Using photovoice to study the experience of living with and beyond the diagnosis of a poor prognostic cancer

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Background:

- 20% of UK cancer research spending was spent on breast cancer research in 2010
- 13% was spent on stomach, oesophagus, pancreas, brain and lung cancers combined
  

- In the 35 years, median cancer survival has increased from 1 to 5.8 years BUT there are huge disparities across cancer sites
  
  ‘Living After Cancer: Median Cancer Survival Times’
  Macmillan Cancer Support Research Briefing Paper Nov 2011

- > 60% of cancers still have a < 5 year survival rate

  CRUK 2009
Interest in sociology

• What does it mean to live with and adjust to a chronic illness?

• Metaphors and myths surrounding cancer/other diseases (e.g. Sontag, Goffman).

• Cultural representation of illness and disease (Radley).
What is it like to live with a diagnosis of a poor-prognostic cancer in a society that celebrates survival?

Drawn from literature and a qualitative, participatory study.

Poor prognosis = a cancer with a survival of <5yrs.

CRUK Cancer Stats http://info.cancerresearchuk.org/cancerstats/
People without a voice

• 30 - 40% of people with HNC are left with no speech or significant speech difficulties following treatment – can be permanent

• Dysepsnoea (e.g. lung cancer)

• Mucositis associated with both chemo & RT

• Emotional/psychological reasons for not wanting to talk about things.
Other ways to capture qualitative data?

- Communication via (for example):
  - Drawing, collage, sculpture
  - Diaries, essays
  - Stories, poetry

- Photography – part of everyday life
  - Photographs can:
    - tell a story
    - reveal a new viewpoint
    - give emotional impact
    - show beauty, horror, love, pain, everyday life...

Photographs “question, arouse curiosity, tell in different voices or see through different eyes” (Edwards 1997, p54)
Photography & research

• 1960s & 1970s – movement to encourage photographic documentation of social life & inequality

• John Collier Jr - ‘photo elicitation’ to investigate themes that were difficult to explore in qualitative interviewing

• 1990s - Caroline Wang developed ‘photovoice’ specifically for use in health and social care:
  ‘A participatory visual research method involving the creation & discussion of photographs by participants to communicate experience’

Photovoice

- Assists communication of things that are ‘difficult to explain’ e.g. pain, disrupted personal identity
- Allows participant to opt in or out of direct personal association
- Potentially reduce researcher bias
- Allows a sensory & emotional recreation of events/perceptions
- When used in personal spaces can generate important data about everyday experience & identity

Photos “jar us into seeing the patient as a person” (Marr 2006)
Study plan:

• Eligible participants identified by clinician or referred selves - written consent obtained

• First interview: what is life like after a diagnosis of cancer?

• Photographs of anything that represents & signifies ‘living with & beyond cancer’ ~ 2 weeks

• 5-10 photographs chosen

• Second interview: about chosen photos

• Invitation to participatory analysis workshop
Ethics and copyright!

- Participants advised about facial recognition, recognition by association, consent, etc
- Blurring of features
- Participants will give written consent before any photos are reproduced in publications or presentations
- The photographer owns their photographs & can copyright their work
## Interviews

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<th>Questions</th>
<th>Themes</th>
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<td>How did your life change when you were told you had cancer?</td>
<td>• ‘Perception’ of cancer (participant/others)</td>
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<td>• Social support</td>
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<td>• ‘Sick role’</td>
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<td>What is it like to survive cancer and cancer treatment?</td>
<td>• Social roles</td>
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<td></td>
<td>• Self esteem</td>
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<td></td>
<td>• Hopefulness/hopelessness</td>
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<td>• Concept of ‘survival’</td>
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<td>Do you think there is anything particular about living in our society today that has affected your experience?</td>
<td>• Metaphors about cancer</td>
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<td>• Media representation</td>
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<td>• Cultural images</td>
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<td>• Information/communication about cancer</td>
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<td>→ impact on people with cancer.</td>
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‘Layered Analysis’

Oliffe et al 2008 and Dowdall & Golden 1989:

1. Initial preview - chosen photographs, interviews & any other documentation & observations examined to seek understanding of participants’ intended representations & how they site themselves within the content & production of photographs

2. Detailed review - interpretations of experience of living with & beyond cancer developed, depicted cultural practices explored & congruence/inconsistency between photos & other data assessed

3. Reflexive comparison - entire photographic collection & narrative categorised & thematically coded

4. Interpretation – categories related to theory
Participants

Bar chart showing the number of participants recruited and the number of UK diagnoses and mortalities for various cancer sites.

- **Oesophagus**
- **Oral (inc throat)**
- **Ovary**
- **Brain & CNS**
- **Cervix**
- **Lung**
- **Non-Hodgkins Lymphoma**
- **Advanced breast cancer**
- **>1 cancer site**

Legend:
- Recruited
- UK diagnosis/yr (1000s)
- UK mortality/yr
Participants

- 30 recruited
  - 23 women
  - 7 men
    - age range 22-82
      - median = 52.5

- Time since diagnosis of poor prognostic cancer
  - 1 – 17 years
    - median = 4 years
Analysis

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<table>
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<tr>
<th>Category</th>
<th>Sub-themes</th>
<th>Notes</th>
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| Greater appreciation     | • “The great outdoors”  
• Returning to “a normal life” e.g. work, driving, social (new) activities  
• Fragility of life | All leading to a greater positivity; often allowing people to focus on important people/things. Post-traumatic growth. |
| A changed self            | • Pride: “a sign of what I’ve been through”, “my badge”  
• Before and after (changes in appearance)  
• Role e.g. homemaker, potential partner, volunteer, work  
• Treatment related – e.g. dental, hearing aid (ambiguous e.g. keeping wig) | Often negative but can be positive e.g. “I’d never have been a volunteer if this hadn’t happened”. Sense of pride linked to ‘achievements’. |
| Loss                     | • Loss of confidence / awareness of danger  
• Physical losses  
• Food eaten (types/amount) – link to sociability  
• Time during treatment  
• People (difficult relationships) | Loss of things that link people to “being normal” Includes “growing old really quickly” (e.g. early menopause) |
| Support                  | • Partners, family, friends  
• Pets  
• Spiritual support | Seen as hugely important & appreciated  
Sometimes linked to goals e.g. being at family celebrations, seeing children grow up |
| Goals and achievements    | • Back to work /studying  
• Enjoying life e.g. holidays  
• Personal achievements  
• ‘Giving back’ e.g. charity/media work  
• Birthday/Christmas/anniversaries | Not just what has been achieved but what can be achieved e.g. regaining ability to start planning for future e.g. by booking holidays which aren’t ‘last minute’. |
| Constant reminders        | • Paperwork  
• Tablets  
• Physical reminders e.g. raised bed  
• Time/clock-watching  
• “Outsider”  
• Cost  
• Rooms/views/home (= need to move) | Intrusions in life reducing spontaneity rather than increasing risk perception BUT sometimes big enough to cause house move, prevent holiday planning, etc |
Greater appreciation

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Greater appreciation

...that’s another one of my nine lives but I am actually a lucky person, even though I don’t win the lottery & I don’t have loads of money luck or anything, I am lucky & alive.

...the domino effect, you know, one thing leads to another?
A changed self
... after [husband had] eaten his I’m still left with the cheese, the potato & a bit of broccoli, so although it ... wasn’t a lot to start off with, but it was still too much

A battery is the fatigue ... I think the fatigue has hit me hard, yes. Yes, it’s a big side effect of the surgery actually; I think the fatigue more so than anything else, because that affects everything that you do and what you can manage to do in a day
A changed self

... a new project, new ideas, new beginnings & the fact that it’s sort of new avenues opening up and new chances & opportunities that didn’t really exist before & the courage to go & do them .... Before I had cancer I would have said ‘Oh no, get someone else to do it.’

... that’s me as a volunteer & it’s not something I would have done unless I’d been through this experience myself.
Loss
Loss

views from windows, because you spend so much time just stuck somewhere looking. I think only people who have been through some kind of illness, hospitalisation, whatever, understand the boredom & banality of being ill, you know, sort of trapped in this state.
I don’t understand why I’ve got cancer, because I eat broccoli and tomatoes and they’re supposed to be anti-oxidant and tomatoes have got something in them that they … and it didn’t make any difference.

I’ve got my shower upstairs, I’ve got glass in the doors, if I had a proper seizure … that wouldn’t be a pretty sight but no one has ever mentioned it, no one has ever talked to me about it or came out to my house & evaluated it. There is all sorts of different things I often think it would have been wise if someone might have said “I’ll come & see your house then if you live alone”.

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Support

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Support

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Support
Support

... that was with friends & family being supportive, but you’re still very much on your own ...
... the scaffolding is like a strong supporting thing, okay, which is how I felt during the disease that I was very well supported by the hospital, by my family, by my friends ... the ladder is like the support that helps you to move on, basically, so you can sort of start to make some progress ... that does reflect how I did feel, that I was supported a lot & you know this is going up into, well who knows where because there is no end to this picture, so ... it’s taking you on & step by step you can make progress.
Goals & achievements
Goals & achievements

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Goals & achievements

... every time it comes out is a new year & it’s almost like marking time & I love it & it smells beautiful & it just makes me feel alive
Constant reminders
Constant reminders
... & then in conjunction with that I’ve got the daisy chain again but me on the outside because I did sort of feel that having had the experience of going through the cancer journey it does place you outside other people’s sort of experience ... I did feel a bit left out in certain things because I missed out on not being at work, not being able to socialise fully.
Constant reminders

That’s a picture of my house with my ‘for sale’ board ... That’s my moving on I think & I feel like I need to ... The only problem is there’s no purpose in where to go with it all but this was what my life was really & I think this was the impact and this will be for years won’t it?
Thank you!

... any questions and/or suggestions?