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

- **United Kingdom**
  - 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”
Overview

Strategy

The Journey

Fellow Travellers

The Future

Conclusions
Interview Structure

- Perceptions of Breast Cancer
- Attitudes, Emotions - before and now
- The Journey
- Relation with Family and Physicians
- Unmet Needs
- Future
Total: 13
6 x IDI’s patients
7 x IDIs with carers

Total: 12
6 x IDI’s patients
6 x IDIs with carers

Reflect Local Market Needs

Pilot funded by Aequus
In collaboration with Synovate - China, Albar - Brazil, Meta Research - Italy, GKA - UK
Overview
Strategy
The Journey
Fellow Travellers
The Future
Conclusions
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”

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

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

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

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

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

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

“An acrid, grey smell, and the smell of vomit”
Words, Smells, Tastes

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## Variations by Age

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

Transformation following op

Realisation
life is precious

Death is inevitable

Relationships rekindled

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
Changes in Family Life

- 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
Acting on Opportunities

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!