A Conversation Analytic Examination of Cancer Helpline Talk

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"The way healthcare professionals communicate with those using the health service profoundly affects the experience of care for patients. **Good communication** can facilitate early diagnosis, improve self-management, reduce emergency admissions...and support people to return to as normal a life as possible following cancer treatment" (DoH 2011, p. 47).

Cancer helplines are **integral** to the delivery of cancer care (DoH, 2010); & are highly valued by the people who use them.

**Quantitative** research past 20 years focussed on caller demographics, reasons for calling & caller satisfaction.

Limited understandings about how those affected by cancer and call-handlers *talk* about the problems associated with a diagnosis of cancer **during** the calls.

This is important based on:
1) the **communication difficulties** associated with talking about cancer and helpline work; &
2) the increasing **demand** for telephone-based cancer care.
Aims & Objectives

1. What problems are brought to cancer helplines and how are they sought?

2. What types of care do call-handlers provide and how are they delivered?

3. If communication difficulties associated with cancer and helpline work arise during the calls, what are they, and how are they managed by the participants?
Methods & Methodology

99 audio-recorded telephone calls to Macmillan cancer support.

Practical, emotional & medical information/support to those affected by cancer.

Team of cancer specialist nurses.

Can provide some forms of advice, but they cannot diagnose symptoms, deliver prognoses or recommend different treatments.

53 patient callers & 46 ‘significant others’ (incl. relatives, partners & friends) with a range of different cancers; and 18 cancer specialist nurses.
Methodology (Cont.)

All calls were transcribed & analysed using the principles of **Conversation Analysis** (CA).

It uses audio & video recordings to enable **direct observation** & **fine grained analysis**, focussing on how people produce and recognise meaningful communication.

**Key elements** to CA analyses:

<table>
<thead>
<tr>
<th>Concept</th>
<th>Explanation</th>
<th>Example</th>
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</thead>
<tbody>
<tr>
<td><strong>Social action</strong></td>
<td>Talk is designed to ‘do’ things.</td>
<td>Requesting help; offering advice; diagnosing symptoms; recommending treatment, etc.</td>
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<tr>
<td><strong>Turn design</strong></td>
<td>Social actions can be produced in different ways</td>
<td>Advice…</td>
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<td></td>
<td>1) <em>Based on the severity of your symptoms &amp; all the bugs currently going around I would suggest you make an appointment with your GP.</em></td>
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<td>2) <em>It sounds terrible…go see your GP immediately!.</em></td>
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<td><strong>Sequence organisation</strong></td>
<td>The interactional consequences of what was said.</td>
<td>What happened next? Are there patterns to participant responses to these different designs?</td>
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(Some) Key Findings

Callers requested assistance about a range of medically-related matters.

- ...including treatment; current symptoms; the future (incl. prognoses, end of life, cancer recurrence and cancer progression); & medical information.
- Callers requested assistance about 2 or more medically-related matters.
- Helpline calls more complex than they are depicted in the current literature.

Some of these concerns were outside the remit of services on offer from the helpline.

- Callers presented with troubling symptoms and wanted the nurses to evaluate (i.e. diagnose) the problem.
- Caller’ requests for prognoses.
- How the call-handlers managed ‘difficult’ topics.

Expressions of caller satisfaction

- Frequently occurred in closing environments.
- ‘Track’ what led to these different expressions.
- More useful for helpline services than questionnaires (which can be unreliable measures of satisfaction).
Management of Prognosis Requests

Background (brief)

Communicating prognoses has been described as ‘complex’ (Clayton, Butow & Tattersall, 2005; Almack et al., 2012; Walczak et al., 2013 Cartwright et al., 2014; Johnson et al., 2015).

- Varying information preferences;
- The clinical difficulty of determining proximal outcomes for cancer;
- The lack of evidence-based guidelines about how to facilitate such discussions (Kaplowitz et al., 1999; Butow et al., 2002; Hagerty 2005b; Parker et al., 2007; Kaplowitz, Campo & Chiu, 2009; van Vilet et al., 2013).

Macmillan call-handlers identified prognosis requests as a challenging aspect of their work (Leydon et al. in preparation).

11 callers requested a prognosis from a nurse.
Management of Prognosis Requests

 Caller requests for a prognosis

 Male patient with two cancers in his throat

 I was wondering what the er (.) prognosis is for er this e- this type of er cancer

 Female patient with endometrial cancer

 U:::m is if it’s (.) gra::de (.) if it’s a more aggressive form of cancer but it’s stage o:ne and it’s been remo:::ved, (0.2) .hhh does that: (.) have (0.4) consequences fo:r (.) your prognosis.

 Daughter of a male patient with terminal lung cancer

 And [what i]s the li:fe expectancy (.) of something like that.

 Daughter of a female patient with tumours in her brain

 [If you are[:: (.) gi]ven a prognosis with (.). one brain tumour a[nd the ]n they do another (0.2) sc:an a[nd fi:]nd ou:t (.) t[hat on]e’s one’s still there a[nd the]re’s two mor[e:],.hh presuming [(0.2) ] that prognosis will now be shorter.

 Key patterns

 Formulated as caller ‘reasons for calling’ & as additional issues.

 Patients & relatives used similar language to request a prognosis.
Management of Prognosis Requests

Nurse Management

Main pattern...

1. Resources to manage the caller's expectations

So it’s all lo::cal. Okay. Alri:ght. .hhh I’ll have ↑little
loo::k. I mean I I I think it’s going to be pretty ha:::rd #er#
t- to get an an definitive ans:wer on thi::s .hh because
everybody’s so different.”

It’s .HHH very very difficult >I mean< I wouldn’t li:ke to say
for your: particular situation ‘cause I think you’d need to
probably talk to your consultant about tha:::t.”

2. Attempt to provide a prognosis or deliver prognostic-related
information

Audio – 3 examples.
The management of prognosis requests

Noticeable difficulties during these sequences.

In-depth analysis revealed *why* the nurses encountered interactional trouble when managing these requests. The use of audio-recorded telephone calls (opposed to self-reported data) could be used to train helpline staff in the future.

Stakeholders meeting with call-handlers & helpline managers thought the use of ‘real’ examples was engaging & useful.

The thesis as a whole...

This conversation-analytic examination led to greater understandings about the complex problems discussed on cancer helplines and how they were discussed.

It was the first study to open the ‘black box’ of cancer helpline communication, but *more qualitative research* is needed in the future.
Acknowledgements

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