

Gaps in care and support for patients with advanced breast cancer: a report from the Advanced Breast Cancer Global Alliance

Article (Published Version)

Fallowfield, Lesley, Boyle, Frances M, Travado, Luzia, Kiely, Belinda E, Jewell, Patti, Aubel, Dawn and Cardoso, Fatima (2021) Gaps in care and support for patients with advanced breast cancer: a report from the Advanced Breast Cancer Global Alliance. *JCO Global Oncology*, 7. pp. 976-984. ISSN 2687-8941

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/100547/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

Copyright and reuse:

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.



Gaps in Care and Support for Patients With Advanced Breast Cancer: A Report From the Advanced Breast Cancer Global Alliance

Lesley Fallowfield, DBE, BSc, DPhil¹; Frances M. Boyle, MD, PhD²; Luzia Travado, PhD³; Belinda E. Kiely, MBBS⁴; Patti Jewell, MPA⁵; Dawn Aibel, EdD, MPH^{6,7}; and Fatima Cardoso, MD³

PURPOSE Although new therapeutic options continue to improve disease-related outcomes in advanced breast cancer (ABC), enhanced focus is needed to improve quality of life for patients currently living with ABC.

METHODS In November 2019, a multidisciplinary workshop to explore patient perceptions of their information and support needs was held at the ABC Global Alliance Annual Meeting in Lisbon, Portugal. Ninety-two attendees from 27 countries participated in the workshop.

RESULTS Several key unmet needs were identified and discussed in the workshop, including the following: (1) Significant patient knowledge gaps exist related to the diagnosis and management of ABC, and the availability of patient-focused information to support these gaps in knowledge remains limited. (2) The development of meaningful relationships between patients and health care professionals, and the role of patients in decision making, is often overlooked for patients with ABC. (3) Multidisciplinary care approaches are crucial for patients with ABC; however, these often lack effective coordination. (4) Access to clinical trials for ABC also remains limited. (5) Caregivers, friends, and family members do not receive sufficient guidance to support patients with ABC and manage their own well-being.

CONCLUSION The variety of unmet needs explored in the workshop demonstrates that patients with ABC still face considerable challenges related to quality of care and support, which will not be resolved until tangible action is taken. Issues highlighted in the workshop should be prioritized by working groups to shape the development of community-based solutions. There is a need for the global community to act proactively to maximize awareness of these ongoing unmet needs and existing resources, while socializing and building new initiatives and resources that will help to close these gaps for patients.

JCO Global Oncol 7:976-984. © 2021 by American Society of Clinical Oncology

Creative Commons Attribution Non-Commercial No Derivatives 4.0 License

INTRODUCTION

Although recent innovations in disease understanding and treatment have led to a high 5-year survival rate for patients diagnosed with early breast cancer (EBC), the same is not true for advanced breast cancer (ABC). Fewer than three in 10 people live more than 5 years after diagnosis of ABC, highlighting a critical need for continuous advances in treatment and management to improve outcomes.^{1,2} The primary aims of most new therapeutic options are focused on disease-related outcomes, but there is a real need to enhance the quality of life for patients currently living with ABC.

The ABC Global Alliance conducted a multidisciplinary workshop at their 2019 Annual Meeting to gain insights into the persistent unmet needs faced by patients with ABC. Primary themes explored during the workshop included the value of information

communicated to patients by health care professionals (HCPs), patients' experiences living with ABC, and how caregivers and family members could potentially enhance patients' quality of life. This report details findings from the workshop and highlights initiatives that the ABC Global Alliance, its members, and the broader breast cancer community could develop.

METHODS

In November 2019, a workshop was held at the ABC Global Alliance Annual Meeting in Lisbon to explore patient perceptions of information and support needs. Ninety-two multidisciplinary attendees from 27 countries participated, including patients, patient advocates, HCPs experienced in ABC (oncologists, nurses, and psychologists), and pharmaceutical company representatives. Further details of participant characteristics can be found in Tables 1-3.

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on May 17, 2021 and published at ascopubs.org/journal/go on June 22, 2021; DOI <https://doi.org/10.1200/GO.21.00045>

CONTEXT

Key Objective

To enable 92 multidisciplinary participants at a novel advanced breast cancer (ABC) Global Alliance workshop to identify and discuss the gaps that exist across different health care systems and cultures, in the provision of support and information by formal and informal caregivers of people with advanced or metastatic breast cancer.

Knowledge Generated

Despite the advances made in the treatment of ABC, many commonalities were highlighted by this relatively well-informed diverse group concerning lack of information about therapeutic options, poor written and verbal communication concerning prognosis and impacts on quality of life, and inadequate access to basic support services. Friends and family of affected individuals often struggled to assist in constructive ways, lacking appropriate education and support themselves.

Relevance

The workshop findings outlined several initiatives that the broader breast cancer community could develop to ensure that the clinical treatment advances are matched with improvements to the quality of survival of individuals with ABC.

TABLE 1. Participant Age

Age, years	No. of Participants
< 40	11
40-60	28
> 60	6
Not provided	19
Total	64

TABLE 2. Participant Countries

Country	No. of Participants
Portugal	15
United States	9
Nigeria	5
Australia	3
Germany	3
Greece	3
India	3
Japan	3
United Kingdom	3
Canada	2
Italy	2
Sweden	2
Switzerland	2
Bulgaria	1
Cameroon	1
Egypt	1
Kuwait	1
Lebanon	1
Libya	1
Mexico	1
New Zealand	1
Uganda	1
Total	64

TABLE 3. Participant Specialties

Specialty	No. of Participants
Patient advocacy	17
Medical oncology	5
Surgery	5
Nursing	4
Clinical oncology	2
Psychology	2
Radiology	2
Gynecology	1
Palliative care	1
Plastic surgery	1
Press	1
Radiation oncology	1
Others	6
Not provided	16
Total	64

Attendees were split into multidisciplinary, facilitator-led groups to discuss the following questions from the patient perspective:

1. What I wish I had known about ABC and/or metastatic breast cancer (MBC) before my diagnosis.
2. Things I still do not understand about ABC and/or MBC and treatment options.
3. Things my health care professionals did that
 - a. helped
 - b. did not help.
4. Things friends and family could do to help when you have ABC and/or MBC.

The group facilitators gathered and documented the insights outlined in this qualitative study.

RESULTS

During the workshop, attendees identified and discussed a number of key unmet needs that exist for patients living with ABC, the details of which are outlined in [Table 4](#).

DISCUSSION

On the basis of the insights provided by the multidisciplinary group, the authors identified opportunities to improve patient understanding and knowledge about ABC, patient-HCP relationships, and support for caregivers, family members, and friends. The opportunities identified are summarized in [Table 5](#).

Patient Perceptions and Knowledge About ABC

1. What I wish I had known about ABC and/or MBC before my diagnosis.
2. Things I still do not understand about ABC and/or MBC and treatment options.

Significant patient knowledge gaps exist related to the diagnosis and management of ABC, and the availability of patient-focused information to support these gaps in knowledge remains limited. Key challenges identified by patients with ABC were a lack of timely and reliable information about diagnosis, recurrence, prognosis, and disease management; the impact of ABC on everyday life; and availability of patient-focused resources. In addition to health care–related matters, patients highlighted the need for advice about continuing to work, making a will, and accessing support for the costs of treatment. Difficulty in obtaining this information left patients feel confused, frustrated, and helpless. Without a clear understanding of their diagnosis or of the treatment and support options available, patients felt unable to make educated choices about their health care and necessary changes to their lifestyle, negatively affecting their quality of life.

Before diagnosis of ABC, many of those diagnosed with and treated for EBC were unaware of the possibility of recurrence; the subsequent diagnosis of ABC left patients shocked, dismayed, and unprepared. However, simply providing information about the risk of recurrence may not effectively improve patient understanding. Although 80% of surgeons and oncologists report discussing recurrence with their patients with EBC,³ one study cited that only 17% of patients could accurately describe their risk of recurrence.⁴ This suggests that the issue may be not only purely a matter of providing information but also one of the effective communications—in particular, checking patients' understanding of the key symptoms to report, the impact of recurrence on longer-term survival, and their prognosis. Some decision-making tools are available to help; for instance, some UK clinicians use a program called *NHS Predict*, which evaluates personal information about the patient and their tumor characteristics to calculate the potential impact of different treatments on survival outcomes, on the basis of the results of clinical trials. Outputs are displayed visually to aid discussion, but are not a substitute for personalized discussion.⁵

Effective communication was an overarching theme throughout the workshop, and participants expanded on the gaps in discussions about diagnosis. For example, a variety of terms are often used to describe breast cancer that has spread to other tissues, beyond the breast. The terms *advanced*, *metastatic*, *secondary*, and *stage IV* are frequently used interchangeably by HCPs, and across different countries, which can be confusing for patients.^{6,7} Some information leaflets and resources available online suffer from the same problem. This is compounded by the generally low health literacy and numeracy among patients, irrespective of socioeducational group, who often struggle to understand medical concepts and terminology.⁸ One study found that approximately 50% of patients with EBC have poor health literacy and informational needs are higher among those with the worst health literacy.⁸ There is a concern that these patients may search for answers from unreliable sources, ultimately further hindering their understanding.

Following an ABC diagnosis, in addition to the challenges surrounding health care education, participants commented on a lack of available and accessible advice on occupational, legal, and financial support. In some countries, tax and employment laws exist specifically to assist those living with cancer; however, patients often do not know that such support is available, whether they are eligible, or how and where to access it. Although several charities produce materials concerning these issues,⁹⁻¹² the laws and available support are very country-specific and there is an urgent need for access to accurate information, nationally and even regionally. Furthermore, language is a frequent barrier to accessing high-quality resources for many patients; often, materials exist only in English. Factors such as support and ongoing family and work commitments can have a significant positive or negative impact on patients' lives, ensuring that relevant information is easy to find, understand, and implement, which could substantially improve patients' and caregivers' quality of life.

On the basis of the experience and expertise of the multidisciplinary participant group, the following opportunities were identified to improve patient understanding and knowledge about ABC:

Before or at Diagnosis

- Using patient-friendly language to assist patients with EBC in their understanding of the risk of recurrence and its impact on longer-term survival and helping patients to recognize the importance of adjuvant therapies in reducing the risk of recurrence and the key role that patients can play in reducing their risk (eg, adhering to drug regimens).
- Providing accurate and personalized information about diagnosis and prognosis in an easily understandable format.

Post-diagnosis

- Directing patients to appropriate resources for further research, such as patient advocacy or health service websites, could enable improved self-education about ABC and avoid the use of unreliable sources. The ABC Global Alliance website serves as a central hub and repository of many resources available worldwide, several of which exist in different languages,¹³ and it is crucial that both health care teams and patient advocates make these resources known to patients with ABC.
- Developing partnerships between health practices and local patient groups to provide patients with information and direction for occupational, legal, and financial support specific to their country or region could address some of the daily needs they face while living with ABC. Access to appropriate information in their native language is critical for patients with ABC.

Impact of Health Care Professionals and Care Coordination

3. Things my health care professionals did that helped or did not help.

The development of meaningful relationships between patients and HCPs, and the role of patients in decision making, can often be overlooked for patients with ABC.

The workshop group defined the need for deeper relationships with HCPs as a key imperative for improved ABC care. Patients felt that their individual circumstances, values, needs, and fears were often overlooked when HCPs made treatment decisions, and many expressed a desire for a greater role in the decision-making process. Additionally, patients reported a lack of sufficient empathy from their health care team, stating that more emphasis should be placed on the honest but hopeful delivery of information and provision of support for the emotional challenges that patients face.

It should be acknowledged that there are universal barriers that hinder the development of meaningful relationships between patients and HCPs. Foremost is a lack of time during physician appointments, which, albeit varied among practices, is often too short to address the emotional needs of patients. Patients reported that in countries with large ABC populations and limited human resources, appointments can be as short as 1-2 minutes. In developed countries, and particularly in private practice, these may reach 30-60 minutes. The primary focus of physicians during appointments is to inform and educate patients about diagnosis, prognosis, and treatment options for ABC, leaving little time to understand patients' holistic needs beyond their disease. However, it is the firm belief of the ABC Global Alliance that the addition of a few short questions about a patient's preferences and well-being is achievable within this time, crucial for treatment decision making, and could improve care for these vulnerable patients dramatically. Furthermore, additional time with other HCPs, particularly trained nurses, can complement the information provided by oncologists

and clarify remaining questions. The role of specialized nurses cannot be underestimated in oncology since they are often the anchor point for patients with ABC.

A secondary barrier to developing patient-HCP relationships is a lack of ongoing training for HCPs in how to relate empathically to patients and consider their individual needs, especially among physicians. Although oncologists are trained to make the most effective treatment decisions for their patients on the basis of scientific evidence, a lack of understanding about patient's lifestyle, cultural or personal needs, and preferences can prevent delivery of an optimal patient experience. One opportunity to overcome this gap is communication skills training, which is now included in the European Society for Medical Oncology/ASCO global curriculum in medical oncology¹⁴ and is progressively being implemented worldwide. This training is associated with significant improvement in communication skills that facilitate empathy and consideration of patient's needs, preferences, and concerns, promoting patient-centered care.¹⁵ Furthermore, this is associated with a positive impact on patients' clinical outcomes.¹⁶ Although communication training for oncologists exists in many countries,¹⁷ it is usually voluntary and not consistently adopted. Incorporating mandatory training at early stages of oncologists' careers will undoubtedly improve the skills of the next generations of physicians.

Additionally, shared decision making can have a significant impact on patient outcomes. Data from multiple disease areas show that patients who understand their condition and have an active role in decision making are significantly more likely to adhere to therapy and experience corresponding improvements in clinical outcomes.¹⁸

Multidisciplinary care approaches are crucial for patients with ABC; however, these often lack effective coordination; access to clinical trials for ABC also remains limited.

In the absence of effective, coordinated, multidisciplinary care, patients stated that the multiple needs of ABC treatment could be confusing and overwhelming, as they interact with a variety of HCPs and specialties throughout the course of their treatment. Patients are often uncertain as to who their primary point of contact should be and who to direct questions to. Additionally, patients struggle with the substantial emotional burden of living with ABC and many expressed a need for both professional and peer psychologic support to be integrated into their care. Unfortunately, many patients shared that they were unaware of where to find peer support or who their local patient advocacy groups were and felt that these resources should be more accessible and advertised in hospitals where they receive treatment.

Another unmet need identified in the workshop was limited access to ABC clinical trials. Currently, many patients with ABC—such as elderly populations, people with active brain metastases, and those with comorbidities—are not eligible to take part in clinical trials, because of strict inclusion and exclusion criteria. For those who are eligible, many real-life

factors prevent participation. Often, the need for clinical trials to be run by specialist oncology centers places a geographic limitation on participation, as many patients are unable to travel long distances. Some patients lack knowledge about clinical trials and tend to fear the experimental aspect of treatment, and in particular the concept of random assignment,¹⁹ which is contrary to the observation that most patients involved in trials are likely to have better outcomes.

To address these challenges, a revolution in oncologic clinical research is needed, with the development of trials focused on clinically relevant questions, appropriate inclusion or exclusion criteria, and meaningful end points. The logistical burden of clinical trials on patients and HCPs must also be eased. Furthermore, provision of psychologic care, expansion of trials, and promotion of trial programs to raise awareness and educate patients on their benefits could also help. There is hope that real-world and big data projects will help to complement clinical trial data, specifically for ABC, to fill existing gaps in epidemiologic and outcomes data.²⁰⁻²⁵

These insights have driven the identification of opportunities to improve patient-HCP relationships and foster an enhanced multidisciplinary care approach:

- Taking time at the beginning of appointments to ask patients open questions about their emotional well-being and expectations for therapy could prompt them to provide additional information that is useful when developing a treatment plan.
- Providing contact details of the health care team, including administrative members, nurses, and physicians, and particularly the patients' primary point of contact, could create a channel for patients to ask questions about their therapy and provide them with a feeling of support and continuity.
- Engaging patients in the decision-making process by explaining treatment options and information in an easy to understand manner could improve patient satisfaction and outcomes. Cultural differences should also be considered when engaging patients in treatment decisions, as individuals from some cultures may feel uncomfortable about certain approaches. Providing adequate written information and links to available resources is key to allow patients to further explore and digest information at home.
- Training HCPs in communication skills that foster empathy could improve their ability to adopt a more holistic approach that considers individual patient needs and life circumstances.
- Asking patients how they prefer to receive information, including test results—for example, via e-mail, telephone, or face-to-face—could improve their engagement.
- Providing patients with information on the availability of professional psychologic services and local peer support groups may help to manage the emotional burden of living with ABC.
- Designing clinical trials focused on clinically relevant questions, appropriate inclusion or exclusion criteria, and meaningful end points could improve access to trials for patients with ABC, whereas educating on the positive outcomes associated with trials could reduce fear and empower patients to participate.
- The generation of real-world data to complement clinical trial data could help to bridge the current gaps in epidemiologic and outcomes data for ABC.

The Role of Caregivers, Friends, and Family

4. Things that friends and family could do to help when you have ABC.

Caregivers, friends, and family members do not receive sufficient guidance to support patients with ABC and manage their own well-being.

Despite the crucial role of caregivers, friends, and family in the lives of people with ABC, the workshop identified a lack of accessible guidance, resources, and support for these individuals. The impact of an ABC diagnosis is far-reaching and extremely difficult for friends and family, who may need support to cope emotionally and practically. Caregivers are often close relations who are not trained to care for those living with ABC and must do so alongside other life commitments, while dealing with the distress of someone very close to them facing an incurable disease.

Friends and family often struggle to show their support for people living with ABC, and although they have good intentions, many can do or say things that are misconstrued or unhelpful to patients. Although patients reported that they appreciate sympathy, at times, they feel that they are defined by their disease and not regarded as an individual. Patients emphasized the need to be included and respected by their friends and family. Many shared that they have been told they look great, to stay positive, or to keep fighting, which often has an unintended but negative impact on patients. Offering medical advice or suggesting unconventional alternative treatments is another common way that friends and family attempt to show support, which can be confusing and unwelcome by patients, leading to feelings of exasperation and unease.

Insights from the workshop highlight the need for greater education and support for families and friends to enable them to care for loved ones living with ABC. Several opportunities were identified to support caregivers, family members, and friends in the crucial role they play with patients:

- Developing educational materials specifically for families and friends that outline information about the diagnosis and practical guidance for day-to-day care could alleviate some of the burden caring for patients with ABC.
- Introducing families, friends, and caregivers to peer groups and other resources could address some of the psychologic and emotional challenges they face and allow knowledge sharing between those affected by ABC.

- Involving primary caregivers as part of the care team earlier could help them to feel validated and included and not just passive recipients of information.
- Providing information at clinics and health care practices could help to prepare caregivers for the challenges they will face. In Australia, there is a project aiming to improve HCP interaction with caregivers, on the basis of consensus guidelines.^{26,27}

Final Considerations

The variety of unmet needs discussed in the workshop highlights that patients with ABC still face considerable challenges. Unfortunately, many of these are not new for patients with ABC, yet remain unresolved.² Findings demonstrate that these issues continue to be common and widespread and will not be resolved until tangible action is taken.

Challenges raised by participants may be magnified by cultural, religious, geographical, and financial reasons. Several issues are most prominent in developing countries with limited resources including, but not limited to, access to care and available treatments, costs of treatment, relationships with doctors, involvement in health care decisions, traditional medicine over medical treatment, and guilt, shame, and stigma associated with an ABC diagnosis.

Issues highlighted should be prioritized by working groups to shape the development of community-based solutions. Aligned with the ABC Global Alliance mission and vision, there is a need for the global community to act proactively to maximize awareness of these ongoing unmet needs and existing resources, while socializing and building new initiatives

and resources to help close these gaps for patients. The following existing initiatives demonstrate steps toward addressing challenges that patients with ABC face: the Seeding Progress and Resources for the Cancer Community MBC Challenge seeks to support country-specific innovative ideas and projects from not-for-profit organizations that address the unmet needs of patients with ABC.²⁸ The Dandelion Toolkit uses visuals to overcome communication barriers and help patients with ABC to understand their disease and its implications, so that they can make well-informed treatment decisions.²⁹ The Global Status of Advanced/Metastatic Breast Cancer 2005-2015 Decade Report revealed where there are substantial gaps in care for patients with ABC.² This report inspired “I’m still here,” an insights report on living with ABC in New Zealand, which has been used to advocate for the approval of new drugs and for the development and implementation of dedicated ABC guidelines lacking in the country.³⁰

Workshop attendees represented a range of different disciplines, including HCPs and patient advocates. Since the predominant voice for patients in the workshop came from patient advocates, who are likely to be more knowledgeable and more informed than most patients, it is possible that the data collected in this study and consequently the unmet needs presented here are an underestimation of the actual emotional and practical burden faced by patients living with ABC. In the community, or outside of a formal workshop setting, the unmet needs identified may be perceived differently. Further patient-centered research is required to understand the full extent and impact of the unmet needs of ABC for both patients and their caregivers around the world.

TABLE 4. Key Unmet Needs Identified by the Multidisciplinary Group

Question Asked to the Multidisciplinary Participant Group	Key Unmet Needs Identified by the Multidisciplinary Participant Group
1. What I wish I had known about ABC and/or MBC before my diagnosis.	A lack of information about diagnosis, recurrence, prognosis, and disease management, the impact of ABC on everyday life, and availability of patient-focused resources
	The need for advice about continuing to work, paying medical costs, making a will, and applying for and receiving financial support
	The terms advanced, metastatic, secondary, and stage IV are frequently used interchangeably by HCPs and across different countries
2. Things I still do not understand about ABC and/or MBC and treatment options	A lack of available and accessible advice on occupational, legal, and financial support (in addition to the above points)
3. Things my health care professionals did that helped or did not help	The need for deeper relationships with HCPs and a greater role in the decision-making process
	A lack of sufficient empathy from health care teams
	Uncertainty of who their primary point of contact should be and who to direct questions to
	The need for both professional and peer psychologic support to be integrated into their care and a lack of information on where to find peer support
	Limited access to ABC clinical trials
4. Things that friends and family could do to help when you have ABC	A lack of accessible guidance, resources, and support for caregivers, friends, and family
	The need to be included and respected by their friends and family
	The need for greater education and support for families and friends to enable them to care for loved ones living with ABC

Abbreviations: ABC, advanced breast cancer; HCP, health care professional; MBC, metastatic breast cancer.

TABLE 5. Opportunities to Improve Patient Understanding and Knowledge About ABC, Patient-HCP Relationships, and Support for Caregivers, Family Members, and Friends

Question Asked to the Multidisciplinary Participant Group	Summary of Key Unmet Needs Identified by the Multidisciplinary Participant Group	Opportunities Identified by the Authors to Improve Patient Understanding and Knowledge About ABC, Patient-HCP Relationships, and Support for Caregivers, Family Members, and Friends
1. What I wish I had known about ABC and/or MBC before my diagnosis	Significant patient knowledge gaps exist related to the diagnosis and management of ABC, and the availability of patient-focused information to support these gaps in knowledge remains limited	Using patient-friendly language to assist patients with EBC in their understanding of the risk of recurrence and its impact on longer-term survival Providing accurate and personalized information about diagnosis and prognosis in an easily understood format
2. Things I still do not understand about ABC and/or MBC and treatment options		Directing patients to appropriate resources for further research, such as patient advocacy or health service websites, could enable improved self-education about ABC and avoid the use of unreliable sources Developing partnerships between health practices and local patient groups to provide patients with information and direction for occupational, legal, and financial support specific to their country or region could address some of the daily needs they face while living with ABC
3. Things my health care professionals did that helped or did not help	The development of meaningful relationships between patients and HCPs, and the role of patients in decision making, can often be overlooked for patients with ABC	Taking time at the beginning of appointments to ask patients open questions about their emotional well-being and expectations for therapy could prompt them to provide additional information that is useful when developing a treatment plan Explaining treatment options to patients and information in an easy-to-understand manner could improve patient satisfaction and outcomes. Cultural differences should be considered, as individuals from some cultures may feel uncomfortable about certain approaches. Providing adequate written information and links to available resources is key to allow patients to further explore and digest information at home Training HCPs in communication skills that foster empathy could improve their ability to adopt a more holistic approach that considers individual patient needs and life circumstances Asking patients how they prefer to receive information, including test results—for example, via e-mail, telephone, or face-to-face—could improve their engagement Multidisciplinary care approaches are crucial for patients with ABC; however, these often lack effective coordination; access to clinical trials for ABC also remains limited Providing contact details of the health care team, including administrative members, nurses, and physicians, and particularly the patients' primary point of contact, could create a channel for patients to ask questions about their therapy and provide them with a feeling of support and continuity Providing patients with information on the availability of professional psychologic services and local peer support groups may help to manage the emotional burden of living with ABC Designing clinical trials focused on clinically relevant questions, appropriate inclusion or exclusion criteria, and meaningful end points could improve access to trials for patients with ABC, while educating on the positive outcomes The generation of real-world data to complement clinical trial data could help to bridge the current gaps in epidemiologic and outcomes data for ABC

(Continued on following page)

TABLE 5. Opportunities to Improve Patient Understanding and Knowledge About ABC, Patient-HCP Relationships, and Support for Caregivers, Family Members, and Friends (Continued)

Question Asked to the Multidisciplinary Participant Group	Summary of Key Unmet Needs Identified by the Multidisciplinary Participant Group	Opportunities Identified by the Authors to Improve Patient Understanding and Knowledge About ABC, Patient-HCP Relationships, and Support for Caregivers, Family Members, and Friends
4. Things that friends and family could do to help when you have ABC	Caregivers, friends, and family members do not receive sufficient guidance to support patients with ABC and manage their own well-being	<p>Developing educational materials specifically for families and friends that outline information about the diagnosis and practical guidance for day-to-day care could alleviate some of the burden caring for patients with ABC</p> <hr/> <p>Introducing families, friends, and caregivers to peer groups and other resources could address some of the psychologic and emotional challenges they face and allow knowledge sharing between those affected by ABC</p> <hr/> <p>Involving primary caregivers as part of the care team earlier could help them to feel validated and included and not just passive recipients of information</p> <hr/> <p>Providing information at clinics and health care practices could help to prepare caregivers for the challenges they will face</p>

Abbreviations: ABC, advanced breast cancer; EBC, early breast cancer; HCP, health care professional; MBC, metastatic breast cancer.

AFFILIATIONS

¹Sussex Health Outcomes Research and Education in Cancer (SHORE-C), Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom

²Mater Hospital North Sydney, University of Sydney, Sydney, Australia

³Breast Unit, Champalimaud Clinical Center/Champalimaud Foundation, Lisbon, Portugal

⁴NHMRC Clinical Trials Centre, University of Sydney, Sydney, Australia

⁵Pfizer Inc, New York, NY

⁶Novartis AG, East Hanover, NJ

⁷Columbia University, New York, NY

CORRESPONDING AUTHOR

Fatima Cardoso, MD, Breast Unit, Champalimaud Clinical Center/Champalimaud Foundation, Av. Brasília, 1400-038, Lisbon, Portugal; e-mail: fatimacardoso@fundacaochampalimaud.pt.

SUPPORT

Support for the meeting and the manuscript writing was provided by the ABC Global Alliance. Writing support for the manuscript was provided by WPP Health Practice.

AUTHOR CONTRIBUTIONS

Conception and design: Lesley Fallowfield, Frances M. Boyle, Belinda E. Kiely, Fatima Cardoso

Collection and assembly of data: Lesley Fallowfield, Frances M. Boyle, Luzia Travado, Patti Jewell, Fatima Cardoso

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by the authors of this manuscript. All relationships are considered compensated unless

otherwise noted. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/go/authors/author-center.

Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](http://OpenPayments)).

Lesley Fallowfield

Honoraria: Voluntas, Genomic Health, NanoString Technologies, Novartis, Pfizer, MSD, Novartis, AbbVie, Clovis Oncology

Consulting or Advisory Role: Puma Biotechnology, Voluntas, AstraZeneca, Takeda, Genomic Health/Exact Sciences, Lilly, Seagen, Roche

Research Funding: Bristol Myers Squibb, Novartis, Lilly

Travel, Accommodations, Expenses: Genomic Health

Frances M. Boyle

Honoraria: Lilly, Eisai, Roche

Consulting or Advisory Role: Roche, Lilly, Novartis, Pfizer

Travel, Accommodations, Expenses: Novartis

Other Relationship: Paxman, Breast Cancer Network of Australia, Clinical Oncology Society of Australia (COSA), Pamgene

Uncompensated Relationships: Paxman

Belinda E. Kiely

Honoraria: Novartis

Consulting or Advisory Role: Roche

Patti Jewell

Employment: Pfizer

Stock and Other Ownership Interests: Pfizer, Merck

Travel, Accommodations, Expenses: Pfizer

Dawn Aubel

Employment: Novartis

Stock and Other Ownership Interests: Novartis

Fatima Cardoso

Consulting or Advisory Role: Roche, Novartis, Pfizer, AstraZeneca, Teva, Astellas Pharma, Merus, Celgene, Eisai, Daiichi Sankyo, Genentech,

Merck Sharp & Dohme, Sanofi, Pierre Fabre, MacroGenics, Amgen, GE Healthcare, GlaxoSmithKline, Mylan, Mundipharma, Seattle Genetics, Samsung Bioepis, Medscape, Prime Oncology
Travel, Accommodations, Expenses: Pfizer, Roche, AstraZeneca

ACKNOWLEDGMENT

The authors would like to thank Roberta Ventura for her continuous support within the ABC Global Alliance.

No other potential conflicts of interest were reported.

REFERENCES

1. National Cancer Institute: SEER stat fact sheets: Female breast cancer. 2020. <http://seer.cancer.gov/statfacts/html/breast.html>
2. Cardoso F, Spence D, Mertz S, et al: Global analysis of advanced/metastatic breast cancer: Decade report (2005-2015). *Breast* 39:131e8, 2018
3. Zikmund-Fisher BJ, Janz NK, Hawley ST, et al: Communication of recurrence risk estimates to patients diagnosed with breast cancer. *JAMA Oncol* 5:684-686, 2016
4. Liu Y, Perez M, Aft RA, et al: Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. *Cancer Epidemiol Biomarker Prev* 19:675-680, 2010
5. Predict Breast Cancer: What is Predict. 2020. <https://breast.predict.nhs.uk/>
6. Cardoso F, Costa A, Norton L, et al: ESO-ESMO 2nd International Consensus Guidelines for Advanced Breast Cancer (ABC2). Simultaneous publication in *The Breast* 23:489-502, 2014; and *Annals of Oncology* 25, 2014
7. Decise D, Palade Gheran M, Kimhi E, et al: Putting words into practice. *Breast* 49:171-173, 2020
8. Halbach SM, Ernstmann N, Kowalski C, et al: Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Educ Couns* 99:1511-1518, 2016
9. Cancer Council: Practical and financial assistance. <https://www.cancer.org.au/support-and-services/practical-and-financial-assistance>
10. Breast Cancer Network Australia: Hope & Hurdles. <https://www.bcna.org.au/resource/kits/hope-hurdles/>
11. Macmillan Cancer support: Benefits and financial support. <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/benefits-and-financial-support>
12. Breast Cancer Now: Financial support when you have breast cancer. <https://breastcancer.org/information-support/facing-breast-cancer/living-beyond-breast-cancer/life-after-breast-cancer-treatment/financial-support-when-you-have-breast-cancer>
13. ABC Global Alliance: <https://www.abcgloballiance.org/>
14. Dittrich C, Kosty M, Jezdic S, et al: ESMO/ASCO recommendations for a global curriculum in medical oncology edition 2016. *ESMO Open* 1:e000097, 2016
15. Fallowfield L, Jenkins V, Farewell V, et al: Efficacy of a cancer research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet* 359:650-656, 2002
16. Epstein RM, Street RL Jr: *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD, National Cancer Institute, 2007. NIH Publication No. 07-6225
17. Boyle FM, Dunn SM, Heinrich P: More than one way to foster communication skills for medical oncology fellows: A national program in Australia. *J Clin Oncol* 21:4255, 2003
18. Hibbard J, Gilbert H: Supporting People to Manage Their Health. https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf
19. Jenkins V, Fallowfield L: Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *Br J Cancer* 82:1783-1788, 2000
20. Sundquist M, Brudin L, Tejler G: Improved survival in metastatic breast cancer 1985-2016. *Breast* 31:46-50, 2017
21. Kobayashi K, Ito Y, Matsuura M, et al: Impact of immunohistological subtypes on the long-term prognosis of patients with metastatic breast cancer. *Surg Today* 46:821-826, 2016
22. Fietz T, Tesch H, Rauh J, et al: Palliative systemic therapy and overall survival of 1,395 patients with advanced breast cancer—Results from the prospective German TMK cohort study. *Breast* 34:122-130, 2017
23. Malmgren JA, Mayer M, Mary K, et al: Differential presentation and survival of de novo and recurrent metastatic breast cancer over time: 1990–2010. *Breast Cancer Res Treat* 167:579-590, 2018
24. Hölzel D, Eckel R, Bauerfeind I, et al: Improved systemic treatment for early breast cancer improves cure rates, modifies metastatic pattern and shortens post-metastatic survival: 35-year results from the Munich Cancer Registry. *J Cancer Res Clin Oncol* 143:1701-1712, 2017
25. Daniels B, Kiely BE, Lord SJ, et al: Trastuzumab for metastatic breast cancer: Real world outcomes from an Australian whole-of-population cohort (2001-2016). *Breast* 38:7-13, 2018
26. Laidsaar-Powell R, Butow P, Boyle F, et al: Facilitating collaborative and effective family involvement in the cancer setting: Guidelines for clinicians (TRIO Guidelines-1). *Patient Educ Couns* 101:970-982, 2018
27. Laidsaar-Powell R, Butow P, Boyle F, et al: Managing challenging interactions with family caregivers in the cancer setting: Guidelines for clinicians (TRIO Guidelines-2). *Patient Educ Couns* 101:983-994, 2018
28. Union for International Cancer Control: Addressing metastatic breast cancer (MBC). <https://www.uicc.org/what-we-do/capacity-building/addressing-metastatic-breast-cancer-mbc>
29. MBC Alliance: Communication Toolkit. <https://www.mbcalliance.org/education-access-initiatives/dandelion>
30. Breast Cancer Foundation NZ: I'm still here. <https://breastcancerfoundation.org.nz/Images/Assets/21894/1/BCFNZ-ABC-Report-2018-Executive-Summary.pdf>

