LIVING BEYOND BREAST CANCER®

Communicate with compassion

Fear of progression and uncertainty in metastatic breast cancer

Advisory support provided by Pamela Ginsberg, PhD, psychologist and member of LBBC's Medical Advisory Board

Recognizing fear of progression

A metastatic breast cancer diagnosis changes everything for patients. The prospect of facing treatment for life can elicit constant fear about which treatments will work and for how long, progression of the disease, and when their treatment options will run out. This fear of disease progression differs from fear of recurrence and represents a key moment when providers can offer support.

Fear of progression may include:

- Uncertainty about the future
- Existential concerns about death and the meaning of life
- Worry about symptoms or treatment changes
- Anxiety about death and end-of-life planning
- Fear related to scans, disease progression, or treatment effectiveness

Psychologist Pamela Ginsberg, PhD, notes that many people living with metastatic breast cancer are navigating enormous existential questions. These concerns may affect emotional well-being, relationships, caregiving responsibilities, work, and long-term planning.

Many patients benefit from ongoing psychosocial support throughout metastatic care. Providers should recognize that patients may need opportunities to discuss fear, uncertainty, mortality, and quality-of-life concerns throughout the treatment trajectory – starting at the beginning.

How fear of progression may affect patients

Fear of progression may affect emotional well-being, communication, relationships, and decision-making in different ways.

Possible impacts include:

- Emotional exhaustion
- Paralysis in decision-making
- Avoidance of difficult conversations
- Isolation from family or support systems
- Distress affecting relationships and caregiving
- Difficulty discussing death and dying
- Avoidance behaviors, like missed appointments, lack of treatment adherence, and reduced symptom reporting

Some patients may become emotionally overwhelmed or feel unable to process difficult information. Others may avoid discussing progression or end-of-life concerns altogether.

Patients may not feel comfortable discussing these fears with family members. Providers should not assume patients already have adequate emotional support or safe spaces to discuss these concerns openly.

Dr. Ginsberg emphasizes that emotional distress becomes more concerning when it interferes with a patient's ability to function, communicate, engage in care, or maintain quality of life.

Three ways to support MBC patients

Dr. Ginsberg recommends these best practices for providers to address fear of progression and end-of-life concerns:

1. Ask how they want to talk about difficult topics.

Honest communication can reduce uncertainty and catastrophic thinking. Patients should be allowed to define how much information they want and how they prefer difficult information to be discussed.

Providers can ask:

"How much detail feels helpful to you right now?"

"Would you prefer to have family present for difficult conversations?"

"How direct would you like me to be when discussing hard topics?"

"What helps you feel most supported during difficult conversations?"

These discussions may help providers better understand individual communication preferences and create more collaborative care relationships.

2. Encourage shared decisions and self-determination.

Collaborative language may help patients maintain dignity, agency, and involvement in care decisions during periods of uncertainty.

This may include phrases such as:

"We'll work through this together."

"I want to partner with you in your care."

"We can make decisions together."

Compassionate honesty and open communication may help patients feel understood and supported while reducing shame or isolation around emotional responses. Normalize fear without minimizing distress.

Consider starting the conversation with:

"Many people feel more anxious as scans or test results approach. How have you been coping with that uncertainty?"

"What concerns have been on your mind since your last appointment?"

"How much is this fear affecting your day-to-day life?"

"What feels most difficult about waiting for answers right now?"

"Are there supports or resources that would be helpful as you navigate these feelings?"

Providers should avoid:

- Minimizing emotional responses
- Overreacting to distress
- Treating fear as automatically pathological

3. Support emotional well-being and access to care

Psychosocial support is an important part of metastatic breast cancer care.

Potential resources may include:

- Psycho-oncology
- Support groups
- Individual therapy
- Peer support communities
- Advocacy organizations
- Virtual support programs

✓ Keep a list:

Dr. Ginsberg recommends that providers maintain a list of trusted local resources that patients can review when they feel ready. These resources may include organizations that provide support services and referrals to:

- Social workers
- Nurse navigators
- Palliative care teams
- Mental health professionals
- End-of-life support resources

Some patients benefit from spaces outside the medical setting where they can discuss fears about progression, mortality, and end-of-life planning openly. Virtual support options may also help improve access for patients in rural areas or communities with limited psycho-oncology resources.

Discuss end-of-life concerns with compassion

Dr. Ginsberg recommends approaching end-of-life conversations with compassionate honesty, too. Providers should explain how palliative care can help, how palliative care is different from hospice, and other supports through mental health providers.

These conversations may evolve over time as a patient's goals, symptoms, health status, treatment options, and emotional needs change. Revisit communication preferences regularly to help patients feel more prepared, informed, and supported throughout metastatic care.

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