“Normal is redefined”; reflections on outcomes for women with breast cancer: an ethnographic study in London

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Advances in Patient Reported Outcomes Conference, 8 June 2017
Background

- Parameters of healthcare quality
  - Outcomes
  - Safety
  - Experience
- Patient reported outcomes
  - counter biomedical definitions of value
  - specific or generic measures of function and quality of life
- What is the relationship between outcomes, safety and experience?
Background

• Breast cancer
  • standard outcomes improving: e.g. 78% of women in the UK survive for >10 years
• Journeys of women with breast cancer
  • London oncology service
  • ethnographic study of breast cancer care
  • focused on experience
Aim

- To explore women’s views on living with and beyond breast cancer to identify specific and general outcomes that women valued
Methods

• Ethnography
  – London cancer service (2013-14)
  – 79 interviews: 33 patients – 56 interviews; 23 staff and carers
  – Observations (75 half days)
  – Mapping

• Analysis
  – We analysed data iteratively across interviews and observation field-notes, i.e. contextual analysis
Results

• Women referred to different concerns, preferences and aspirations.
• Desired outcomes were affected by the experience of treatment, changed over time, and influenced decisions about care.
• Three major themes emerged:
  – Dependency
  – Normality
  – Reciprocity
Dependency

- Not wanting to become dependent
  - "... a decent quality of life to carry on, because there are lots more things I want to do. ...But I don't want to be dependent."
  - "who will care for you when you are old and vulnerable? ... I don't want to live too long, please"
  - "[I don’t] ... want to be one of those people where the body works but the mind is gone"

- Needing and choosing to care for others
  - Women described young children, partners and elderly parents who they needed “...to take care of"
Dependency and treatment decisions

• Balancing quality and quantity of life
  • Some chose less aggressive treatments in order to have a "decent quality of life to carry on"
  • others chose radical treatments to maximise their chance of “staying around”
• One woman did not want her children to feel responsible for her, and that this spurred her to get back to “normal”
  • “I knew as long as I looked helpless, they would help me."
Normal is redefined

• Some women looked forward to “getting back to normal”
  • hair growing back
  • returning to work – how to avoid pity
  • No longer on treatment

– Life events
  • attending a wedding, kayaking
  • seeing a grandchild start university

• Many recognised that they would never be the same again
  • “you are changed, recalibrated, normal is redefined”
  • Rethinking priorities “a bit more laid back”
Reciprocity

• Many women talked of wanting to give something back
  – New career
  – Volunteering
  – Fundraising – walks, runs, sky-dives
  – Taking part in research
• Challenge to “give back” in the NHS
  – Directed towards charities and lobby groups
Discussion

- Are “outcomes” different from “experience”?
- Danger of assuming a linear process – not applicable in complex, chronic conditions
- A journey
  - desired destination may change along the way
  - route may also change
Conclusion

• Defining standard patient reported outcomes is complex and may be counterproductive

• Outcomes by other patients not necessarily any better than doctors

• Important in practice to recognise and respond to evolving preferences and priorities of individuals, avoiding a narrow focus on outcomes defined by others
Acknowledgements

- Funding from
  - Imperial NIHR Biomedical Research Centre
  - Imperial Health Charity

- Thanks to patients, staff and other participants

- Investigators
  - Prof Sophie Day
  - Prof Charles Coombes

- Research staff
  - Louise McGrath-Lone
  - Claudia Shoenborn
  - Jane Bruton
  - Tanvi Rai