Women with metastatic breast cancer: life, needs, illness

A Europa Donna Italia investigation

GfK Eurisko
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What we investigated...

- Experience of the disease and its impact on daily life
- **Impact of treatment on daily life** (particularly side effects and what a woman needs to cope with them)
- **Choice of treatment centre** (influences, difficulties, needs)
- Relationship with physician
- Support and assistance needs
- **Bone metastases** (experience, impact on daily life, importance of treatment)
Study design

- Community of 15 patients with metastatic breast cancer
- Duration 2 weeks
  - ...a sheltered environment where women could exchange views and experiences
  - ...where they could talk freely about their hopes, fears and needs

- Structured questionnaire completed by 69 women with Metastatic breast cancer
  - .. to investigate and experiences, needs, and expectations
The characteristics of the women
The characteristics of women interviewed

- **YOUNG.** Average age 54 years, almost 30% under 45 years
- **COMMITTED:** with job, family and loved ones
- Central role in family: most married, half have a child under 18 years
- Nearly half have a job (like most Italian women of the same age)
Experience of the illness
Experience of the illness: a monster

“A MONSTER”
“A BEAST”

- Cruel, Unconquerable, Unstoppable
- An Alien Presence, Insidious, Unwanted

... they describe how they are engaged in a LIFE OR DEATH STRUGGLE

DEATH
Degeneration and worsening of the illness

LIFE
Determination to live and be healthy

A struggle in which it is essential to PLAY AN ACTIVE PART
... stop being a PASSIVE VICTIM
and TAKE CONTROL of one’s treatment and life
Experience of the illness: patients in their own words

"... After my initial despondency and uncertainty, I know my true self will reassert itself: I will struggle against this beast and expel it..."

"It is not the first time, although psychologically it’s more difficult than before,

I want to fight this illness, I want to look after myself ...

My husband said “you yourself are not ill, you simply have a condition"
This thought gives me strength."
The disease generates anxiety and worry, and disrupts normal life …although most women fight to live their lives to the full

*Over the last month to what extent did your disease …*

<table>
<thead>
<tr>
<th></th>
<th>Molto</th>
<th>Abbastanza</th>
<th>Poco</th>
<th>Per niente</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>... make you feel worried or anxious</td>
<td>34%</td>
<td>37%</td>
<td>23%</td>
<td>6%</td>
<td>3.0</td>
</tr>
<tr>
<td>... interfered with activities of daily living</td>
<td>31%</td>
<td>29%</td>
<td>23%</td>
<td>17%</td>
<td>2.7</td>
</tr>
<tr>
<td>... stopped you enjoying life</td>
<td>33%</td>
<td>24%</td>
<td>32%</td>
<td>11%</td>
<td>2.8</td>
</tr>
<tr>
<td>... made you feel depressed</td>
<td>27%</td>
<td>21%</td>
<td>32%</td>
<td>20%</td>
<td>2.5</td>
</tr>
<tr>
<td>... disturbed your sleep</td>
<td>21%</td>
<td>42%</td>
<td>20%</td>
<td>17%</td>
<td>2.7</td>
</tr>
<tr>
<td>... made you feel you are a burden to others</td>
<td>19%</td>
<td>22%</td>
<td>23%</td>
<td>36%</td>
<td>2.3</td>
</tr>
<tr>
<td>... made it difficult to concentrate, and take decisions that need a clear head</td>
<td>16%</td>
<td>29%</td>
<td>26%</td>
<td>29%</td>
<td>2.3</td>
</tr>
<tr>
<td>... made you feel you are no longer a tower of strength for others</td>
<td>16%</td>
<td>17%</td>
<td>24%</td>
<td>43%</td>
<td>2.1</td>
</tr>
</tbody>
</table>

* Those with a job
** Those with husband/partner
Experience of the illness: patients in their own words

“This morning I woke up feeling as if I had been crushed by tank – pain in my bones everywhere. I walked unsteadily into the bedroom of my two daughters. Their smiles gave me the strength to make breakfast and go to work. How do I experience this disease? It not easy to explain. I have been under treatment for two years: check-ups, scans, endless needles....it has completely changed my life”

“I have been fighting this disease for many years. And just when it seems I’m in the clear, it re-intrudes into my life, without an invitation … It wants to take over. But I won’t make it easy .... I am extremely determined. I have willingly submitted to all the treatments, even the most difficult. Just breaking down and giving up doesn’t help anyone”
The disease interferes with work and play, emotional life and sexual life

**To what extent does your disease interfere with..**

<table>
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<tr>
<th></th>
<th>Molto</th>
<th>Abbastanza</th>
<th>Poco</th>
<th>Per niente</th>
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</thead>
<tbody>
<tr>
<td><strong>... home activities</strong></td>
<td>31%</td>
<td>35%</td>
<td>23%</td>
<td>11%</td>
</tr>
<tr>
<td>(e.g. housework, shopping, looking after your family)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>... work</strong></td>
<td>22%</td>
<td>48%</td>
<td>26%</td>
<td>4%</td>
</tr>
<tr>
<td><strong>... sex life</strong></td>
<td>29%</td>
<td>23%</td>
<td>23%</td>
<td>25%</td>
</tr>
</tbody>
</table>

* Those who go out to work
** Those with a partner
Impact on emotional and sexual life is greater for young women

To what extent does your disease interfere with..

Impact on emotional and sexual life is greater for young women

To what extent does your disease interfere with..
Experience of the illness: patients in their own words

“It’s also difficult for my husband: I’m not the woman I was before treatment. The treatment has changed my moods, my desires, my sexuality... I no longer feel as I once did toward my husband”
Treatments
It emerged that women are highly ambivalent about their treatments

“One the one hand it’s an ally, that helps you fight the disease …

…on the other hand it poisons your body.. the side effects are really awful, and you have to convince yourself you need the treatment …

… deep down it repels you, you want to stop it, get away from it, forget it”
It emerged that women want help to support the side effects of their treatments. They want to be able to prevent or reduce them, with free medication and free access to specialist doctors.

*With regard to treatment side effects, to what extent is it important for you....*

<table>
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<tr>
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<th>Abbastanza</th>
<th>Poco</th>
<th>Per niente</th>
</tr>
</thead>
<tbody>
<tr>
<td>... to prevent them</td>
<td>79%</td>
<td>17%</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>... to have free drugs to combat them</td>
<td>76%</td>
<td>20%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>... to be able to rely on a specialist if necessary</td>
<td>76%</td>
<td>18%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>... to manage them with specific medications</td>
<td>73%</td>
<td>21%</td>
<td>3%</td>
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Bone metastases
It emerged that bone metastases have a strong emotional impact.

To what extent do bone metastases...

- ... make you feel worried
  - Molto: 45%
  - Abbastanza: 35%
  - Poco: 20%
- ... make you feel depressed
  - Molto: 30%
  - Abbastanza: 21%
  - Poco: 19%
- ... impede your normal daily activities
  - Molto: 30%
  - Abbastanza: 30%
  - Poco: 23%
  - Per niente: 17%
- ... disturb your sleep
  - Molto: 30%
  - Abbastanza: 20%
  - Poco: 33%
  - Per niente: 17%
- ... stop you enjoying life
  - Molto: 29%
  - Abbastanza: 24%
  - Poco: 29%
  - Per niente: 18%
Signe and symptoms leading to the diagnosis of bone metastases (Patients with bone metastases, n=43)

When bone metastases were diagnosed, did your doctor suggest specific treatment?

- Yes, immediately: 83%
- Yes, later: 14%
- No, I’m not taking anything specific: 3%

What treatment for bone metastases were your prescribed?

- Radiotherapy: 49%
- Chemotherapy: 44%
- Bisphosphonates: 30%
- Hormones: 21%
- Pain control: 12%
It emerged that specific treatment for bone metastases is essential: gives hope that the disease can be stopped.

How important is it for you to have a specific treatment for bone metastases?

- Very: 93%
- Quite: 7%
- Little / not at all: Mean 3.9%

What does this treatment mean for you?

- It is necessary, fundamental for slowing illness progression: 100%
- It is only a palliative, I could do without it: 0%

Metastasi Ossee: 62%

Diagnosis of metastases for ~ 20 months: 38%
Importance and significance of specific treatment for metastases: patients in their own words

“When I learnt I had metastases I was in despair, I lost hope…
But when the doctor told they could be controlled, that treatments could be effective, I started fighting again.”
Needs
Over half the women said they needed more support, especially from the doctor.

**Do you feel the need for more support and attention?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>54%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>46%</td>
</tr>
</tbody>
</table>

**Who do you wish would support you more?**

- The Doctor at the breast cancer clinic: 29%
- My family doctor: 15%
- Husband/partner: 12%
- Psychologist: 10%
- Children: 7%
- Other family members: 6%
- Friends/aquaintances: 3%
2/3rds of the women felt the need for more information about the disease and its treatment…. particularly from the doctor.

Do you feel the need for more information about the disease and its treatment?

- **Yes**: 57%
- **No**: 43%

**Who do you wish would give you more information?**

- The doctor looking after me: 51%
- Family doctor: 13%
- Specialist magazines: 9%
- Internet: 7%
- Patient associations: 6%
Fundamentally, the patient wants the doctor to listen to her, to be sympathetic, to give information … the patient also to be involved in decisions about her treatment

**How important is it for you that your doctor….**

<table>
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<tr>
<th>Description</th>
<th>Molto</th>
<th>Abbastanza</th>
<th>Poco</th>
<th>Per niente</th>
</tr>
</thead>
<tbody>
<tr>
<td>... dedicates time to you, listens to you</td>
<td>95%</td>
<td>3%</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>... gives you accurate information about the treatments and their side effects</td>
<td>94%</td>
<td>4%</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>... is sympathetic and understanding</td>
<td>86%</td>
<td>12%</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>... consults you about treatment decisions</td>
<td>81%</td>
<td>14%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.8</td>
<td></td>
<td></td>
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</table>
“I think a hospital has a duty to inform patients of their rights particularly about invalidity payments and travelling expenses. But they tell us nothing. It is the patients who inform each other: when I see another patient looking lost I ask if they want help and offer information. Some doctors are irritated when asked for certificates, they say they don’t have time, that I should wait till next time …”

“New and perhaps better treatments are often given only if you are in a clinical trial. But patients don’t know where these trials are conducted or how to get enrolled. Often the treating doctor gives no information, for fear of losing the patient if the trial is being conducted at another center”
Patients’ rights
Patients fear losing the right to healthcare. Their greatest fear is losing their entitlement to treatment.

*In the current economic climate in Italy, do you fear that you right to health cases may be jeopardy?*

- Very much: 20%
- Quite a lot: 36%
- Little: 21%
- Not at all: 23%

*Mean 2.5*

*If health spending were cut, what cuts or increased costs would cause you most difficulties?*

- Medicines to treat my disease: 91%
- Diagnostic examinations: 59%
- Seeing a specialist: 57%
- Medicines against treatment side effects: 38%
- Travelling costs: 23%
- Supplements and para-pharmaceuticals: 12%

Scala di valutazione

1. Per niente
2. Molto
3. Molto
4. Molto
Fears about the right to healthcare in the future: patients in their own words

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to rights by such penny-pinching. Cancer patients need prompt treatment. They should have the right to any treatment that may help them.”
Fears about the right to healthcare in the future: patients in their own words

“With regard to new treatments: too much time passes before they become available to patients …. Time for approval in Italy is from 6 months to 2 years, according to Region. This is a negation of the right to healthcare, which should be sacrosanct”
Summary of main findings
Characteristics of the women interviewed

- Mean age 54 years, almost 30% under 45 years
- Most are married, half have a child under 18 years
- Nearly half have a job outside the home
Living with metastatic breast cancer

• Metastatic breast cancer was perceived as a **LIFE AND DEATH STRUGGLE**
  ...
  A struggle in which women tried to take control of their own destinies

• The disease created worry and anxiety, totally disrupting women’s lives
  ....although most fought to live their lives to the full

• The disease disrupted activities of daily living, work, affective life, and sexual life

• The disruption of sexual life was felt most acutely by young women: the disease forced them to redefine their femininity and their sexual identity
Treatments

The women were strongly ambivalent about their treatments

- One the one hand it was an ally... helping them fight the disease.
- On the other it was a poison...
- The side effects were considered “really awful”, women had to convince themselves they needed the treatments ...but deep down they wanted stop them, get away from them

  - Treatment side effects affected young women the most: drastically disrupting their emotional and sexual lives

- The women strongly felt the need for help to combat the side effects of treatments with free medicines and access to specialists

- They wanted specific treatments for bone metastases to maintain hope that illness progression could be slowed
Needs

- Over half the women felt the need for more support and sympathy from the doctor
  
  - Two thirds felt the need for more information about their disease and its treatment… especially from the doctor

- Less red tape, with rapid access to examinations and their results, was also considered fundamental

- Not only did women want a sympathetic and listening doctor, they also wanted to be involved in decisions about their treatment
Fears about the right to healthcare in the future

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to right by such penny-pinching. Cancer patients need prompt treatments. They should have the right to any treatment that may help them.”
The right to healthcare

Strong fear that the right to healthcare could be revoked

Strongest fear that the right to treatment could be revoked

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to right by such penny-pinching. Cancer patients need prompt treatments. They should have the right to any treatment that may help them.”

“The government has instituted this ‘super-ticket’ for cancer drugs, so that letrozole for example costs 7 euro. This is not a high price but some can’t afford it. And it is a disgrace. In all parts of Italy – even the richest Regions – we have to pay for breast cancer drugs. A civilized country should not seek to save money by making cancer patients pay for their treatments. These drugs are matters of life or death for cancer patients”