Doctors need to believe in miracles too: making sure you understand the therapeutic aims of cancer treatment

Professor Dame Lesley Fallowfield
Enhancing patient-centred decision-making in metastatic cancer

- Communication must include information about:
  - therapeutic intent (cure, palliation etc)
  - information about all available options
  - what is involved - treatment regimens, visits required
  - associated risks, harms and likely benefits

- Incorporating your own values and goals into decisions not always easy
Problems

• Relationship is not usually symmetrical

• Difficult for a sick, anxious patient to convey their values, life-style and treatment preferences

• Doctors have considerable power through knowledge and do not have to experience consequences of treatment

• They do not always find it easy to ‘share’ decisions if they have a clear view as to what might be in your best clinical interests
Survey 500 women in the MBC Alliance (US)

**Do you know your cancer type?**

- Yes: 96%
- No: 46%

**What is your cancer type?**

- No answer: 13%
- Stage/location only: 21%
- Partial description: 20%
- Included both HER2 and hormone status: 46%

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- 33% felt they don't have enough knowledge to participate in decision making
- 58% felt rushed and that starting treatment was urgent; 24% got a second opinion; 38% did not research prior to starting treatment
- 71% did not recall goals and hobbies as part of pretreatment discussions
Censoring of information

- Drs often ‘protect’ patients from sad & bad news especially prognosis
- Well-intentioned, misguided notion that what you do not know will not harm you
- Expectation that you will:-
  - ask if you wish to know
  - experience unnecessary emotional distress
  - lose hope and not enjoy the time left
- Outcomes too difficult to predict with accuracy
Outcomes too difficult to predict with accuracy

- Western cultures inclined to deny death, celebrating instead medical advances

- Consequently HCPs and patients often harbour unrealistic expectations about likely therapeutic benefits of modern medicine

- Failure to prognosticate not just unpredictability

- Prediction accuracy poor, direction of error (90%) in optimistic direction, better doctor knows patient in length and intensity of contact more likely to overestimate survival (Christakis, BMJ, 2000)

- ‘Doing something’ behaviours result instead of the honest but painful conversations needed (Fallowfield et al, J Supp Care in Ca. 2017)
Novel drugs

• Pts value QoL not just LoL but often there is insufficient information for drugs that have shown only PFS or modest OS in clinical trials

• Hypothetical studies suggest PFS is ‘worth’ treatment related SEs

• We studied premise contemporaneously in Accessing the Value to patients of Progression Free Survival (AVALPROFS)

• Aims were to:-
  • measure QoL in pts starting drugs with only PFS benefits
  • establish a) how worthwhile pts felt control of cancer was v SEs experienced b) time pts would require treatment to continue controlling cancer as SE severity increased
  • what benefits doctors expected to see
Procedure following consultations

• Oncologists completed checklists re information provided about management options and indicated:
  - how much they thought patient had understood
  - % of patients *in general* who achieved clinical benefit from drug prescribed
  - benefits expected for patient they had just seen and life expectancy with and without further treatment

• Patients were interviewed at home within 2 weeks of consultation, then again if drug stopped for toxicity or due to progression

• They completed:
  - cancer and treatment specific QoL questionnaires monthly
  - made time-trade off type assessments as to how worthwhile tmt was (or would be) with different SEs against time treatment might continue to control cancer
Therapeutic aims of drugs offering only progression-free survival are misunderstood by patients, and oncologists may be overly optimistic about likely benefits

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Study involved 32 oncologists treating 90 pts with metastatic lung, breast, ovarian, colon, renal, H&N cancer and MM
Understanding PFS
(Fallowfield et al, EJC, 2015)

• Only 4/90 pts recalled any explanation of therapeutic aim or PFS

• 51/90 (57%) had ‘no idea’ or were ‘unclear’ what PFS meant

  “no idea what phrase means sounds hopeful”

• 29/90 (32%) thought it was about ‘controlling cancer’

  “you’ve still got cancer but treatment is controlling it”

• 10/90 (11%) that it was about ‘extending life’

  “hopefully tumour won’t grow give me longer time alive”
• 45/90 (50%) pts thought the therapeutic aim was “to help me live longer” and 35/90 (39%) pts expected that this would be achieved

• 35/90 (39%) thought the aim was “to help me feel better/improve QoL” and 40/90 (44%) had an expectation that this would be a benefit of treatment

• >half 49/90 said that having treatment “gives me hope”
AVALPROFS doctors’ expectations

- Pts expected in general to derive any medical benefit from given drug – variable, expected benefits with treatment often exceeded clinical trial results

- Drs thought 46/90 (51%) of their own pts would derive some medical benefit

- No likely benefit/uncertainty for 44/90 (49%) who were nevertheless prescribed treatment

- Many treatment decisions very difficult to understand some patients died or were in a hospice before we could interview them

- 51% pts said palliative care options were not discussed
Patients views of how worthwhile PFS was

"Do drugs that offer PFS or modest OS benefits improve QoL in pts with advanced cancer?"  (Fallowfield et al, J.Supp.C.Ca, 2017)

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<th>Interview</th>
<th>Grade I</th>
<th>Grade II</th>
<th>Grade III</th>
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<tr>
<td>Baseline</td>
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<tr>
<td>Yes - worthwhile</td>
<td>95%</td>
<td>88%</td>
<td>44%</td>
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<td>6 weeks</td>
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<tr>
<td>Yes - worthwhile</td>
<td>97%</td>
<td>89%</td>
<td>52%</td>
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Is (or would) the benefit of the drug in terms of controlling the cancer be worth the following Grades of SE severity?

- Pts considered their most troublesome SE
  - As SE severity increased:
    - significantly fewer pts (p<0.0001 BL and 6 weeks) agreed benefit of treatment was worthwhile
  - also required drug to control cancer for 6 mths or longer to make tmt worth the SEs (p=0.009, BL, p=0.026 6 weeks)
Early referral to palliative and supportive care services

- Many data show early referral benefits psychological and physical well-being and survival of patient, value for care-givers also

- But doctors admit to difficulty initiating such discussions especially if have close emotional bond with patient and family (Horlait et al, 2016)

- Some feel it an admission of defeat and personal failure as a doctor

- Others are responding to unrealistic hopes of patient and family for implausible outcomes from further anti-cancer treatment
Blurring of boundaries in the dr/pt relationship
(Fallowfield et al, Lancet Oncology, 2014)

‘I find it hard to be truthful about prognosis with patients whom I like’

ESMO Survey N= 338

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<th>women</th>
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<td>58%</td>
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Communication about metastatic breast cancer: areas you might want to cover

1. What is the purpose of the interview
2. What are the implications of any current test results (and of any others that might be needed)
3. Therapeutic aims of any further treatment/likelihood of benefit with different options/likely prognosis
4. Physical and emotional side effects, burdens associated with different treatments
5. Potential clinical trials
6. Palliative and supportive care options

Doctors are human beings too and may also want to believe in miracles
Acknowledgements