

A Conversation Analytic Examination of Cancer Helpline Talk

Catherine J. Woods¹

Supervisory Team: Geraldine M. Leydon¹ & Paul Drew²

Affiliations: ¹The University of Southampton & ²Loughborough University

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The National Institute for Health Research School for Primary Care Research (NIHR SPCR) is a partnership between the Universities of Bristol, Cambridge, Keele, Manchester, Newcastle, Nottingham, Oxford, Southampton and University College London.

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Background

“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).

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.

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

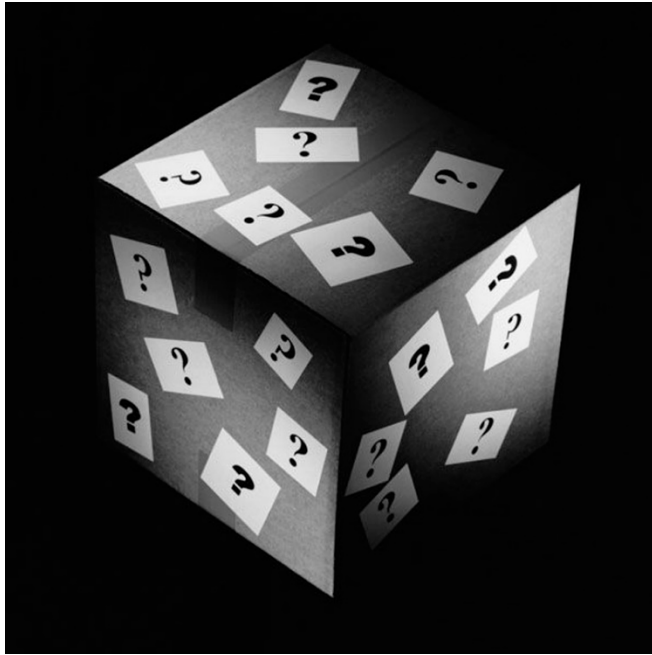


Quantitative research past 20 years focussed on caller demographics, reasons for calling & caller satisfaction.



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

Aims & Objectives



To open the ‘black box’
of cancer helpline
communication

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.



**MACMILLAN
SUPPORT LINE**



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

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.

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:

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

(Some) Key Findings

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



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



Expressions of **caller satisfaction**

- ...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.
- 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**.
- 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.



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Management of Prognosis Requests

Nurse Management

Main pattern...

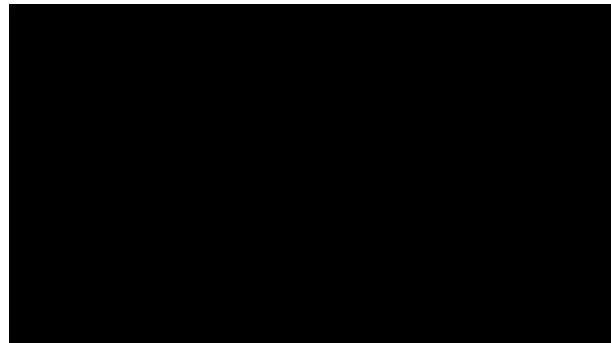
1. Resources to manage the caller's expectations

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.



Summary

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.

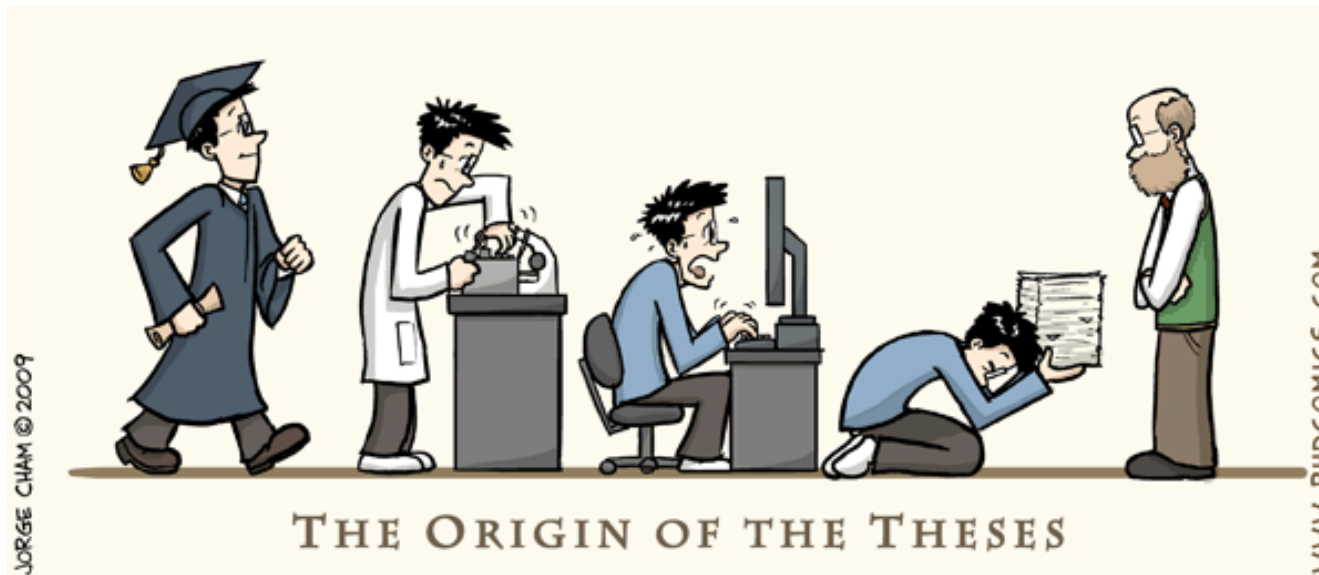
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