

Conference Speech:

CECo Narrative Theme Conference – 28th-29th March 2007, Lancaster University

Narratives of Living and Dying with Cancer: Sociological Perspectives

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The title of this paper is the title of my current ESRC funded research project – running for 17 months from Jan 07.

It has Research Associate input from Tom Lynch, a PGR student in Lancaster's Institute for Health Research (IHR).

This project involves the re-analysis of two datasets comprising in-depth interviews with adult cancer patients and their main informal carers: 88 patients and 50 carers in total. The interviews were conducted in 1998-99 and 2001-02 as part of two large NHS-funded research projects on cancer experiences – the first on the psycho-social needs of cancer patients and their carers, and ii) the second on the preferences for place of death of terminally ill cancer patients and their carers.

The secondary data analysis in this new project makes use of **narrative analysis methods**, something not attempted in the original rounds of qualitative data analyses.

Research questions:

1. From a sociological perspective, what narratives about living and dying with cancer are embedded in the interview accounts?
2. What do different theoretical and methodological approaches have to offer to the study of cancer narratives?
3. What narrative themes does this interview dataset contain on 'differences' associated with gender, age, socio-economic status, co-morbidity, and clinical characteristics (tumour type and disease stage)?
4. [My particular interest] Do themes associated with disability and disablism feature in these cancer narratives?

Expected Outcomes:

- The project will make an original contribution to knowledge of sociological (sociology of cancer) and practitioner (supportive and end of life care services) significance. A book and related journal papers will result, and research experiences will be fed, throughout, into the *Cancer Experiences Collaborative* (CECo).
- **Current phase:** At this relatively early stage, I am educating myself in narrative research – particularly narrative analysis approaches in sociology, and its sub-discipline, medical sociology. So, I'm reading, thinking, and looking at a selection of interview transcripts – in an attempt to move toward an analytical framework to use with all the data.
I want to share a small element of this thinking process with you today.
- One very useful book I've been reading is: **Ken Plummer's Documents of Life 2. An Invitation to Critical Humanism.** **London: Sage.** – published in 2001. A Sociology Professor at Essex, Plummer has written very informatively on narrative methods in sociology – including an earlier book: (1995) *Telling Sexual Stories: Power, Change and Social Worlds.* London: Routledge.
- Making use of Plummer's discussion of 'life narratives' in chapter 9 of Documents of Life2, I've posed the following questions to myself about how to analyse both the content and the form of the cancer narratives – using Plummer's observations to inform what to think about and what to look for when engaging with the interview data.
- Before getting to these questions - it is important to remember throughout this talk that the cancer narratives I'm looking at are **elicited** or invited stories about cancer experiences and their consequences for self and others. They were elicited in guided interviews where the interviewer had a pre-set list of areas to try to cover – for example, of symptoms, cancer diagnosis, experiences of health care systems and health professionals, practical difficulties, impacts on sense of self and body image, emotional and spiritual challenges, social support networks, and preferences for place of care/death.

- So, we are not dealing with spontaneously offered cancer narratives – spoken or written - or accounts written retrospectively by survivors or by close relatives of cancer patients.
- **The questions and issues to resolve that arise, for me, from Plummer’s overview are as follows:**
 - First, how do cancer patients and carers give intelligibility and coherence to their current life phase with cancer by infusing their cancer story with we might call deeper stories about themselves and their lives? Put the other way around: how do life stories, and stories of self, manifest themselves in the ‘living with cancer’ stories told. And what does this tell us about how people manage to cope – or not to cope – with cancer? It is already clear that the cancer narratives are indeed infused with life stories, and that these are profoundly related to ways of living and dying with cancer – but how can we disentangle the links and relationships involved?
 - Second, how are these stories immersed in the narrative conventions of our contemporary culture? How do people use cultural and linguistic conventions to tell their cancer stories – as they must do in order to make the narrative comprehensible both to the teller and to the listener. But what are these narrative conventions, and how do they take shape in the cancer narratives that I’m looking at? A related question is: what cultural and academic conventions – and assumptions - will I use when conveying these cancer stories to a wider audience (to readers & listeners)? As researcher, I will impose an order upon inchoate worlds – but what are the rules and logics that I use in this organisation? I need to be up front in this regard – that is, to be a fully **reflexive** researcher.
 - Thirdly, what makes these cancer interview narratives phenomena of our time and historical moment? That is, I need to be thinking about what gives them historical specificity – both in terms of how and what is told, and in terms of the social impact of the telling – including what I, in turn, produce and ‘tell’? It seems likely that the kinds of cancer narratives generated in the interviews (at the end of the 20th century) would not have been thought possible earlier in 20th century, when speaking about living with such stigmatised diseases was not culturally acceptable or imagined, when ‘the patient voice’ was rarely heard or sought, and when poorer survival rates did not make stories of ‘living with cancer’ so available. Indeed, the existence of

programmes such as CECo are the product of important social changes that have occurred over time – giving status to experientially based knowledge about cancer.

- Fourth: what are the contents of the **stories** that people tell? Plummer notes that the *story* is the most basic element of a life narrative. He refers to the literary critic, Kenneth Burke (1945), who long ago suggested that a well-formed story should answer the following question: '*What was done (act)? When or where was it done (scene)? Who did it (agent), how he/she did it (agency) and why (purpose)?*' This approach suggests that cancer narratives will almost always take the form of strong if unfinished stories: – the key act is the cancer diagnosis, the key scene is the doctor's clinic or the hospital ward; the key agents are the doctors, other health professionals, close family members and friends; the agency of interest is how these 'characters' behave and respond - but the purpose element of the story is usually yet to be known. Indeed, the end of the story is usually not known to the tellers, and this makes cancer narratives different.
- Moving on, in addition to a story, narratives have *plots*. Plots are more complex than the story itself – they are the dynamos of stories – the arrangement of the incidents. There are plots and sub-plots in life stories – but what do these look like in the cancer narratives? A typical plot structure in cultural stories moves through the following stages: first, the calm – then the conflict/crisis – leading up to a climax (the 'epiphany' – as Denzin (1997) calls it - i.e. interactional moments and experiences which leave marks on people's lives) – then leading on to a conclusion - and back to calm – the resolution. This cultural convention is found in literature, in film etc. But what about cancer narratives elicited in interviews? The first two stages may be present – my life was moving along as normal (the calm) then the crisis (symptoms, diagnosis) occurred. But what about the end of the story? The people interviewed may not have reached, or may not ever reach, a resolution and a return to calm waters. Interviewees had minimal opportunities to engage in the purposive or retrospective structuring of an account so that it could closely resemble conventional cultural narrative types – not least because the 'end' of the story may not be known. Did the narrators strive to meet cultural conventions nonetheless? This needs to be looked at with care. Perhaps illness narratives inevitably diverge from

conventional cultural narratives, or render them in particular ways. What might these be? How does this relate to the work of Arthur Frank and his illness narrative plot types in *The Wounded Storyteller*¹ - the restitution narrative, the chaos narrative, the quest narrative?

- Moving on, life narratives are typically peopled by recognizable *Characters*, or 'imagoes' (McAdams, 1985). These can take the form of cultural tropes: villains, heroes, fools – 'storytypes' (close to stereotypes). Plummer says: 'Usually there will be a protagonist, an antagonist, and a witness of some kind.' (p.188). There may be cultural prototypes such as 'Earth Mother', 'Wise Old Man', 'Gods and Daemons'. Our cancer narratives are certainly peopled – not least because the interview encounters *invited* stories about people – health professionals, family members, friends, employers. So it will be interesting to look not so much at *which* people are talked about, but at *the way* in which these characters are **personified** by the narrators. I'm particularly struck by the recurrence of 'doctor stories'. Preliminary examination reveals that the narratives are replete with accounts of the 'good'/'bad' or 'caring/uncaring' doctor. I need to think about the cultural tropes drawn upon to portray 'the characters', and the felt impact of the key characters.
- Another dimension of the narratives to consider is the **themes and story-lines** to be found. In 1985, Dan McAdams (1985: 62) refers to '**recurrent content clusters in stories**'. These may be social or psychological themes relating to power, intimacy, belonging, separateness, closeness, remoteness, gender options, and so forth. So what are the themes and story-lines in the cancer narratives, and are they variable along the lines of sample 'differences': that is, in association with age, gender, carer/patient, tumour type, 'critical moment' in cancer journey, socio-economic status? I already know that there are recurring clusters of talk relating to 'the doctor story', the diagnosis story, the treatment story, the 'impact on my family'

¹ Extract from my book (C. Thomas (2007) *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave Macmillan: The narrative theme was taken further by Arthur Frank in his influential book, *The Wounded Storyteller* (1995). Frank argued that people with serious medical conditions make sense of their lives by telling illness stories *through* their diseased bodies. In an embodied sense, they give voice to an experience that medicine cannot describe (ibid: 18). He identified three illness narrative types: the restitution narrative ('tomorrow I'll be healthy again'), the chaos narrative ('all is lost') and the quest narrative ('I'll use this illness to seek to improve myself, and others'). People may move between these narrative types during their illness journeys.

story, the 'response of friends and others' story, the 'why me now' story.

- Another question posed by Plummer is what are the **genres and structures** in the narratives? Are there thematic lines that lead to the narratives falling into definite patterns, types and structures – such as the 'tragedy' narrative, or those identified by Arthur Frank? Some genres identified by Langdon Elsbree (1982) seem particularly relevant for the cancer stories: i) engaging in a contest, or fighting a battle, ii) taking a journey, iii) enduring suffering, iv) pursuing consummation.

Moreover, with regard to my own **presentation** of these narratives, what social scientific genres do I make use of?

- Finally, Plummer notes that researchers always locate life stories in some wider 'frame' – either conceptual or substantive, but there are variations in how social scientists do this (p.191). What is my wider frame? No doubt the writings of sociologists on **illness narratives** will be important, as will my instinctual desire to balance and integrate conceptual and empirical material. But how will I blend the conceptual text with the empirical materials? This is a big challenge.

There are lots of other questions that can and will be asked of the interview data... but you can see that there is already a great deal to be getting on with!

References

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