

Living with Advanced Breast Cancer

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Survivors of advanced breast cancer (ABC), also known as metavivors, are often left with fewer treatment options in the landscape of a cure culture. Metavivors have unique psychosocial and physical needs distinct from patients with early-stage breast cancer.

metastatic breast cancer

side effects

metavivorship

breast neoplasms

1. Introduction

Breast cancer is the most common type of cancer in women, with a lifetime incidence of 12.9%. Additionally, it affects a small percentage of men. There were an estimated 281,550 new cases diagnosed in 2021 ^[1]. Of these patients, 6% will be diagnosed with de novo or recurrent advanced breast cancer (ABC). Historically, this group has faced a 5-year survival of just 29% ^[2]. Furthermore, 30% of those diagnosed with early-stage breast cancer will develop metastatic disease ^[3]. The short life expectancy for patients diagnosed with ABC has led to their exclusion from survivorship services frequently offered to patients with early-stage, localized breast cancer ^[4]. ABC survivors are left with fewer options in the landscape of a cure culture where treatment options aimed at eradicating disease are the main focus of treatment, research and funding. However, those living with ABC have unique psychosocial and physical needs distinct from patients with early-stage breast cancer, and they merit recognition ^[5]. The National Institutes of Health (NIH), American Society of Clinical Oncology (ASCO), and other entities have recognized that this limited focus has resulted in a dearth of research in the area of “metavivorship”, a focus on the well-being of patients with advanced cancer ^[6]. Novel treatments for this population have dramatically improved survival, particularly for patients with hormone receptor-positive and HER2-positive breast cancer ^[7]. It is critical that researchers consider the various side effects patients with advanced breast cancer experience in relation to their treatment. Furthermore, research has shown that supportive care, including early involvement of palliative care, improves outcomes for patients with metastatic cancer ^{[8][9][10]}. The results of these studies counter the conventional practice of providing palliative care only in end-of-life situations. They highlight the importance of conducting clinical research on the lived experience of patients with ABC. To this end, researchers must seek to mitigate or remove any barriers to participation patients may experience.

2. Known Side Effects

2.1. Fatigue

Fatigue can be debilitating for patients with ABC. A meta-analysis by Al Maqbali et al. of 129 clinical trials conducted between 1993 and 2020 estimated that 60.6% of patients with advanced breast cancer experienced fatigue [11]. Fatigue is common among those who have been treated with chemotherapy, immunotherapy, or hormone therapy [12], and can be associated with the site of metastasis [13][14]. While fatigue is inherently difficult to quantify, studies employ questionnaires beginning at the time of treatment and continuing at fixed intervals afterward to identify chronic treatment-related symptoms. These studies show that 30–60% of patients report moderate to severe fatigue during treatment, and up to a quarter of them still experience symptoms 10 years after treatment [15]. Studies have also uncovered correlations between reported fatigue and overall lack of motivation as well as negative mood [16]. Studies focused on patients with ABC are more limited but suggest that effective treatment strategies may be distinct from those known to be effective for patients with limited stage disease. For example, a trial conducted by Poort et al. evaluating patients with ABC found greater benefit with cognitive behavioral therapy (CBT) compared with exercise and usual care [17]. CBT in this entry addressed patients' sleep; coping strategies; self-efficacy; physical, social, and mental activities; and social support. These findings underscore the need for specialized treatment for ABC.

2.2. Anxiety

Anxiety among patients with metastatic cancer is an area frequently analyzed. Studies have found that those diagnosed with depression or anxiety have worse outcomes. Wang et al. performed a systematic review and meta-analysis of 2.6 million patients with any cancer diagnosis by assessing reports of anxiety/depression and measured outcomes. This analysis revealed higher cancer incidence, poorer survival, and higher cancer-specific mortality among patients with a diagnosis of anxiety and depression [18]. An Australian study of 227 patients with ABC found that over a third experienced anxiety, depression, or both, and 17% of these patients were ultimately diagnosed with an anxiety disorder [19]. Dobretsova and Deraskan found a link between anxiety, traumatic stress and decreased cognitive function. Recommending social support is an important intervention in buffering against these effects [20]. Given the broad availability of effective treatments for anxiety and depression such as psychotherapy [21], mindfulness [22], and anti-depressant medications [23], it is critical that patients are regularly screened using multimodal assessments (questionnaires, GAD10, PHQ, etc.) and subsequently referred for appropriate mental health services [24]. Unfortunately, relatively few studies have evaluated treatment for anxiety among patients with advanced cancer. Sakamoto and Koyama evaluated current medical management strategies and suggest that the medication quetiapine could be a better alternative to the more commonly prescribed benzodiazepines or selective serotonin reuptake inhibitors (SSRIs) [25]. Current guidelines therefore recommend a personalized and stepped model for treatment delivery [26].

3. Areas of Need for Future Study

3.1. Caregiver Support

Family-centered care is key to the health of patients with metastatic breast cancer. Emotional support is important for the well-being of all people, and vital for patients with ABC. It is clear from studies focused on caregivers that

they have unique needs, and the tremendous weight of their responsibilities as caregivers can lead to negative outcomes such as lower quality of life and impaired workplace productivity [27][28]. Northouse and others found that caregivers who employed maladaptive coping strategies such as alcohol use, affected the patient's quality of life [29]. Caregiver quality of life seems to benefit from patient referral to palliative care provided early in treatment [30]. Lack of access remains a key barrier. For example, qualitative studies focused on caregivers of patients living in rural areas have confirmed caregiver demand for palliative care services and highlighted lack of access to both in person and telehealth options [31]. Maslow, Allicock and Johnson's study of 41 Black cancer survivors and their caregivers consisted of a focus group to discuss cancer survivor and caregiver needs. Both survivors and caregivers expressed their concern about the availability of culturally appropriate support services [32]. There is a great need for community-based support structures, and it is healthcare centers' duty to explore ways to provide these services. Caregivers are an important part of the care team and should be included when considering treatment for patients with ABC. Deeper research into how best to support caregivers is warranted.

3.2. Financial Toxicity

There are substantial financial costs associated with any major illness, and cancer is no exception. Economically disadvantaged patients are not only lacking monetary wealth to overcome financial toxicity (FT) but are also less likely to have knowledge of financial fail-safes such as those listed in **Table 1**. FT can lead to decreased quality of life, and general cancer-related distress [33]. A recent study by Wan et al. evaluated the financial toxicity among patients with ABC by stratifying groups using an 11-item survey dubbed the Comprehensive Score for Financial Toxicity (COST). The groups most frequently experiencing FT included Black patients, hormone receptor-negative patients, low-income patients, and unmarried patients [34]. Lifelong continuous treatment for ABC continues to be as debilitating financially as it is medically. Expanded research and financial assistance programs directed toward patients with ABC will be crucial moving forward.

Table 1. Several financial assistance programs can allay financial strain resulting from extensive cancer therapy. However, many are geared toward short-term treatments provided for early-stage cancers. Here, researchers list resources tailored to assist with management of long-term cancer treatment.

Organization	Website	Phone	Assistance
American Cancer Society	www.cancer.org (accessed on 22 April 2022)	800-227-2345	Reimbursements for costs associated with cancer treatment
Breast Cancer Assistance Fund	https://breastcanceraf.org (accessed on 22 April 2022)	866-413-5789	Need-based financial assistance for non-medical costs of getting a patient to treatment and other living

Organization	Website	Phone	Assistance
			expenses that may be incurred
Cancer Care	www.CancerCare.org (accessed on 22 April 2022)	800-813-HOPE	Counseling, education, support groups, need-based financial aid for treatments
Cancer Care Co-Payment Assistance Foundation	www.cancercopay.org (accessed on 22 April 2022)	866-552-6729	Copay assistance
Cancer Financial Assistance Coalition	https://www.cancerfac.org (accessed on 22 April 2022)	not applicable	Coalition of financial assistance organizations joining forces to help cancer patients experience better health and well-being by limiting financial challenges.
Cancer Supportive Care	http://www.cancersupportivecare.com/drug_assistance.html (accessed on 22 April 2022)	Not applicable	Listing of pharmaceutical drug assistance programs with contact information.
The Health Well Foundation	www.healthwellfoundation.org (accessed on 22 April 2022)	800-675-8416	Need-based financial assistance with coinsurance, copays, premiums, and deductibles.
Needy Meds	www.needymeds.com (accessed on 22 April 2022)	Not applicable	Non-profit organization with a database of patient assistance programs to include drug discount programs and state assistance programs.

Organization	Website	Phone	Assistance	
Susan G. Komen	www.komen.org (accessed on 22 April 2022)	877- 465-6636	Need-based financial assistance with treatment payments	
Patient Access Network Foundation	www.panfoundation.org (accessed on 22 April 2022)	866-316-7263	Need-based financial assistance with copays, deductibles, and medications.	
Partnership for prescription assistant	https://www.phrma.org/patient-support (accessed on 22 April 2022)		Non-profit organization sponsored by Pharmaceutical Research and Manufacturers of America's (PhRMA), civic groups, and patient advocacy organizations. This group is dedicated to helping patients find free or low-cost brand-name prescriptions.	
Patient Advocate Foundation on CoPay Relief	www.copays.org (accessed on 22 April 2022)	866-512-3861	Need-based financial assistance with copays for prescription drugs	experiencing
^[35] Remember Betty ^[38]	^[36] http://rememberbetty.com ^[37] (accessed on 22 April 2022)		Helps minimize the financial burden associated with breast cancer for patients and survivors so they can focus on recovery and quality of life.	der. It is in reported cell count ons to the an bolster l meaning ing skills,
RxHope	https://www.rxhope.com/ (accessed on 22 April 2022) ^[39]	Not applicable	Rx Hope advocates for patients and helps them navigate available	remains an d spiritual

Emotional distress is a primary inhibitor of a patient's quality and enjoyment of life. While not quite synonymous with "fear of the future" ^[40], distress is often a result of helplessness stemming from a metastatic cancer diagnosis ^[41]. Left unmanaged, emotional distress can lead to decreased quality of life and is associated with several

Organization ^[42]	Website	Phone	Assistance	Assessment and
	^[43]		assistance programs.	patients with

advanced cancer experienced mood disorders ^[44]. It has also been found that patients who engaged in active coping with a support person experienced fewer mood disorders ^[45]. While quality of life (QOL) surveys are ubiquitous in the study of patients with breast cancer, a more specialized and holistic analysis tailored to ABC would be valuable in helping future patients cope with their diagnosis.

3.4. Long-Term Immune Therapy Effects

Immunotherapy is standard of care for patients with triple-negative breast cancer and will likely play a larger role in the treatment of all cancers moving forward. As treatment with immunotherapy becomes increasingly commonplace, studies evaluating immune-related adverse events (irAEs) will be critical. Patients who experience a complete response to immunotherapy treatment and achieve long-term survival will likely have unique long-term needs resulting from their treatment. These may include treatment for new chronic conditions such as type 1 diabetes, Addison’s disease, hypothyroidism, and others. IrAEs such as fatigue and anxiety present complex needs, and further study is needed to address their treatment.

3.5. Education

Patients with ABC have unique psychosocial, physical, and treatment needs distinct from those patients with early-stage breast cancer ^[46]. Previous studies illustrate that clinical trials are foundational to the improvement of healthcare delivery. However, clinical trials only succeed when patients have access to the opportunity and consent to become involved. Furthermore, inequities in clinical trial focus related to supportive care screening and lack of diversity in participant population further fuel a cycle of inequality.

As such, educating all eligible patients about clinical trial opportunities is key. The education should include what clinical trials are, why they are standard of care, and when they should be considered.

References

1. American Cancer Society. Cancer Facts & Figures 2022; American Cancer Society: Atlanta, GA, USA, 2022.
2. Surveillance, Epidemiology, and End Results (SEER) Program. Available online: <https://seer.cancer.gov/statfacts/html/breast.html> (accessed on 22 April 2022).
3. O’Shaughnessy, J. Extending Survival with Chemotherapy in Metastatic Breast Cancer. *Oncologist* 2005, 10, 20–29.
4. Di Lascio, S.; Pagani, O. Is it time to address survivorship in advanced breast cancer? A review article. *Breast* 2017, 31, 167–172.

5. Mayer, M.; Grober, S. Silent Voices: Women with Advanced (Metastatic) Breast Cancer Share Their Needs and Preferences for Information, Support and Practical Resources; Living Beyond Breast Cancer: Bala Cynwyd, PA, USA, 2014.
6. Jacobsen, P.B.; Nipp, R.D.; Ganz, P.A. Addressing the Survivorship Care Needs of Patients Receiving Extended Cancer Treatment. *Am. Soc. Clin. Oncol Educ. Book* 2017, 37, 674–683.
7. Kay, C.; Martínez-Pérez, C.; Meehan, J.; Gray, M.; Webber, V.; Dixon, J.M.; Turnbull, A.K. Current trends in the treatment of HR+/HER2+ breast cancer. *Future Oncol.* 2021, 17, 1665–1681.
8. Haun, M.W.; Estel, S.; Rücker, G.; Friederich, H.C.; Villalobos, M.; Thomas, M.; Hartmann, M. Early palliative care for adults with advanced cancer. *Cochrane Database Syst. Rev.* 2017, 6, Cd011129.
9. Pallotti, M.C.; Ricci, M.; Rossi, R.; Cecconetto, L.; Barone, D.; Maltoni, M. Palliative care: Not only for treating symptoms: A case report. *Tumori* 2020, 106, Np1–Np4.
10. Temel, J.S.; Greer, J.A.; Muzikansky, A.; Gallagher, E.R.; Admane, S.; Jackson, V.A.; Dahlin, C.M.; Blinderman, C.D.; Jacobsen, J.; Pirl, W.F.; et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N. Engl. J. Med.* 2010, 363, 733–742.
11. Al Maqbal, M.; Al Sinani, M.; Al Naamani, Z.; Al Badi, K.; Tanash, M.a.I. Prevalence of Fatigue in Patients With Cancer: A Systematic Review and Meta-Analysis. *J. Pain Symptom Manag.* 2021, 61, 167–189.
12. Thong, M.S.Y.; van Noorden, C.J.F.; Steindorf, K.; Arndt, V. Cancer-Related Fatigue: Causes and Current Treatment Options. *Curr. Treat. Options Oncol.* 2020, 21, 17.
13. Delrieu, L.; Anota, A.; Trédan, O.; Freyssen, D.; Maire, A.; Canada, B.; Fournier, B.; Febvey-Combes, O.; Pilleul, F.; Bouhamama, A.; et al. Design and methods of a national, multicenter, randomized and controlled trial to assess the efficacy of a physical activity program to improve health-related quality of life and reduce fatigue in women with metastatic breast cancer: ABLE02 trial. *BMC Cancer* 2020, 20, 622.
14. Headley, J.A.; Ownby, K.K.; John, L.D. The effect of seated exercise on fatigue and quality of life in women with advanced breast cancer. *Oncol. Nurs. Forum.* 2004, 31, 977–983.
15. Bower, J.E. Cancer-related fatigue--mechanisms, risk factors, and treatments. *Nat. Rev. Clin. Oncol* 2014, 11, 597–609.
16. Lacourt, T.E.; Vichaya, E.G.; Escalante, C.; Manzullo, E.F.; Gunn, B.; Hess, K.R.; Heijnen, C.J.; Dantzer, R. An effort expenditure perspective on cancer-related fatigue. *Psychoneuroendocrinology* 2018, 96, 109–117.
17. Poort, H.; Peters, M.; van der Graaf, W.T.A.; Nieuwkerk, P.T.; van de Wouw, A.J.; Nijhuis-van der Sanden, M.W.G.; Bleijenberg, G.; Verhagen, C.; Knoop, H. Cognitive behavioral therapy or

- graded exercise therapy compared with usual care for severe fatigue in patients with advanced cancer during treatment: A randomized controlled trial. *Ann. Oncol.* 2020, 31, 115–122.
18. Wang, Y.H.; Li, J.Q.; Shi, J.F.; Que, J.Y.; Liu, J.J.; Lappin, J.M.; Leung, J.; Ravindran, A.V.; Chen, W.Q.; Qiao, Y.L.; et al. Depression and anxiety in relation to cancer incidence and mortality: A systematic review and meta-analysis of cohort studies. *Mol. Psychiatry* 2020, 25, 1487–1499.
 19. Grabsch, B.; Clarke, D.M.; Love, A.; McKenzie, D.P.; Snyder, R.D.; Bloch, S.; Smith, G.; Kissane, D.W. Psychological morbidity and quality of life in women with advanced breast cancer: A cross-sectional survey. *Palliat. Support. Care* 2006, 4, 47–56.
 20. Dobretsova, A.; Derakshan, N. Cognitive function and emotional vulnerability in metastatic breast cancer: Moderating effects of age and social support. *Psychooncology* 2021, 30, 1563–1571.
 21. Chong Guan, N.; Mohamed, S.; Kian Tiah, L.; Kar Mun, T.; Sulaiman, A.H.; Zainal, N.Z. Psychotherapy for cancer patients. *Int. J. Psychiatry Med.* 2016, 51, 414–430.
 22. Oberoi, S.; Yang, J.; Woodgate, R.L.; Niraula, S.; Banerji, S.; Israels, S.J.; Altman, G.; Beattie, S.; Rabbani, R.; Askin, N.; et al. Association of Mindfulness-Based Interventions With Anxiety Severity in Adults With Cancer: A Systematic Review and Meta-analysis. *JAMA Netw. Open* 2020, 3, e2012598.
 23. Busby, J.; Mills, K.; Zhang, S.D.; Liberante, F.G.; Cardwell, C.R. Selective serotonin reuptake inhibitor use and breast cancer survival: A population-based cohort study. *Breast Cancer Res.* 2018, 20, 4.
 24. Zimmaro, L.A.; Carson, J.W.; Olsen, M.K.; Sanders, L.L.; Keefe, F.J.; Porter, L.S. Greater mindfulness associated with lower pain, fatigue, and psychological distress in women with metastatic breast cancer. *Psychooncology* 2020, 29, 263–270.
 25. Sakamoto, R.; Koyama, A. Effective Therapy Against Severe Anxiety Caused by Cancer: A Case Report and Review of the Literature. *Cureus* 2020, 12, e8414.
 26. Andersen, B.L.; DeRubeis, R.J.; Berman, B.S.; Gruman, J.; Champion, V.L.; Massie, M.J.; Holland, J.C.; Partridge, A.H.; Bak, K.; Somerfield, M.R.; et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: An American Society of Clinical Oncology guideline adaptation. *J. Clin. Oncol* 2014, 32, 1605–1619.
 27. Hasson-Ohayon, I.; Goldzweig, G.; Braun, M.; Galinsky, D. Women with advanced breast cancer and their spouses: Diversity of support and psychological distress. *Psychooncology* 2010, 19, 1195–1204.
 28. Lambert-Obry, V.; Gouault-Laliberté, A.; Castonguay, A.; Zanolli, G.; Tran, T.; Mates, M.; Lemieux, J.; Chabot, P.; Prady, C.; Couture, F.; et al. Real-world patient- and caregiver-reported outcomes in advanced breast cancer. *Curr. Oncol.* 2018, 25, e282–e290.

29. Northouse, L.; Kershaw, T.; Mood, D.; Schafenacker, A. Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psychooncology* 2005, 14, 478–491.
30. McDonald, J.; Swami, N.; Hannon, B.; Lo, C.; Pope, A.; Oza, A.; Leighl, N.; Krzyzanowska, M.K.; Rodin, G.; Le, L.W.; et al. Impact of early palliative care on caregivers of patients with advanced cancer: Cluster randomised trial. *Ann. Oncol.* 2017, 28, 163–168.
31. Dionne-Odom, J.N.; Taylor, R.; Rocque, G.; Chambless, C.; Ramsey, T.; Azuero, A.; Ivankova, N.; Martin, M.Y.; Bakitas, M.A. Adapting an Early Palliative Care Intervention to Family Caregivers of Persons With Advanced Cancer in the Rural Deep South: A Qualitative Formative Evaluation. *J. Pain Symptom Manag.* 2018, 55, 1519–1530.
32. Haynes-Maslow, L.; Allicock, M.; Johnson, L.S. Cancer Support Needs for African American Breast Cancer Survivors and Caregivers. *J. Cancer Educ.* 2016, 31, 166–171.
33. Rosenzweig, M.; West, M.; Matthews, J.; Stokan, M.; Yoojin Kook, Y.K.; Gallups, S.; Diergaarde, B. Financial Toxicity Among Women With Metastatic Breast Cancer. *Oncol. Nurs. Forum.* 2019, 46, 83–91.
34. Wan, C.; Williams, C.P.; Nipp, R.D.; Pisu, M.; Azuero, A.; Aswani, M.S.; Ingram, S.A.; Pierce, J.Y.; Rocque, G.B. Treatment Decision Making and Financial Toxicity in Women With Metastatic Breast Cancer. *Clin. Breast Cancer* 2021, 21, 37–46.
35. Sephton, S.E.; Koopman, C.; Schaal, M.; Thoresen, C.; Spiegel, D. Spiritual expression and immune status in women with metastatic breast cancer: An exploratory study. *Breast J.* 2001, 7, 345–353.
36. Hulett, J.M.; Johnstone, B.; Armer, J.M.; Deroche, C.; Millspaugh, R.; Millspaugh, J. Associations between religious and spiritual variables and neuroimmune activity in survivors of breast cancer: A feasibility study. *Support. Care Cancer* 2021, 29, 6421–6429.
37. Lewis, S.; Salins, N.; Rao, M.R.; Kadam, A. Spiritual well-being and its influence on fatigue in patients undergoing active cancer directed treatment: A correlational study. *J. Cancer Res. Ther.* 2014, 10, 676–680.
38. Kohls, N.; Sauer, S.; Offenbächer, M.; Giordano, J. Spirituality: An overlooked predictor of placebo effects? *Philos. Trans. R Soc. B Biol. Sci.* 2011, 366, 1838–1848.
39. Palmer Kelly, E.; Meara, A.; Hyer, M.; Payne, N.; Pawlik, T.M. Understanding the Type of Support Offered Within the Caregiver, Family, and Spiritual/Religious Contexts of Cancer Patients. *J. Pain Symptom Manag.* 2019, 58, 56–64.
40. Lebel, S.; Rosberger, Z.; Edgar, L.; Devins, G.M. Emotional distress impacts fear of the future among breast cancer survivors not the reverse. *J. Cancer Surviv.* 2009, 3, 117–127.

41. Willis, K.; Lewis, S.; Ng, F.; Wilson, L. The experience of living with metastatic breast cancer--a review of the literature. *Health Care Women Int.* 2015, 36, 514–542.
42. Syrowatka, A.; Motulsky, A.; Kurteva, S.; Hanley, J.A.; Dixon, W.G.; Meguerditchian, A.N.; Tamblyn, R. Predictors of distress in female breast cancer survivors: A systematic review. *Breast Cancer Res. Treat.* 2017, 165, 229–245.
43. Mosher, C.E.; Johnson, C.; Dickler, M.; Norton, L.; Massie, M.J.; DuHamel, K. Living with metastatic breast cancer: A qualitative analysis of physical, psychological, and social sequelae. *Breast J.* 2013, 19, 285–292.
44. Kissane, D.W.; Grabsch, B.; Love, A.; Clarke, D.M.; Bloch, S.; Smith, G.C. Psychiatric disorder in women with early stage and advanced breast cancer: A comparative analysis. *Aust. N. Z. J. Psychiatry* 2004, 38, 320–326.
45. Giese-Davis, J.; Hermanson, K.; Koopman, C.; Weibel, D.; Spiegel, D. Quality of couples' relationship and adjustment to metastatic breast cancer. *J. Fam. Psychol.* 2000, 14, 251–266.
46. MBC Alliance. Metastatic Breast Cancer Landscape Analysis: Research Report. In *Changing the Landscape for People Living with Metastatic Breast Cancer*; MBC Alliance: New York, NY, USA, 2014.

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