxicities and physicians take into consideration treatment guidelines alongside recent literature and personal clinical experience, which should be communicated to the patient (Wanchoo et al., 2017). Despite importance of SDM in clinical practice, implementation of SDM practice has been lackluster in general and patients report not having enough shared decision making on MBC (Spronk et al., 2018).

MANY PATIENTS REPORT LACK OF COMPASSION IN PROVIDER INTERACTIONS

Many respondents, given their years as patients or working with patient populations felt their level of care was insufficient. Comments ranged from a perceived lack of time and level of concern on the part of the physicians to less than caring receptions from office staff. Many felt there should be more training for treating MBC populations and their unique needs.

> "I think just having an inclusive medical team that would treat them personally as a whole and address the person. Again, I speak from experience in that you wait for two hours for your appointment and the doctor looks at you for two minutes or talks to you for a minute and then out the door."

There is a wish that providers are more positive (as well as other staff). Speakers at the MBC conference discussed the idea that physicians need the flexibility and training to address each individual patient as a unique case that may need treatments or medications not among the most common used in most treatment plans. One respondent noted that she did not fit a typical profile (young, pregnant), and her experience lead her to believe providers need to have training on how to work with others like her. "That was the hugest barrier. It's just being written off as too young," she said. She shared that staff disregarded her concerns attributing her concerns with other characteristics, "'Oh, it's just related to being hormonally with pregnancy, you have lumpy breasts,’ but I have very dense breasts.” She also noted that when she had imaging during the time she was breastfeeding, she was not told to pump first, and the presence of nursing milk meant the image was not clear.”

When patients receive a diagnosis, they want things to proceed quickly, but they feel this sentiment – or at least an understanding of the emotions – are not shared by the staff they have to interact with to get treatment.

> One shared: “It was just like -- and I know it's part of their everyday but it's no big deal to them, but to me it was a big deal. I just felt there wasn't an urgency about it like I was feeling.”
>
> Another respondent added: “I mean, if there were any was, I remember one point making an initial appointment with my oncologist. It would had to be a couple weeks out, which was always that's kind of a heartache, you know, you want to see doctors, you want to see doctors right away because you have cancer, and you have that sense of urgency.”

PATIENTS DESIRE MORE INFORMATION FROM PROVIDERS

Many respondents to our key informant interviews expressed a desire for more or better information and communication about their treatment and support options. A few patient respondents in our study felt they had an excellent experience with their treatment, trusting their doctors and feeling they were on the correct path. However, one of those respondents noted from her communications with other MBC patients that her experience was the exception rather than the norm. And this was reflected in interviews with other patients. Most patients felt they needed to do significant research on treatments, support services, and access to trials. They most often used the internet but lamented the lack of consolidated resources. This sentiment was also expressed by providers; one of whom noted that she downloaded information on chemotherapy treatments from a Canadian website, finding it more realistic and complete than what her office provided for patients. Some patients took steps to fully change providers, one even changing insurance companies in order to do so, in an effort to receive what they perceived as better treatment options.

NAVIGATION AND SUPPORT SERVICES

There is a regular sentiment among all respondents that things should not be so difficult. Patients entering a reality they find overwhelming and confusing requested assistance for everything from charting a treatment path to scheduling appointments to accessing services to handling insurance issues to having an understanding of what to expect financially.

> "I think if the hospitals and the doctors' offices made those people available more or like -- it was never suggested to me we have a nurse navigator who will help guide you through this maze of -- guide you through the whole system and what goes on and how we do it. It would have been really helpful. I learned of the role later. I just think that would have been incredibly important. Certainly, that role would relieve the medical doctors and other people who get a lot of questions they can answer."

One respondent now leads a support service organization after losing her mother and sister to MBC. She believes a navigator would have had a significant impact on the outcomes, specifically in the case of her sister:

> "She didn't know that she needed to follow up with her doctors on a time, like on a schedule every three months or every so many months and wasn't getting her labs done, didn't have the follow up treatment that she needed, didn't have the emotional psychosocial support that she needed. By the time we found out, it was too late, and she died."

Respondents who had experienced the benefits of a navigator sang the praises of the service:

> "And the woman I met with was, you know, so amazing and so helpful, and you know, kind of gave you the hug, but also walked you through exactly what to expect to the extent that you can, you know, chart that course. Because at that point, you know, I was like, wait, do I do radiation, wait surgery? You know, I didn't even know what the order was, and what this was going to look and feel like, and what having a port meant, and who was going to do what, and that role was priceless to me at that time."

The sponsorship of navigation services are inconsistent, patients may have them through the facility where they receive care, or through their insurance provider, or through an outside organization. At the MBC conference, participants discussed the expansion of "lay navigators", but noted a need for increased definition of the position and their responsibilities, and patient education to set appropriate expectations for services. There was also inconsistency about the source of navigation services, which might be offered by insurance companies, hospitals or cancer centers, or support organizations. Key informants attributed the inconsistency to a main factor – services are not universally covered by insurance.

> “To me, what I find mind-blowing and totally unacceptable is around patient navigation at the cancer center level and that the services that are provided by the patient navigators are not billable through insurance.”

As providers are often asked about connections to resources, one patient believes navigators can help office staff as well: “Certainly that role would relieve the medical doctors and other people who get a lot of questions they can’t answer.”

RESOURCES – DIRECTING PATIENT TO SERVICES

Not only do patients express frustration about the challenge finding information on support services, wishing there was a “they want like resources, like, is there a one-stop shop and -- you know, sometimes I don't think there is…”

Patients who had the time and resources to do their own research expressed concern for those that were not in that same situation:

> “I feel that if you don't go out and seek and ask yourself, it is very hard to find those things, and I'm always a person that is very resourceful and researching things…. if somebody was not as resourceful as myself, or if I not have the contacts, then it would probably be very difficult, especially language bearing too.”

Providers feel the same, one study participant noting it would be great if providers had the ability to connect patients with resources:

> "If there was more physician awareness of online resources in person, support groups, even virtual peer-to-peer support, I think that would actually help patients a lot.”
>
> Resources also need to be specific to MBC patients, and not more general breast cancer patients. “All these things added up can be pretty frustrating for that community and make them feel like there aren't any resources specific to them.”

CONNECTIONS TO OTHER MBC PATIENTS

In the absence of easily identifiable resources, patients are reaching out to other patients for information and connection. Some patients looked to social media platforms to find these connections. Twitter and other social media platforms are increasingly used in several different public health applications, including using its data to monitor diseases and outbreaks, gauging public reaction, using the platform for informational campaigns, and as a virtual venue for discussion and social support among patients, clinicians, advocates, and researchers (Cutshall et al., 2020; Hancher-Rauch et al., 2019; Ke et al., 2017; Park et al., 2016; Sedrak et al., 2019).

MBC patients seek connections with others who have been through the experience. In particular, they want to know what to expect as they progress through treatment, and whether or not things that they are experiencing are "normal" and be reassured that their experiences are both common and receive advice on how best to manage new issues. One patient respondent specifically noted the benefit of participation in a group with MBC women who have other types – for example spread to bone versus organs. They all crave connection with other patients who really understand what they have gone through, what they are currently experiencing, and what they need to prepare to deal with. One respondent noted that an MCB group on social media was the most valuable resource she had in her fight.

> "Honestly, when I was first diagnosed, I would've wanted to talk to the person who had what I had that lived the longest."
>
> "In the beginning, I had no idea what was out there and what was available. I can remember initially I just wanted to talk to another patient who had this."
>
> "I had this deep desire to connect with another individual. I didn't care who it was. I started calling around. I went on the internet and I started calling around and I came upon this support group that I'm still part of."

A non-clinical provider also noted the importance of separate groups for early-stage breast cancer and MBC patients:

> "If you've been diagnosed with breast cancer, but because there are some unique needs and for those living with stage four, they don't really get addressed or maybe they don't feel welcome with other breast cancer patients or earlier stage. I think the easiest examples in support groups, a lot of metastatic breast cancer patients are not comfortable and don't feel welcome in general breast cancer support groups."

TRANSPORTATION AND LODGING

Geography can also exacerbate other challenges, such as patients who face transportation barriers. In the example of South Lake Tahoe, women are travelling as far as Truckee (~ 45 miles), Sacramento (~100 miles) or the Bay Area (~200 miles) for care. While there are services that provide transportation to treatments, this distance can exceed usual services. Patients often need to drive themselves but may not feel well enough after treatment to make the journey back home. However, there are more limited resources for hotel stays for the patients that need accommodations for a night post-treatment. For some patients with families and/or jobs, an overnight is not an option.

SOME SERVICES ARE NOT EASY TO ACCESS

Geography impacts the availability of services, both clinical and support services. One respondent from South Lake Tahoe started a support groups for breast cancer patients because prior to her diagnosis, none existed. MBC patients, and non-clinical providers, also noted that when it comes to support groups, it can be important that it is separate from groups open to all breast cancer patients. One patient made the case: “Talking about death and fears of prognosis and time left and things like that are not topics that earlier stage breast cancer patients want to talk about or comfortable talking about but are some things specific to the MBC community.”

Attendees at the MBC conference also noted that support groups need to improve their accessibility with more scheduling options for participants, an increased language representation for limited English language speakers, and availability of additional groups for families and other caregivers.

Many support services are run by charitable organizations and/or volunteers, creating uneven availability in many locations. One respondent shared that there was only one wig shop in San Francisco that offered mastectomy bras covered by her insurance.

All respondents lamented a lack of a centralized resource database – this impacts patient, as well as clinical and non-clinical providers. Respondents noted an appreciation for all of the available services but wondered why access required such a significant time and effort. A few wished that applications for services could be coordinated among various providers, so one form could connect a patient with the organizations operating in their area.

In addition to support groups, other services are even more difficult to access with patients with certain cultural or language characteristics. Few support services can accommodate multiple languages, and information about support services are often not translated into many languages. For patients seeking connections to other with similar experiences, the available resources are even smaller.

TIME LIMITS ON PROGRAMS

Some support programs are limited as to the number of times a patient may utilize the services or have a cap on benefits or coverage. However, as noted by one respondent: "for the MBC community, their treatment and disease is not temporary."

SOCIAL RISK FACTORS

Individual characteristics of patients in California influence their experience in getting care and services crucial to their outcomes. Factors such as race, age, insurance status, geographic location, language, health literacy and immigration status were identified from the literature review and key informant interviews.

For example, in a study of 163,569 cases of first primary female invasive breast cancer from the California Cancer Registry, researchers found significant disparities in breast cancer mortality, due to race/ethnicity, SES, and urbanization (Parise and Caggiano, 2017). There was increased risk of mortality for African Americans compared to Whites in four out of the eight regions of California examined by the authors. SES was a significant risk factor for mortality in the majority of the regions and urbanization was a statistically significant factor for mortality in Los Angeles. Researchers are trying to better understand how geography and neighborhoods affect breast cancer outcomes, for example via proximity to high-quality hospital and geographic access to care as measured by a variety of variables such as distance to nearest oncologist, per capita number of oncologists and hospices, local area chemotherapy rate, and local area poverty (DeGuzman et al., 2017; Keating et al., 2016; Leopold et al., 2016).

While more studies are needed to understand the complex relationships between poverty, access to care, and neighborhood exposures, the findings across studies suggest striking disadvantages and disparities in outcomes for African American cancer patients, particularly in inner city and rural areas (Charlson et al., 2017; Chavez-MacGregor et al., 2016; Coughlin, 2019; Dreyer et al., 2018; Leopold et al., 2016; Nattinger et al., 2017; Parise and Caggiano, 2017; Silber et al., 2018; Thompson et al., 2018). The seminal reports *Ensuring Quality of Cancer Care* and *Unequal Burden of Cancer,* both published over 20 years ago by the Institute of Medicine, brought to light the urgent need for eliminating health disparities by race/ethnicity to optimize cancer care, yet disparities in cancer outcomes continue to persist (Institute of Medicine (IOM), 1999). Social determinants of health such as poverty, lack of education, neighborhood disadvantage, residential segregation, racial discrimination, lack of social support, and social isolation all appear to play an important role in breast cancer diagnosis, treatment, and survival (Coughlin, 2019).

Respondents to the key informant interviews reported that patients experience barriers due to language, cultural characteristics, lack of health literacy, and immigration status.

CULTURAL CHARACTERISTICS AND LANGUAGE

Given the highly diverse population in California and the large immigrant diasporas, cultural characteristics and language are common barriers that often cross-over. Provider respondents report being caught in tough situations when patients are reluctant to talk about their diagnosis due to cultural considerations.

> ““We do have a lot of patients who don’t speak English here. That’s a huge barrier in providing care … sometimes we have cultural and language barriers that come up. How do we address that with patients? What do we tell them when they don’t understand you, but their family is like, ‘Don’t say the word chemo or don’t say the word cancer?’”

This is compounded when a family member is often called on to stand in as an interpreter during provider visits.

> “I feel that if you don't go out and seek and ask yourself, it is very hard to find those things, and I'm always a person that is very resourceful and researching things…. if somebody was not as resourceful as myself, or if I not have the contacts, then it would probably be very difficult, especially language bearing too.”

> “I'm Chinese. I speak four different languages in Chinese as well, including English and Spanish, but you know, if I was only speaking Chinese, and I didn't speak much English, I think it would be very, very difficult.”

One respondent in the San Diego area was aware of many women seeking care across the border in Mexico. She felt the two biggest reasons for this was the lack of providers in the area for Medi-Cal enrollees – which she attributed to low reimbursement rates - and an increased comfort for Spanish-speaking patients to speak with providers in their native language. She noted that this practice created additional issues for these patients, as records and tests were not shared across the border.

Language and culture are also a factor in seeking support services. The diversity of California also includes many communities that have limited English language proficiency, and this provides a significant barrier to care. While this study was only conducted in English, some respondents were engaged with these communities and expressed concern:

> "I feel that we need to develop much more intuitive tutorials or informational sites to give access to people; especially people who don't speak English more information about where they can get resources that are readily available. If I were to search on the Internet today in Chinese related to my disease and resources that would come up for me, it would be basically non-existent."

The need for in-language resources traverses all categories of care, including navigator efforts.

HEALTH LITERACY

Many respondents believe that the level of a patient's health literacy impacts care. In addition, several patients referred to a steep learning curve once they were diagnosed.

> "I think the only reason I got a straight answer from her is because I was able to pronounce the name of the drugs and really pinpoint her and be like, "Uh-huh, that's not right." Back to my example of that other girl that I'm helping, she doesn't even know her diagnosis. How she could catch something like that?"

Many did not know the 'language' of cancer, making it difficult to access trials and know if they qualify. Respondents were split on whether or not they felt like they were provided all options and made fully aware of the implications of their choices (side effects, other interactions). Some who did do their own research and disagreed with recommended treatments were mixed as to whether or not their provider supported their decision.

> "That was a learning curve. What is a cancer center? It's just a whole new world that you don't -- the vocabulary of all of it was brand new obviously too."

Health literacy also impacts the ability to try to identify a trial that might be appropriate. "Then, to research a clinical trial, it's not in layman's terms. Could you even find what you qualify for?"

> "Something like being able to go on and see what the research on whether you do chemo or a mastectomy first. In layman's terms, it would have been a great resource for me as a patient, but, of course, I didn't even know how to ask for that."

AGE

Age is strongly associated with risk of mortality, with elder patients most at risk of early mortality due to MBC (Iqbal et al., 2015). However, young women are also at risk of aggressive disease; while about less than 10% of all breast cancers are diagnosed among women younger than 45 years, the incidence in this age group has increased considerably over time (Anastasiadi et al., 2017; Guo et al., 2018; Rosenberg and Partridge, 2015). When found in young women, breast cancer is typically diagnosed at more advanced stages, is more aggressive, is less responsive to treatment, and results in poorer survival outcomes compared to breast cancer in older women (Lima et al., 2020).

> "I think just public awareness of what to do when you don't have insurance, how can you access the scan at a younger age."
>
> "Everybody knows to get a mammogram when you're 40, but for those of us who weren't 40 and we didn't meet the criteria to know that you can, and especially for those who have a history going forward like of my daughter, for example. That number is going to be a lot earlier, but the insurance doesn't want to cover that earlier."

IMMIGRATION STATUS

Non-clinical providers offer support services regardless of immigration status and felt this population experience added barriers to screening, treatment and services because of their status. One shared: "I feel this whole issue with immigration and fear around receiving treatment or getting treatment or pursuing treatment, how it may affect their residency, I think that's an issue for people that are immigrants or are here like they're not permanent residents."

POLICIES TO IMPROVE THE WELL-BEING OF WOMEN WITH MBC

Our legislative scan documented areas where California has made progress and identified areas of need based on our study findings (Appendix D). Below we review selected typologies from our findings and propose policy recommendations that have not been proposed in past legislative sessions. For each typology, the policy recommendations should include special provisions for groups with high social risk factors.

REDUCING FINANCIAL BURDEN

Acknowledging the high cost of treatment, stemming mostly from the high cost of anti-cancer drugs, California has passed a number of legislative actions to cap the monthly out of pocket costs of drugs. For example, in 2018, California Assembly Bill 1860 capped patients' out-of-pocket costs for oral chemotherapy to $250/month per drug. Supportive cancer care services to address financial burden, might also be an area of promise for helping to mitigate racial/ethnic inequities in cancer care outcomes. Samuel et al (2020) note that only few patients in their study reported receiving financial assistance for cancer treatment costs. Financial assistance requires awareness of such programs and resources to apply and use these programs. Improving equitable access to financial assistance services might be an area for policymakers to consider addressing the disparities in financial burden by race/ethnicity.

Policy recommendations

- Provide financial assistance for cancer treatment and support services to patients that need it.

REMOVING INSURANCE BARRIERS

Legislative efforts to improve treatment choices for patients involve the easing of or the removal of prior authorization or step therapy review for medications. For example, proposed in 2020, SB 1452 states that health insurance plans cannot limit which manufacturer's biological products or biosimilars are to be used when medically necessary. The bill also prohibits plans and policies from requiring prior authorization or step therapy requirements that limit which manufacturer's biological products or the respective biosimilars are to be administered by a physician or clinician to an enrollee. Other states have considered bills that specifically remove prior authorization and step therapy for metastatic cancer patients; California has not yet passed a bill that removes prior authorization or step therapy for drugs used by patients with metastatic disease.

Feeling the need to spend significant amounts of time was expressed by key informants in discussing several barriers to care including time spent battling insurance companies for authorizations, coordinating payment of bills with providers and insurance companies), scheduling appointments, traveling to and receiving treatment, doing a lot of their research into clinical trials or available support services.

Policy Recommendations

- Reimbursement for retesting of receptor status and genetic changes during course of treatment.
- Improve prior authorization (PA) and step therapy (ST) processes for quicker turnaround time. Consider eliminating PA and ST for metastatic cancers given the special need for timely treatment.
- Facilitate connection to all services with one application.

ACCESSING DISABILITY INSURANCE

Disability insurance can be an important source of financial assistance for individuals undergoing cancer treatment. In 2019, at the federal level, The Metastatic Breast Cancer Access to Care Act was proposed to waive the five-month wait before someone with breast cancer could access Social Security Disability Insurance (SSDI). The bill has not moved forward as yet but could be a step forward for those who pay into the SSDI. This received a good amount of attention in news media and social media, recognizing that it brought to light financial challenges faced by teachers on extended sick leave and the extra costs cancer patients often face in addition to their treatment costs. Public school teachers in California do not pay into the state disability insurance program and thus are not able to draw any benefits from it. Under the California Education Code, teachers receive ten days of sick time each year, after which they are allowed one hundred days of extended sick leave and during this time the cost of the substitute teacher is deducted from their salary. While a change to this practice would require a change in the California Education Code, it is possible other financial assistance programs could be advanced to help teachers with this financial burden. Identifying and promoting awareness of private sources or grants for financial assistance is something that nurse or peer navigators could potentially address.

Policy Recommendations

- Provide financial assistance for co-payments and deductibles for specifically for teachers and contract workers and other occupations that do not pay into the state disability programs who are undergoing treatment for MBC.
- Improve disability insurance awareness and programs to help women with MBC apply for these programs.

PROVIDING PALLIATIVE CARE

The need for better integration of MBC treatment with palliative care and support services was a common theme throughout the tasks of this study. There has been a good deal of attention and interest in improving support services. In 2019, California passed AB 1287 to help elders, caregivers, and people with disabilities greater access to community services and support. Similar initiatives have been made to improve access to palliative care for all patients who need it. For example, in 2018, California enacted SB 1004, which required Medi-Cal managed care providers to offer home-based palliative care to seriously-ill patients. However, enrollment in the program has been lower than projected. In a study of clinician-perceived barriers to access to palliative care by Medi-Cal patients, researchers found lack of physician knowledge, challenges in providing education about palliative care to patients, cultural and language barriers, lack of time, and competing demands of physicians (Enguidanos et al., 2019).

Policy Recommendations

- Provide referral and reimbursement for care teams to take the time to make patients aware of support services.
- Improve quality of life (QOL) reporting so patients provide routine QOL information to their care team.

Providers also identified social risk factors, including cultural barriers, mistrust regarding the health-care system, lack of social services meeting needs, such as adequate and safe housing. Based on these findings, Enguidanos et al (2019) call for an increase physician education and awareness of palliative care and the home-based program available to Medi-Cal beneficiaries. They further note the need for culturally appropriate services and a need to develop programs that improve health literacy.

Policy Recommendations

- Improve awareness of Medi-Cal’s home-based palliative care program.
- Investment in a comprehensive study into the degree of access to patient navigation among MBC patients in California and how it differs by insurance status, race/ethnicity, and geography.

ACCESSING CLINICAL TRIALS

A key piece of legislation that addresses a barrier identified by key informants and our literature scan related to clinical trial participation challenges was SB 583, which was passed in 2019. SB 583 was passed to address participation in clinical trials related to any life-threatening diseases or conditions, allowing enrollee self-referral to access benefit coverage related to the clinical trial (referral by a provider no longer required), and expanding the existing mandate's requirement that in-network cost sharing to apply to noncancer trial related services. This bill additionally requires coverage of out-of-network providers when a related service is not available in-network and require that all cost-sharing be at in-network rates.

To increase participation and address gaps in clinical trial research, the Metastatic Breast Cancer Alliance stresses the need for repeat biopsies for characterization or biomarker testing, the creation of a national or global registry where standard of care clinical samples are linked to bioregistries, recording of outcomes data of patients who are not treated with the associated targeted therapy to better understand which patients do not need more than standard-of-care therapy and an investment in resources to ensure high-quality biopsy samples (Flowers et al., 2017; Malmgren et al., 2020). Innovative repositories of data have emerged in the past few years, leveraging the power of social media. The Metastatic Breast Cancer Project has collected clinical and genetic data from thousands of MBC patients participating in clinical trials who learned about this project from social media and volunteered to participate (Parry, 2018). Participants share their medical records with investigators, provide saliva samples for the extraction of germline DNA, and make their tumor tissue available for next-generation sequencing. More efforts will be required to increase participation among African American patients, who are generally underrepresented in clinical trials (American Cancer Society. Cancer Action Network, 2018).

Policy Recommendations

- Cost assistance to MBC patients in clinical trials for travel and other costs associated with participation
- Investments in programs to increase participation among African American patients in clinical trials

IMPROVING COMMUNICATION/INFORMATION

While AB 15, which passed in California in 2015 significantly improved access to end-of-life options by legalizing physician aid in dying, communication around end-of-life appears to still be a barrier along the spectrum of care. Based on literature on MBC advance care planning and hospice care, there are notable communication deficit regarding end-of-life care (Clark et al., 2017; McDonald et al., 2017). Part of the challenge is providers may try harder to communicate hope and a positive outlook, focusing on treatment options to prolong the patient's life, rather than planning and discussing end-of-life issues, suggesting providers may benefit from communication training and having tools to aid in these conversations. Nurse and lay patient navigators may also be an important means of improving conversations and decision-making on end-of-life issues for advanced stage cancer patients (Niranjan et al., 2018; Niranjan et al., 2020; Reiser et al., 2019).

Policy Recommendations

- Improve communication regarding end-of-life care, including advance care directives.
- Adopt measures to improve geographic access to hospice care
- Train and reimburse patient navigators to support women with MBC in their decision-making for treatment, support services, palliative care and end-of-life issues.

PROVIDING NAVIGATION AND SUPPORT SERVICES

Respondents would prefer that an MBC diagnosis input into a system would trigger a series of actions such as faster access to appointments, connection to a navigator, faster approvals for pre-authorizations from insurance companies, and a resource for services offered to MBC patients. One respondent even posited that patients could elect to waive HIPPA rights to have their contact information provided to approved support services so that organizations would be proactive and make the connection to services smoother.

Respondents also recommend that an MBC diagnosis should come with an automatic connection to a navigator to help with the treatment path. “If you’ve got diagnosed, you don’t have to wait a month to get into an appointment or something.”

Policy Recommendations

- Provide navigation services that includes hotline and remote consultations to women newly diagnosed with MBC.
- Ensure navigation services are accessible by language and culturally appropriate.

SOCIAL RISK FACTORS

Factors such as race/ethnicity, age, insurance status, geographic location, language, health literacy and immigration status were identified from the literature review and key informant interviews to influence the patient access to care and services and the quality of these services. Greater investment in programs for groups with high social risk factors can help improve disparities in care for MBC patients.

Policy Recommendations

- Include provisions in legislative proposals for groups with high social risk factors for the barrier/issue that the intended policy aims to address

SUMMARY

This report examined barriers and challenges to breast cancer care in California experienced by those with metastatic breast cancer using a multi-method approach drawing on key informant interviews, the peer reviewed literature, grey literature, a legislative scan, and Twitter chat. We synthesized the findings from these differing yet interlinked sources of information, producing a typology of barriers identified as the most significant for women with metastatic breast cancer as well as policy and system solutions to improve care.

Many of the barriers identified in the current analysis were raised in the research team's earlier report on barriers to care for breast cancer patients in California (Ponce et al., 2018). However, what we heard in the current analysis was that these barriers are more palpable for those with MBC due in part to the severity of the disease, the greater likelihood of need for palliative care, and uncertainty resulting from the variety of treatment options for MBC. Cutting across the barriers we heard that many MBC patients would characterize their care experiences as requiring inordinate amounts of time, contributing to significant frustration, and leading them to frequently feel overwhelmed. One patient described it this way: "people forget that you're still dealing with what you're dealing every day for the rest of your life. So, it's just a little frustrating."

We believe there are options for addressing these frustrations, and here we provide specific policy recommendations for each type of barrier identified in this analysis. These recommendations can be used to guide efforts of policy-makers to improve timely access to care for women living with MBC in California. We hope that potential solutions can be found in policy remedies that address these key issues and affect global changes at the health care system level and assistance for nonclinical support services for metastatic breast cancer patients.

APPENDIX A: REFERENCES

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APPENDIX B: INTERVIEW PROTOCOLS

ORGANIZATION PROTOCOL

[Interviewer note: This questionnaire is intended to be a guide for a semi-structured interview. Follow-up questions may be needed for clarification or further details, and may lead to new questions about specific information relayed by the participant.]

Organization Name:
Representative Name:
Representative Title (or position):

Thank you for agreeing to talk to us today. Our study is seeking to identify barriers to care that are faced by patients who have been diagnosed with breast cancer that has metastasized. Your participation helps us hear the crucial voice of the patients. We are seeking to identify any barriers as well as possible solutions to removing those barriers.

By barriers, we mean any obstacle - real or perceived - that causes a patient to delay or miss out on receiving care to treat their cancer, help them manage symptoms, or support them or their family members psychologically.

Okay I am going to start the recording now:

Can you please state you name for the recording?

What organization do you work with?

What is your role?

How often do you interact with patients who have metastatic breast cancer?

What is the nature of your organization's interactions with women who have advanced breast cancer?

Please describe the target population that your organization aims to serve through your work? (Follow-up probes as needed to define racial/ethnic minority groups targeted, region served-city, county, state, national, low income/uninsured etc).

What would you say are some of the barriers that women who have metastatic breast cancer face?

Follow-up probe: How does insurance status influence these barriers-different for uninsured, publicly insured-still present for privately insured?

Please describe TREATMENT barriers (surgery, chemotherapy, radiation therapy, targeted therapy. Hormonal therapy) faced by women with metastatic breast cancer [with modifications to the question based on the populations served as answered in question 2]

Are any of these barriers specific to women who have metastatic breast cancer?

Are you aware of barriers that are specific to women who are uninsured?

Are you aware of barriers that are specific to women who are publically insured?

Are you aware of barriers that are specific to women who have private insurance?

Can you describe any additional barriers facing women who seek palliative care? Hospice Care?

Please describe SUPPORT SERVICES (wigs, scarves, mastectomy bras, financial assistance for food, housing and/or medical insurance) barriers faced by women with metastatic breast cancer [with modifications to the question based on the populations served as answered in question 2]

Are any of these barriers specific to women who have metastatic breast cancer?

Are you aware of barriers that are specific to women who are uninsured?

Are you aware of barriers that are specific to women who are publically insured?

Are you aware of barriers that are specific to women who have private insurance?

Are there any additional barriers facing women who seek palliative care?

How do you think that implementation of ACA has affected women's access to metastatic breast cancer treatment?

How have you come to be aware of these barriers?

In what ways does your organization attempt to address these barriers? [Examples may include services, education, advocacy]

Do you have ideas about policy changes that could be made to address barriers? [note: refer to answers for question 5]

Does your organization collect any quantitative data (such as surveys) on the barriers faced by patients?

Does your organization collect any qualitative data or stories shared by patients that you work with (anecdotal, such as those heard through group discussions)?

Do you have suggestions for other individuals or organizations that we should interview for this project?

PATIENT PROTOCOL

Interviewer note: This questionnaire is intended to be a guide for a semi-structured interview. Follow-up questions may be needed for clarification or further details, and may lead to new questions about specific information relayed by the participant.

Call-in: 712-770-4010
Access Code: 632 975#
Convener Code: *7598

Thank you for agreeing to talk to us today. Our study is seeking to identify barriers to care that are faced by patients who have been diagnosed with breast cancer that has metastasized. Your participation helps us hear the crucial voice of the patients. We are seeking to identify any barriers as well as possible solutions to removing those barriers.

By barriers, we mean any obstacle - real or perceived - that you feel caused you to delay or miss out on treatment completely, or to receiving the best possible treatment or in obtaining the support you need.

Do you have any questions before we begin? May I start the recording now?

Can you please state you name for the recording?

And can you share your diagnosis status with me? (Confirming patient has or had metastatic or Stage 4 breast cancer)

What is/was your insurance status? (uninsured, private insurance, public insurance)

What is your age?

Where do you live? (Zip Code)

[Interviewer note: I think we should start off asking them about any barriers they faced in getting the care they need,then can follow-up with probes related to who, what, where, when, how for what they brought up initially and then follow-up with some more specific probes (problems with diagnostic stage, treatment stage, after initial treatment, symptom management etc..)]

Now I would like to talk to you about when you were first diagnosed.

After diagnosis, do you feel you were made aware of all of your treatment options, and corresponding side effects for each? Is there additional information you had to seek outside your doctor's office? Do you feel you had all of the information you needed? If not, what other information do you believe patients should be provided?

Please describe any barriers you encountered during the DIAGNOSTIC stage of your treatment (genomic tests such as BRCA test and OncotypeDx or gene expression profiling).

Follow-up: In what ways have you sought help to address this barrier? [probe about organizations that assisted, if appropriate]

Please describe any barriers you encountered during the TREATMENT stage of your treatment (surgery, chemotherapy, radiation therapy, targeted therapy. Hormonal therapy)

Follow-up: In what ways have you sought help to address this barrier? [probe about organizations that assisted, if appropriate]

Please describe any barriers you encountered during the SUPPORT SERVICES throughout your treatment (wigs, scarves, mastectomy bras, financial assistance for food, housing and/or medical insurance, support for your family members)

Follow-up: In what ways have you sought help to address this barrier? [probe about organizations that assisted, if appropriate]

Are you seeing a Palliative Care Provider? Did you have any barriers seeking that care?

Do you feel these barriers would have been different if your insurance status was (change from answer to question 3)?

Do you have ideas about policy changes that could be made to address barriers? [note: refer to answers for question 5]

Do you have suggestions for other individuals or organizations that we should interview for this project?

PHYSICIAN/PROVIDER PROTOCOL

[Interviewer note: This questionnaire is intended to be a guide for a semi-structured interview. Follow-up questions may be needed for clarification or further details, and may lead to new questions about specific information relayed by the participant.]

Thank you for agreeing to talk to us today. Our study is seeking to identify barriers to care that are faced by patients who have been diagnosed with breast cancer that has metastasized. Your participation helps us hear the crucial voice of the patients. We are seeking to identify any barriers as well as possible solutions to removing those barriers.

By barriers, we mean any obstacle - real or perceived - that causes a patient to delay or miss out on receiving care to treat their cancer, help them manage symptoms, or support them or their family members psychologically. Do you have any questions before we begin? May I start the recording now?

Can you please state your name for the recording?

What type of provider are you?

(If appropriate) How would you describe your organization's role in providing care for women who may have/been diagnosed with metastatic breast cancer?

Please describe the demographics of metastatic breast cancer patients that your organization serves? (Follow-up probes as needed to define racial/ethnic minority groups targeted, region served-city, county, state, national, low income/uninsured, stage in treatment etc).

After a patient's diagnosis or initial meeting with you, what kind of information do you provide regarding treatment options and potential side effects of each? (F/U is it written information, and if so, in what form?) Do you feel the material is adequate for patients to make informed decisions? If not, what other sources to you direct patients to? What kind of information do you wish was available to provide?

I'm now going to ask several questions about possible barriers in specific aspects of care and how those barriers may vary across patient types.

Please describe DIAGNOSTIC (genomic tests such as BRCA test and OncotypeDx or gene expression profiling) barriers faced by women with metastatic breast cancer [with modifications to the question based on the populations served as answered in question 4] For MDs: How would you characterize the clinical impact of these barriers?

For non-physicians: How would you characterize the psycho-social impact of these barriers?

Are you aware of barriers that are specific to women who are uninsured?

Are you aware of barriers that are specific to women who are publicly insured?

Are you aware of barriers that are specific to women who have private insurance?

Please describe TREATMENT barriers (surgery, chemotherapy, radiation therapy, targeted therapy. Hormonal therapy) faced by women with metastatic breast cancer [with modifications to the question based on the populations served as answered in question 4]

For MDs: How would you characterize the clinical impact of these barriers?

For non-physicians: How would you characterize the psycho-social impact of these barriers?

Are you aware of barriers that are specific to women who are uninsured?

Are you aware of barriers that are specific to women who are publically insured?

Are you aware of barriers that are specific to women who have private insurance?

What barriers arise for women who are moving into palliative care? And hospice care?

Please describe SUPPORT SERVICES (wigs, scarves, mastectomy bras, financial assistance for food, housing and/or medical insurance) barriers faced by women with metastatic breast cancer [with modifications to the question based on the populations served as answered in question 4]

For MDs: How would you characterize the clinical impact of these barriers?

For non-physicians: How would you characterize the psycho-social impact of these barriers?

Are you aware of barriers that are specific to women who are uninsured?

Are you aware of barriers that are specific to women who are publically insured?

Are you aware of barriers that are specific to women who have private insurance?

How does your organization attempt to address these barriers? [Examples may include services, education, advocacy] PROBE: What has proven effective in your experience; why?

How might changes to the ACA affect women's access to breast cancer treatment?

Thinking about different levels of the health care system (provider organization, state level, federal) do you have ideas about policy changes that could be made to address barriers? [note: refer to answers for questions 6-8].

Does your organization collect any data (such as surveys) on the barriers faced by patients?

Do you have suggestions for other individuals or organizations that we should interview for this project?

That's all the questions I have, would you have any additional thoughts on topics we didn't cover or advice to offer to further improve this research?

OK, thank you very much for your time and insights

APPENDIX C: LITERATURE SYNTHESIS, 2015-2020

Key Papers on MBC barriers (n=85), 2015-2020

Authors	Title	Journal	Date
Attai, D. J., Cowher, M. S., Al-Hamadani, M., Schoger, J. M., Staley, A. C. and Landercasper, J.	Twitter Social Media is an Effective Tool for Breast Cancer Patient Education and Support: Patient-Reported Outcomes by Survey	J Med Internet Res	2015
Hao, Y., Meyer, N., Song, X., Shi, N., Johnson, W., Juneau, P., Yardley, D. A. and Willemann Rogerio, J.	Treatment patterns and survival in metastatic breast cancer patients by tumor characteristics	Curr Med Res Opin	2015
Lewis, S., Yee, J., Kilbreath, S. and Willis, K.	A qualitative study of women's experiences of healthcare, treatment and support for metastatic breast cancer	Breast	2015
Low, C. A. and Stanton, A. L.	Activity disruption and depressive symptoms in women living with metastatic breast cancer	Health Psychol	2015
Palmer, N. R., Weaver, K. E., Hauser, S. P., Lawrence, J. A., Talton, J., Case, L. D. and Geiger, A. M.	Disparities in barriers to follow-up care between African American and White breast cancer survivors	Support Care Cancer	2015
Santa-Maria, C. A. and Gradishar, W. J.	Changing Treatment Paradigms in Metastatic Breast Cancer: Lessons Learned	JAMA Oncol	2015
Sheean, P., Kabir, C., Rao, R., Hoskins, K. and Stolley, M.	Exploring Diet, Physical Activity, and Quality of Life in Females with Metastatic Breast Cancer: A Pilot Study to Support Future Intervention	J Acad Nutr Diet	2015
Vaz-Luis, I., Lin, N. U., Keating, N. L., Barry, W. T., Lii, H., Winer, E. P. and Freedman, R. A.	Racial differences in outcomes for patients with metastatic breast cancer by disease subtype	Breast Cancer Res Treat	2015
Wan, S. and Jubelirer, S.	Geographic access and age-related variation in chemotherapy use in elderly with metastatic breast cancer	Breast Cancer Res Treat	2015
Count Me In	Social Media Ups Clinical Trial Enrollment	Cancer Discov	2016
Accordino, M. K., Wright, J. D., Vasan, S., Neugut, A. I., Hillyer, G. C., Hu, J. C. and Hershman, D. L.	Use and Costs of Disease Monitoring in Women With Metastatic Breast Cancer	J Clin Oncol	2016
Bramley, T., Antao, V., Lunacsek, O., Hennenfent, K. and Masaquel, A.	The economic burden of end-of-life care in metastatic breast cancer	J Med Econ	2016
Cardoso, F., Harbeck, N., Mertz, S. and Fenech, D.	Evolving psychosocial, emotional, functional, and support needs of women with advanced breast cancer: Results	Breast	2016

Authors	Title	Journal	Date
	from the Count Us, Know Us, Join Us and Here & Now surveys		
Diaby, V., Adunlin, G., Ali, A. A., Zeichner, S. B., de Lima Lopes, G., Kohn, C. G. and Montero, A. J.	Cost-effectiveness analysis of 1st through 3rd line sequential targeted therapy in HER2-positive metastatic breast cancer in the United States	Breast Cancer Res Treat	2016
Ecclestone, C., Chow, R., Pulenzas, N., Zhang, L., Leahey, A., Hamer, J., DeAngelis, C., Bedard, G., McDonald, R., Bhatia, A., Ellis, J., Rakovitch, E., Vuong, S., Chow, E. and Verma, S.	Quality of life and symptom burden in patients with metastatic breast cancer	Support Care Cancer	2016
Irwin, D. E., Masaquel, A., Johnston, S. and Barnett, B.	Adverse event-related costs for systemic metastatic breast cancer treatment among female Medicaid beneficiaries	J Med Econ	2016
Le Du, F., Fujii, T., Park, M., Liu, D., Hsu, L., Gonzalez-Angulo, A. M. and Ueno, N. T.	Impact of clinical trial on survival outcomes	Breast Cancer Res Treat	2016
Lee, J. Y., Lim, S. H., Lee, M. Y., Kim, H. S., Ahn, J. S., Im, Y. H. and Park, Y. H.	The Impacts of Inclusion in Clinical Trials on Outcomes among Patients with Metastatic Breast Cancer (MBC)	PLoS One	2016
Leopold, C., Wagner, A. K., Zhang, F., Lu, C. Y., Earle, C., Nekhlyudov, L., Ross-Degnan, D. and Wharam, J. F.	Racial disparities in all-cause mortality among younger commercially insured women with incident metastatic breast cancer	Breast Cancer Res Treat	2016
Quillet, A., Defossez, G. and Ingrand, P.	Surveillance of waiting times for access to treatment: a registry-based computed approach in breast cancer care	Eur J Cancer Care (Engl)	2016
Shin, J. A., El-Jawahri, A., Parkes, A., Schleicher, S. M., Knight, H. P. and Temel, J. S.	Quality of Life, Mood, and Prognostic Understanding in Patients with Metastatic Breast Cancer	J Palliat Med	2016
Sledge, G. W., Jr.	Curing Metastatic Breast Cancer	J Oncol Pract	2016
Accordino, M. K., Wright, J. D., Vasan, S., Neugut, A. I., Gross, T., Hillyer, G. C. and Hershman, D. L.	Association between survival time with metastatic breast cancer and aggressive end-of-life care	Breast Cancer Res Treat	2017
Bergqvist, J. and Strang, P.	The will to live - breast cancer patients perceptions' of palliative chemotherapy	Acta Oncol	2017
Carson, J. W., Carson, K. M., Olsen, M. K., Sanders, L. and Porter, L. S.	Mindful Yoga for women with metastatic breast cancer: design of a randomized controlled trial	BMC Complement Altern Med	2017
Clark, M. A., Ott, M., Rogers, M. L., Politi, M. C., Miller, S. C., Moynihan, L., Robison, K., Stuckey, A. and Dizon, D.	Advance care planning as a shared endeavor: completion of ACP documents in a multidisciplinary cancer program	Psychooncology	2017
Fingleton, B., Lange, K., Caldwell, B. and Bankaitis, K. V.	Perspective on the interpretation of research and translation to clinical care with therapy-associated metastatic breast cancer progression as an example	Clin Exp Metastasis	2017

Authors	Title	Journal	Date
Flowers, M., Birkey Reffey, S. and Mertz, S. A.	Obstacles, Opportunities and Priorities for Advancing Metastatic Breast Cancer Research	Cancer Res	2017
Li, N., Du, E. X., Chu, L., Peeples, M., Xie, J., Barghout, V. and Tang, D. H.	Real-world palbociclib dosing patterns and implications for drug costs in the treatment of HR+/HER2- metastatic breast cancer	Expert Opin Pharmacother	2017
Martin, E., Pourtau, L., Di Palma, M. and Delaloge, S.	New oral targeted therapies for metastatic breast cancer disrupt the traditional patients' management-A healthcare providers' view	Eur J Cancer Care (Engl)	2017
Peart, O.	Metastatic Breast Cancer	Radiol Technol	2017
Ryan, C.	Improving patient care: expert nursing and service development	Br J Nurs	2017
Senkus, E. and Łacko, A.	Over-treatment in metastatic breast cancer	Breast	2017
Vaz-Luis, I., Lin, N. U., Keating, N. L., Barry, W. T., Winer, E. P. and Freedman, R. A.	Factors Associated with Early Mortality Among Patients with De Novo Metastatic Breast Cancer: A Population-Based Study	Oncologist	2017
Wanchoo, P., Larrison, C., Rosenberg, C., Ko, N., Cantril, C., Moeller, N., Parikh, R. and Djordjevic, A. M.	Identifying Educational Needs of the Multidisciplinary Cancer Team in the Treatment of Metastatic Breast Cancer	J Natl Compr Canc Netw	2017
Blackwell, K., Gligorov, J., Jacobs, I. and Twelves, C.	The Global Need for a Trastuzumab Biosimilar for Patients With HER2-Positive Breast Cancer	Clin Breast Cancer	2018
Guo, F., Kuo, Y. F., Shih, Y. C. T., Giordano, S. H. and Berenson, A. B.	Trends in breast cancer mortality by stage at diagnosis among young women in the United States	Cancer	2018
Hattori, M. and Iwata, H.	Advances in treatment and care in metastatic breast cancer (MBC): are there MBC patients who are curable?	Chin Clin Oncol	2018
Hopson, S., Casebeer, A., Stemkowski, S., Antol, D. D., Tao, Z., Howe, A., Patton, J., Small, A. and Masaquel, A.	Does site-of-care for oncology infusion therapy influence treatment patterns, cost, and quality in the United States?	J Med Econ	2018
Lee, C. K., Hudson, M., Simes, J., Ribi, K., Bernhard, J. and Coates, A. S.	When do patient reported quality of life indicators become prognostic in breast cancer?	Health Qual Life Outcomes	2018
Leopold, C., Wagner, A. K., Zhang, F., Lu, C. Y., Earle, C. C., Nekhlyudov, L., Ross-Degnan, D. and Wharam, J. F.	Total and out-of-pocket expenditures among women with metastatic breast cancer in low-deductible versus high-deductible health plans	Breast Cancer Res Treat	2018

Authors	Title	Journal	Date
Li, Y., Humphries, B., Yang, C. and Wang, Z.	Nanoparticle-Mediated Therapeutic Agent Delivery for Treating Metastatic Breast Cancer-Challenges and Opportunities	Nanomaterials (Basel)	2018
Marquart, J., Chen, E. Y. and Prasad, V.	Estimation of the Percentage of US Patients With Cancer Who Benefit From Genome-Driven Oncology	JAMA Oncol	2018
Matsuoka, J., Kunitomi, T., Nishizaki, M., Iwamoto, T. and Katayama, H.	Advance care planning in metastatic breast cancer	Chin Clin Oncol	2018
Müller, V., Nabieva, N., Häberle, L., Taran, F. A., Hartkopf, A. D., Volz, B., Overkamp, F., Brandl, A. L., Kolberg, H. C., Hadji, P., Tesch, H., Ettl, J., Lux, M. P., Lüftner, D., Belleville, E., Fasching, P. A., Janni, W., Beckmann, M. W., Wimberger, P., Hielscher, C., Fehm, T. N., Brucker, S. Y., Wallwiener, D., Schneeweiss, A. and Wallwiener, M.	Impact of disease progression on health-related quality of life in patients with metastatic breast cancer in the PRAEGNANT breast cancer registry	Breast	2018
Park, E. M., Gelber, S., Rosenberg, S. M., Seah, D. S. E., Schapira, L., Come, S. E. and Partridge, A. H.	Anxiety and Depression in Young Women With Metastatic Breast Cancer: A Cross-Sectional Study	Psychosomatics	2018
Parry, M.	Introducing the Metastatic Breast Cancer Project: a novel patient-partnered initiative to accelerate understanding of MBC	ESMO Open	2018
Parry, Marina	Introducing the Metastatic Breast Cancer Project: a novel patient-partnered initiative to accelerate understanding of MBC	ESMO open	2018
Pe, M., Dorme, L., Coens, C., Basch, E., Calvert, M., Campbell, A., Cleeland, C., Cocks, K., Collette, L., Dirven, L., Dueck, A. C., Devlin, N., Flechtner, H. H., Gotay, C., Griebsch, I., Groenvold, M., King, M., Koller, M., Malone, D. C., Martinelli, F., Mitchell, S. A., Musoro, J. Z., Oliver, K., Piault-Louis, E., Piccart, M., Pimentel, F. L., Quinten, C., Reijneveld, J. C., Sloan, J., Velikova, G. and Bottomley, A.	Statistical analysis of patient-reported outcome data in randomised controlled trials of locally advanced and metastatic breast cancer: a systematic review	Lancet Oncol	2018
Poorvu, P. D., Vaz-Luis, I., Freedman, R. A., Lin, N. U., Barry, W. T., Winer, E. P. and Hassett, M. J.	Variation in guideline-concordant care for elderly patients with metastatic breast cancer in the United States	Breast Cancer Res Treat	2018
Spronk, I., Burgers, J. S., Schellevis, F. G., van Vliet, L. M. and Korevaar, J. C.	The availability and effectiveness of tools supporting shared decision making in metastatic breast cancer care: a review	BMC Palliat Care	2018

Authors	Title	Journal	Date
Thrift-Perry, M., Cabanes, A., Cardoso, F., Hunt, K. M., Cruz, T. A. and Faircloth, K.	Global analysis of metastatic breast cancer policy gaps and advocacy efforts across the patient journey	Breast	2018
Tometich, D. B., Mosher, C. E., Hirsh, A. T., Rand, K. L., Johns, S. A., Matthias, M. S., Outcalt, S. D., Schneider, B. P., Mina, L., Storniolo, A. M. V., Newton, E. V. and Miller, K. D.	Metastatic breast cancer patients' expectations and priorities for symptom improvement	Support Care Cancer	2018
Tosello, G., Torloni, M. R., Mota, B. S., Neeman, T. and Riera, R.	Breast surgery for metastatic breast cancer	Cochrane Database Syst Rev	2018
	Cancer Research Driven by Patients and Technology	Cancer Discov	2019
Bergqvist, J. and Strang, P.	Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy	J Pain Symptom Manage	2019
Gogate, A., Rotter, J. S., Trogdon, J. G., Meng, K., Baggett, C. D., Reeder-Hayes, K. E. and Wheeler, S. B.	An updated systematic review of the cost-effectiveness of therapies for metastatic breast cancer	Breast Cancer Res Treat	2019
Goyal, R. K., Carter, G. C., Nagar, S. P., Smyth, E. N., Price, G. L., Huang, Y. J., Li, L., Davis, K. L. and Kaye, J. A.	Treatment patterns, survival and economic outcomes in Medicare-enrolled, older patients with HR+/HER2- metastatic breast cancer	Curr Med Res Opin	2019
Houts, A. C., Olufade, T., Shenolikar, R., Walker, M. S. and Schwartzberg, L. S.	Treatment patterns, clinical outcomes, health resource utilization, and cost in patients with BRCA-mutated metastatic breast cancer treated in community oncology settings	Cancer Treat Res Commun	2019
MacDonald, Taylor, Krishnan, Vignesh and Wilson, William Alexander	Palliative care access in the elderly metastatic breast cancer population: obstacles and opportunities	Translational Cancer Research	2019
Reiser, V., Rosenzweig, M., Welsh, A., Ren, D. and Usher, B.	The Support, Education, and Advocacy (SEA) Program of Care for Women With Metastatic Breast Cancer: A Nurse-Led Palliative Care Demonstration Program	Am J Hosp Palliat Care	2019
Reyes, C., Engel-Nitz, N. M., DaCosta Byfield, S., Ravelo, A., Ogale, S., Bancroft, T., Anderson, A., Chen, M. and Matasar, M.	Cost of Disease Progression in Patients with Metastatic Breast, Lung, and Colorectal Cancer	Oncologist	2019
Rocque, G. B., Rasool, A., Williams, B. R., Wallace, A. S., Niranjan, S. J., Halilova, K. I., Turkman, Y. E., Ingram, S. A., Williams, C. P., Forero-Torres, A., Smith, T., Bhatia, S. and Knight, S. J.	What Is Important When Making Treatment Decisions in Metastatic Breast Cancer? A Qualitative Analysis of Decision-Making in Patients and Oncologists	Oncologist	2019

Authors	Title	Journal	Date
Rosenzweig, M., West, M., Matthews, J., Stokan, M., Yoojin Kook, Y. K., Gallups, S. and Diergaarde, B.	Financial Toxicity Among Women With Metastatic Breast Cancer	Oncol Nurs Forum	2019
Smeeding, J., Malone, D. C., Ramchandani, M., Stolshek, B., Green, L. and Schneider, P.	Biosimilars: Considerations for payers	P and T	2019
Subbiah, I. M., Hamilton, E., Knoll, M., Shanahan, K. and Meisel, J.	A Big World Made Small: Using Social Media to Optimize Patient Care	Am Soc Clin Oncol Educ Book	2019
Waks, A. G. and Winer, E. P.	Breast Cancer Treatment: A Review	Jama	2019
Williams, C. P., Azuero, A., Kenzik, K. M., Pisu, M., Nipp, R. D., Bhatia, S. and Rocque, G. B.	Guideline Discordance and Patient Cost Responsibility in Medicare Beneficiaries With Metastatic Breast Cancer	J Natl Compr Canc Netw	2019
Yu, J. B., Pollack, C. E., Herrin, J., Zhu, W., Soulos, P. R., Xu, X. and Gross, C. P.	Persistent Use of Extended Fractionation Palliative Radiotherapy for Medicare Beneficiaries With Metastatic Breast Cancer, 2011 to 2014	Am J Clin Oncol	2019
Feinberg, B., Kish, J., Dokubo, I., Wojtynek, J., Gajra, A. and Lord, K.	Comparative Effectiveness of Palliative Chemotherapy in Metastatic Breast Cancer: A Real-World Evidence Analysis	Oncologist	2020
Ginter, A. C.	The day you lose your hope is the day you start to die: Quality of life measured by young women with metastatic breast cancer	J Psychosoc Oncol	2020
Gradishar, W. J., Anderson, B. O., Abraham, J., Aft, R., Agnese, D., Allison, K. H., Blair, S. L., Burstein, H. J., Dang, C., Elias, A. D., Giordano, S. H., Goetz, M. P., Goldstein, L. J., Isakoff, S. J., Krishnamurthy, J., Lyons, J., Marcom, P. K., Matro, J., Mayer, I. A., Moran, M. S., Mortimer, J., O'Regan, R. M., Patel, S. A., Pierce, L. J., Rugo, H. S., Sitapati, A., Smith, K. L., Smith, M. L., Soliman, H., Stringer-Reasor, E. M., Telli, M. L., Ward, J. H., Young, J. S., Burns, J. L. and Kumar, R.	Breast Cancer, Version 3.2020, NCCN Clinical Practice Guidelines in Oncology	J Natl Compr Canc Netw	2020
Haslam, A., Herrera-Perez, D., Gill, J. and Prasad, V.	Patient Experience Captured by Quality-of-Life Measurement in Oncology Clinical Trials	JAMA Netw Open	2020
Kim, K. N., Qureshi, M. M., Huang, D., Ko, N. Y., Cassidy, M., Oshry, L. and Hirsch, A. E.	The Impact of Locoregional Treatment on Survival in Patients With Metastatic Breast Cancer: A National Cancer Database Analysis	Clin Breast Cancer	2020
Komorowski, A. S., Warner, E., MacKay, H. J., Sahgal, A., Pritchard, K. I. and Jerzak, K. J.	Incidence of Brain Metastases in Nonmetastatic and Metastatic Breast Cancer: Is There a Role for Screening?	Clin Breast Cancer	2020

Authors	Title	Journal	Date
Li, A., Schleicher, S. M., Andre, F. and Mitri, Z. I.	Genomic Alteration in Metastatic Breast Cancer and Its Treatment	Am Soc Clin Oncol Educ Book	2020
Malmgren, J. A., Calip, G. S., Atwood, M. K., Mayer, M. and Kaplan, H. G.	Metastatic breast cancer survival improvement restricted by regional disparity: Surveillance, Epidemiology, and End Results and institutional analysis: 1990 to 2011	Cancer	2020
Niranjan, S. J., Turkman, Y., Williams, B. R., Williams, C. P., Halilova, K. I., Smith, T., Knight, S. J., Bhatia, S. and Rocque, G. B.	I'd Want to Know, Because a Year's Not a Long Time to Prepare for a Death: Role of Prognostic Information in Shared Decision Making among Women with Metastatic Breast Cancer	J Palliat Med	2020
Qi, X., Wang, K., Sun, D. and Zhang, L.	Does Choice of Reconstruction Type Affect Survival in Patients With Metastatic Breast Cancer?	J Surg Res	2020
Samuel, C. A., Spencer, J. C., Rosenstein, D. L., Reeder-Hayes, K. E., Manning, M. L., Sellers, J. B. and Wheeler, S. B.	Racial differences in employment and cost-management behaviors in patients with metastatic breast cancer	Breast Cancer Res Treat	2020
Savas, P. and Loi, S.	Metastatic Breast Cancer: TIL it is Too Late	Clin Cancer Res	2020
Trogdon, J. G., Baggett, C. D., Gogate, A., Reeder-Hayes, K. E., Rotter, J., Zhou, X., Ekwueme, D. U., Fairley, T. L. and Wheeler, S. B.	Medical costs associated with metastatic breast cancer in younger, midlife, and older women	Breast Cancer Res Treat	2020
Van Mechelen, M., Van Herck, A., Punie, K., Nevelsteen, I., Smeets, A., Neven, P., Weltens, C., Han, S., Vanderstichele, A., Floris, G., Lobelle, J. P. and Wildiers, H.	Behavior of metastatic breast cancer according to subtype	Breast Cancer Res Treat	2020
Vyas, A. M., Aroke, H. and Kogut, S.	Guideline-Concordant Treatment Among Elderly Women With HER2-Positive Metastatic Breast Cancer in the United States	J Natl Compr Canc Netw	2020
Williams, C. P., Pisu, M., Azuero, A., Kenzik, K. M., Nipp, R. D., Aswani, M. S., Mennemeyer, S. T., Pierce, J. Y. and Rocque, G. B.	Health Insurance Literacy and Financial Hardship in Women Living With Metastatic Breast Cancer	JCO Oncol Pract	2020

APPENDIX D: LEGISLATIVE SCAN, 2015-2020

California Legislation Related to MBC

Year	Bill	Bill Status
Awareness & Detection		
2015-2016	ACR 62, Baker. California Cancer Survivors Day.	Passed
2015-2016	AB 1795, Atkins. Health care programs: cancer.	Passed
2015-2016	ACR 63, Steinorth, Breast Cancer Awareness and Prevention Month	Passed
2017-2018	SCR-160 Metastatic Breast Cancer Awareness Day.	Passed
2017-2018	SB 440, Hertzberg. Personal income taxes: voluntary contributions: California Breast Cancer Research Voluntary Tax Contribution Fund and California Cancer Research Voluntary Tax Contribution Fund.	Passed
2017-2018	SB 1034, Mitchell. Health care: mammograms.	
2019-2020	ACR 94, Reyes. Inflammatory Breast Cancer Awareness Day of 2019.	Passed
Diagnosis		
2015-2016	AB 2325, Bonilla. Ken Maddy California Cancer Registry.	
Treatment (including costs of care, Rx)		
2015-2016	AB 1795 Health care programs: cancer	Passed
2015-2016	AB 2209, as amended, Bonilla. Health care coverage: clinical pathways.	Not passed

2015-2016	AB 2764, Bonilla, Mammography	Not passed
2017-2018	SB 945, as introduced, Atkins. Breast and Cervical Cancer Treatment Program.	Not passed
2017-2018	AB 315, Wood. Pharmacy benefit management.	Passed
2017-2018	SB 1021, Wiener. Prescription drugs.	Passed
2017-2018	AB 265, Wood. Prescription drugs: prohibition on price discount.	Passed
2017-2018	AB 1353, as amended, Waldron. Health care coverage: prescription drugs: continuity of care.	Not passed
2017-2018	AB 1107, as amended, Nazarian. Oncology Clinical Pathway Act of 2017.	Not passed
2017-2018	AB 1860, Limon. Cancer treatment.	Passed
2017-2018	SB 500, Portantino. Fertility preservation.	Passed
2017-2018	SB 583, Jackson. Clinical trials.	Passed
2019-2020	SB 746, as amended, Bates. Health care coverage: anticancer medical devices.	Not passed
2019-2020	AB 2144, as amended, Arambula. Health care coverage: step therapy.	Pending
2019-2020	SB 1452, as amended, Morrell. Biological products.	Pending
2019-2020	AB 2640, as introduced, Gonzalez. Health care coverage: genetic biomarker testing.	Pending
Palliative Care, Management, Care Coordination		
2015-2016	SB 815, Hernandez. Medi-Cal: demonstration project.	Passed
2015-2016	AB 1568, Bonta. Medi-Cal: demonstration project.	Passed

2015-2016	SB 1002, as amended, Monning. End of Life Option Act: telephone number.	Not passed
2015-2016	SCR 117, Pan. Palliative care.	Passed
2017-2018	SB 294, Hernandez. Hospice: services to seriously ill patients.	Passed
2019-2020	AB 567, Calderon. Long-term care insurance.	Passed
2019-2020	AB 1287 Universal assessments: No Wrong Door system	Passed
End-of-Life		
2015-2016	AB 15, Eggman. End of life.	Passed
2017-2018	SB 1336, as amended, Morrell. Public health: End of Life Option Act.	Not passed

State and Federal Legislation Directly Related to MBC

Year	Bill	Federal or State	Description	Status
1998	Federal Breast Reconstruction Law (Women's Health and Cancer Rights Act)	Federal	Requires health insurance plans that cover mastectomy to cover breast reconstruction surgery and other post-mastectomy procedures	Passed
2001	Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001	Federal	Native American Women with breast or cervical cancer are included in Medicaid eligibility	Passed
2003	Breast Cancer Patient Protection Act of 2003	Federal	Require health insurance coverage for a minimum 48 hour stay for patients undergoing a mastectomy	Passed
2018	HR 820 Childhood Cancer STAR Act	Federal	Provide support to the NIH for childhood cancers to better understand the cancers and effects of treatment	Passed
2018	HB 4821	Illinois	Provides that health insurance coverage be required to cover treatment for stage 4 metastatic cancer	Passed
2018	A09586	New York	Relates to duties of providers of mammography services to notify and inform patients if a mammogram shows dense breast tissue	Passed

2018	HB 258	Utah	Requires a facility that performs mammography to notify patients who have dense breast tissue	Passed
2019	Act 181	Arkansas	Concerns the pursuit of a National Cancer Center at the University of Arkansas	Passed
2018	Stage Four Advanced Metastatic Cancer Step Therapy	Colorado	Prohibits carriers from requiring step therapy for covered patients with stage four metastatic cancer	Passed
2019	HB 62 Margie's Law	Georgia	Requires mammography providers to notify patients about their breast density	Passed
2019	HJR 12	Texas	Proposes a constitutional amendment authorizing the legislature to increase to maximum amount authorized for the Cancer Prevention and Research Institute of Texas	Pending
2019	HR 1730/S741 Cancer Drug Parity Act	Federal	Requires any health plan that provides coverage for chemotherapy to provide coverage for self-administered chemotherapy at a favorable cost	Pending
2019	HR 913 Clinical Treatment Act	Federal	Guarantees coverage for clinical trials for Medicaid enrollees	Pending
2019	HR 2428 Access to Breast Cancer Diagnosis Act	Federal	Prohibits health plans from imposing cost-sharing requirements with respect to exams for breast cancer	Pending
2019	HR 2689 Breast Cancer Research Stamp Reauthorization Act	Federal	Extends authority to USPS to raise funds for breast cancer research	Pending
2019	S 562/HR 1370 Breast Cancer Patient Equity Act	Federal	Provides for Medicare to cover custom fabricated breast prostheses following mastectomy	Pending
2019	S 946/ HR 1966 Henrietta Lacks Enhancing Cancer Research Act of 2019	Federal	Calls for the GAO to complete a study regarding federal agencies actions to address barriers to participation in cancer clinical trials by underrepresented populations	Pending
2019	HR 647/ S 2080 Palliative Care and Hospice Education and Training Act	Federal	establish Palliative Care and Hospice Education Centers and to provide support for projects that fund the training of physicians who plan to teach palliative medicine.	Pending
2019	HR 2777/ S 1936 Protecting Access to Lifesaving Screening Act	Federal	Protect access to annual mammograms with insurance coverage with no-copay starting at age 40	Pending
2019	HR 2178/ S 1374 Metastatic Breast Cancer Access to Care Act	Federal	eliminate the waiting periods for disability insurance benefits and Medicare coverage for individuals with metastatic breast cancer, and for other purposes.	Pending

2019	Breast Cancer Patient Equity Act (S. 562, H.R. 1370)	Federal	provides for Medicare coverage of custom fabricated breast prostheses following the surgical removal of the breast (i.e., a mastectomy), including replacements of such prostheses.	pending

APPENDIX E: TWITTER CHAT DATA: #BCSM MBC 18 NOVEMBER 2019

Participant	N (%)	Unique Tweet (N)	Retweet (N)	Total
Patient or advocate	23 (56%)	122	22	144
Clinical provider	7 (17%)	91	24	115
Advocacy organization	6 (15%)	6	4	10
Researcher/academic	5 (12%)	5	3	8
Total	41	224	53	277

Question	Participant Tweet
Q1 - what are some of the most significant healthcare communication barriers faced by patients w/metastatic breast cancer?	“One big issue is agreeing on next line of therapy when it’s chemo esp [especially] when onc [oncologist] insists on giving maximum dose. Just spoke to helpline caller today & she was freaking out about being able to have QOL [quality of life] with new tx [treatment] suggested. Need pt [patient] centered dosing.” “MBC pts often try to look as good as possible at their onc appts and may not report QOL issues unless oncologist asks. Some don’t ask.” “MBC is not treated under a curative manner like early stage. Goal is to extend length and QOL. Lower doses have been shown to be effective. So why throw an atomic bomb at an MBC pt who obviously won’t tolerate it?” “From an insurance perspective, they don't always feel the urgency. Just waiting on approvals can feel like an eternity when there is progression” “What about insurance pre-approvals for routine scans and being rejected? That is a real anxiety builder for MBC pts who are vulnerable because they don’t know if they’ve had progression. Sleepless nights.” “As I reflect back on the "chaos" of #metastatic #breastcancer faced by #theloveofmylife obviously, I think about Maureen and her pain first. But that same "chaos" is external... docs, insurance, pharmacy, etc.” “There are misunderstandings in terminology. Onc says “Your MBC is stable” and [patient] hears “your tumors aren’t shrinking. Bad news!”” “Big communication issue is communication style – pt usually has a preference for how detailed they want their [oncologist] to be. Need to discuss this up front. Otherwise pt often seeks new onc.”

Question	Participant Tweet
Q2 - what are the palliative care barriers faced by those with metastatic breast cancer?	“I heard earlier from pt on clinical trial, couldn't keep palliative care team” “Palliative care is not always discussed with patients and not explained well. For a long time I thought palliative care and hospice were synonymous.” “My plan’s Palliative Care Team is still figuring out what they do for a living. Right now focus is mainly advanced directives and pain meds [medications]. Should get better but not yet.” “Denials from insurance companies for meds/treatments that have been proven standard of care & deemed necessary by patients oncologist. Fear of step therapy. Fear of FDA limiting access to needed/necessary drugs to function and have decent QOL.”
Q3 - what are the financial challenges faced by patients w/metastatic breast cancer?	“Surprise co-pays for new therapies once the line of therapy is established. Then scrambling for payment assistance when already stressed by progression.” “Was recently told that I could not continue PT [physical therapy] because I had already had 35 and anything beyond would be out of pocket. So now I either pay for PT or just wait until January.” “To make matters worse/more frustrating - for treatment meds taken at home... Many private insurers change their formulary lists twice/year…MD [doctor] offices often can't keep up with those changes & pts find out after the fact.” “Disability. I haven't been down this road, but know people who have. Stressful when [it’s] reviewed and you have to go [through] whole process again.”

Question	Participant Tweet
Q4 - what are barriers to obtaining disability?	“Big barrier to getting disability is the pt doesn’t know the process of applying if employed, small companies don’t know what to do.” “[Regarding] disability I've also seen some tweets from patients that if they apply for medication financial assistance program that can limit their disability... doesn't seem right” “There are lots of people who are contract workers (especially in high tech). They don’t have disability insurance as aren’t aware of state disability.”
Q5 - what health system or policy changes would you suggest to improve the care experience for patients w/metastatic breast cancer	“Besides patient centered dosing, we need to make it easier to be in clinical trials without requiring expensive travel costs to pts. We limit who can be in a trial by pts who are unable to pay for travel.” “Would love for [insurance] companies to have a separate group just for metastatic (maybe unrealistic) but would have training and understand the unique needs of that group.” “We need MBC pts to undergo retesting for receptor status & genetic changes upon progression, esp when pt was on a therapy for a good amount of time. If we don’t, next therapy line may be totally ineffective.” “Maybe it would be a good idea to have a national nurse navigator organization that would work like a hotline. So even remote access.” “Obviously we need resources. We need support, we can’t find things we don’t know exist. There should be a universal guide given to all patients at diagnosis.” “Metastatic patients don’t have nurse navigators.” “Nurse navigators aren't always diagnosis specific, they are clinic & practice specific (or they freelance). Sadly, they aren't widely available. Some cancer ctrs [centers] have none, some have several, & some private oncology groups have 2! Very uneven.”

Question	Participant Tweet
	“I'm too tired to type now but have list of challenges. Constant battle to get care from health teams that will preserve QOL. Neuropathy, GERD, rare side effects, and on and on. I'm adept at article reviews to take info to doc. But it's exhausting.”