The Breast Cancer Journey

*It’s as vital as the air that they breathe ...*
Abstract

Worldwide, breast cancer patients and their families undergo a medical and emotional journey.

Pharmaceutical companies that seek competitive advantage must:

- Understand specific unanswered needs of metastatic patients and families
- Pinpoint key differences in new markets
- Understand patients’ relationships with family and physicians
The Current Picture

- Most common cancer in women
- 1 in 9 women develop breast cancer
- Increasing incidence in breast cancer worldwide
- Second most common cause of malignancy related deaths
- More women are living longer and surviving the disease
Statistics by Market

- UK: 44,091 new cases, 74 cases per 100,000, Mortality: 29 per 100,000
- Italy: 37,302 new cases, 76 cases per 100,000, Mortality: 19 per 100,000
- Brazil: 49,470 new cases, 52 cases per 100,000, Mortality: 17 per 100,000
- China: 43.8 cases per 100,000, Mortality: 16 per 100,000
Universal Risk Factors

- Age
- Race
- Familial Risk
- Lifestyle
- Exposure to Estrogen
- History of Benign Breast Cancer
- Heavy Alcohol Consumption
"I can now bear to look at myself in the mirror naked again and feel like a normal woman"
Interview Structure

- Perceptions of Breast Cancer
- Attitudes, Emotions - before and now
- The Journey
- Relation with Family and Physicians
- Unmet Needs
- Future
Reflect Local Market Needs

Pilot funded by Aequus

In collaboration with Synovate - China, Albar - Brazil, Meta Research - Italy, GKA - UK
Two Journeys

Two Interdependent Journeys:

- Medical Journey
- Emotional Journey
Initial Discovery

- Most discovered lump by chance in shower
- Some ignored it
- Husbands often found it
- Examination commonly by needle biopsy, mammogram, ultrasound and blood tests
- China – patients bought drugs for benign hyperplasia. When lump grew, visited physician
Perceptions of Breast Cancer

Pre-Diagnosis
Security
Cancer happens to other people

After Diagnosis
Hinterland of anger, terror and despair
Loss of femininity

Re-Occurrence
Mindset: anger, resentment, disbelief, acceptance of death
Words, Smells, Tastes

“Red like a flame – something that burns and travels through you with such skill and ferocity”

“It’s a violent, red, aggressive colour”

“Really black, a darkness as though everything had been switched off”

“A constant hammering sound like that of an MRI scan”

“It has a metallic taste – the smell of a playground fence when I was little”

“A black fear, an unknown of what will happen next”

“An acrid, grey smell, and the smell of vomit”
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## Variations by Age

<table>
<thead>
<tr>
<th></th>
<th>Younger Group &lt; 45yrs</th>
<th>Older Group &gt; 45yrs</th>
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<tbody>
<tr>
<td><strong>First Diagnosis</strong></td>
<td>Patients</td>
<td></td>
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<tr>
<td></td>
<td>Devastated, fear of death</td>
<td>Fighting spirit</td>
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<td></td>
<td>Family member</td>
<td></td>
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<tr>
<td></td>
<td>Regretful, financial and relationship pressure</td>
<td>Face it, cure it</td>
</tr>
<tr>
<td><strong>Re-occurred / Metastised</strong></td>
<td>Patients</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Regretful, resentful, fear, frustrated</td>
<td>Devastated, frustrated, fight it</td>
</tr>
<tr>
<td></td>
<td>Family member</td>
<td></td>
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<tr>
<td></td>
<td>Horrible, pity, reality</td>
<td>Manage it, live with it, resentful</td>
</tr>
</tbody>
</table>

*Re-occurred and/or Metastised occurred.*
Emotions after Surgery

- Transformation following op
- Relationships rekindled
  - Realisation
    - Life is precious
  - Death is inevitable
  - Hope
    - Fresh start
    - Fear of relapse
Emotions after Re-occurrence / Metastasis

- Pessimism, anger
- Depression and despair
- No longer information-hungry
- Accepting and fighting
- Desire to prolong life, even at expense of QoL
- Unable to plan for future

“I just want my wife. I don’t want her to die; we have everything to live for. Why this?” Husband
Emotional Journey

**Diagnosis**
- Disbelief, fear, anger
- financial pressure,
- depression, hatred,
- regret, worry,
- need for information

**Treatment**
- Loss of femininity,
- depression,
- insecurity,
- anxiety

**Remission**
- Hope, fear of relapse,
- reconstruction surgery

**Re-occurrence / Metastasis**

**Guilt / concerns for family, surrender (China),
- depression, fear, savouring every moment,
- realisation and acceptance of death**
Breast cancer affects not only the patient, but everyone close to her.

Husbands help with housework after diagnosis.

Family often pay more attention to their own health.

Realisation of value of living in the moment.

Inability to plan for future.
Support Groups

Advantages

Feel better, less self-conscious, not alone
Members exchange coping skills and console each other

Disadvantages

Reduces patients’ contact with non-cancer world
One patient’s death or disease progression can worsen fears of other members in group
What is Your Greatest Hope?

Patients
- Not to pass on disease
- Family to be strong
- Cure / longer life
- Relief of symptoms / side effects
- Minimise pain in last months

Family
- Patient is happy and relaxed
- More effective medicine
- Better palliative care
- Patient lives longer / cure
These are the testimonials of real women living with breast cancer
Universality of Journey

- Universal emotional stages across markets
- Pharmaceuticals viewed as simply profit-orientated and distant
Key Cultural Differences

China
- Increased emotional struggles
- Low rate of reconstruction surgery

Latin America & Asia
- Families appear more supportive - patient lives with family

Europe
- Family cares but less involved
- UK - some resentment over publicity of celebrity breast cancer ‘survivors’
Identifying Opportunities

- Realization across markets that hospitals / physicians under enormous budgetary pressure translating into inferior care / attention
- High cost of drugs a burden for many families
- Palliative care poorly resourced, low in budget priority and below par care
- Patients come to expect ‘poor’ bedside manner
- Lack of psychological support particularly in China
Identifying Opportunities

Perception that treatment has not advanced for more than a decade

- There is a need for treatment that improves QOL of the patient
- There is a need for treatment that prolongs survival
- There is a need for treating the patient as an individual
- Huge benefit from breast conserving surgery
Acting on Opportunities - to seek the competitive advantage

Pharma companies need to become more customer facing, adopting a SOFTER approach.
1. Focus on improving QoL in the adjuvant and palliative care setting

- Address side effects of disease and treatment

2. Address psychological damage

- Psychological training for oncologists
- Importance of breast-conserving surgery
- Psychological interventions for families

3. Improve diagnostics

- Earlier screening - prioritization of relatives
- DNA testing
Acting on Opportunities

4. Improving chemotherapy
- An oral compound!
- Administration in the home
- Fewer side effects

5. Communicate with the customer
- Guidelines how to detect relapse - for doctors & patients
- How to access clinical trials
- Creative use of media - books/hotlines/websites/CDs/DVDs explaining drugs and treatment, suggestions for diet, tips for relaxation
Communicating With the Customer - China

Need for Greater Psychological Support
- Psychological training for oncologists
- Need for psychotherapists in cancer care

Benefit of Breast Reconstruction
- Need for better communication between doctors and plastic surgeons
- Combat misconceptions and ignorance
- Issue of cost

Reduce Stigma of Breast Cancer
- Counter misconceptions about sex after diagnosis
Accessing New Audiences - methodological implications

- Debate methodological approach and recruitment process
- Gain trust with the patient - recruit via oncologist
- Allow maximum time for recruitment / interview - patients have good and bad days
- Central viewing facility - may not be an option!
Accessing New Audiences - methodological implications

- Be sensitive to the vulnerability of the patient and carer
- Tread carefully through the interview and be flexible with questions
- Patients and families may block out illness - design guide with this in mind
- Remember we are trained interviewers and NOT trained counsellors!