Healthcare Professionals Communication Support Guidance for Patients with Advanced Breast Cancer
Introduction

This resource has been produced for healthcare professionals (HCPs) and is a learning resource sponsored by Novartis Oncology.

The pan-European call-to-action was established by Novartis Oncology in partnership with the Breast Cancer community to address the unmet need in Advanced Breast Cancer (ABC). The call-to-action identified the importance of the ‘patient navigator’ role, whether in broader care or multidisciplinary teams in providing patients with improved support, management and access to information about their condition. Continued professional development opportunities and best practice sharing for specialised healthcare practitioners and those with a current role/interest in ABC were identified as key priorities.

This resource has been created with this need in mind, and aims to improve the communication skills of all HCPs involved in ABC care.

Breast cancer is the most common cancer in women,¹ with about 1.4 million women being diagnosed every year worldwide.² One in three women with early breast cancer go on to develop advanced disease, which is currently incurable.³

As recognised in international guidelines, the level of care and support available for early breast cancer (EBC) is not available for patients with ABC.⁴,⁵ There is also evidence that shows there is a high degree of unmet social and psychological need in ABC.⁶

The relationship between the HCP and patient, and how they communicate with each other is important; these conversations have been shown to improve patient understanding when conducted effectively.⁷ Patients look to their HCPs to provide them with not only factual information, but also social and decisional support once they have been diagnosed.⁷ Communication between HCPs and patients needs to be open, honest and informative about the nature of the disease, the potential treatment pathways, and available clinical trials.⁷
There are a number of challenges and issues surrounding communication between a HCP and an ABC patient. One study found that 38 percent of patients had never discussed their prognoses with their oncologist. The way HCPs communicate with patients using health and social care services profoundly affects how patients experience care.

It is also important to support HCPs managing the emotional and psychological support of patients with ABC.

This resource has been developed to provide training information and tools to help support you in your communication with ABC patients specifically and in managing the emotional and psychological support patients with ABC need.

The resource consists of four modules covering different aspects of communicating in ABC care that you may face, and how best to cope with them:

- **Module one: Diagnosis and Patient Journey**
- **Module two: Communicating Clinical Trials**
- **Module three: Psychosocial Communication**
- **Module four: Managing your Emotions**

Each module provides guidance and practical exercises to help develop a sense of empathy with, and understanding of the emotions of, patients and their families, as well as expand your skills to address these.
This module provides advice for the communication of bad news, shared decision making, transition to palliative care and end of life. Good patient-HCP communication is important because when patients openly share their concerns and partner with their HCP and surrounding team, they are more likely to receive quality care.\(^\text{10}\)

**Engaging patients in their care (should they want this):**\(^\text{11}\)
- Increases their knowledge and understanding
- Improves their overall experience as a patient
- Can improve adherence to medication

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**Diagnosis and terminal diagnosis – ‘breaking bad news’**

Giving bad news is a frequent and significant communication challenge for HCPs.\(^\text{12}\) Receiving the diagnosis is a dramatic moment for anyone and a key event in a patient’s journey through cancer, although it’s been reported that between 40-80% of medical information provided by HCPs is forgotten immediately.\(^\text{13}\) The diagnosis of ABC, therefore, must be communicated in a sensitive and effective manner. Below are some simple, practical steps you can take to achieve this.

**Communicating a diagnosis of ABC\(^\text{12,14}\)**

**Meeting preparation**

- **Think about the environment** for the discussion; does your room have sufficient privacy to discuss sensitive, personal issues? A private room or office is ideal, but, if one is not available, find some space that is quiet and private. Acknowledge that patients and their family/loved ones may be upset, recommend having tissues and water available.

- **Prepare for the meeting** by reviewing the plan for telling the patient (with the MDT) and anticipate any potential difficult questions. Always go in with a plan. It is always better to have over-prepared for the meeting than under-prepared, perhaps thinking through treatment/palliative care options, additional HCPs who will be involved, clinical trials etc.
• **Prepare for afterwards**: if possible, ensure a nurse or patient navigator is available to talk to the patient immediately after your consultation, should the patient want to talk to them.

• **Involve significant others.** Most patients want to have someone else with them but this should be the patient’s choice. When there are many family members, ask the patient to choose one or two family representatives. If this isn’t an option, perhaps ask if they’d like to bring a friend or specialist nurse with them.

• **Manage time constraints and interruptions.** Inform the patient of any time constraints you may have or interruptions you expect. Set your pager/phone on silent if you can, or ask a colleague to respond to your pages/calls.

• **Sit down.** Sitting down relaxes the patient and also indicates that you have plenty of time.

• **Make a connection** with the patient. Hold eye contact and acknowledge empathy through touch if appropriate. This will help establish rapport and shows care and understanding.
  
  • Be aware of cultural sensitivities here and ensure the patient feels comfortable

**If this is a new patient: assessing the patient**

• Take a few minutes to **assess the patient** to determine how much the patient really wants to know, ask open ended questions to find out how the patient perceives the medical situation. Depending on their cultural background, personal history, or medical status, people may have different expectations and preferences about what they should be told. Based on this information you can tailor the news to the patient’s understanding and requirements. Ensure you are giving sufficient time for understanding or bring in a translator where your patient is not a native language speaker.

• **Determine what the patient and family know,** for example: ‘what is your understanding of your present condition?’ or ‘what have the doctors told you?’ **Listen carefully** and acknowledge the patient’s and family’s emotions and body language and adapt your response to reflect both the meaning and emotion of their response.

**Structuring your conversation**

• Consider giving an overview of the patient’s situation to date, so that everyone is on the same page.

• **Warning the patient** that the news is not good may lessen the shock: ‘I am afraid I have bad news to tell you’ or ‘I’m sorry to tell you...’ then pause for a moment allowing the patient to prepare themselves.

• Using **simple language** aimed at the comprehension and vocabulary of the patient, avoiding technical words for example ‘spread’ rather than ‘metastasised’ and try not to be too blunt to help soften the message.

• Present the news in a **succinct and direct manner**, giving information in small chunks, pausing and checking periodically that the patient has understood.

**Sitting down** relaxes the patient also indicates that you have plenty of time
Addressing the patient’s response

Responding to the patient’s emotions is one of the most difficult challenges of breaking bad news. Patient’s reactions to finding out that they have ABC may vary from silence to disbelief, crying, denial, or anger. Patients look to their oncologist as one of their most important sources of psychological support, and combining empathic responses with exploratory questions is one of the most powerful ways to provide the support they need – reducing isolation, expressing solidarity, and validating the patient’s feelings as normal or to be expected.

- Give the patient time to absorb the information and wait for their response. Patients often express quiet acceptance, shock, feelings of isolation, denial, ambivalence, overwhelming distress, and grief.
- Offer the patient support and solidarity with empathetic responses: ‘I can see how distressed you are’
- Observe emotion – tearfulness, sadness, silence, or shock.
- Identify emotion by asking open, exploratory questions to find out how the patient is feeling and what they are thinking: ‘Tell me what’s going through your mind’
- After you have given the patient time to express their feelings, let the patient know you have connected the emotion with the diagnosis of ABC. For example: ‘This must be disappointing after all you’ve been through’

Summarising and discussing next steps

- Wait for the patient to regain their composure before continuing.
- Ask the patient if they are ready to discuss next steps and a treatment plan.

Shared decision making: treatment pathway

Once a patient has been diagnosed with ABC, and has been fully briefed on the incurable nature of the disease, the next step is to discuss the treatment pathway. Patients who have a clear plan for the future are less likely to feel anxious and uncertain and in a recent survey, 90% of patients said they wanted to partner with the healthcare team in decision making. However, before discussing a treatment plan, it is important to determine whether the patient is ready for this discussion. It is part of the HCPs role to educate patients on ABC, elicit any concerns and help them focus on and weigh up the treatment options.

A shared responsibility for decision-making with the patient may reduce any sense of failure and improve the quality of the decision. A high quality decision is one that is based on the patient’s values, understanding of the evidence and rationale for the decision. Decision-making should be a two way discussion between the HCP and patient, checking the patients’ understanding to ensure they don’t overestimate the efficacy or misunderstand the treatment purpose. Below are some simple, practical steps you can take:

90% of patients said they wanted to partner with the healthcare team in decision-making

‘Tell me what’s going through your mind’
A 3 step process

1. **Information exchange:** successful engagement ensures that patient concerns are elicited and explanations about treatment options are understood, thus laying the foundation for shared decision making to take place. On the basis of their information exchange, treatment options can be evaluated within the context of the patient’s specific situation and needs rather than a standard menu of options.

**How to improve communication and elicit patient concerns:**
- Make time for your patient;
- Consider individual patient concerns when making recommendations;
- Respect the patient’s life priorities beyond cancer;
- Offer continual reassurance;
- Encourage patients to:
  - Take notes;
  - Educate themselves about ABC;
  - Ask questions;
  - Share any fears/concerns about side effects, symptoms and effects on quality of life – i.e. loss of job, inability to care for family, pain and suffering, hardship on others, impaired mobility;
- Be honest about how much information they want and how involved they wish to be in making treatment decisions;
- Be an active partner with their healthcare team in making decisions;
- Bring a family member, friend or specialist nurse to serve as an extra set of ears and source of support.

2. **Deliberation:** this process of evaluating options before arriving at the final decision requires HCPs to elicit patient preferences for outcomes and opinions about their preferred treatment.

**Things to consider when mapping out or evaluating treatments:**
- Understand patient priorities;
- Educate patients about various options;
- Help them weigh the risks and benefits;
- Be positive but do not promise impossible things/patronise;
- Be mindful that goals often change over time;
- Clarify misconceptions (palliative care ≠ dying);
- Decisions are often made when emotions are high.

If the patient asks about treatment costs and/or restrictions on some medications it is important to answer as clearly as possible and honestly, as this can be a delicate issue and the patient will ask you on the basis of trust.

3. **Final decision:** If there is a difference of opinion and preferences, HCPs will need to facilitate the discussion and negotiate with patients and arrive at a decision that is acceptable to both.

**Treatment should aim to:**
- Delay disease progression and/or prolong survival, if possible
- Manage symptoms
- Optimise quality of life – ABC and/or treatment side effects can affect patients’ functioning, whether it is physically, emotionally, socially or spiritually

Keep in mind that patients say **trust and confidence in their healthcare team are major factors when making decisions.**
Transition to palliative care

Palliative care focuses on improving quality of life for patients with life-threatening illness and their families. Understandably, people find the transition from curative to palliative care a stressful experience. End of life is not an easy thing to talk about. It is recognised as a critical moment in the cancer journey. The challenge is how to facilitate a sympathetic transition from curative to palliative care. Building your communication skills can assist the transition through this difficult phase and increase the prospect of better experiences for patients with ABC and their families: talk about living with ABC, instead of dying from it.

The transition to palliative care is recognised as a difficult and uncertain time for patients, their families and HCPs. Communicating with dying patients can be complicated by the HCP’s own reactions such as anxiety, sadness, and frustration. HCPs may fear having to tell patients that their ABC is not responding to treatment, there is no cure and they need to re-evaluate the treatment pathway, moving towards specialist palliative care. Over 40% of oncologists from western countries reported that they “occasionally” to “almost always” withheld prognosis from patients. Effective and supportive communication can assist the patient and their family in navigating a successful transition to palliative care.

ABC patients facing death may have myriad concerns that include the following:

- Leaving children and other loved ones behind;
- Decline in the socially based aspects of one’s identity;
- Being unable to fulfil normal roles;
- Fear of burdening loved ones;
- Loss of control;
- Deterioration in personal appearance;
- Needing help with intimate personal care and routine activities of daily living;
- Worries about mental awareness
- Pain and management of symptoms;
- Quality of life;
- Dignity;
- Achieving a sense of completion;
- Having a good death;
- Abandonment.

Talk about living with ABC, instead of dying from it.
During the transition, patients want their HCP to provide them with biomedical information, show them that they care, and balance hope with realism. This is a difficult balance to meet. Below are some simple, practical steps you can take to communicate more effectively with your ABC patient transitioning to palliative care:

• **When to discuss the transition to palliative care?** Increasing evidence suggests that a timely enrolment of palliative care can increase quality of life for patients and their caregivers.²¹ It is important that medical attention focusing on symptom control and psychosocial issues are initiated at an appropriate time. If this decision is made too late, meaningless treatment can result in suffering for the patient. Palliative care can also be delivered concurrently with anti-cancer treatments, when there is scope to reduce the tumour burden and relieve distressing symptoms. HCPs should communicate this information and lay emphasis on securing effective palliation in relieving difficult symptoms, and helping patients maintain their dignity. The transition to palliative care becomes smoother when the doctors/nurse communicate the disease status and prognosis, the questions and emotions of patients and families are adequately answered, and a discussion about palliative care takes place proactively.

• **Explain what is meant by palliative care:** most people associate the term ‘palliative care’ with dying so patients may take the decision to transition to palliative care to mean ‘the end of the road’. Assure them that this is not the case; palliative care often offers patients rehabilitation and can allow patients to effectively manage their symptoms.¹⁷ Perceptions of when is the best time to introduce palliative care services vary. It has been suggested that the introduction of the palliative care team as part of the multidisciplinary team early after the diagnosis of ABC, as opposed to waiting until severe symptoms emerge may aid the adjustment process. However, ultimately the timing should be guided by each individual’s preferences.

• **Negotiate new goals of care** by first asking whether the patient wishes to discuss future treatment options, then introducing the role of palliative care services and providing realistic reassurances and hope.

It has been recommended that, after indicating that further curative treatment has a low chance of being effective, the clinician should introduce the option of effective palliative treatment options that focus not only on symptom control but a range of quality of life issues.²⁰
Use the term “supportive care” explicitly to maintain open and honest communication, ensuring the term is understood and any misperceptions are corrected. Provide relevant information on palliative care that is appropriate to the situation and explain that symptom management can be given at the same time as treatment to control the spread of cancer. Positively promote the holistic nature of palliative care and the wide range of services provided. If a patient continues to ask for their current treatment, respond to the emotions underlying these requests and provide realistic reassurance and helping them refocus their hopes on realistic, plausible options and outcomes.

- **Maintain continuity of care** by referring to the palliative care health professionals as part of the multidisciplinary team and reassuring the patient that they will not be abandoned.

- It’s important to **reassure the patient** that the team the patient has had along their treatment trajectory will still be there as and when needed.

- **Address family concerns.** It is vital to include family members in the discussion surrounding the transition from curative to palliative care and meet their needs as well as the patient’s needs. It is strongly recommended that HCPs routinely ask about the family, how they are coping at home and if there are children, asking about their concerns, and clarify what assistance might be needed.

- **Supporting and maintaining hope** is essential to patients and their families at the end of life. When discussing end of life, HCPs need to help redefine hope by exploring and reinforcing patients’ hopes and goals by being open and honest in their discussion about what can be done. Rather than hoping for a cure, their ABC patients may hope for a good death, freedom from pain, clear decision making, preparation for death, having a sense of completion, contributing to others, affirmation of the whole person, being at peace spiritually/religiously, being in the presence of family and being kept comfortable etc. This transition of goals of hope is delicate but if communicated effectively helps lessen the distress to patients, rather than being told that “nothing more could be done.”

- **Conclude the discussion** by summarising the main points, checking the patient understands, emphasising the hope-giving aspects, checking the need for other referrals such as a counsellor, help at home with a social worker and asking for final questions. A written summary of the consultation should also be given to the patient and a date/time for a follow-up appointment agreed.

- **Inform other members** of the team, especially palliative care HCPs, about the discussion, your perception of the person’s understanding and document it.
Raising and managing communication around end of life care and the issue of ‘dying’

Many cancer HCPs follow their patients through the trajectory of the illness, yet preparing them for dying and death requires a shift in the HCP mindset and is hard, particularly when there has been a long relationship with the patient. The goal of end of life care has been described as helping people die with dignity. Rather than treatment and side effects to treatment, discussion shifts to physical, psychosocial, spiritual, and practical aspects of preparing for death. HCPs should consider their own preconceptions and prejudices about the benefits of supportive care, as any nihilistic views could unintentionally be passed to the patient.

Patients and caregivers may want to talk about the disease process, likely future symptoms and how these can be managed, and life expectancy with a HCP who shows empathy, honesty, and sensitivity to different levels of understanding. Patients may want to know about a range of issues such as pain control, non-abandonment, information about hospice. Allow patients time to prioritise and prepare for the future, and reduce suffering in bereavement for those left behind. HCPs need to be equipped with the appropriate knowledge, skills and attitudes to communicate effectively with patients who are dying. HCPs and patients also need time: time to adjust, time to understand preferences, to build trust, to meet loved ones and break the bad news.

Key things to remember when communicating with a dying patient:

- Consistency among colleagues and openness to questions and discussion;
- Provision of specific information needed to care for the patient;
- Value of having separate discussions with patient and caregiver (if agreed by patient).

Discussing and covering the following issues:

- Pain and symptom control;
- Avoiding inappropriate prolongation of dying;
- Strengthening important relationships;
- Achieving a sense of control;
- Finding a sense of closure.

Recommendations for preparing patients and family caregivers for dying and death:

- Start with a broad framework of patient goals and values, addressing specific interventions such as cardiopulmonary resuscitation (CPR) and do not resuscitate (DNR) wishes.
- Consider the value of separate discussions with caregivers and patients because of distinct informational and emotional needs.

Good communication allows patients and their families to make informed decisions about healthcare, to prepare for the future, and to express and meet their preferences for end-of-life care.

Supporting and maintaining hope is essential

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Module Two:

Communicating Clinical Trials

Patients may consider becoming involved in clinical trials for a number of reasons, including if their current treatment becomes ineffective or they stop responding to a previous treatment plan. At this time, they may decide to explore the option of treatments currently being researched and tested. This module provides advice for communicating information on ABC clinical trials, how to increase awareness of them to your patients, how to discuss with your patient what’s involved in taking part in a clinical trial and, dispelling any misconceptions.

Communication well with patients and families about ABC trials presents many challenges, for example, poor awareness of the trials themselves, lack of clarity about the nature of the trials and inadequate discussion of palliative care options. This module aims to equip you with the communications skills to help promote better understanding of clinical trials and encourage patients to participate when appropriate.

Discussion and raising awareness of clinical trials

Clinical trials are an essential part of the development of new interventions and tests that can help your patients and may alleviate the symptoms of ABC. Talking to your patients about clinical trials is important because patients look to their HCPs for trusted medical advice and guidance on all aspects of their ABC care. The HCP plays a crucial role in raising awareness of clinical trials to their patients, informing them on the benefits and the risks of participation and assisting in their decision making process.22

It is important you find out about ABC clinical trials that are currently recruiting in your area and discuss the possible treatment options with your patients. Patients need to be made aware of their options, provided with information about what’s involved in participating in a clinical trial and given further resources to aid informed decisions. Evidence has suggested that patients taking an active role in their health and/or those who take part in a clinical trial tend to do better than other patients with same disease or condition who do not;23,24 which supports that patients may benefit from taking part in clinical trials beyond the impact of the treatment under testing itself.
Dispelling the misconceptions about clinical trials and overcoming the barriers

The ethics of promoting greater awareness of clinical research must be considered carefully. The focus of discussions between HCPs and patients should be to raise awareness of clinical trials and educate patients to help them make an informed decision on participation. Information should be accurate and balanced, providing resources to help individuals make informed decisions promoting the understanding of the true risks and benefits of participation. By holding these discussions, awareness is also increased about the role of clinical trials in healthcare and how treatments have improved over time due to clinical research and the participation of patients in clinical trials.

Patients who have been diagnosed with ABC may be interested in clinical trials either to better understand and manage their condition or to play a part in improving healthcare. You can initiate a discussion about clinical trials to raise awareness and open the possibility of participation or answer questions if the patient is already interested.

Information patients may want to know

There are often many questions patients with ABC may ask surrounding clinical trials and what is involved in taking part. Below are some typical questions with suggested responses to help guide your discussion, and some additional questions for you to think through in advance of speaking to your patient about clinical trials:

Five general principles to follow when talking to your patients about clinical trials include:

1. **Good, clear communication between patients and HCPs has many benefits.** Good communication can help to build trust and could lead to increased understanding of the disease and treatment options.

2. **Adapt the level of information to your patient needs.** Factors such as age, health status, education and cultural background can affect communication. Recognising these factors and meeting the needs of the patients will help improve communication.

3. **Information on risks and benefits needs to be comprehensive and accessible.** When communicating risks and benefits of clinical trials try to remain objective, useful and unbiased.

4. **Perceptions of risk and benefits are complex and priorities may differ between the patient and HCP.** Different influences such as personal experiences, emotions and education shape a person’s perception of risks and benefits. Communicate these perceptions to help the patient/HCP understand the other’s perspective.

5. **Patients vary in how much participation in decision making they desire.** Some patients prefer to make their own decisions about their healthcare; while others prefer to leave the responsibility to the HCP. Final decisions must meet the needs of the patient and must fulfil informed consent priorities.
What are clinical trials?25

Clinical trials are research studies that look at different aspects of patient care. They are a routine part of the work of specialist breast cancer centres. The results of past clinical trials help doctors give advice on current treatment.

There are many different types of trials. Many breast cancer trials look at new treatments or different ways of giving existing treatment, such as surgical techniques, chemotherapy or radiotherapy. New cancer drugs or treatments are first tested and researched thoroughly. Before a trial begins it has to be approved, first by a group of independent scientists and then it is reviewed by the research ethics committee and the health authority. These committees are often based at local hospitals and are made up of HCPs and non-medical people. Following approval, patients can then be tested before the treatment is licensed if benefit is demonstrated and available for widespread use.

How long does a trial take?25

The time clinical trials take to complete and publish their results varies from a few months to several years depending on what is being researched.

Who might take part?25

Every clinical trial has strict guidelines about who can be involved. A trial might be for a certain age group or for a particular type or stage of cancer, which means that not everyone is able to take part.

What are the benefits versus the risks?25

Benefits

- Patient may be one of the first to benefit from a new treatment.
- Patient has the opportunity to help others and improve breast cancer treatment.
- Patient will probably be seen more frequently by doctors than people not in the trial as extra information about the effects of the treatment may be needed.
- Patient may benefit even if they are having the standard treatment as they may have extra tests and therefore be monitored more closely.

Risks

- There may be unexpected side effects from the new treatment.
- There may be extra hospital visits required which may not be convenient or desirable.
- The extra tests may make patients feel more nervous or preoccupied with their breast cancer. These tests may cause additional discomfort and inconvenience. The effects of these additional tests will be explained by the research team.
- You may not receive the new treatment but be part of the standard treatment (control) group.

It’s important to note that:

- The new treatment may not be any more effective than the standard treatment.
- The new treatment may be effective for some but it may not work for your patient.
What are placebo or double blind trials?

In some trials a new drug is compared with a placebo, which has no active ingredients but is made to look exactly like the drug being tested. Using a placebo means the effect of the new drug can be measured much more accurately. This is because sometimes people appear to do better just because they are involved in a trial, even if they are not given the new drug. It’s not known why this occurs. It may be because they are monitored more closely or because they or their doctor are optimistic about the benefit of the new treatment.

The patient will not know whether they are receiving the active treatment or the placebo. Sometimes the doctor does not know either – this is known as a double blind trial. This helps to reduce bias and means the trial results should be more accurate. If necessary, doctors can find out whether or not a patient is getting the new treatment, for example if there are unexpected side effects. In some cases, trials may be halted early in order to allow patients on placebo faster access to the treatment being tested if it is proven to be very effective.

The majority of clinical trials are not placebo-controlled nor double blinded. This only occurs in phase III trials (late development).

Further questions patients may ask about the trial

- What is a randomised clinical trial?
- How many people have been treated with this new medicine?
- What is the aim of the trial and how will it help people?
- How many people are in the trial?
- How long will I be in the trial?
- When will the results of the trial be known?
- What happens if I stop the trial treatment or leave the trial before it ends?
- If I have to have extra tests what are these likely to be?
- Will I have to have extra hospital visits? If so, will the trial pay for my travel to and from hospital?
- Is the data collected about me kept confidential?
- Who will I be able to contact if the research nurse is not available?
- Will I need to donate blood or tissue samples, and if so, is this an optional or mandatory part of the trial?
- Will there be a questionnaire or diary to fill in? If so, ask if they would require help filling it in
- How might the treatment affect me physically and emotionally?
- What treatment will I receive if I do not enter the trial?
- Will I get to know the results?
- How will being on this trial affect my prognosis?
- Can I talk to other patients on the trial to try and find out if I’m on the placebo or research treatment arm?
Social stress, psychological distress, and psychosocial support affect the adjustment of ABC patients, influence their experience of and adherence to medical treatment, and may affect the course of the disease. Clear and open communication, expression of appropriate emotion, and collaborative planning and problem-solving enhance adjustment and improve outcomes. This module provides advice for understanding psychosocial care and the benefits it has to ABC patients and aims to set out the skills required by HCPs to address the psychosocial concerns of ABC patients.

Understanding psychosocial care and the benefits to patients

The impact of being diagnosed with ABC

Diagnosis of breast cancer can be devastating and can trigger several adverse reactions for the majority of patients. Many patients can develop symptoms of psychological distress such as anxiety, depression, fatigue, anger and stress. For patients whose disease recurs locally, or who develop metastatic disease, the emotional implications are enormous as the diagnosis can be overwhelming. The Here&Now survey found that, for the majority of patients, the diagnosis is associated with depression (30%), fear (30%) and panic (20%). As a result of the side effects of cancer treatments, some women may develop low self-esteem, self-perception and / or a negative body image from losing their feminine physical characteristics through hair loss (secondary to chemotherapy) or the loss of one or both breasts (following mastectomy). The psychosocial stress and the physical burden of the disease may reduce patients’ opportunities in life and increase social rejection and isolation. Thus, their level of emotional well-being is decreased along with poor health outcomes. Qualitative data has indicated that women with ABC feel that HCPs have limited understanding of their emotional predicament, an experience which exacerbates the isolation felt by these patients.

What are common psychosocial issues?

Patients with ABC face both medical and psychosocial challenges. Psychosocial issues tend to be issues that are outside the patient’s immediate medical concerns and are often related to daily family life, finances, relationships, self-esteem, and sexual identity. These could include:

1. The immediate family, such as spouse and children, particularly when the patient is the primary caregivers, of the families.
2. The woman’s own identity as a woman. Treatment can affect a woman’s sexual identity and affect her view of herself even within the marital relationship.
What is psychosocial care?

Psychosocial support involves the culturally sensitive provision of psychological, social and spiritual care. HCPs play a unique role in supporting patients; by building dialogue with patients HCPs can begin to understand how patients view themselves as individuals, what is important to them, and how their relationship with others may affect their decisions and their ability to live with those decisions during their treatment and beyond.

Cancer is a major psychological stress and represents a threat to every aspect of a person’s life.31

Good communication and assessment skills are essential to building a rapport with patients and can help the HCP develop a clinical relationship with the patient and their family. HCPs strive to treat patients individually as each patient requires specific physical, symptomatic and psychosocial care. The provision of good psychosocial care has been shown to be beneficial for patients by reducing both psychological distress and physical symptoms through increasing quality of life, enhancing coping and reducing levels of pain and nausea with a consequent reduction on demands for hospital resources.32

Why is psychosocial care important?

The provision of psychosocial care and support is important; it has a huge impact on quality of life and encompasses a broad spectrum of issues including physical problems such as illness or disability, psychological problems, and family and social concerns such as those related to employment and insurance.4

All ABC patients will be affected in some way by their treatment and should be provided with advice and support. Written information is especially important for newly diagnosed ABC patients who may not be able to retain a lot of information.13

Structured assessment enables HCPs to identify patients at risk of poor adjustment early. Once identified the direct use of interventions aimed at fostering a sense of optimism and improving quality of life during survivorship can be put in place. Patients will need to be monitored throughout their cancer journey as psychosocial coping can change at any time along the disease trajectory.

It has been recommend that routine distress screening should be a mandated component of cancer care and patients should have access to services like cognitive behavioural therapy (CBT).31

The disease burden28

>50% of women with ABC felt they were perceived negatively by society

37% stated they have lost confidence or a sense of personal identity since their ABC diagnosis

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Addressing psychosocial concerns

Providing emotional and social support

A patient with ABC is likely to be faced with many concerns that can vary widely and change with time. These include coping with fears over her health and future, undergoing unpleasant treatments and coping with physical symptoms. They can also include practical concerns such as not being able to do the things that are important to them or everyday tasks like the washing, and the possible impact of their illness on employment and financial stability. Patients could be concerned about the impact of ABC on their partner and children; how they cope can affect the whole family.

The extent to which a patient has support and feels supported has been identified as an important factor in their adjustment to ABC. Below are recommended steps to help ensure that patients with ABC have adequate emotional and social support:

1. Support from the treatment team
   - Ask the patient how they are feeling emotionally at every visit.
   - Ask the patient how they are feeling about treatment.
   - Listen to fears and concerns about treatment and prognosis.
   - Provide access to an oncology nurse, or other allied health professional, eg social worker, at all phases of care, where appropriate and available.
   - Provide the patient with information about counselling and arrange a referral, if needed.
     - If this is not possible, provide the patient with charity help-line telephone numbers and on-line resources.
     - Do not under-estimate the emotional support that patients derive from clinicians who deliver their surgery, chemotherapy, endocrine therapy and radiation therapy.

2. Assess support provided by family and friends
   Ask the patient about:
   - Their support network and the level of support provided.
   - How their family and/or partner are dealing with their cancer.
   - Others with whom they can openly discuss their thoughts and feelings about their situation.
   - Who they have to assist with practical issues, e.g. transport, work, childcare.

3. Providing additional support services
   Provide the patient and their family and carers with information about support services and peer support programs and how these can be accessed.

Providing psychosocial care

Providing good psychosocial care is a result of good verbal and non-verbal communication skills, communication that provides empathy and support, and medical information and advice that is understood and retained. The HCP needs to establish a good working relationship that is based on trust, open and honest understanding, being present, respectful, setting mutual goals and providing social support.

Consider the patients’ sexuality, spirituality, optimism and hope when assessing psychosocial care and quality of life living with ABC.
Learn about options for psychosocial support of patients with ABC so you can better assess your patient’s personal characteristics and health education needs; share this knowledge with your patients and colleagues.

Ask your patients with ABC to describe their support system, information needs, and coping styles so you can provide psychosocial support in a manner they view as constructive and make individualised recommendations regarding psychosocial support options:

- Younger women with ABC may prefer support and information that is related to contraception, fertility, a healthy lifestyle, and changes in sexuality.
- Patients with ABC may prefer individual or group support that involves others of like circumstances or ethnicity in order for them to better relate to participants and lessen feelings of isolation or loneliness.
- All patients with ABC require education regarding treatment risks and benefits, body image, femininity, and sexuality. Verbal education provided during clinician visits or during group support sessions that is reinforced by written information for subsequent review can help to allay anxiety and fear.
- Patients with ABC can benefit from group support sessions during which they can share experiences and concerns.
- Advocacy groups, or a spiritual advisor can also be beneficial for patients and caregivers.
- Encourage your patients with ABC to bring their spouses/significant others with them to medical appointments and support groups so spouses/significant others can also learn about ABC and benefit from psychosocial support.

Assess your patients who have ABC for unmet psychosocial needs at each clinical visit, and provide information for support options that meet their changing needs.

It’s imperative that the written information notes on all interventions in patients’ medical records are very clear to ensure no omissions and not too many replications.
Body image issues

Breast cancer and its treatment can significantly change the way a patient thinks and feels about their body. In women, ABC may involve a single or double mastectomy, and in both men and women, ABC can leave scars, and/or loss of hair. Body image matters to most men and women and addressing body image and intimacy concerns should be addressed alongside clinical treatment. Patients can often feel reluctant to talk about these personal issues and therefore HCPs need to be alert to body image concerns. Explore whether the patient has significant concerns by asking questions like:

‘Although it is often hard to talk about, many men and women worry about how they will look and feel about themselves after treatment. Can you tell me how you feel about these changes?’

‘Have you discussed any concerns with your partner/specialist nurse?’

It is important to ascertain the degree of distress, and the extent to which the patient avoids situations such as catching sight of themselves, allowing their partner to see them naked or undressing in public changing rooms. Support and education from a specialist breast nurse may help with these issues, or in more severe cases referral to a clinical psychologist may be the most appropriate course of action.

Keep leaflets on this to hand in case the patient requires more information

Sexual issues

Every human being has a sexual dimension and need for human intimacy. Anxiety, depression, despair, feelings of social isolation, lowered self-esteem, fear of abandonment, loss of control over bodily functions, and so on may also affect one’s manifestation of sexuality. Questions about sexual adjustment should be part of routine clinical care and follow-up. Skilful communication can make it easier for patients to disclose sexual concerns. However, many patients will feel reluctant to broach the subject of sexual difficulties and may be more willing to discuss issues of sexuality with certain members of the treatment team if they feel comfortable with them.

Comments such as the following may help put patients at ease:

‘Having breast cancer affects many aspects of a person’s life. One concern patients often have, but which they may find hard to talk about, is their sex life, and their intimate relationship. Can you tell me if anything like that is worrying you?’

This may be followed with more specific questioning and the HCP should consider referring patients who are experiencing difficulty to personal and/couple counselling.

Keep leaflets on this to hand in case the patient requires more information
Impact on the family

The diagnosis of ABC has been shown to impact negatively on marital and other relationships. Some patients may feel their partner fails to appreciate the devastating news, thus failing to meet their needs. Many families may be even more distressed by the diagnosis than the patients and some family members may simply avoid the discussion because they are uncertain of what to say, including parents of young patients.

Families play a major role in the patient’s coping with breast cancer, and open communication styles and expression of feelings generally facilitate adjustment. Patients should be encouraged, where possible, to express fears and feelings and maintain open communication with her family and friends.

Families may benefit from being informed about support services and groups that can provide practical assistance, support and counselling.

Spiritual issues

Existence issues such as concerns about death, freedom, isolation and the question of meaning may become increasingly important to people with ABC. Spirituality is often awakened at the end of life as patients seek meaning and purpose. Evidence suggests that those spiritually grounded to their faith and religion believe that God will help them. Faith has also been shown to help reduce anxiety. A review conducted in 2010 found that spirituality was the strongest predictor of social well-being and a significant predictor of social and emotional well-being in the quality of life of patients and families with cancer.\(^\text{[3]}\)

Ensure that appropriate members of staff are identified to facilitate these needs for patients.

Screening for spiritual distress may be facilitated by a simple assessment tool.

Financial issues

It’s possible that patients and their families may have faced considerable financial strain before the diagnosis of cancer. Concerns about costs and availability of and access to services, and access to relevant information may add to the emotional burden of patients and their families and may influence treatment choices. Open discussion of these issues and the provision of relevant information and advice are important to the overall care of the patient.

Clinicians can explore whether patients are concerned about costs and ascertain the extent of assistance available for the issues outlined below by asking questions like:

‘I know that this may result in considerable costs for you and your family. Sometimes people are worried about this. How do you feel about it – are you concerned about these costs?’

It is also important to find out whether the patient is able to access the services he/she may require.

‘I hope that getting to (insert appropriate) will not cause you any difficulties. Do you have means of transportation or can you easily get there by public transport?’

Information about the availability and types of treatment, services, supportive therapies, prostheses, aids etc, or advice about how to obtain information or access support should be provided to all patients.
Module Four: Managing your Emotions

Dealing with patients with cancer is understandably a source of stress for many HCPs, exposing them to emotional and psychological distress on a daily basis. HCPs may experience frustration and a sense of professional failure in dealing with ABC patients, when transitioning from their curative goals to palliative or end-of-life management. Often feeling inadequately equipped to deal with the emotional response of patients and their families can further add to stress. This module aims to provide advice on managing emotions.

Managing stress and emotions

Oncology can be enormously rewarding but is fraught with many challenges. Dealing with anxious patients facing life-threatening disease, conveying the true prognosis, discussing disease progression, discussing the complexity of modern treatments, explaining the unavailability of certain drugs, the side-effects and likely therapeutic aims of treatment are complex areas HCPs have to communicate to their patients. However, getting closer to the emotional needs of patients and their families can also put doctors and other healthcare professionals at certain psychological risks unless they have skills to navigate the boundaries between personal and professional involvement.

Research clearly demonstrates that social support in the workplace can help to maintain the wellbeing of staff who work in this field. It is important that HCPs talk to colleagues about the stresses of their daily work, and that they draw on the expertise of the members of the multidisciplinary team and they themselves seek professional help when required. This not only ensures they are managing with their workload and the stresses that come with their job, but also aim to help them come to terms with the sense of loss that may arise once a patient passes. Unfortunately work-related grief and bereavement is an unavoidable consequence of working in this field, and HCPs will benefit from utilising counselling-based services provided by employers.

Self-care practices such as spending time with friends and family and participating in exercise have also been shown to be key strategies for preventing burnout and achieving balance.
References


