

Narrative Methods in
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Palliative
Care An Annotated
Bibliography

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Liz Rolls
Sheila Payne
Janice Brown

NARRATIVE METHODS IN SUPPORTIVE AND PALLIATIVE CARE

AN ANNOTATED BIBLIOGRAPHY

Liz Rolls, Sheila Payne and Janice Brown

Cancer Experiences Collaborative
(CECo)

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This annotated bibliography is dedicated to the memory of Janice Brown who sadly died near the completion of this work. The authors are grateful for her contribution.

DEDICATION

To the memory of

Janice Brown

PREFACE

The Cancer Experiences Collaborative is one of the most exciting research undertakings that I have found internationally. This annotated bibliography is both an extremely useful clinical and methodological reference tool and a succinct introduction to narrative analysis. Even if a reader does not proceed to any of the books and articles that are described, the descriptions are sufficiently thorough to make reading the annotations a worthwhile pursuit in itself.

Both clinicians and scholars will appreciate the CECo's work in assembling so many sources and giving readers an indication of which may be most useful. The editors begin with a review of narrative analysis that may be the most useful available at its length. They summarize while avoiding any sense of closure, because they realize that narrative studies have no boundaries. Moreover, new work is constantly appearing. Any bibliography is necessarily a work in progress.

The CECo's emphasis on narrative shows the seriousness of their choice of name for their association. The emphasis on the plural of *experiences* underscores what anyone who studies stories quickly realizes: any story always comes from other stories and leads to still more stories. Stories give shape and substance to experiences, and stories are constantly being retold with variations. In life and practice there is no singular of *story* any more than there is a singular of *experiences*; both are always plural.

The *collaboration* in CECo is not only among institutions and researchers, it also marks the collaboration required for the telling of stories. This collaboration is not only between tellers and listeners. It stretches back to include previous storytellers who have put in place the narrative resources used by in the present, and it looks forward to future storytellers who will rely upon those resources and adapt them to their circumstances.

End-of-life care offers the privilege and professional duty to witness people's storytelling at a time when their lives are melding into the stories of these lives. The CECo's leadership in assembling this rich diversity of writing about storytelling is a contribution for which we should all be grateful.

Arthur W. Frank, Ph.D., FRSC
Professor, Department of Sociology
University of Calgary

**NARRATIVE METHODS IN SUPPORTIVE AND PALLIATIVE CARE -
AN ANNOTATED BIBLIOGRAPHY**

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INTRODUCTION

This Annotated Bibliography is one outcome of the work of the Cancer Experiences Collaborative (CECo) Narrative Methods sub-theme. It is divided into four parts.

Part 1: Context

Part 1 provides details of the two contexts of this Annotated Bibliography: the Cancer Experiences Collaborative (CECo) for supportive and palliative care research and the purpose of the Bibliography as part of this work, and the field of Narrative as a form of inquiry. It also describes how the Annotated Bibliography is constructed, and provides some guidance on how to use it.

Part 2: The Annotated Bibliography: Narratives in palliative care and end-of life

Part 2 contains the Annotated Bibliography of a selection of material.

Part 3: References

Part 3 contains two reference lists: a Reference List of Annotated Bibliography texts, and the References used throughout the document.

Part 4: Appendix

Appendix 1: Literature Assessment Form

Appendix 2: Index of some Keywords

PART 1: THE CONTEXT OF THE ANNOTATED BIBLIOGRAPHY

INTRODUCTION

Part 1 provides details of the two contexts of this Annotated bibliography: the Cancer Experiences Collaborative (CECo) for supportive and palliative care research; and the field of Narrative as a form of inquiry. This Part also describes the purpose of the Bibliography, how it was constructed, and provides some guidance on how to use it.

THE CANCER EXPERIENCES COLLABORATIVE (CECO) FOR SUPPORTIVE AND PALLIATIVE CARE RESEARCH

The 'Cancer Experiences' collaborative (CECo), one of two funded by the National Cancer Research Institute, is a collaborative initiative between five UK universities: Lancaster, Liverpool, Manchester, Sheffield, and Southampton, with its administration base in Southampton. It includes Help the Hospices, four of the UK's largest hospices (St Christopher's Hospice, Sydenham; St Luke's Hospice, Sheffield; St Ann's Hospice, Manchester; and Countess Mountbatten Hospice, Southampton), as well as palliative care and oncology clinicians and academics, various professional organisations, and academics from a broad range of social science, health and medical backgrounds across England. User involvement has also been adopted as a key strategy.

CECo has created a vibrant community of collaboration to build capacity, raise research standards, leverage new resources, publish in high impact journals, encourage emergent ideas, support relevant organisations, develop new methods and bring about a 'step change' in both research capacity and the quality of supportive and palliative care research, such that service development becomes knowledge rich and clinical innovation is evidence based. The purpose is to work together to make substantive progress in *research capacity and the quality of research in supportive and palliative care*. In the period 2006 - 2011, CECo activities include three inter-related research themes:

- innovative approaches to complex symptoms;
- planning for the care of older adults towards the end of life; and
- innovations in research methodology, including narratives of cancer and other life limiting illnesses.

The Narrative sub-theme

The narrative sub-theme is focused on:

1. developing knowledge through research, using narrative data collection and analysis approaches through generating and drawing on people's experiences of cancer and life-limiting illness from a range of perspectives, including patients, informal carers/family and professionals
2. effective application and evaluation of knowledge and evidence from narrative inquiry for service improvement and practice development
3. narrative inquiry as an area of methodological innovation, including therapeutic practices (e.g. counselling, art therapy)

There are two indicative research projects:

Project 1: Illness stories: Informing policy and practice through narrative, whose objective is to compile a categorical listing of narrative themes and topics that have been generated through qualitative research studies focussed on the experiences of patients and carers living with cancer and other life threatening diseases.

This Annotated bibliography is one output within Project 1, and is designed to enhance researchers' understanding of narrative research.

Project 2: Confronting and defying life-threatening illness through narrative writing, whose objectives are to identify the experiences, benefits and penalties of writing the story of 'illness and dying' for a) persons facing death and b) informal carers, and to examine reasons for presenting the narrative in a particular form (prose or poetry; print or Internet). Funding for this project is being sought.

More details of the work and progress of CECO are available from their Website: <http://www.ceco.org.uk/>.

Other useful resources are:

- Centre for Narrative Research University of East London

<http://www.uel.ac.uk/cnr/index.htm>

- [Centre for Narrative and Transformative Learning, University of Bristol](http://www.bristol.ac.uk/education/research/centres/central)

<http://www.bristol.ac.uk/education/research/centres/central>

- Centre for Narrative and Autobiographical Studies, University of Edinburgh

<http://www.sps.ed.ac.uk/NABS/>

- Centre for Life History Research, University of Sussex

<http://www.sussex.ac.uk/clhr/>

- Narrative Synthesis in Systematic Reviews, Lancaster University

<http://www.lancs.ac.uk/fass/projects/nssr/>

- Health Talk Online.

<http://www.healthtalkonline.org/>

Health Talk Online is based on qualitative research into patient experiences of health and illness, and will enable patients, families, and healthcare professionals to benefit from the experiences of others. These can be used as transcripts for analysis. Full informed consent was given by interviewees for the use of their transcripts for research purposes.

THE FIELD OF NARRATIVE AS A FORM OF INQUIRY

Narrative, as a form of inquiry, has been described as a subtext of qualitative research (Chase, 2005). However, whilst there is an increasing interest amongst a range of disciplines, it does not fit neatly within the boundaries of any one scholarly field (Riessman, 1993). Together with life history studies, it stands 'at the intersection between the personal and the political, stories and history, context and narrative, the teller and the told, identity and representation' (Jessop and Penny, 1999: 213). Furthermore, a number of terms are used across disciplines including 'story', 'narrative', 'narrative research', 'narrative analysis', and 'narrative inquiry'.

Narratives serve many purposes. Riessman (2002) draws on Bamberg and McCabe (1998) to suggest that they are created to remember, argue, convince, engage, or entertain their audience. It is assumed that people are storytelling (Smith and Sparkes, 2008), and that human beings and stories are intertwined (Webster and Mertoiva, 2007). Narratives are powerful forms of communicating to others about our lives, and a means of knowing about our own. Narrative is a collaborative practice (McLeod, 1997; Riessman, 2002) and is, therefore, a form of social action that helps constitute and construct our identities and ways of being (Somers, 1994; Frank, 2000; Smith and Sparkes, 2008). Organising experiences gives 'coherence and meaning to events and provide a sense of history and of the future' (Rappaport, 1993: 240). Narrative practices are understood to be located in culture, as it assumes tellers and listeners/questioners interact in particular cultural milieux—historical contexts essential to interpretation (Riessman, 2002). Somers (1994) identifies different dimensions of narrative:

1. *Ontological* narratives, that help make sense of a person's life and produce action based on how this is defined;
2. *Public* narratives that are attached to institutions and cultures, and upon which individuals selectively draw;
3. *Meta*-narratives – the grand dramas of our time; and
4. *Conceptual* narratives, constructed as explanations by social researchers.

Researching narratives, narrative research

Narrative inquiry is 'set in human stories of experience' (Webster and Mertoiva, 2007:1), offering insights about the world and/or people's experiences of it (Smith and Sparkes, (2008). As a form of research, it is an 'amalgam of interdisciplinary analytic lens, diverse disciplinary approaches, and both traditional and innovative methods - all revolving around an interest in biographical particulars as narrated by the one who lives them' (Chase, 2005: 651). Narrative can refer to the entire life story; a whole story; to brief, specific stories about a specific event told in response to a single question and which focuses on characters, plot, and setting; to complex problems as forms of storytelling and how it frames experience; or to extended accounts of lives that develop in interviews over time (Riessman, 2002; Webster and Mertoiva, 2007).

Nevertheless, although this results in a variety of methodological assumptions and strategies of analysis,

there are some shared, basic understandings that distinguishes narrative (Riessman, 2002; Elliott, 2005):

- Narration is *sequenced and temporal* (Elliott, 2005), in which one action follows another, over time, and ordered thematically or episodically (Riessman, 2002). Time is connected to past and future through structure (McLeod, 1997);
- The narrator is the actor or observer in the story, expressing emotion, thought, and reflection through which they *convey meaning* which relates them to a definite resolution or conclusion – narratives have a *causal dimension*. (Gergen, 2002; Elliott, 2005);
- They are produced in relationship to a *specific audience* – the listener – which is the context for whom the narrative is meaningful (Elliott, 2005);
- As they are constructed through ‘joint actions’ (Plummer 1995: 20), narratives are inherently social; the narrator shapes their experience, their reality, and their identity through interaction. Narratives are, therefore, *co-produced* (Elliott, 2005);
- Narrators and listeners, each of whom have a history as a subjective being, are ‘*positioned*’ in different discourses (Davies and Harre, 1990; Riessman 2002; Riessman, 2002a). Positions may be imposed on another by the narrator (interconnected); imposed on the narrator by another (interactive), or taken up by narrator (reflexive) (Davies and Harre, 1990;). Positions, however, are not static. They signify performance of identity, and are dynamic over time and context (Riessman, 2002);
- Stories draw upon culturally available genres - myths, folklore, Freudian, atrocity stories, urban tales (Atkinson and Delamont, 2006) - and are shaped by *cultural conventions* (Plummer, 1995);
- The point of the story is to make a point, and it is in this that the narrator takes up a moral position (Gergen, 2002). Narratives are, therefore, inherently *ethical*;
- Meanings of life events are not fixed or constant, but *evolve* as a result of subsequent life events (Riessman, 2002);
- Researchers are also narrators for whom the above apply (Elliott, 2005).

Disciplinary approaches

Chase (2005) has identified some of the different disciplinary approaches to narrative research:

- *Psychological*, in which the emphasis is on how narrative is formative, affecting how people live. This emphasises the ‘*what*’ of story that contributes to identity which can change over time;
- *Sociological*, concerned with *how* life is lived/experienced and with categories of construction produced in specific settings that shape lives, which encompass the complexity of this;
- *Sociological*, concerned with *discursive practices* (as well as what/how), with a focus on the interaction with the interviewer. This approach uses historical, cultural discourses that are transformed or resisted;
- *Anthropological* or narrative ethnography, where the researcher is involved in a community or group over time. The individuals, narrator, and researcher are presented in a multi-vocal text;

- *Autoethnography* is used to show, rather than tell, the story, through plays or collaborative research.

Narrative analysis: Story analysts and storytellers

Narratives includes oral narratives; written narratives (such as autobiographies, letters, journals, and diaries); visual narratives; and performative narratives, transformed to stage, poetry, and fiction (Chase, 2005; Elliott, 2005). Narrative inquiry involves a *selection* of experience for attention, and a *patterning* of these according to ways available. Narratives are identified in two ways: either through eliciting stories through interviews, or through analysing pre-existing material (Andrews et al., 2000; Smith and Sparkes, 2008). Smith and Sparkes (2008) have created a typology of narrative analyses and these are shown in the reproduced Figure below. They argue that, whilst narrative approaches may not be considered as linear and structured as their Figure implies, this, nevertheless, functions as a heuristic device to facilitate knowledge. They are also explicit about a number of features of the typology, including that: it is not exhaustive, it is not hierarchical or evaluative, and it is not mutually exclusive - different approaches may be combined.

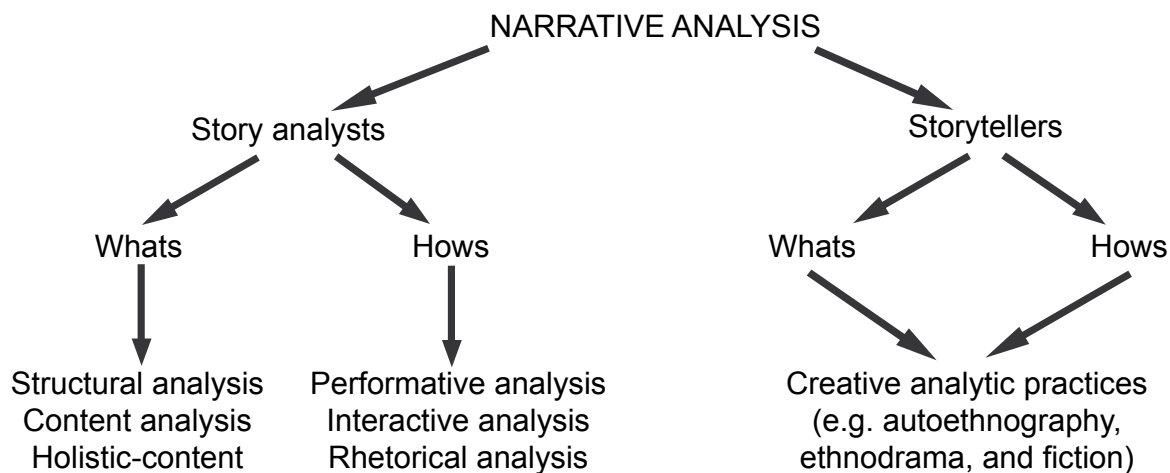


Figure 1: A typology of narrative analyses (Smith and Sparkes, 2008: 20)

In this Figure, Smith and Sparkes (2008) differentiate between two starting places, or standpoints, of narrative as either that of the story analyst or the storyteller. They suggest that *story analysts* research stories by conducting a narrative analysis through the use of systematic and rigorous strategies and techniques designed to identify, explain and think about the features of the story. In contrast, for the *story-teller*, analysis is the story.

To differentiate these further, story analysts are situated within a disciplinary perspective, such as those outlined earlier, from which theories are generated, and they adopt the conventions that characterise this position, namely 'experiential authority, the participant's point of view and interpretive omnipotence'

(Smith and Sparkes, 2008). Smith and Sparkes (2008) describe this as turning a story told into a story to be analysed. In contrast to this 'realist' perspective, they suggest that stories do the work of analysis and theorising; they are themselves analytical. Thus, they argue, when people tell their stories, they utilise analytic techniques to interpret their worlds. The goal for storytellers is not abstract theorising and explaining, but evocation and embodied participation with stories. Drawing on Richardson (2000), Sparkes and Smith (2008) argue that to support this, storytellers write creative analytic practices, and narrative analysis is a project of representation, with writing the method of analysis.

In moving down the Figure, Smith and Sparkes (2008) differentiate between the '*whats*' and '*hows*' of story analysis and the '*whats*' and '*hows*' of storytelling. The '*whats*' of story analysis include content analysis of the central units of content, whilst analysis of the formal properties is concerned with the way the narrative is structured or organised. Analysis may focus on the development of plotlines, the type of plot (for example, heroic or victim; 'at the crossroads'; 'life as trial and error'), or variations in structure. However, they also identify the risk that the focus on structure can hide the dynamic and socially constructed nature of the narrative created between narrator and listener, as well as the risk of subsuming an individual's stories within a unifying, more general, plotline. The main '*how*' of story analysis upon which they focus is performative analysis - the manner and purpose for which the story is constructed, at particular times in specific contexts. Types of questions that narrative analysis asks are: Why was the narrative told in that way and in that order? How is the narrator located in relation to other characters and to the audience? What are the identity claims and how are these performed? Smith and Sparkes (2008) draw on their own study of the narratives of disabled people (Smith and Sparkes, 2002) [and included in the Bibliography as Smith and Sparkes, (2005)] as an example of the question: 'How is coherence constructed in the story?' rather than 'What does the story tell us about coherence?'

Examples of methods of story analysis

Two examples of narrative research methods include:

- Labov and Waletzky's (1997) structural analysis of narrative identifying the following:
 - Abstract: a summary of the key point;
 - Orientation: to place, time events people;
 - Complicating action: what actually happened;
 - Evaluation: of the meaning and significance;
 - Resolution: what finally happened;
 - The coda: the narrator's return to the present perspective
- Wengraf's (2001) Biographical-Narrative Interpretive Method (BNIM), which comprises a series of stages (Buckner, 2005). Narration is encouraged through the use of a single narrative-inducing question that allows the narrator to frame their own story, for example, 'Tell me the story of'. The researcher takes a stance of 'active listening' and restricts their responses to those that encourage continuation of the story. A second session follows in which the narrator is asked questions, in the original order, about topics they have raised. An additional optional session can

elicit any further information of interest. The purpose of the analysis of biographical-narrative interviews is to interpret both content and performance to yield detailed understanding. It is undertaken by panels of researchers in stages, ranging from initial analytic reflections on chunks of data, through stages of panel hypothesising and counterhypothesising about the respondents' 'lived life' and their 'told story' (Buckner, 2005)

Narrative researchers can also adopt the stance of a storyteller, in which analysis is the story, that is, the storyteller moves back and forth, in tandem, between the '*what*' and '*how*' components. Through forms such as poetic representations, autoethnography, ethnodrama and fictional representations, they show the story (*what*) and *how* it is performed through writing, indicating that content and form are both important and cannot be separated. The writing itself is a method of analysis, the aim of which is to 'practice an artful, poetic, evocative, empathetic, multi-voiced social science in which meanings stay open and writers and readers know not just the 'facts' in their heads, but can keep in their minds and feel in their bodies the complexities of culture, society and concrete moments of lived experience' (Smith and Sparkes, 2008: 24). Speedy (2005) describes this as 'writing as a form of inquiry' in which representational practices are made as explicit and transparent as possible. Writing is a research tool or craft in its own right and/or a method of re-presenting the words of participants.

For a further discussion and critique of this typology of story analyst/storyteller, see Atkinson (1997), and also Frank (2000; 2002) [in this Bibliography].

Methodological issues

There are a number of methodological issues in relation to narratives, including:

- *The research relationship.* Although subject to critique [see, for example, Atkinson and Silverman (1997) and Gubrium and Holstein (2002), and also Bury (2001) in this Bibliography], the interviewer-interviewee research relationship is now redefined as one of a listening to the authentic, storied voice of the narrator (Chase, 2005);
- *The interpretive process* is, therefore, different, focussing firstly on themes within, rather than across, narratives. A narrative strategy could identify the narrator positions of: self and others; self and audience; self-self, as identified above, or the subject positions, interpretive practices and ambiguities (Chase, 2005);
- *The researchers voice and narrative strategies*
Chase (2005) has identified a typology of four researcher voices:
 - Authoritative, interpretive, voice;
 - Supportive voice, for example, through testimonias or anthropological commentary;
 - Interactive voice, where the researchers own voice is examined;
 - The particular and the general: small numbers need not be generalisable, any narrative is significant.
- *The 'truth' and validity of the narrative.* Narrative inquiry does not seek verifiable facts of a story; rather it is concerned with the shifting connections forged in narrative between past, present, and

future (Riessman, 2002). Furthermore, narrative research does not make claims to truth, but rather to verisimilitude that is supported by criteria such as transparency, reflexivity, impact and transformation, and trustworthiness made visible through, for example, a meaningful analysis (Polkinghorne, 1988; Speedy, 2008). Several texts in this Bibliography address some of these issues, for example, Riessman (1993), Atkinson (1998), and Bury (2001).

- *Reflexivity*. Linked to the four aspects above, is the question of how the social location and emotional responses of the researcher influences the research, and shapes interpretation of the respondent accounts (Mauthner and Doucet, 2003). Strategies for a reflexive approach include keeping a journal or diary, field notes, and memos that show the researcher's philosophical position and decision-making processes.

Narratives of illness, palliative care and end-of-life

In the social sciences, narrative research searches out, analyses and works with stories that relate significantly to people's lives (Elliott, 2005), and narratives related to illness, dying and bereavement have become a significant sub-genre of these. As Frank (1995) argues, whether ill people want to or not, becoming seriously ill calls for stories. He suggests that these repair the damage that illness has done to the ill person's life trajectory, and these are stories that have to be told to many people: family and friends, employers, and medical practitioners. Listening to patient stories is described as an advanced form of medical history-taking, and can assist in treatment options, and improve patient-Doctor relationships (Greenhalgh and Hurwitz, 1999), and are valuable in the diagnostic encounter, in the therapeutic process, in the education of patients and professionals, and in research (Greenhalgh and Hurwitz, 1998). They give witness to what medicine cannot describe (Frank, 1995), and some would argue that the increase in illness narratives is a way of reclaiming illness from bio-medicine (Bury, 2001; Hellman, 2005) in which the taxonomy of the practitioner recasts the disease experience in such a way as something is lost that does not receive attention (Kleinman, 1988). By 'doing justice' and by not looking away (Riessman, 2002), practitioners can offer relief from suffering (Johns, 2004) [see this Bibliography], and researching the meaning of chronic illness, palliative care and end-of-life experience can challenge understandings of medicine (Kleinman, 1988; Bury 2001).

As well as broad discussions on illness narratives (Kleinman, 1988), part of the literature identifies illness narratives as typologies: for example, Frank (1995) has identified a typology of '*restitution*' '*chaos*' and '*quest*', and Hydén (1997) [in this Bibliography] a typology of 'illness as narrative', 'narratives *about* illness', and 'narrative as illness' [and see Bury (2001), in this Bibliography, for an interesting framework for analysis of illness narratives], and these are then drawn upon by others in their own narrative analysis [see, for example, Smith and Sparkes (2005) in this Bibliography]

Questions to have in mind when reading narratives:

This brief introduction raises a number of issues and perspectives, which it is useful to have in mind when

reading illness and end-of-life narratives. Some of the questions with which to interrogate a study – as a reader – include those about:

- **The Narrator (s)**
 - What type of narrative genre is being used?
 - Why was the narrative told in that way and in that order? Does the researcher give an account of this?
 - How is the central issue constructed in the story? How coherent is it?
 - What are the identity claims being made, and how are these performed? Does the researcher explore these?
- **The Methodology:**
 - What strategy of narrative analysis is being used?
 - Is this clear to the reader?
- **The Position:**
 - How is the narrator positioning themselves in relation to other characters and to the audience?
 - What is the position of the researcher in relation to the story-teller?
 - How is the researcher positioning themselves in relation to the reader?

HOW THE ANNOTATED BIBLIOGRAPHY HAS BEEN CONSTRUCTED

The selection of papers

The Annotated Bibliography is a compilation of 57 papers, drawn from a relatively wide time-span and disciplinary approach, which serve as *examples* to demonstrate the scope of narrative research in the field of illness, palliative care and end-of-life. The papers include examples from academic, professional and lay literatures. The Bibliography makes no claim to be a systematic review, and does not constitute, therefore, a comprehensive search and critique of available literature. Nevertheless, some inclusion and exclusion criteria have been applied as follows:

Inclusion	Exclusion
Adults	Children
Written in English	Non-English speaking
Post-1980	Pre-1980
Published Written materials	Web-based materials [although please note the two Internet-related studies of Moss et al., (2004); and O'Brien and Clark, (2006)]
Cancer and other illness Illness, Palliative care, End of life experience	Not learning disability or Psychiatric illness

Categorisation of papers

Papers were categorised according to a number of criteria using a Literature Assessment Form, and this is provided in Appendix A. These categories were generated deductively prior to reading, and sub-categories expanded inductively as reading progressed. The papers within the Bibliography are written by authors from Australia (6), Canada (7), Ireland (1), France (1), the Netherlands (1), Sweden (6), the United Kingdom (20), and the United States (15). Given the type of journal or the focus of the paper, texts appeared to be directed towards a particular audience, either academic (17), practitioners (12); or lay people (1). However, number appeared to be directed at more than one category of audience of academic/practitioner (24), lay/practitioner(1) or lay/policymakers (2) . Although many papers contained aspects of narrative theory, 11 of these papers are specifically offering a theoretical discussion, and a further 23 are papers describing primary research studies. Papers also concern a particular class of narrator of either patient (18), carer (4), practitioner (14), or researcher (5). Others include more than one, drawing on the perspectives of patient/practitioner (3), carer/practitioner (1), patient/carers/practitioner (4), and patient/researcher (1).

How the Annotated Bibliography is organised

The papers are organised alphabetically. In the categorisation of papers, each was given a number of keywords, which may not necessarily be the words provided by the authors. These keywords are given in each study/text item and, to assist a search for papers related to a specific keyword, an Index of some, *but not all*, of these has been provided in Appendix 2 .

A number of papers by the same author have been included. There are three papers by Charon (2000; 2001; 2004). These have been included to show how papers can be linked, not only in their subject matter, in this case, of narrative medicine, but also in their referral one to the other. This linkage helps to expand and elaborate their value and the meaning of the genre of narrative writing, to remodel and deepen the clinical relationship. There are five papers by Frank (2000; 2002; 2002a; 2002b; 2006) – a key figure in illness narratives. These have been included to show the value of all types of material. For example, a book review (Frank, 2006) not only indicates whether the book in question is worth pursuing, but also demonstrates that something can be learnt from reading the critique: how it is written; what perspective it takes; what ideas it promotes; what debates it engenders.

Three patient/carer auto/biographies are included. As well as stories of personal experience, three of these stories are set within a specific social context of health care, illuminating emancipatory, and ethical, action. These UK/US/Ireland based narratives complement more theoretical papers, such as those of Charon (2000), Myers (2002), and Mishler (2005) in offering insight into the similarities and differences between the way in which the different health care systems (the hospital organisation and environment, the medical interventions, the patient-Doctor relationship and Health Insurance) impact on the experience of illness and dying. Two are written to help change aspects of the specific system – for example, the time-consuming and worrying nature of the system of insurance and payment (US/Ireland) are described in two of the three stories, with only one system (UK) free of the anxieties and fears that issues of insurance generated. However, the UK system appears to have other drawbacks, for example, less access to Consultants, and less clarity about treatment options.

Three practitioner-based auto/biographical texts have been included. The first (Elfick and Head, 2004) is a book of poetry. Although the only one to have been included, it provides a vivid example of poetry as a rich source of ‘performative’ narrative. The other two are practitioner reflections: one in the form of a reflexive diary (Johns, 2004) and the other prompted by an Editor’s interest in palliative care practitioners’ stories (Mason, 2002).

SUGGESTIONS FOR USING THE ANNOTATED BIBLIOGRAPHY

As well as reading papers of specific interest, there are a number of ways in which this Bibliography can be approached. For example, there is value in reading narrative theory alongside a particular study, such as Byrne’s (2006) autobiography and Frank’s (2002a) critique. In addition, whilst texts can be read individually, the Bibliography, nevertheless, constitutes a collection - a grounding in a range of issues.

As a result, reading papers across themes, for example, of hope helps build a picture, not only of patient perspectives, but also of the different qualitative or narrative approaches to researching hope.

When reading the narratives, particular features to note are:

1. The differences, noted by Bingley, et al., (2008) [in this Bibliography], between:
 - studies involving narrative analysis as the application of an analytic technique devoted to narrative; and
 - qualitative studies applied to narratives;
2. Whether the focus is:
 - the content, form and/or structure of a narrative that has been generated for this purpose; or
 - a story embedded within a wider text (Riessman, 1993; Bingley et al., 2008)
3. How lay voices are mediated in the academic literature, either by the narrator's own status as an academic [for example, Craib (2003); Johnson and Bourgeois (2003); and Laungani (2003)], by a researcher [for example, Feldman, (1999) and Eliot and Olver (2007)], or by an interviewer on behalf of an academic journal [see, for example, Dokken and Ahmann, (2006) excluded from the Bibliography as it concerned end-of-life decisions about an infant].

PART 2: THE ANNOTATED BIBLIOGRAPHY: NARRATIVES IN PALLIATIVE CARE AND END-OF-LIFE

Abma, T. A. (2005) Struggling with the fragility of life: A relational-narrative approach to ethics in palliative nursing. *Nursing Ethics*, 12, 4, 337-348.

Status of author (s)	Academic: University Department for Health Care Ethics and Philosophy
Nationality	Netherlands
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: The phenomena of narrative Using narrative analysis: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Case study
Whose perspective	Carers and Health practitioners
Intended audience	Practitioners
Keywords	Cancer; Complementary and Alternative therapies; Dying; Ethics; Fragility of life; Frank; Health practitioners (Nurses, Palliative care); Standpoints/Positions; Stress; Typology of Narratives;

Based on a larger evaluation project on palliative care practice, this is a case study, from both perspectives, of a difficult relationship between a carer and oncology ward staff. Conversational interviews were undertaken with the carer and two of the palliative care nurses involved in the patients' care, followed up one year later with a second interview with the carer. The fully transcribed texts were analysed with a focus on themes, narrative structures and language.

A relational-narrative framework was used to understand the protagonist's stories. A holistic context analysis identified themes of the carer's concern over his wife's well-being, and the lack of support he felt he experienced. As an alternative to subjective immersion and objective detachment, Abma introduces Gadaw's (1999) notion of 'relational narrative'; that is, the narrative that arises through mutual engagement in a dialogue that creates understanding and opportunities to develop ways of managing a situation. Abma situates narratives within an ethical framework, and argues that these are not just representatives of experience, but are vehicles that enable people to know how to act. Abma positions linear illness narratives within a Kantian conceptualisation of the good life in which control and prediction are most important values. Whilst this assumption - of the future without change that negates the fragility of life - might be appropriate in acute illness, it is unsuitable in chronic disease or in life-threatening illness where recovery is impossible.

The text identified the carer's linear 'chaos' narrative structure of events unfolding in time, and a plot developed to understand the situation, whilst the linguistic analysis identified the meaningful metaphor of a 'beggar' that the carer used. This linear 'chaos' narrative, that included a search for recovery and the

denial of death, is not heard. The nurses' narratives indicated a primary relationship with the patient, rather than with the family. Nurses expressed what they felt was the carer's disrespect for their knowledge and expertise after he had learnt some skills, and that his constant presence at the bedside claimed space that they could not enter. The nurses also acknowledged the difficulties that arise from heavy loads in providing good nursing care. The discussion highlights the position in which many nurses find themselves: trying to meet the demands of many as well as the one, within an institutional context, bounded by time and space, and inexperience or lack of skill in dealing with existential and spiritual needs.

This is a very clear and 'readable' text. It is unusual and interesting to have the voices of all parties in a conflict [see, for example, in this Bibliography, Anonymous (1998) and Hok (2007)] who provide a narrative of 'one-side' of the event]. Nevertheless, it stands alone as a case of interest, in which the competing perspectives of the participants can be understood. The paper also offers researchers a detailed background discussion on narrative and data analysis.

Andersson, B. and Öhlén, J. (2005) Being a hospice volunteer. *Palliative Medicine*, 19, 602-609.

Status of author (s)	Academics: University Department of Nursing
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Phenomenology
Whose perspective	Health practitioners
Intended audience	Academics and Practitioners
Keywords	Be/longing; Dying; Meaning; Phenomenological-hermeneutics; Ricoeur; Volunteers

This is a phenomenological-hermeneutic study of what it means to be a volunteer in a country without a tradition of hospice and palliative care voluntary services. A convenience sample of 10 volunteers (9 women and 1 man), who had worked between 6 months and 10 years duration in 3 strategically sampled hospices, was used. Each interview was initiated with a question – 'What made you become a volunteer here?' - and participants were then asked to describe personal experiences arising from their work. The stance of the interviewer was that of a reflective listener. Tape recordings (8) and contemporaneous notes (2) were fully transcribed, and analysis was undertaken in three steps: naïve reading in which the text was approached with an open mind in order to get a sense of the whole; an analysis of the meanings of parts of the narratives shared across the stories, including the motives of the volunteers and their encounters with the hospice and with the patient; and an interpretation of the meanings disclosed together with the researchers' pre-understanding and ideas, brought together as a whole.

The reasons why volunteers became involved in hospices included helping others, making others happy,

and their own longing for social fellowship and support. Their encounters with the hospice included dimensions of getting to know the atmosphere of the hospice, being assigned a constructive task and longing for fellowship. Their encounters with the patient included wanting to understand the needs of the patient, imagining the situation for the patient, and retaining the encounter with the dying. The interpretation as a whole indicated the importance of the reciprocal nature of fellowship, and what it means to a volunteer if their personal need, to be affirmed as a caring person and incorporated into the fellowship of the hospice, cannot be fulfilled.

This is a useful paper on volunteer experience and the meaning that they give to this. It is distinguished from other hospice and palliative care volunteer research by the emphasis on the existential meaning derived from the story experience, in particular the aspects of 'longing' and 'belonging'. Their interpretation appears to be based on fragmented texts from across volunteers, rather than on the individual story of each volunteer. It provides researchers with a study based on the interpretation theory of Ricoeur (1981; 1991), as well as categories of meaning that would be useful for comparative analysis.

Anonymous (1994) The inhumanity and humanity of medicine: Dying for palliative care. *British Medical Journal*, 309 (24 December), 166-169.

Status of author (s)	Partner
Nationality	UK
Type of Author (s)	Lay
Study/Text	Auto/Biographical accounts of: End of life
Type of text	Personal experience: Autobiography
Type of study	Case study
Whose perspective	Carers
Intended audience	Practitioners
Keywords	Anger; Cancer; Dying; Hope; Living will; Health practitioners; Pain; Suffering

This paper, written from a carer's perspective, focuses on their own experience and that of their partner in their relationship with Health practitioners, as the partner struggles with the late stages of acute myeloid leukaemia. It is a description of the experience of standing alongside someone as they struggle with illness and dying. The narrative account, based partially on the diary kept by the carer during the last weeks of his partner's life, begins with an introduction to the background to the text, and then charts, through the diary entries, the traumatic and painful last six weeks of life.

This is a poignant paper, written by a lay person who is critical of the medical care received during the late stages of cancer. In describing the personal experience of the sorrow and helplessness in watching someone in pain and suffering as they become increasingly ill and troubled with symptoms, the narrative reveals some of the struggles that patients and carers encounter: the trials of treatments that have no hope of altering the outcome and which fail to control symptoms, the dashing of small hopes,

the attempts to grab small oases of normality, and the effort-ful self-care and the care of carers. Their attempts to overcome or ameliorate the bodily and emotional consequences of treatments and dying of cancer by engaging their medical practitioners in their support are described, and the underlying anger at the perceived negligence, the inconsistent views about treatment protocols, and the impact of the hospital structure of frequent changeover of Registrars described as ‘too many doctors for one patient’, is revealed.

The paper, published in the British Medical Journal, ‘speaks for itself’. It is of value to researchers to consider alongside other carer experiences [see, for example, Abma (2005) and Hok et al, (2007) in this Bibliography]. As a narrative in the public domain, it is also available for narrative analysis [see O’Brien and Clark (2006) in this Bibliography for a critique on the ethics of this].

Atkinson. R. (1998) *The life story narrative*. London: Sage.

Status of author (s)	Associate Professor: University of Southern Maine, Centre for the Study of Lives
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Research methods / Narrative
Type of study	discussion
Whose perspective	Researchers
Intended audience	Academics
Keywords	Ethics; Interviews; Life story; Meaning; Reflexivity; Truth;

This book, divided into five chapters, contextualises and describes the life story interview as methodology. Atkinson suggests that story-telling is giving a narrative account of an event, an experience, or any other happening, and that this reflection uncovers deeper meaning and makes life understandable and coherent. Its principle distinguishing feature is the presentation of a 1st person narrative in the words of the person telling their life story, and it acts, therefore, as both a primary document, and as a secondary research tool for information and data. How this 1st person narrative is presented varies in different traditions, with ethnographers, for example, often only presenting small percentages of the description in the insiders’ words or language. The life story is defined by Atkinson as close to 100% in the words of the teller.

He elaborates this meaning and its application within disciplinary settings, to include: understanding development and personality (psychology); measures of cultural similarities and variations (anthropology); understanding and defining group interactions and memberships (sociology);, an new way of knowing and teaching (education); and understanding ageing and generation and ways of improving quality of life (gerontology). In research, uses of life story interviews include:

- *psychological*: understanding the self; developing identity; counselling and therapy; and the

narrative study of lives;

- *sociological*: understanding roles and standards, the reality described by story, and the social consequences of the story itself, and people's understanding of social events. The sociological uses also include the:
 - socio-linguistic*: exploring the relationship between language and social practice/social identity;
- *mystical-religious* particularly found in anthropology to portray religion and spirit as lived experience, an individual's deepest wishes, the conflicts and struggles of human life; and
- *cosmological-philosophical*: as a presentation of a cosmic world view, or a way in which the world is viewed.

Atkinson notes the patterns and elements of story-telling: beginnings; conflicts; resolutions, and suggests that life stories can be used to explore life-as-a-whole, but also the themes of continuity, purpose, commitment and meaning, and their major developmental influences. In not only constructing meaning and coherence for the teller, it also provides information about how lives are experienced, how life and historical events are interpreted, and what strategies are used to reconcile and resolve difficulties. Atkinson acknowledges personal, subjective, truth, and emphasises that whilst a relatively uniform research method, with its own standards of validity and reliability, can be applied, there needs to be accommodation in the use of questions that takes account of the interviewee, the research focus, and the setting. The 'truth' or internal consistency can be identified through corroborators or indicators, or through the development of coherency as a part of a collaborative process, but Atkinson warns that this depends on how willing and open the story-teller is to telling a truthful story. Whatever story is given, this can be used to accomplish research goals, or for interpretation.

Suggestions are made for planning, undertaking, and interpreting the interview. Planning includes: deciding who to interview; taking time to prepare; and identifying the right setting. In 'getting the story', particularly through the use of an open-ended interview question, Atkinson emphasises the transforming experience of life-story interviewing as deeply moving for the researcher, with personal connectedness to the interviewee, and to one's own past. A helpful discussion is given on the ethical and moral dimensions of life-story interviews concerning the nature of this relationship, what happens in the interview, and to the interview, raising the question of whose story it is. He offers guidance about the negotiation with interviewees to safeguard their rights. 'Doing' the interview includes paying attention to the way in which questions are asked and what questions are asked to elicit meaning, and over 200 examples of questions within 11 categories are provided, although Atkinson emphasises the importance of minimal structure in the interview in order to the person's own story. He argues that the interviewer needs to be able to be both in the process, and to observe it at the same time.

Responsivity, flexibility, and listening well are emphasised, and a warning on the emotional dimension for the interviewer made. In terms of interpretation, subjectivity is highlighted, but Atkinson also emphasises the need to maintain a balance between objectivity and subjectivity, and the importance of both validating the story and exploring the meaning of it; a process that takes place throughout the planning, doing, and interpreting phases. The concern of interpretation with meaning - the story's; the story teller's and the

researcher's – emphasises accepting the story as a text that has something to say about life and a life. This, therefore, emphasises intuiting the connections, meanings or patterns of the story itself. Atkinson discusses disciplinary-based theories that can contribute to interpretations alongside subjective ones. These are to indicate the different starting points that each theoretical approach makes.

This is a useful book from one of the leading proponents of life story interview. Atkinson provides useful directions to accommodate the interests of readers from different disciplines, and he offers specific, and practical, suggestions and guidelines for undertaking and transcribing life story interviews. He also discusses important dimensions relating to the interpretation and use of the narratives, including those of truth, interpretation and meaning-making. The text includes a number of useful references to key thinkers in the field.

Benzein, E., Norberg, A. and Saveman, B. I. (2001) The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, 15, 2, 117-126.

Status of author (s)	Assistant Professors and Professor: University Departments of Nursing and Social Work
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Phenomenology
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Cancer; Dying; Fear; Hope; Meaning; Pain; Phenomenological-hermeneutics; Ricoeur;

The study focuses on the experience of hope in those terminally ill with cancer. The sample included 11 patients, 6 of whom died within 2-9 weeks of interview and 5 within 9-12 months. Narrative interviews were undertaken in which interviewees were asked how they felt when they were first diagnosed, and then to narrate situations where they experienced hope. The authors adopted the phenomenological-hermeneutics of Ricoeur which involved a three-stage spiral process of: reading each narrative as a whole; undertaking a structural analysis in which the text was divided into meaning units, condensed and organised into themes; and interpreting the narratives as a whole in the light of pre-understanding and researcher reflections. A thematic content analysis was also undertaken to part of the context for the study.

The thematic content analysis of aspects of living with cancer identified that hope was situated in the awareness of having incurable cancer. It revealed the limitations of the interviewees current daily life but that, with the awareness of their limited future, they lived for the day. It revealed the uncertainty in which

interviewees lived, and the experience of belonging both to life *and* to death; a situation which, because it was out of their control, they had to accept. Priorities were re-evaluated and the meaning of life became more important. Fears of total dependency as they became increasingly dependent were also identified. Through the structural analysis, the authors identified four themes. Despite their intellectual awareness of the incurability of their cancer, interviewees hoped for a cure, or at least of getting better. This hope was linked to on-going palliative treatment and good symptom control, especially related to pain. The hope for living a normal life involved lowering their sights of what could be realised, and setting short-term goals that were subject to change. The presence of confirmative relationships, which included themselves, significant others (close family, friends, other patients, and staff), the milieu of home, pets, and a transcendent relationship, was an important dimension in hope. Lastly, a reconciliation with life and death gave hope. This included being prepared for death practically, financially, and emotionally, and an acceptance of the inevitability of it.

The findings interpreted as a whole identified that living with incurable cancer involved the experience of hope as a dynamic between 'hoping for something' – a cure and living normally, and 'living in hope' – in confirmative relationships, and reconciliation and comfort with life and death. Marcel's (1965) philosophy indicates that reconciling the contradictory nature of 'being' hopeful and 'acting' hopefully is to view hope as an ontological mystery, accomplished through the re-collection of oneself as a unity. By joining together 'being' and 'doing', the dichotomy is transcended.

This is a valuable paper for researchers. It links thematically to Sparkes and Smith (2005) and Elliott and Olver (2007) in this Bibliography, and it provides the useful theoretical discussion of phenomenological-hermeneutics, locating the findings in a philosophical tradition. The method of sampling, and data collection and analysis are clearly described and the findings linked to data and to other studies.

Bingley, A. F., McDermott, E., Thomas, C., Payne, S., Seymour, J. and Clark. D. (2006) Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases. *Palliative Medicine*, 20, 183-195.

Status of author (s)	Academics: Cancer Experiences Collaborative at Lancaster University, and the University of Sheffield
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: The phenomena of narrative
Type of text	Research: Secondary
Type of study	Review
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Breaking bad news; Cancer; Dying; Frank; Identity; Pain; Typology of narratives;

This paper reviews published and unpublished narratives by people facing death from cancer and other diseases since 1950, and it asks a number of questions about *who* has written *what* and for *what purpose, and where* or *how* narratives have been made accessible. Such a review is invaluable for both researchers and practitioners, as it identifies the respective approaches to narratives across a range of authors, and highlights how these differ according to different diseases and the different purposes for which they have been written. Bingley et al., note the recent appearance within narrative and poetry - of the personal experiences of dying, and they explore the place of this, when situated within a wider autobiography as opposed to a narrative expressly written as an account of the experience of illness and dying or that describes one aspect of this experience.

Across all narratives a number of themes emerged, most notably the moment of receiving their diagnosis. Whilst they acknowledge a degree of bias arising from the possibility that those who have a good experience of this do not write illness narratives, it is, nevertheless salutary to learn that, despite training and education to help practitioners with the difficult task of 'breaking bad news', the authors found that this moment is 'almost unanimously, and breathtakingly, appalling (p.187). They also identify the extent to which this relates to those diagnosed with cancer, rather than illnesses such as a heart attack or stroke that are comparatively more straight-forward to diagnose. Other significant aspects of the narratives draw attention to medical interaction, symptom control including pain relief (or lack of it), and facing death. Whilst Bingley et al., of these narratives not only vividly describe these experiences, they also often make suggestions for how these could be improved. The discussion focuses on the reasons why a person chooses to write down these experiences. Drawing on key theories, the authors identify three perspectives of: therapeutic meaning-making (making sense of dying); the description itself (of a journey, of restitution, chaos or quest, to be witnessed); and the creation of a new identity (a continuity of the self).

The structure of the paper is a little confusing, with some sub-themes being given prominence over a full discussion of the recurrent content themes. Nevertheless, the paper provides researchers with a valuable analysis of narratives over time, and a useful introduction to key theorists. Furthermore, it offers a number of insights into the experience of the impact of practice upon which researchers and practitioners can usefully reflect. This is, therefore, a useful starting point for researchers and practitioners alike.

Bingley, A. F., Thomas, C., Brown, J., Reeve, J. and Payne. S. (2008) Developing narrative research in supportive and palliative care: The focus on illness narratives. *Palliative Medicine*, 22, 653-658.

Status of author (s)	Academics: Cancer Experiences Collaborative at the University of Liverpool, Lancaster University, and the University of Southampton
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Research methods
Type of study	Discussion paper
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Hope; Research methods; Truth;

This is a helpful and clearly written paper. It builds on the work of Riessman (1993) [see this Bibliography] to discuss the value of narrative research in supportive and palliative care. The authors situate ‘story’ as central to narrative research, and they identify the role of a ‘breach’ or ‘disruption’ in the patterns of life in generating stories, and the subsequent search for meaning that demands story. They make a number of helpful distinctions that enable readers to situate themselves more clearly as they approach the increasing growth in the number of stories being written about illness and end-of-life experience.

The first of these is the distinction made between qualitative studies applied to narratives and narrative analysis as the application of an analytic technique devoted to narrative. This involves a focus on the content, form and/or structure of a narrative that has been generated for this purpose or is identified within a wider text as a story. This difference is made more distinctive through the presentation of examples of each form, and the nature of what it is possible to express through these different approaches is clarified. A second important distinction is made in relation to the question of validity. Like Riessman (1993) upon whom they draw, Bingley et al., present arguments about the nature of truth and its applicability to human experience as presented in stories. In this, they make distinctions between facts as truth and the function of meaning-making through story. They argue that the importance in narrative research is not so much seeking ‘objective truth’ as revealing experience through the application of rigorous analytic methods.

This paper is of value to both academics and practitioners alike, as it provides a useful bridge from narrative analysis as a theory of method to its potential application as a method through which to understand illness

and end-of-life experience.

Bolton. G. (2004) Editorial: Death, dying and bereavement. *Medical Humanities*, 30, 1, 49-52.

Status of author (s)	Editor of column in an academic journal
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Patients, Carers and Health practitioners
Intended audience	Practitioners
Keywords	Dying; Health practitioners (Doctors); Writing;

Although only a one-page Editorial and written as an Introduction to two narrative pieces on death, this paper makes a useful contribution to discussions about the place of narrative in medicine and health care, whether written in the form of poetry, fiction, or the expressive and exploitive writings of those close to dying.

Bolton suggests that death is culturally feared partly because it does not have a role in everyday life; it has been tidied away. The responsibility for the story of one's life, constructed by ourselves and others, may be devolved to others. However, Bolton argues that death and dying disrupts our, hitherto, accepted life story, and that writing and narrative can be helpful for both patients, relatives, and clinicians in bringing understanding to their own life, and the life of others. Thus, she argues, reading and writing about death and dying make a contribution to clinicians understanding, and to finding a route through the existential questions about the self and the life that has been lived.

Bolton's editorial is, in part, a response to Strawson's (2004) critique, published in the Guardian newspaper, of a US University Narrative Programme as only restating the truism that doctors should listen to their patients more, and that narrative understanding is an effective strategy that enables them to do this. She argues that narrative is more than this; it is the processes of writing that offers so much, including: the calming order of rhythm, the strengths of metaphor, and the release of expressing emotion. For researchers on palliative care and end-of-life, this Editorial provides a background to, and an argument for, the value of narrative research.

Bolton, G., Field, V. and Thompson, K. (Eds.) (2006) *Writing works: A resource handbook for therapeutic writing workshops and activities*. London: Jessica Kingsley.

Status of author (s)	Freelance consultant in therapeutic writing and reflective practice writing
Nationality	UK
Type of Author (s)	Professional: Practitioner
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Narrative
Type of study	Review /Reflection
Whose perspective	Health practitioners
Intended audience	Practitioners
Keywords	Reflexivity; Workshops; Writing;

The book is edited by three people, and contains 49 named contributors. As well as an Introduction and a Conclusion, it contains 10 chapters divided between two headings: '*Writing from without*' and '*Writing from within*'.

In the *Introduction*, therapeutic writing, as a form of writing for self as an expression of personal experience and personal development, is differentiated from literary writing orientated towards a literary product, although therapeutic writing may end in published form. They argue that the response to the reader is different; with published literature, the focus is on what the writer says, whilst in therapeutic writing the emphasis is on the writer as a person. The many forms of writing are described, and they identify the need for tutors of writing courses to care for the writer and not only the development of writing, which may require the tutor to seek supervision. They emphasise the importance of the foundations of shared aims, boundaries, contracts, ground rules, and supervision. Key pieces of advice on running a therapeutic writing group is given. They identify Pennebaker's (1997) book as a pioneer in providing evidence for the benefits for mental and physical health, and suggest that the context and focus of the group – lying somewhere on the continuum from writing for pleasure that may be therapeutic to a writing-as-therapy group – be made explicit. Practicalities include consideration for the venue, the content of sessions, time management, and the role of facilitator/tutor.

Part 1: *Writing from without* includes a combination of 'how to's', narrative reflections, and end products, and it includes a series of chapters entitled: '*Warming up/working together*', '*Writing about place*', '*Writing from objects*', '*Writing from published poems*', and '*Writing in form*'. Part 2: *Writing from within* includes chapters entitled: '*What people need to write*', '*Different Masks, Who am I?*', '*Life's journey*', and '*Loss and change*'.

Whilst this is a 'how-to' book for therapeutic writing and includes many ideas for running exercises, activities, and workshops, it is, nevertheless, a useful text for researchers who are pursuing narrative or other qualitative methodologies. It emphasises different forms of writing, each of which are of value

to help generate reflexive diaries and a more narrative style of writing. It also identifies strategies for structuring writing events, and the dimensions that need to be taken into account. This detail provides useful support to researchers who may consider workshops as a mode of innovative data collection [and see also Feldman (1999) and Moss et al., (2004) in this Bibliography for examples of this]

Brannström, M., Brulin, C., Norberg, A., Boman, K. and Strandberg, G. (2005) Being a palliative nurse for persons with severe congestive heart failure in advanced homecare. *European Journal of Cardiovascular Nursing*, 4, 4, 314-323.

Status of author (s)	Academics in University Departments of Nursing, Geriatric Medicine, Public Health and Clinical Medicine
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Phenomenology
Whose perspective	Health practitioners
Intended audience	Academics and Practitioners
Keywords	Dying; Health practitioners (Nurses, Palliative care); Heart failure; Meaning; Phenomenological-hermeneutics; Ricoeur;

The focus of the study is to describe and understand the meaning of being a palliative care nurse for patients with Chronic Heart Failure (CHF) in advanced palliative home care. The study included 11 nurses (10 women and 1 man), aged between 30-59 years, who had worked as nurses for between 7-36 years and for between 1-9.5 years in an advanced palliative home care. Participants' were asked to describe their experience of being a nurse for persons with CHF in advanced home care. Probing questions encouraged participants in their narration. The text was transcribed verbatim, including verbal and non-verbal cues. All the text was used in the process of analysis informed by the phenomenological-hermeneutic principles of Ricoeur. This involved three phases of: naïve reading followed by a structural analysis. This included an analysis and division of the text into 'meaning units' which were then compared with each other and arranged according to meaningful connections. Condensation and abstraction of these revealed 13 sub-themes and 4 themes. Finally, a comprehensive interpretation was made drawing on the naïve reading, the themes as well as the researchers' pre-understanding, and a reflection on the research question.

The naïve reading of the text indicated that being a palliative nurse meant striving to see the 'whole' person in their home situation, and this was a pre-requisite for alleviating the specific problems of CHF. This position differed from being a palliative nurse with those with cancer, as CHF is an unpredictable disease and a feeling of uncertainty arises making it more difficult to talk about existential issues. Palliative nursing focussed on co-operation with the patient, acting on their behalf, and mediating security for them

and their family. The themes identified in the structural analysis were:

- *participating in the patient's everyday life*, including being a guest in the patient's home; being trustworthy, mediating calm, and security; being adaptable to the patient's way of life;
- *facilitating the patient's everyday life*, including showing the patient's ways to continue their life; tailoring care in dialogue with the patient; and striving to keep one step ahead;
- *being on unstable ground about the unpredictable process of dying*, including their uncertainty about this, and concern about not preparing their patient and next of kin for death, and being uncertain about integrating curative and palliative care; and
- *being strong and weak in a secure atmosphere*, including responding to the responsibility for the patient in cooperation with team members; being able to accept and be forgiven when one falls short; having support and togetherness with team members, and being grounded in a shared value system.

The comprehensive interpretation and reflections identified the extent to which the nurses were guided by the principles of a palliative care culture, but that this culture may be in conflict with what is best for patients with CHF. Being adaptable to the patient's way of life and the unpredictable course of their illness may carry more weight than preparing a patient and their family for the impending death. There were frustrations and feelings of inadequacy arising in these 'tight corners', but there were limits to the nurses pliability and they had already made up their minds about what is good for the patient, including that resuscitation is not an option. Nevertheless, despite the challenges, there were positive aspects and this responsibility was shared with a secure working team characterised by openness, trust and forgiveness when falling short. The study gives prominence to the question of the dominance of cancer care in setting norms for what is good for palliative care patients, and it reveals that these values do not always correspond with CHF.

This is a clearly written paper that provides a useful example of a study using narrative analysis, in which the authors provide a sufficiently detailed summary of the analytic methods, and the process from data to interpretation. The tables outlining an example of structural analysis, and the subsequent sub-themes and themes emerging from it, are helpful in illuminating the process of identification and development. This paper, concerned with the meaning of being a palliative nurse within those with CHF, is a companion paper to Brannström et al., (2006) [see this Bibliography] whose focus is on the patient with CHF. It raises a number of issues for researchers: it indicates potential difficulties in interviewing people with CHF, and provides insights into an analysis using the phenomenological-hermeneutic principles of Ricoeur (1976).

Brannström, M., Ekman, I., Norberg, A., Boman, K. and Strandberg, G. (2006) Living with severe chronic heart failure in palliative advanced home care. *European Journal of Cardiovascular Nursing*, 5, 4, 295-30.

Status of author (s)	Academics in University Departments of Nursing, Geriatric Medicine, Public Health and Clinical Medicine
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Phenomenology
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Health practitioners (Nurses, Palliative care); Heart failure; Meaning; Phenomenological-hermeneutics; Ricoeur;

The focus of the study was to describe and understand the meaning of living with severe Chronic Heart Failure (CHF) in palliative advanced home care. The sample comprised four patients from a county-based unit for palliative advanced home care. It included 3 men and 1 woman, 2 of whom lived with a partner and 2 of whom lived alone, who had experience of palliative advanced home care of between 3 months and 2 years. Participants' were asked to describe their experience of being a person with CHF in advanced home care. Probing questions encouraged participants in their narration. The text was transcribed verbatim, including verbal and non-verbal cues. All the text was used in the process of analysis informed by the phenomenological-hermeneutic principles of Ricoeur (1976). It included three phases of: naïve reading followed by a structural analysis. This involved an analysis and division of the text into 'meaning units' which were then compared with each other and arranged according to meaningful connections. Condensation and abstraction of these revealed 12 sub-themes and 4 themes. Finally, a comprehensive interpretation was made drawing on the naïve reading, the themes as well as the researchers' pre-understanding, and a reflection on the research question..

The naïve reading of the text identified the variety of symptoms from which patients were suffering, including shortness of breath and feebleness, and loss of body function. The feelings of abandonment and fear of loneliness, as well as the gradual or sudden shift between feeling better and worse, were also identified. The themes identified in the structural analysis were:

- *being aware that one's life hangs by a fine thread* including sensing one's bad heart; visiting death's door, and being reminded about one's failing health in physiological measurements;
- *struggling to cope with one's unpredictable deteriorated body*, including facing difficulties: in keeping one's weight stable; with the varying degrees of laborious shortness of breath, pain in addition to that from the heart, and fatigue; and difficulties standing on one's legs and walking;
- *struggling with isolation*, including feeling lonely and trapped at home; and

- *being positively dependent on receiving care that facilitates a life at home*, including feeling secure when receiving palliative advanced home care, and managing to be technically and pharmacologically at home.

The comprehensive interpretation and reflection identified the emerging meaning of living with severe CHF as an on-going oscillation - a roller coaster life - between 'knocking on death's door' but surviving with unpredictability, not knowing what to expect, and having to face a complex array of symptoms characterised by varying degrees of laboriousness. The will to live appeared strong and was accompanied with a confidence in one's ability to survive. The authors suggest that this differed from other studies, where awareness of imminent death led to a loss of belief in the future. Furthermore, whilst patients awareness of signs of worsening led them to blame themselves when they failed to do something about it, it also meant they were able to call for help without delay. The authors emphasise the importance of understanding symptoms in clusters, and they suggest that a metasynthesis has indicated that fatigue should be investigated as part of the experience, and not an isolated construct, of CHF. The authors argue that palliative advanced home care offers an adjustable safety belt, evoking feelings of security, and facilitating an everyday life at home.

This paper, focussed on the meaning of living with CHF, is a companion paper to Brannström et al., (2005) [see this Bibliography] whose concern is those of the palliative nurses who work with people with CHF. It is a clearly written paper that provides a useful example of a study using narrative analysis, in which the authors provide a sufficiently detailed summary of the analytic methods and process from data to interpretation. The tables outlining an example of structural analysis, and the subsequent sub-themes and themes emerging from it, are helpful in illuminating the process of identification and development.

Brown, J. and Addington-Hall, J. (2008) How people with motor neurone disease talk about living with their illness: A narrative study. *Journal of Advanced Nursing*, 62, 2, 200-208.

Status of author (s)	Academics: Cancer Experiences Collaborative at the University of Southampton
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/texts	Using narrative analysis: Illness experience
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Decision-making; Ethics; Frank; Hope; Motor Neurone disease; Reflexivity; Suffering; Survival; Typology of narratives; Wengraf;

This study explores patient experiences and how they talk about living and coping with Motor Neurone disease (MND). In their background text, the principal types of MND are described, and Brown and

Addington-Hall then briefly outline the problems identified in the literature of those living with MND, including the uncertainty of the progress of the condition, the incremental disability, and the increasing social isolation, and their needs, in the short- and long-term, for practical information about treatments, entitlements, and research and improved communication between health practitioners and users. They then offer a brief rationale for the benefit of the use of narrative as a therapeutic influence, and the value of patient stories in increasing understanding of patient conditions. Prior to the study these were unknown in relation to MND.

Thirteen participants, aged between 39 and 85 years, across four types of MND were recruited through the MND Association, each of whom met the inclusion criteria of being over 18 years, with a firm diagnosis, and able to communicate. Narrative interviews were undertaken at 3-monthly intervals over a period of 18 months, resulting in 6 rounds of data collection. Interviews were organised in three parts. The first part began with a guide question in which the participant was invited to speak without interruption, whilst the researcher listened and took occasional notes, the second part involved questions that invited further elaboration of particular issues, and the third part involved asking more general questions. Data analysis involved five iterative stages:

- '*Immersion*' in the data by focusing, through reading and re-reading the transcripts, on what can be learnt;
- '*Analysis of narratives*' that identified elements and segments of narrative that describe how the illness is lived;
- The construction of a '*Trial Framework*' of types of narrative emerging across interviews;
- '*Framework mapping*' of narrative types by identifying narrative segments across interviews;
- '*Narrative types and Storylines*' of MND are confirmed across transcripts.

The reflexive strategies, and the process of dialogue and scrutiny within the research team and advisory group, are also described.

The study identified four types of narrative or storylines, each of which could exist alongside the other, reflecting strands in a complex life:

- '*Sustaining*' the remaining positive aspects of life by living positively each day - a narrative underpinned by a realistic hope for what can still be achieved;
- '*Enduring*' the unwelcome and difficult situation - a narrative that speaks of the quiet suffering involved;
- '*Preserving*' life through seeking opportunities to increase chances of survival – a narrative that seeks hope, but which oscillates between optimism and despair; and
- '*Fracturing*' of life in which plans for the future are shattered – a narrative that tells of fear, confusion, trauma, and loss, as well as of being out of control in a surreal notion of time.

In their discussion, Brown and Addington-Hall are clear that these do not represent stages of illness nor people's characters. Rather, understanding storylines arising from disordered experiences can enable a person's choices and decisions to be more fully understood, in the context of their life - as well as in their broader culture. They suggest what it might mean for health practitioners to hear each of these storylines,

and identify the challenges presented by listening to the ‘fractured’ storyline.

This study is useful to researchers for a number of reasons. Firstly, Brown and Addington-Hall identify the value of the narrative approach in enhancing understanding illness experience. Secondly, it is an example of a study informed by a theoretical basis – in this case, of Berger and Luckman’s (1966) social constructionism, which underpins the narrative analysis of the cultural ‘plot’ of the story line. In doing this, Brown and Addington-Hall provide a useful discussion about Frank’s repertoire of plots, and briefly explore alternatives such as Robinson’s (1990) typology of narratives (‘*progressive*’, ‘*regressive*’, and ‘*stability*’) in people with multiple sclerosis. Thirdly, the ethical considerations and reflexive strategies are clearly outlined, and fourthly, and most usefully, it is a good example of a study using narrative analysis, in which the authors provide a sufficiently detailed summary of the analytic methods [in this case of Wengraf (2001)], and the process from data to interpretation.

Bury, M. R. (2001) *Illness narratives: Fact or fiction? Sociology of Health and Illness*, 23, 263-285.

Status of author (s)	Academic: University-based Sociologist
Nationality	UK
Type of Author (s)	Academic
Study/Text	About narrative methodology: Theory, and Study of the phenomena of narrative
Type of text	Theoretical: Sociological and Narrative
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics
Keywords	Bio-medicine; Coping; Frank; Identity; Kelly; Patient-doctor relationships; Robinson; Suffering; Time; Typology of narratives;

This paper focuses on the background to the interest in illness narratives, provides a framework for analysing illness narratives, and discusses methodological issues that narrative analysis raises.

In his *Introduction*, Bury locates narrative in the universality of stories, conveyed within culturally-based symbolic repertoires, linguistic rules, and social conventions, that create, maintain, and repair, the meaning of individual and social life. He also considers the question of time in its mundane sense in which chronic illness unfolds, but also in its existential sense in which body, mind, and everyday life, are disrupted. Bury argues that it is the examination of this dual process that constitutes the study of illness narratives – firstly in exploring the nature of disrupted experience, and secondly in revealing links between identity, experience, and ‘late modern’ cultures. Bury explores these themes throughout the paper.

Bury then turns his attention to *the rise in chronic illness and the crisis of bio-medicine narratives* to reflect on the historical context of the rise in illness narratives. Here he reflects on the encounter between

patients and doctors before the bio-medical model of understanding disease, where the patients story was of paramount importance. The rise in scientific medicine, Bury argues, separated the study and treatment of disease from the individual. He identifies the shift from 18th Century concerns with restoring the 'natural' state from which disease was seen as a deviation, to the 19th Century concerns with restoring disease to a 'normal' state based on statistical indicators. The increasing expansion of treatments and procedures has widened the gap between lay and professional worlds, where the patient is seen as increasingly passive and their suffering silenced. More recently, however, managing and caring for the increased impact of chronic illness and an ageing population have superseded these, resulting in a reassertion of the subjective patient view, and it is in the space created by the 'loosening of the bio-medical grip' (p. 267) that lay narratives flourish. In these situations, the physician may act as a witness to suffering and a source of advice. Bury also introduces two other changes: the reduction in hierarchical relationships in late modern cultures resulting in a more democratic, accessible, and user-friendly health care, and the expansion of information on illness.

Bury then considers the three *forms and content of chronic illness narratives* as a framework for analysing illness narratives:

- Contingent narratives

These give an account for the beliefs and knowledge about the origin of disease, the causes of the illness episode, and its effects on everyday life. To assist his discussion, Bury argues that concepts of disease and illness can be divided into two broad types: *categorical views*, characteristic of the bio-medical approach, in which normal and pathological are separate and the disease course and onset is relatively clear-cut, and *spectral views*, characteristic of a more personal and social perspective, in which the difference is a matter of degree and a function of the social processes of everyday life. Bury draws on his study on chronic arthritis (Bury, 1982; 1988) to identify the overlap which can be observed, especially in chronic illness, where a growing familiarity with medicine merges with lay concerns and perceptions to be used in a meaningful account of the unfolding events of illness. Furthermore, drawing on Davidson et al., (1991; 1992), Bury argues that lay accounts may be more in keeping with scientific epidemiology than the mechanistic views of risk found in bio-medicine and health promotion. Illness accounts, however, become increasingly practical and emotional in terms of what is to be done to normalise life and cope in the face of illness, and Bury suggests that these aspects feature prominently in 'contingent narratives' – a term similar to Riessman's (1990:1196) 'habitual narratives' 'about what happened in general'. Bury elaborates normalisation as two kinds of process in a patient's experience of chronicity: maintaining activity and disguising symptoms - in an attempt to keep life and identity intact or redesignating 'normal life' to incorporate illness, and coping - as it links the mundane to the moral dimension of experience and the moral components of storytelling; it is not only what, but how, illness is spoken about.

- Moral Narratives

These make visible the moral stances that link the personal relations and the social context in illness accounts, through the conscious or unconscious expression of an evaluative dimension. Bury provides examples of narratives that reflect moral opprobrium, culpability, blame, and shame, as well as those which attempt to maintain 'normal appearances' and the virtuous 'presentation of self' – for example, of

not being a burden [see McPherson et al., (2007) in this Bibliography for an example of this]. Bury then considers the work of Frank as an espousal of the more positive moral dimensions of the narratives of the renewal and change presented by illness, but which, in emphasising the positive, may lose sight of the actual relationships in which the person is embedded, and imply a criticism of those that fail [see Moss et al., (2004) in this Bibliography for an example of this].

- Core narratives

Bury then turns his attention to the last form: culturally specific core narratives that underpin all forms of narrative, and which account for, and fashion, experience. He draws on Kelly's (1994) genres of narratives which include: '*epic or heroic*'; '*tragic*'; '*comic or ironic*'; '*disembodied or romantic*'; and '*didactic*', Robinson's (1990) types of '*stable*'; '*progressive*' and '*regressive*', and what he describes as Frank's and Charmaz's more recent kinds of 'moral analysis' (p. 280) to elaborate how these genres, despite ambiguity and complexity, can be detected, and how they may be approached. In particular he emphasises that, as they depend on context and intention, these accounts are not static in a particular form and may move from one to the other.

In his *concluding remarks*, Bury restates the value of narrative analysis as a means by which to link body, self and society. However, whilst acknowledging narratives as attempts to normalise the disruption of chronic illness, he advises caution against accepting narratives at face value, rather than exploring how they are shaped by motives and context. In this discussion, he argues that, rather than constitute 'unalloyed subjective truth' (p. 281), narratives have many forms and uses that requires an evaluative and contextual interpretive approach on the part of the investigator; that is, an understanding of 'why was the story told that way?' Bury then raises the question of who should determine what a narrative means, and draws on Riessman (1993) to suggest that whilst the teller is the 'first word' upon which the interpretation depends, it is the reader who judges the 'fit'. Whilst acknowledging the starting point of narrative as the need, as Kleinman (1988) expresses, to witness the suffering of illness and the dehumanising effects of a medicalised society, Bury again argues for a distinction to be made between the verbal accounting processes and the different levels of experience to which they refer, so that the wider context of narrative form and identity construction – a particular self - can be understood.

This is a key theoretical paper for researchers. It locates the genre within a historical context, and provides a well-argued sociological critique of narrative analysis. As well as offering an interesting range of typologies of illness and other narratives, which researchers can use to explore their own texts, it presents a thoughtful discussion on methodological issues, and offers a framework for analysing illness narratives.

Byrne, J. (2006) *If it were just cancer: A battle for dignity and life*. Dublin: Veritas.

Status of author (s)	Cancer patient
Nationality	Irish
Type of Author (s)	Lay
Study/Text	Auto/biographical accounts of illness
Type of text	Personal experience: Autobiography
Type of study	Case study
Whose perspective	Patients
Intended audience	Lay and Policy makers
Keywords	Anger; Dignity; Fear; Health care policy; Hope; Identity; Insurance; Pain; Suffering; Survival; Time

In this book, Janette Byrne describes the experiences that surrounded her diagnosis and treatment for cancer. However, as the title indicates, she also describes not only the battle for life, but also what she has called a battle for dignity, and it is this dimension that places her text in the transformative genre of narrative types.

It is written in the form of journal entries and these are interspersed with sub-headings that act as punctuations to the linear 'diary entry' form of narrative. She begins by 'looking back' at the troubled and lengthy time during which she was trying to get her symptoms of illness recognised and validated; a period in which she sought a diagnosis. This came to an end in the crisis of her admission to the Accident and Emergency department when she was prostrate and unable to breathe. Her narrative shifts then to the illness narrative of diagnosis and treatment for cancer, in which she vividly describes the settings, the systems, and the people (family, staff, other patients, the public), and most of all, the feelings that arose through her relationship with each of these. This absorbing and vivid description of her worry and fear about the diagnosis for herself and her family, her fear rather than feelings of security and safety in the system - and, at times, the people - that were supposed to help her, and the experience of being a patient amongst other vulnerable people, is written in a most compelling and articulate way. She describes her need not to hear others' tales of woe but, rather, to hear about survival and to find life-giving moments of inspiration,

The book is well-written and structured using a number of helpful techniques. Byrne writes in the first person present tense even when describing the past, and this gives the story an immediacy that contributes to its vivid, and absorbing, character. Feelings of guilt, disgust, anger, rage, shame, loneliness, and sadness, permeate the text. Nevertheless, it is a narrative of survival and hope, even as it describes the less glamorous reality of what it has taken to fight (the illness and the system) and to survive. She narrates aspects of her changing identity, for example, her body image, her self as having cancer, and her angry self provoked to action. She also uses the concept of 'time' in many ways. We are taken through events in chronological time, but we are also given a sense of time as the long haul through the micro-moments of pain, indignity, uncertainty, panic, solidarity with others, not only because of the cancer, but

because of the system.

The journal entries are infused with sub-text headings - for example '*Relationships suffer*'; '*A family helpless*'; '*The world's loss*' (the stories of deaths along the way); '*Moments lost forever*' (her intimate and sexual life slipping away); '*Diagnosis*' '*A typical; day on the war*'; each of which punctuate the linear text, stopping the flow of the narrative to give a different, but related story. Byrne illuminates the limitations of a particular system (the Irish system of access to health care via Insurance, and set in a hospital system structured in ways rather similar to the UK), and the experience of illness in that system, but she also gives an account of her radical, transformative action, and what this entailed. She raises a number of cultural issues through her sub-headings, to include the role of family and community; cultural fear of cancer; and religion and faith. She locates her fellow patients as a source of companionship and support. Lastly, she describes 'finding her way back' charting the struggle it involved - a year on and still feeling so ill, and the feelings of guilt and anger with which she still finds herself experiencing. She acknowledges the value of counselling and other forms of support, such as meditation and relaxation, as contributing to her recovery and future well-being.

This book is useful for researchers in three ways: it stands alone as a compelling narrative of hope, and of a person transformed by the experience of her own fight and her fight for others, but it also provides researchers with material available for analysis [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this]. It can also be used as a comparative text against which other narratives can be set. It is also an example of Frank's (2002a) extrospection [see this Bibliography], where story is used, not only to describe personal experience, but to locate and reflect upon that experience in the wider context of care systems. In this way, it stands as an example of Frank's (2002) notion of re-enchantment, linking personal troubles to public issues.

Charmaz, K. (1999) Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research*, 9, 3, 362-382.

Status of author (s)	Academic: Professor of Sociology
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Narrative
Type of study	Discussion
Whose perspective	Patients and Researchers
Intended audience	Academic
Keywords	Boundaries; Dignity; Moral status; Pain; Self; Standpoints/positions; Suffering; Symbolic interaction; Writing

In this paper, Charmaz draws on her previous research to provide a symbolic interactionist analysis of suffering, and the relationships between suffering and the self in the face of illness and its spiralling

consequences. She pays attention to three areas of interest.

Firstly, Charmaz explores *forms of suffering*, and argues that it has a bodily dimension in, for example, the experience of pain, malaise, and discomfort, but also an existential dimension in the form of the problem of identity and continuity of self, which arises from attempts to control and cope with a suffering life. It also involves an emotional dimension through the loss of control, certainty, and future. Charmaz highlights the movement of suffering from the foreground to the background, and the regrets arising from a person's incapacity or inability to act in the past, both of which help to lock suffering into the present. Together with the increasing limitation on activities, these contribute to the muting and invisibility of suffering. She argues that suffering becomes apparent when there is a disjuncture between past and present, for example, in a person's recognition and acknowledgement of the restrictions to social and physical activity that had increasingly been placed on them. She notes that her participants' experience of suffering is described in the present, in terms of experiences of, for example, pain, or sadness, rather than as 'I am suffering'. She notes also how they do not talk of suffering, or describe themselves in ways that might diminish their worth or elicit moral judgements.

Charmaz then turns her attention to *the relationship between suffering and self*, and the implicit moral meanings that shape this. She begins by drawing on Geca's (1982) definition of self that distinguishes between the self as process (unfolding, developing, becoming) and the self as object (a self-concept of attributes, values, and characteristics), and raises four important points in relation to suffering, quoted here in full:

- When and under which conditions does suffering permeate the boundaries of the self? Clearly it does in some circumstances and not in others; we need to know more.
- How does an individual gain a strong core of self that weathers crises and will not be buffeted, like a sail in the wind?
- What sustains the self in suffering and limits or deters its spread?
- What place does a person's story have? Which moral claims are imbedded in the story? How does the storyteller position self? When do people adopt their stories of sickness as part of their self-concept? (p.367).

Charmaz argues that suffering is a profoundly moral status, conferring relative human worth, moral rights and entitlements, and these are reflected upon, redefined, and resisted in stories. She outlines a number of features of moral status:

- It is not static - it can be elevated or eroded;
- There is a hierarchy ranging from:
 - *high moral status with validated moral claims*, through
 - *sustained moral status with acceptable moral claims*, to
 - *diminished moral status with questionable moral claims*.
- It is relative based on prior understandings of decorum and dignity, but these standards may not be shared claims, and status can be contested;

- Protection of moral status involves risks of more suffering, choices, and possible acts of defiance;
- Gender plays a part. Charmaz found that the men in her study took more risks in maintaining definitions of self, by trying to stay in control and exert autonomy.

Finally, in a *Methodological epilogue*, Charmaz asks questions about how researchers' tell an analytic story about their respondent's story, and she makes a number of suggestions, including: interviewing in a way that listens to cues that are then pursued; returning to respondents'; using memos (a part of Grounded Theory); and writing as a way of clarifying and developing ideas [for further discussion of this idea, see Speedy (2005)]. Charmaz also provides a set of 'Guidelines for Ethnographic Writing, including: 'Pulling the reader in'; 'Recreating experiential mood'; 'Adding surprise'; 'Reconstructing ethnographic experience'; and 'Creating closure for the story'.

This is a thought-provoking paper. It challenges practitioners and researchers to see suffering as a profoundly *moral status*, and encourages them to consider how an ill person's story will be heard in relation to a moral hierarchy of suffering. The descriptions of suffering are situated within a specific cultural context of social policy, in this case the US, where particular resources are unavailable through social welfare provision. However, drawing on Anderson and Bury (1988), Charmaz notes that whilst suffering is a category invoked by scholars, the British use the term 'sufferer' in relation to those experiencing illness. These differences draw attention to the role of culture in both creating the experience, and informing the expression, of suffering. It also provides an interesting methodological discussion on the analytic process, and useful guidance for writing respondents' stories.

Charon, R. (2000) Medicine, the novel, and the passage of time. *Annals of Internal Medicine* ,132, 63-68.

Status of author (s)	Physician in a University hospital
Nationality	US
Type of Author (s)	Professional: Researcher/Academic and Practitioner
Study/Text	Usefulness and impact for health care practice development and service improvement
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Health practitioners
Intended audience	Practitioners
Keywords	Health care policy; Health practitioners (Doctors); Medical charts; Patient-doctor relationship; Time;

This paper is focussed on the examination of two medical charts (Case notes) to illustrate how these can be both read as a novel, and support reflective practice. Charon writes poetically of the value of reflection on the medical charts of patients over time, and suggests that re-reading a medical chart as if it was a

novel can illuminate both patient-doctor relationships and medical practice.

Charon begins the paper by identifying the way in which doctors chart the consequences of time on the individual's body and the individual life, doing what can be done in the face of time and death to improve life. She notes the 18th Century shift in the stories of the first novelists, no longer representing the unchanging universals of timeless heroes, but writing sharply observed particulars of the individual life. The history of the novel, with its interest in the development of characters in the course of time, identifies the simultaneous rise alongside the clinical report and the autopsy, both of which also inspect and embody life and death within time. Charon argues that the practices and texts of doctors and novelists bear further inspection. Both charts and novels – each a narrative arranged in time – confront the problems faced by humans as time runs out. However, it is not, she suggests, simply a matter of ordering events chronologically. Time has a plasticity – it can be experienced slowly and appear to pass quickly – and it can define discontinuities, for example, before and after diagnosis. Patient-doctor relationships are also lived in time.

Charon presents and discusses the charts of two patients. It is clear from the text that the first patient is one with whom she has had contact in her capacity as physician over a long period, as she reflects in the first person on aspects of her encounters with Mr Estrada, as well as on charted aspects of his care by other colleagues and students of hers with whom he has come into contact. However, it is less clear who the physician of the second patient is – described as a 'same-aged' female patient – as these reflections are written in the third person. [That the physician is her is, however, made clear in Charon (2001) – see in this Bibliography]. The contrast between these lives is deeply felt by the physician who has seen the disorder and turmoil with which her female patient has had to endure over the course of 18 years, and which are now, she reflects, inscribed upon her patient's body.

Charon argues that the key event – the 'brooding' on a journey taken together over time – is valuable in enriching the physicians' vision of individual patients, and of themselves. This reflection is only possible within the context of a long relationship, and she raises important questions about the policies and practices that govern patient-doctor relationships and impact on their continuity.

This is an interesting paper from a research perspective. It offers a description of the use of medical charts as a form of narrative for exploration and understanding, as well as a physician's narrative, available for exploration in its own right [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this].

Charon, R. (2001) **Narrative medicine: Form, function, and ethics.** *Annals of Internal Medicine*, 134, 1, 83-87.

Status of author (s)	Physician in a University hospital
Nationality	US
Type of Author (s)	Professional: Researcher/Academic and Practitioner
Study/Text	About narrative methodology: Theory Usefulness and impact for health care practice development and service improvement
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Patients and Carers
Intended audience	Practitioners
Keywords	Clinical practice; Ethics; Health practitioners (Doctors); Medical education; Narrative medicine; Writing; Writing genres;

This is a reflective and analytic examination of narrative medicine. Charon suggests that the narrative act of writing about illness enables the sufferer to endure the chaos of illness better, and doctors to confer understanding on their medical practice.

Charon identifies five genres of medical writing, to which she adds a possible sixth during the course of the paper:

- *Medical fiction* consisting of invented stories about patients and doctors that transcends, but may include authorial experience, in order to express vision and coherence;
- *Lay exposition* – in Charon’s context meant as stories written by doctors and published in lay journals – serving to inform and educate the public;
- *Medical autobiography*, which is often transformative of the experience of discontinuity of medical training and the acts it requires (dissecting cadavers, inflicting pain);
- *Stories from practice* adopting, as their purpose, the narrative stance of the insider in contrast to lay exposition and medical autobiography, to present experience to other doctors as a form of ‘brooding’ aloud about experiences or seeking forgiveness for actions; and lastly
- *Writing exercises of medical training*, which include the narrative practices that are adopted in medical education to encourage medical students to reflect on the experience of the patient and of themselves, as they care for the sick and dying.

Charon considers the consequences of this writing from her own experience of writing stories about patients who troubled her. These include: changing her relationship to become more curious and engaged with them, and sharing her written accounts of encounters with her patients, who respond to these ‘chapters’ in their life with texts of their own that have significance for their current physical and emotional health. She raises a number of ethical questions about the consequences of narrative writing in each of the respective genres, including how to write responsibly, and what obligations are incurred in writing

and publishing. She underscores the importance of obtaining permission when publishing papers about individual patients, but also suggests that, as narrative medicine is a powerful treatment intervention with therapeutic potential, altruism recommends disclosure to the patient, even in the absence in publication. This, she argues, shifts the goal of writing away from self-expression and self-promotion on the part of the doctor, with its attendant potential for exploitation, to that of clinical hypothesis-testing situated alongside other activities such as diagnosis.

This is a very helpful, clearly articulated, paper. It clarifies the typology of a genre of narrative writing and the issues related to it. In doing so, it enables researchers to consider these issues in relation to their own position, and to the stance being taken by the narratives they study. It also builds on Charon (2000) [see this Bibliography] to identify the value and power in ‘reading’ both sides of an event. Charon’s thoughtful text raises issues about how a number of ethical questions related to publishing an account of the context of narratives, in this case an encounter with an individual patient, can and should be managed. She draws attention to the forces that erode patient-doctor relationship including: market forces; the revolution in informatics; and specialisation that diminishes the importance of the personal context of illness.

Charon, R. (2004) Narrative and medicine. *New England Journal of Medicine*, 350, 9, 862-864.

Status of author (s)	Physician in a University hospital
Nationality	US
Type of Author (s)	Professional: Researcher/Academic and Practitioner
Study/Text	Usefulness and impact for health care practice development and service improvement
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Patients and Health practitioners
Intended audience	Practitioners
Keywords	Decision-making; Ethics; Health practitioners (Doctors); Narrative competence; Suffering;

In this brief discussion paper, Charon explores the relationship between narrative and medicine, emphasising the therapeutically consequential understanding of persons, as well as the diagnostic benefits of hearing narratives told of illness. In addition, she gives importance to the ‘telling’ of both doctor and patient, through which transcendent truths about illness and suffering are helped to be understood.

Charon outlines the benefits of the practice of narrative competence – the capacity to combine textual, creative and affective skills – which can enable a doctor to quickly and accurately hear and interpret what patients say, as well as understand more fully the disease process itself. Narrative competence confirms the patient’s place in the story and incorporates attention to the ethical complexity of a relationship marked by duty and gratitude.

She argues that the development of narrative skills provides the capacities of empathy, sensitivity and

reflection that medicine sometimes lacks. Teaching specific aspects of narrative competence equips practitioners to interpret and make sense of patient stories, helps uncover understandings of their own and their patients feelings, and offers therapeutic benefits. She argues strongly that the information revealed through the patients narrative can illuminate the complexities of illness, and help formulate the role of doctors with their patients, both in the technical dimensions such as diagnosis, but also in dimensions of meaning. Finally, she indicates that research into the benefits and outcomes of narrative writing and consequences of training is being undertaken, and the health benefits explored.

Although this is a brief paper, it makes a case for narrative as a beneficial approach to enhancing the patient-doctor relationship, diagnosis and treatment decisions, and improving patient experience. As such, it acts as a 'benchmark' for claims that can be explored by researchers in their study of the narrative skills of Health practitioners or of more formal narrative therapeutic interventions, as well as in their exploration of the illness narratives of patients suffering from a range of conditions. Charon's arguments also apply to the practice of narrative research.

Craib, I. (2003) Fear, death and sociology. *Mortality*, 8, 3, 285-295.

Status of author (s)	Professor of Sociology/Psychoanalyst (Group), now deceased.
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Auto/biographical accounts of illness
Type of text	Personal experience: Autobiography
Type of study	Discussion paper
Whose perspective	Patients
Intended audience	Academics
Keywords	Anger; Cancer; Dying; Fear; Grief; Loss; Philosophy; Psychoanalysis; Sociology

This paper is a contemplation on the absence, within sociology, of an academic discourse that helps Craib understand his own personal experience of a diagnosis of cancer. It constitutes a personal, if brief, memoir of the experience of diagnosis of cancer, focussing particularly on the feeling of fear. Craib brings his own disciplinary perspectives (sociology and psychoanalysis, but also philosophy) to bear on a dialogue with other 'death and dying' sociologists. In doing so, he critiques his own discipline of sociology and what he sees at its inability to understand personal experience.

It is clear and accessible paper even for those unfamiliar with the sociological literature, and is written in a reflective manner - reading as if Craib is speaking his thoughts in conversation. He provides an intelligent reflection on his experience, in which he reveals aspects of his self with wry humour. His account is riveting, moving as it does between reflection on his own experience of fear in the face of his diagnosis of cancer, and on how the academic literatures account, or rather fail to account, for this. Whilst this narrative remains a personal account, it is, nevertheless, rooted in a tradition, and it is the shortcomings

of this tradition that is exposed, as well as the depths of his own emotional experience.

What make this a useful text for researchers is it's four-fold contribution: firstly, it is a thoughtful and thought-provoking narrative account of an individual's fear in the face of death; secondly, it contributes to the cross-disciplinary debates about how death and dying is represented in the respective academic literatures, in which fear is largely omitted; and thirdly, in doing this, it enables researchers (and practitioners) to see more clearly the problematic nature of the construction of 'truth' and 'meaning' and the relationship between disciplinary knowledge and personal experience. Finally, it is a text available for exploration in its own right [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this].

DeIVecchio Good, M.-J., Gadmer, N. M., Ruopp, P., Lakoma, M., Sullivan, A. M., Redinbaugh, E., Arnold, R. M. and Block, S. D. (2004) Narrative nuances on good and bad deaths: Internists' tales from high-technology work places. *Social Science and Medicine*, 58, 939-953.

Status of author (s)	Academics in University Departments of Social Medicine; Psychosocial Oncology and Palliative Care
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Mixed methods
Whose perspective	Health practitioners
Intended audience	Academics
Keywords	Bio-medicine; Dying; Futile care; Health practitioners (Doctors); Medical education; Quality of life; Technology; Time;

A mixed method study on 'Physicians emotional reactions to their patients death' was part of a larger study designed to improve clinician training in palliative care. The researchers interest was focussed on factors that influenced this emotional reaction, including their relationship to the patient; emotional and collegial support; previous experiences with death; and position in the training hierarchy. One hundred and sixty-three physicians were recruited into the study from one of three categories: interns (1st year post-graduate clinical trainees), residents (2nd to 4th year trainees), or attenders (members of the clinical faculty). Two deaths per week were selected for a total of 66 patient cases whose primary diagnostic category included oncological disorder (17%), cardiac disease (24%), respiratory disorder (24%), and other disorders (35%). These participants were interviewed about stories of their experience of their most recent death, as well as an emotionally powerful one. They were asked to describe the deaths and how they were affected, and to describe the sequence of their reactions. They were not asked whether the death as 'good' or 'bad'.

In order to situate the experience of patient deaths within a wider context of influencing factors, participants also completed a range of attitudinal measures - some of which were designed especially for the study and 5 of which were pre-existing - that elicited information about a number of issues, including ratings of how emotionally powerful the death was, how close they felt to the patient, and how much the patient suffered. The narratives of 75 physicians were selected to build the extensive thematic analysis. The measurement ratings of this group were compared with the rest of the sample, and no statistically significant difference was identified. A further 33 physicians were also recruited to maximise power for statistical analyses. The qualitative data was subject to an extensive thematic analysis utilising ATLAS/ti (a qualitative data management programme) and the quantitative data was analysed utilising SAS® (a statistical software package). This paper consists of case material derived from descriptive data of the total of 163 physicians.

In the Introduction, the researchers identify the, at times contradictory, relationship between public and professional responses to death and dying, including the differing concerns and responses to the use of biomedical technology. They suggest that, whilst this technology has influenced the formulation of these narratives, Glaser and Strauss's (1965; 1968) sociological analysis of the organisation of the work of caring for dying patients and the temporal narratives of dying trajectories continue to have relevance, and it is in this theoretical context that the paper is situated. The researchers described seven emerging themes and provided two case study examples of physician narratives:

- *Relationships with dying patients:* These were characteristically brief, with only 7% present at the time of death and 69% caring for their patient for a week or less. As a result, they did not feel close to the patient, and identified more with the family. In contrast, in the most emotionally powerful death, physicians were more likely to be present at the time of death, and rating for closeness was almost twice as strong;
- *Are these 'good' and 'bad' deaths?* These terms were not common metaphors used by physicians. However, complex tales using multiple narrative plots were used to speak about them;
- *Images of patient death, medical work, quality of care, and communication;* The mode of narrating stories of deaths intertwined with their own work, interaction and communication, in a way similar to Glaser and Strauss's (1968) observations. Positive and negative categories about *time and process*, *medical care*, and *communication* were identified, with specific deaths being a mixture of these;
- *Characteristics of dying:* These were expressed in terms of the expectation of death, its timeliness, and the quality of the dying experience. 'Good' deaths were described as 'smooth and easy', whilst 'bad' deaths were described in relationship to its inappropriate timeliness, and to the physicians' own feelings and their interpretation of those of the family;
- *Quality of caring and questioning high-technology interventions:* Accounts of disturbing deaths involved futile, aggressive care or error, as well as those that appeared to disrupt the patient's dying trajectory. The limits of technology and drug regimes were also included in physicians' stories;

- *Quality of communication*: This was a fundamental aspect of the physicians' assessment of the quality of the process of dying, and positive and negative stories were associated with the quality of their relationship with the patient and family. Negative stories, occurring in relationship between themselves and their patient, the family, and/or other health care personnel, included expressions of sadness, experiences of distrust, confrontation, and power struggles. However, the positive and negative dimensions were not certain and unambiguous. Rather, physician's stories of patient deaths, woven into dynamic tales of their end-of-life care, indicated their nuanced, qualities;
- *Time and process*: Through the case vignettes of Mr. F, an older man, and Mrs E, a young cancer patient, the researchers elaborated these nuanced dimensions. The physicians' concept of timeliness was linked to patient age and disease state, but also to their own actions and communications, and to the time-consuming nature of clinical tasks. Physician's narratives between the two cases also highlighted the comparison between the distinctive plot of a timely and smooth transition to a peaceful death, and a medically untimely, chaotic and distressed transition, even if 'in the end', the death was peaceful.

The concluding reflections draw attention to the large degree of biomedical description in the physicians' stories, and the authors argue that, whilst temporality, dying trajectories, and management of the patient and kin persist, biotechnology and specialism, including in the division of labour of who cares for the dying, has changed the organisation of clinical care. The discourse of medical futility is recognised as increasingly salient, whilst the impact of bio-technology on the disruption of the dying trajectory is also recognised.

The descriptions of US physicians took a little time to get used to, and it was not always easy to follow the complex relationship of presented material to the original study, nor to keep in mind the complex methodology and sampling procedures. However, this paper, which links to Kingson (2005) and Ferrell (2006) [see this Bibliography], provides an excellent background discussion that situates Bio-medicine and death and dying in a contemporary US cultural context. It also demonstrates the value of situating narratives within a theoretical framework - in this case of Glaser and Strauss as well as one of its own making in the form of the structural analysis. The mixed methodology and the theoretical framework provided opportunities for a structural and historical analysis of narrative as well as a personal one.

Elfick, H. and Head, D. (2004) *Attending to the fact - Staying with dying*. London: Jessica Kingsley.

Status of author (s)	Hospice Trustee and Poet, and a Hospice Chaplain
Nationality	UK
Type of Author (s)	Professional: Practitioners
Study/Text	Auto/biographical accounts of illness and end of life
Type of text	Personal experience: Poetry
Type of study	Reflection/Review
Whose perspective	Patients, Carers and Health practitioners
Intended audience	Practitioners
Keywords	Dying; Hope; Loss; Poetry

The title of the book situates these 82 poems as acts of attending - that is, of listening to those who are ill, dying, or grieving - and the purpose is to offer comfort and consolation. The poems are located in the context of Christian belief and the cyclical rhythms of the natural world, ordered through the movement from illness, incapacity, care, pain and comfort, death, loss, and grieving.

There are a number of authors involved. As well as the two poets, the text is introduced by the Editor and the importance of the poems is emphasised in a Forward, written by the Chair of the Association of Palliative Medicine in Great Britain and Ireland. Illustrations are also provided that act as artefacts for contemplation in their own right, as well as acting in a complementary way to the text. The subjects of the poems are also present as instigators of the carefully chosen words. The Editor describes the process of selecting the poems, and identifies the capacity of the poetry to story experience, both of those of whom the poems speak, and also of the poet. The inclusive use of the word 'we' in many of the poems is noted as expressing loss as part of the experience of us all: subject, poet and reader. The book is not necessarily a linear read, nor is it one to be read from cover to cover, and it is acknowledged that readers will take their own individual route through the book, and have particular feelings about the poems. They evoke many feelings, including those of joy, sorrow, fear, and vulnerability, and they act as narratives that link the personal, subjective world of story to the story of contemporary cultural and social life. Reading each poem is to enter into the imaginary space created through the words and cadence, but it is in the 'coming back to the present', at times, shocked and startled by the thoughts and feelings that the words evoked, which provides the powerful moment full of promise for reflection and contemplation.

These poems are useful to researchers for a number of reasons. The Editorial provides a useful discussion on the technical aspects of selection of the poems, including for the sharpness of language, use of sound, interesting line breaks and stanza patterns, as well as the rhythms and register of the language, and this gives insight into the analytic methods of the poetry genre of narrative [and see for example, Hok (2007) in this Bibliography]. The poems are of interest in their own right, but also provide a text that raises questions about what story is being expressed through each poem, and through the collection as a whole. In addition, these poems can provide a useful counterpoint from which to reflect on the narratives of those

with whom they come into contact in their research. The meaning within the poems are not always readily available, and require a contemplative reflection that draws on the readers own experience and story. This contemplative act can form part of the researcher’s foregrounding of their own beliefs, assumptions, and experiences.

Elliott, J. A. and Oliver, I. N. (2007) Hope and hoping in the talk of dying cancer patients. *Social Science and Medicine*, 64, 138-149.

Status of author (s)	Based in University Hospital oncology centre
Nationality	Australia
Type of Author (s)	Using narrative analysis: End-of-life/Palliative care
Study/Text	Using narrative analysis: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Cancer; Decision-making; Discourse and conversational analysis; Dying; Hope;

This is a study of the narratives of hope of those with a terminal illness, embedded in a wider study on decision-making at the end-of-life. The sample included 28 mixed sex (13 female and 15 male), Stage IV cancer patients, for whom death was expected within 3 months. Their average age was 61 years. For the wider study, participants were asked a question at the end of the interview ‘Can you tell me about hope and hoping’ (the responses to which are to be the subject of another paper). This paper focuses on the use of hope as it emerged in unprompted talk. A discourse analysis of ‘string-pattern-search for ‘hop[e]d[es]less[eful]fully[ing]’ in context was undertaken, that is, retained in the context of everyday life of how hope was used and to what effect in speech. The analysis is not provided, but sections of text are given as examples of categories.

The authors identified the use of hope in two ways, each of which had different implications. Firstly, hope was used *as a noun*, for example, as ‘the hope’ or ‘no hope’. Two dimensions were elaborated: as an objective attribute of circumstance, referenced to medical discourse and/or used by patients as justifications of action, or as subjective possession of the patient, an object they have or have not. The authors identify the underlying assumption that some thing, action or entity will delay/prevent their death, and that to acknowledge the inevitability of their demise requires a ‘giving up of hope’, and justifies their refusal to participate in end-of-life decisions. They suggest that these represent two sides of the same coin - a culturally held assumption that agency is outside the patient and with the medical profession. The second use was hope *as a verb* for example, as ‘I hope’ or ‘hoping’. This implies a doing, active patient as a participating subject in their own life. Two dimensions were identified: an imagined positive and negative future which identifies what the patient values for the future whether or not this will or can be realised, and/or having interpersonal implications, for example, moral obligations for a doctor to respond as the patient would like. Hope-as-a-verb serves to value both the desired object of hope and the one

desiring it.

This is a thoughtful and useful paper. The findings are linked theoretically to other studies, for example, to Little and Sayer (2004) to whom they refer, and to Benzein (2001) and Sparkes and Smith (2005) [all in this Bibliography]. It is clearly written and well-argued. There is a helpful background discussion to the issue and to their study, and it clarifies the way in which hope is articulated in the discourse of different disciplines (bioethics, medicine, nursing, psychology and sociology). This is an important area for end-of-life and palliative care practitioners, and the authors make distinctions that have useful implications for practice (although these are not extensively elaborated) in how practitioners might consider the function and consequences of the way in which hope – as indicative of meaning - is being expressed. For researchers, this study provides a useful example of the way in which unprompted speech can offer insight into particular experiences and is, therefore, worthy of study. It also offers an example of an analysis of narrative thought in which the implications of meaning are elaborated.

Feldman, S. (1999) Please don't call me 'dear': Older women's narratives of health care. *Nursing Inquiry*, 6, 4, 269-276.

Status of author (s)	Academic: Unit for Women and Ageing, Centre for Study of Health and Society.
Nationality	Australia
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Longitudinal study
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Ageing; Health care; Memory work; Older women; Writing; Workshops;

This paper is based on autobiographical stories and narratives of older women, written as part of two funded projects: a pilot project entitled '*Women and writing: Stories of ageing*' and the extended study entitled '*Stories of ageing: A longitudinal study of women's self-representation*'. It explores the stories ageing women tell about their lives. Forty women aged between 70 and 85 participated in a collaborative, co-constructed workshop-based activity, influenced by Frigga Haug (1987), in which narratives were generated. The researchers taught the participants strategies for writing, and participants wrote stories each week over a seven-week period on a suggested theme that were then subject to the critical comment of the workshop participants. The story texts and the discussions were transcribed, and a thematic analysis of recurring patterns undertaken.

Whilst not valorising old age, the richness of the women's' stories gave personal meaning to their ageing, and challenged stereotypes. Three themes integral to the women's health and quality of life were identified:

- *Power of the stereotype*: Narratives in this theme identified the difference between their reality, and the typical cultural stereotypes. The participants, themselves leading independent and engaged lives, expressed feelings of anger at the persistence of the stereotypical images of older women as dependent and a burden on society,
- *Please don't call me dear*: The fear of loss of independence and health was highlighted in this theme, and the importance of the attitude of health practitioners to older women was underscored. Participants expressed anger at being treated, at times, with ageist attitudes,
- *Living lone lives*: This theme identified the disruption of the death of their partner, confronting widowhood, and their emergence into a life lived alone. Feelings of power and powerlessness were identified in the stories, as well as the support they needed during this transition into a new phase of life. One story is presented and discussed in terms of its staging (a procession and a triumphal marching song), and its evocation of children's story genre.

In this paper, narrative data are mostly described rather than presented, and no in-depth description of the analytic methods are provided. Nevertheless, it is a useful paper in terms of the themes it generated through the collaborative method. Furthermore, it provides an example of an interesting approach to generating narratives [and see Bolton et al., (2006) for ways of structuring workshops, and Moss et al., (2004) for an example of workshops as a method of data collection, both in this Bibliography].

Ferrell, B. R. (2006) Understanding the moral distress of nurses witnessing medically futile care. *Oncology Nursing Forum*, 33, 5, 992-930.

Status of author (s)	Nurse Researcher in a Medical Centre Department of Nursing Research and Education
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Mixed methods
Whose perspective	Health practitioners
Intended audience	Practitioners
Keywords	Anger; Bio-medicine; Decision-making; Dying; Ethics; Futile care; Health care policy; Health practitioners (Nurses, Palliative Care); Moral distress; Quality of life; Suffering; Survival; Technology; Writing;

This paper explores the impact on nurses of 'medically futile care', described as life-sustaining care that is highly unlikely to result in meaningful survival, and is offered by the journal as suitable for reading and discussion in a Journal Club. As a result, the paper is prefaced by a number of questions designed to generate discussion.

The study generated written 'surveys' of 108 nurses participating in two End-of-Life nursing education courses, each of whom gave their permission to publish. In the first course, a journaling activity, described as a written survey and entitled '*Moral distress and futility*', was completed by nurses on their first day. They were asked them to describe *a distressing clinical experience* when they witnessed care described as futile, and how it affected them. Responses averaged one side of a single-sized typed page. As depictions of moral distress and theologic elements, and implications for the profession of nursing were infrequent, the survey questions were adapted for the second course to include reference to their experience *as a nurse*, their views of the affect on *nursing as a profession*, and whether there were *religious/spiritual factors influencing the situation*. The journal surveys were typed and a quantitative coding identified the setting, the type of conflict, those involved, cultural factors, spiritual/religious factors, and the nurses response or emotion. Narratives were analysed to identify concepts of nurses' experience of morally distressing and futile care [see also DelVecchio Good et al., (2004) in this Bibliography].

Whilst the primary setting was the Inpatient hospital unit, followed by Intensive care units, there were occurrences across all settings. 'Aggressive care' was identified as the most common conflict, because the continuing attempts to cure denied palliative care. Conflicts were most commonly cited as occurring between physicians, patients, families and nurses, within families, and between physicians and nurses, or nurses and nurses. Culture was infrequently cited as contributing to futile care, and in the first journaling exercise only 7 of the 51 narratives referred to religion or spirituality compared with 36 of the 57 surveys in the second. Geriatric patients and people with cancer were the most cited diagnosis or disease. Conflicts arose between physicians' and a patient proxy – decision makers when patients were unable to make their own informed choice. Nurses felt they became strong advocates for patients' best interests, but also felt demoralised, powerless, angry, and guilty.

The Journal Club preface makes this paper particularly accessible as the points for discussion act as a form of guide, helping readers to consider the findings of a study in the relation to their own practice. The paper has been included in this Bibliography for a number of reasons. Firstly, the literature review is useful as a basis for other studies. It identifies the context in which narratives are constructed, in this case the changes in social expectations arising from the advances in medical technology, that contribute to a view that death can be avoided. The discussion of the legal implications highlights the increasingly US based 'defensive medicine', in which decisions made on the side of 'doing' more rather than less have implications that are fraught with legal and moral issues. The contribution of theological issues to nurses' distress are also discussed, in particular the place of strong religious belief on family demands for aggressive care. The paper explores the nature of professional distress in relation to care and a number of factors are identified. These include disagreement about the direction of the dying person's care, poor physician communication with family members, action that prolonged patient suffering, and family factors such as the non-acceptance of poor prognosis and over-riding patients' advanced directives. Social justice (arising from inequitable access to the US health care system) [see also Kingson (2005) in this Bibliography] was also cited as a part of nurses' distress. However, a number of issues are raised rather provocatively in the review - for example, a feminist ethical acknowledgement of the power and domination of medical technology, and a critique of the inappropriate use of technology in prolonging life - but there is little discussion of these ideas, nor is use made of the nurses' narratives to extend debate. Secondly, and although it appears not to have been exploited, it is an example of a particular data collection method and the use of mixed methods of analysis. The weighting and presentation of the narratives is disappointing, and the conclusion that the narratives revealed information about the relationship of ethics, theology, and culture is not substantiated in the paper. Whilst practitioners might find the content useful as a basis for discussion, for researchers, it leaves many questions unanswered. These gaps, however, point to useful areas for research. Thirdly, it is also an example of an albeit interesting study, where the use of the word 'narrative' belies the essentially quantitative data content, with the narratives placed within the paper and largely left to 'speak for themselves'.

Frank, A. W. (2000) The standpoint of story teller. *Qualitative Health Research*, 10, 3, 354-365.

Status of author (s)	Professor of Sociology
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics
Keywords	Ethics; Narrator/listener; Narrative structure; Reflexivity; Remoralising; Standpoints/positions; Storytelling relationship;

This paper is essentially a response to Atkinson's (1997) paper entitled 'Narrative turn or blind alley?' in which Atkinson positions Frank as part of the blind alley of narrative and story. Frank raises five points:

- He identifies the relationship between stories that people tell and the underpinning narrative structure on which they rely, and challenges the exclusive focus on structure that risks omitting what is important to storytellers;
- Storytelling is a relationship between teller and listener and acts to reaffirm and shape this relationship;
- Stories are used to re-moralise individuals in the face of demoralising illness;
- As the purpose of storytelling is relationship building, including with those who analyse the story, entering too quickly into this analysis risks misunderstanding. Frank's intention is to maintain the focus of attention on the respondent; in particular on how a relational self, threatened by crisis, is sustained;
- As a result, Frank rejects what he sees as Atkinson's dichotomy between storytelling and story analysis, arguing that this has a place in the relations of storytelling.

Frank's standpoint privileges the ethical over the methodological, and locates illness narratives as the foundation for practical ethics and clinical understanding. He understands the notion of 'standpoint' as a 'political and ethical act of self-reflection' (p. 356), and that these are never static and are not optional. Frank's standpoint, which he argues is in contrast to Atkinson's, is that advocacy is part of a principled investigation, by which he means, rather than describing their experiences, enabling the ill to experience their situations differently. He draws on Smith (1987) to argue that sociological descriptions of illness do not match the lived experience of it [This links to the discussion between Craib and Seale in Craib (2003) in this Bibliography], and that remoralisation is an attempt to cross this separating 'line of fault' (Smith, 1987). He identifies the need for 'hybrid discourses' (p.357) which draw on a range of disciplinary ideas and concepts to address multiple audiences. Frank makes a distinction between being ill and being a patient, and identifies the different interests of medical sociology (and the medical profession) in patients *inside* the clinic, and his interest in people who are ill and the way they narrate their experience *outside* of it. In discussing advocacy, Frank questions the limits of what can be said about someone else's story.

This centres on whether to speak in the name of others or to provide possibilities for them to speak for themselves, and the role of the analyst in this. He argues that identifying the underlying code implies being a master of it, and whilst he says he himself works in this way, wonders about privileging one code over another. To make sense of a story, he argues, is an experiential question, not solely an analytic one. In the paradoxical moment of dependence upon, and resistance to, medicine, pervading illness, and 'health' experiences, Frank argues that these require multiple standpoints and works.

This is useful as a text for researchers as it elaborates some of the tensions in the 'narrative' world, between listening to stories, telling stories, analysing stories, and analysing structures of stories. It provides an example of the construction of one-side of an argument. Whilst it may be helpful to have read the paper to which this is a response, it is not essential. Frank's perspective and the criticisms to which he is responding are clearly laid out. However, it is not possible to draw one's own conclusions about the debate without this reading.

Frank. A. W. (2002) Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods*, 1, 1, 1-20.

Status of author (s)	Professor, Department of Sociology
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Sociological
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics
Keywords	Authenticity; Disenchantment; Ethics; Identity; 'Knockers'; Meaning; Moral life; Political; Standpoints/Positions;

Originally a lecture at the *Advances in Qualitative Methods* conference held at the International Institute for Qualitative Methodology, Edmonton in 2001, this paper discusses the nature of authenticity in personal storytelling, and presents a case for narrative analysis.

Frank begins by drawing on Weber's (1958) understanding of modernity, at the core of which is the notion of disenchantment of the world that results from the 'mastery' afforded by the real powers in modernity of technology and calculation. Weber questions whether modernity has lost access to meanings (enchantment) that go beyond the purely practical and technical, and draws on Tolstoy to suggest that science is meaningless because it gives no answer to the only important question: "What shall we do and how shall we live?"

Frank's argument is that one solution to the problem of disenchantment is the idea of re-enchantment occurring in the stories of the mundane practices of everyday life. He offers suggestions about the value

of stories as moral education that help identify what is needed to live: a kind of cleverness; the humour required to persevere; particular people or situations to look out for, and exemplary actions, providing a sense of the world as a 'narratable' place, that is, a place of which stories can make sense of the world. One vocation for the social sciences, he argues, is to collect narrative fragments of these acts of re-enchantment, and to suggest answers to questions about how we should live.

Frank's discussion then turns towards the question of authenticity. He begins this discussion by arguing that social theory has been suspicious of the personal. He cites Atkinson and Silverman's (1997) critique of the 'interview society', and locates himself alongside Bauman's (2000) criticism of personal narratives and interviews as vehicles for consumption - stamping acceptability on emotive states. Frank agrees with Bauman's view that contemporary society has lost a sense of the political – the idea of civic involvement in social change and the common good. Where Frank disagrees with Bauman is in how to restore this, seeing narrative as a political solution to this problem, rather than as a symptom of it. Frank suggests that Bauman's critique is in the tradition of Taylor's (1991) 'knockers' of the idea of authenticity. Whilst the scientific attitude dismisses talk of authenticity as woolly, and the humanist as an expression of moral laxity, Frank argues that Bauman represents a third type of 'knocker' who sees the narrative self as a ruse of an individualised, commodity culture. Unlike Bauman, and because of its capacity to make experience narratable, Frank follows C. Wright Mills' and other's [not referenced in the text] in seeing story-telling as the means to link the notion of 'personal troubles' to public issues.

Frank then moves his attention to Taylor's argument as a reprise to disenchantment. In elaborating Taylor's theory, Frank suggests that authenticity as a dialogical relationship to things that matter, rather than a relativist individualism. However, Frank raises the question of the cultural pressure (what Bourdieu (1998) terms symbolic violence) on people about what counts as things that matter. His response is that it is what matters that instigates stories, affirming these in relation to how life is lived; stories in which, as Taylor argues, a moral ideal or a search for authenticity (being true to oneself) is being expressed. Nevertheless, Frank wrestles with the dilemma inherent in the notion of 'better' or 'higher' modes of life, and suggests that 'higher' standards are contingent, provisional, and local, and cannot be universalised over time to one life or onto other lives. It is through stories that the exploration of the moral life takes place, and through which dialogical affirmation of authenticity occurs.

But again, Frank questions whether narrative analysis really believes this, however - using Taylor's words - 'debased' and travestied' they are. He cites Taylor again, who argues that the condemnation of the 'knocker' position is counter-productive because it does not move us closer to the heights, before returning to the question of the place of narrative analysis in hearing and representing stories to others. He argues that social scientists are not solely collectors of stories, but, with an emphasis on humility, can firstly enhance stories by showing how different types participate in the conventional rhetoric of a cultural context, at the same time questioning the assumptions embedded in that rhetoric; and secondly, call attention to the way stories seek the moral ideal of authenticity. This raises three questions. How do stories make claims to an identity and on what values do these depend? How does the story-telling work

dialogically? And how do stories address disenchantment?

In this paper, Frank presents the researcher with a challenging set of ideas. He draws on many disciplines to discuss the issues and to present his argument for the ethics of narrative analysis. Through a Socratic dialogue – posing questions and providing argumentation – Frank considers the ethics of research into stories, not only in gaining consent, but in what constitutes respect for stories in narrative analysis. He emphasises both the researcher’s assent to enter into a relationship and to become part of the persons struggle towards a moral life, and the researcher’s position vis-a-vis the value of what might be experienced as the morality of the story. Whilst the researcher’s validation of specific actions may be withheld, nevertheless, it involves a recognition of the moral imperative to make life narratable. He also suggests narrative analysis can be a model for story-telling, in which the moral impulse of stories that provide provisional moments of re-enchantment can be amplified. Narrative analysis can be seen as initiating a significant political intervention. [For examples of auto/biographies that attempt to link personal troubles to public issues, see Kingson (2005) and Byrne (2006) in this Bibliography]

Frank. A. W. (2002a) *The extrospection of suffering: Strategies of first-person illness narratives.* In W. Patterson (Ed.) *Strategic narrative: New perspectives on the power of personal and cultural stories.* New York: Lexington Books, 165-178.

Status of author (s)	Professor, Department of Sociology
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics
Keywords	Authenticity; Ethics; Extrospection; Political; Standpoint/positions; Suffering;

As with other papers by Frank [see for example, Frank (2002) in this Bibliography], this paper offers a defence against the criticisms of, for example, Bauman (2000), in which he argues that what are perceived as public issues are actually the private problems of public figures.

Frank begins with an historical review of written illness narratives as a genre, and notes that, whilst not historically the case, the contemporary genre is dominated by the United States. In this review, Frank foregrounds the extent to which 19th Century slave narratives had an impact on the perception of the institution of slavery and those involved in it, and he suggests that illness narratives are affecting social perceptions of illness in the same way. As a result, he argues, they are strategic, and he develops this idea to suggest that this is generally to elicit the participation of the other in the sufferer’s as yet unfinished project. Frank draws on Beliah et al., (1985) to situate the impetus towards personal narratives, in printed

form, within the dominant tendencies of the 'utilitarian individualism' (to make something of it) and the 'expressive individualism' (to give something voice) of American culture. However, he reminds us that there is also a European tradition of thinking about lived experience that expresses life's 'point' and 'measure'; that is, it is understood to have a moral significance that can be discovered and expressed through narrative, as well as regained and refashioned in the case of illness. Furthermore, drawing on Taylor (1991), Frank suggests that it is only in the inherently social dialogical (in communication and community) that the point of life is found. It is this re-visioned self in unimagined relation to others that Frank terms 'extrospection'.

In response to critics of narrative, Frank provides interesting examples of narratives, and draws on these and social theory to argue that narrative constitutes a standpoint from which politics (the relations, powers, and forces that shape experience) is explicated and made visible. Thus, Frank argues, social theory needs narratives and narratives need social theory. He states this two-fold argument clearly – that illness narratives contain the powerful moral ideal of a self seeking authenticity and that this ideal impels those who recognise it towards the political. In addition, he argues, the strategy of illness narratives is to consider the experience of health care from the standpoint of those who suffer illness, drawing attention to those in power, to the shortcomings or limitations of a system staffed by what Wolgast (1992) calls 'artificial persons' people who act, not on their own moral authority, but as agents of an authority beyond themselves, and whose function is to relate to those who are ill from the perspective of the extralocal, administrative, counter-texts of organisational bureaucracy. Narrative, he argues, holds policy accountable to the question of what decisions mean and how they impact on an individual life, and then what this means to a society if everyone is treated this way.

Although some of these arguments are found elsewhere in Frank's work [see for example, Frank (2002) in this Bibliography], this paper makes an interesting and thought-provoking contribution to the question of the value of illness narratives. It challenges researchers to consider their own position vis-a-vis the arguments, and invites them to be cognisant of the competing views about the place and value of narrative, as well as aware of the value of narrative to those with whom they speak.

Frank, A. W. (2002b) The painter and the cameraman: Boundaries in clinical relationships. *Theoretical Medicine*, 23, 3, 219-232.

Status of author (s)	Professor, Department of Sociology
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory Using narrative analysis: End-of-life/Palliative care
Type of text	Research: Secondary
Type of study	Discussion paper
Whose perspective	Health practitioners
Intended audience	Academics
Keywords	Boundaries; Communication; Decision-making; Ethics; Pain; Patient-doctor relationships; Reflection; Standpoints/Positions;

In this paper, Frank presents four stories in which boundary crossings in clinical relationships are explored as a self-conscious topic. Frank draws on two metaphors of Benjamin (1969) through which to explore these. The first metaphor is that of the ‘painter’ who sees the whole, although remaining at a respectful distance, and the second is that of the ‘cameraman’ who penetrates reality by seeing only parts which are then re-assembled to create a new narrative logic: a story edited from these fragment. These two metaphors are used to reflect on the question of boundaries in clinical relationships - in particular, the qualities of closeness and distance, cross-cut with the dimension of approachability.

Early in the paper, Frank introduces Benjamin’s (1969) term ‘aura’. This refers to that aspect of an object that is not reproducible, and which is an aspect that a later period considers gives an object its authenticity or essence that is not available in copies. This aspect is also a phenomena of closeness and distance; an aura sustains distance, as it sets apart the original object from reproductions, even when that original, such as a painting or signed book, is held in proximity. Linked to this phenomena is the psychological dimension of approachability, which may or may not correspond to distance.

Frank clarifies these boundary relationships between painter/cameraman and closeness/ distance/ approachability through explicating Benjamin’s example of Rembrandt’s painting of the *Anatomy Lesson*, in which the subject of the painting, the painter, and the viewer are all situated in different relationship. He suggests that medicine, like art, has its painters and its cameramen. The phenomena of too close/ distance is considered in relation to the physical boundaries (inside/outside) of the body, as well as to inter-personal, moral and spiritual boundaries (involved/detached, approachable/unapproachable). Frank argues that this question of boundaries is not solved by ethical guidelines, but through constant self-reflection and interrogation, and that more can be learned from the stories of what people do as they practice medicine, rather than exploring the different distinctions which, he suggests, are heuristic simplifications. The four stories he presents provide examples of health care providers (physicians and nurses) orientating themselves to prior assumptions of boundaries, and expressing concern – weighing

risk against cost – when these are too close or too distant.

The first and second story involve ambiguity – either the results of boundary crossings, or the reasons not to cross a boundary. The first story (Biro, 2000), has been entitled '*Doctors don't say things like that*' and is of a physician who, as a patient, struggles with making a treatment decision about which two of his physicians disagree. Through this story, Frank identifies a number of interpretations that can be made about the respective perspectives of the protagonists, but he emphasises that what is most important is that the way in which boundaries are evoked is an essential aspect of how an encounter is created and re-created through it; the story-teller acts and reacts as part of a process of becoming, or remaining, the person they want to be. As part of this encounter, each of the protagonists; the patient and the doctors locate themselves, and are located by the other, at a boundary in which they see each other or are seen from the perspective of cameraman or painter.

The second story, (Neher, 1999) has been entitled '*Unable to share what I was feeling...*'. These words were spoken by a young physician, in relation to an encounter with the stoicism of a patient whom he was treating for a massive heart attack and his wife, in which he relinquishes his position of medical cameramen for that of painter, seeing his patient in the wider social context of his life. Frank contrasts these two stories, each of which concerned the physicians' in/ability to express their feelings to a patient - to explore the physicians relationship to the boundaries they felt that might have been transgressed, or not. In relation to this story, Frank remarks that it is the ethics of boundaries that define 'the job' rather than the other way around.

The third and fourth stories explore the imaginary and the real. In the third story (Barnard et al., 2000) entitled '*I had overstepped my boundary*', Frank considers the idea of boundary as self-preservation. The story is told by a physician (Towers) who quotes a palliative care nurse describing her patient who is in considerable pain, and the experience of this nurse who, in imagining the patient's pain, develops her own physical pain that necessitates some time off sick. Frank identifies linguistic shifts across different segments of the story, from orientation, to the use of first person, to a more detached 'assessment language', to finally a more generalised statement, which, Frank argues, can be read as a self-reflective resolution. Frank's analysis of this text is of the nurse speaking about the boundary of boundaries, in which the boundaries are not just those *between* a patient and practitioner and whether these have been crossed, but are *within* a practitioner. He reads of this text that repairing an internal boundary crossing enables the nurse to be open to the external boundaries between herself and her patient.

In the final story (Bridgewater, 1999), entitled '*It's so intimate – too intimate*', Frank again explores the interior/exterior boundaries. Through this story of the attempted resuscitation of an older woman, written in two parallel columns - one in a medical voice and the other in an internal dialogue - he explores the intimacy that has been enforced by the narrating doctor's lack of equipment that has put her in the direct, unmediated, contact with the body of the patient. Whilst it was professionally appropriate, Frank suggests that it has no way of being expressed professionally, and he asks questions about why this might be so.

What keeps these parallel columns separate and who is served by this?

Frank concludes by reiterating that boundaries, between psyche and soma, engagement and disengagement, imagination and enactment, are complex and dynamic, rather than a static dichotomy of appropriate/less appropriate. He argues that the position of the physician is both cameraman *and* painter and requires both an aura of distance and approachability. Medicine is a play on boundaries for which adjudication might be required after an event and, whilst not denying the need for boundaries, Frank suggests that how they are maintained or crossed will always be contested, but that stories, whilst not prescribing the rules, do exemplify the ethics of continual reflection.

This is a useful paper for researchers in a number of ways. It is an example of a narrative analysis of existing material, and of how narratives can be explored in relation to theories and concepts, in this case of boundaries. In addition, it provides researchers with some reflections on boundaries that might be useful to consider in relation to own their work in general, and narrative analysis in particular, whilst Benjamin's (1969) metaphor of painter and cameraman is a useful one to consider in other contexts.

Frank, A. W. (2006) Interpretive phenomenology, clinical ethics and research. *Health*, 10, 1, 113-116.

Status of author (s)	Professor of Sociology
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Book review
Type of study	Review/Reflection
Whose perspective	Patients, Carers and Health practitioners
Intended audience	Academics
Keywords	Decision-making; Ethics; Interpretive phenomenology; Technology;

This is a review of a book entitled ' *Conversations on the edge: Narratives of ethics and illness*' (2004, Washington, DC: Georgetown University Press) and written by *Richard M. Zanar*, now professor Emeritus at Vanderbilt University where he was Director of the Clinical Ethics Programme. It situates Zanar's book as describing his engagement with people who are both edgy (tempers are often frayed) and who are also at the margins of experience, where they are called upon 'to make decisions that they never suspected anyone *decided*' (p.113).

The book contains six discrete essays that are concerned with medical intervention and life support (how long should it persist, which to withdraw and when, refusal of it, how it is negotiated). What Frank admires is Zanar's capacity to keep open the question as to who people are and what is happening. Frank describes 6 reasons for reading Zanar:

- Zanar emphasises the place of interpretive phenomenology as a discipline of seeing and knowing,

rather than a procedure to reach some conclusion (a methodology). It enables new interpretations of self, the situation, and the relationships, which enable new possibilities for action;

- It offers insight into how ethics as a hospital activity/department can effect clinical practice;
- It offers insight into the gap that increasingly exists between high technology and common-sense morality, and affirms the need for patients and families to have a dialogue through which decisions can be made;
- It presents conceptualisations of humans' reflexive being as the origin of an ethical sense of morality;
- It emphasises listening deeply to what the encounter seemed to be about, and to what seemed bent on being told, rather than a rush to code, as the core of interpretation;
- It offers wisdom gained from reflections, and locates the recurring themes of how chance affects life.

This is an enticing review in which Frank strongly recommends researchers to read Zanar, as it provides both material for social scientific analysis and a model of how researchers can situate themselves. What makes this review particularly useful to researchers is that it:

- Directs them to the little known set of texts by Zanar based on narratives and clinical tales from his ethics practice;
- Provides an interesting critique of Interpretive phenomenology; and
- Highlights a number of important issues for researchers to pursue.

Garnet, M. (2003) Sustaining the cocoon: The emotional inoculation produced by complementary therapies in palliative care. *European Journal of Cancer Care*, 12, 129-136.

Status of author (s)	Academic: University Lecturer in Palliative Care
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Grounded theory
Whose perspective	Health practitioners
Intended audience	Academics and Practitioners
Keywords	Bio-medicine; Complementary and Alternative therapies; Discourse analysis; Dying; Health practitioners (Nurses, Palliative care); Identity; Ontological security; Trust;

The aim of this qualitative study was to explore, from a medical sociological perspective, the use of complementary therapies by palliative care nurses. In her introduction, Garnett both acknowledges, and sets aside, the justifications for the use of complementary therapies in cancer and palliative care, in order to focus on the ideas of Giddens' (1990; 1991) as an alternative way of understanding their use in these

settings. The key concepts of Giddens' vocabulary of: '*trust*' and '*trustworthiness*'; '*ontological security*', '*existential anxiety*', '*emotional inoculation*' and '*protective cocoon*'; and '*fateful moments*' and the '*return of the repressed*', are brought into dialogue with the diagnosis of a terminal illness as a particular '*fateful moment*' in which trust in practitioners, threatened by death itself, becomes paramount. Garnett draws on these concepts to facilitate understanding of the use of complementary therapies in palliative care that might otherwise remain hidden.

Eighteen palliative care nurses who used complementary therapies (mainly massage, aromatherapy, and reflexology) were recruited, and this was later extended to include the views of 13 other staff members (5 nurse managers, 4 doctors, and 4 complementary therapists). Semi-structured interviews were undertaken, fully transcribed and entered into NUD*IST. Participants were asked to talk about themselves and their background and how they became interested in complementary therapies, and to describe the different aspects of their use of these. Garnett describes her practice of both '*feminist*' and '*active*' interviewing, elaborating the nature of it as a social encounter in which meaning is made, and which includes not only what is conveyed, but how the process unfolds (Holstein and Gubrium, 1997). The narratives were analysed from a discourse analysis perspective giving interview data the status of both a topic and a resource as well as paying attention to the content and form (Potter and Wetherell, 1994).

The nurse therapists presented themselves as not only being involved in activities that were considered important in generating trust, but also as thinking that these were important.

- *Ontological security/protective cocoon*: In complementary therapies, the importance of making someone feel 'looked after' was indicated through words such as 'nurtures', 'safe', 'secure' that the participants used, but also in the contrastive rhetoric of 'mutilated', 'invaded', and 'abused', which were used to describe how patients felt in orthodox medical treatment. This rhetoric was also identified, in relation to the '*protective cocoon*' complementary therapies provided, as something not experienced since being a child.
- *Existential anxieties*: Garnett identifies how nurse therapists construct complementary therapies as a solution to existential anxieties, and the role of complementary therapies in helping patients with the spiritual dimensions of illness and dying.
- *Fateful moments*: Garnett links Giddens' theory of fateful moments, as times when people have more recourse to traditional or familiar modes of activity and are reskilled and empowered, to the narratives of her interviewees in which they describe helping clients reconstruct their self identity.

In her discussion, Garnett links the nurturing benefits of complementary therapies and the shield they help maintain against existential anxiety to Giddens' concepts. In acting in a trustworthy way and in providing a nurturing and sustaining cocoon, nurse therapists facilitate trust, not only in formal carers and the '*expert system*' of palliative care, but also in the wider health care system. Drawing on Giddens' notion of the sequestration of experience, in which hospices make visible to their patients experiences that are increasingly hidden from view, the function of '*cocoon maintenance*' is also facilitated through the

use of complementary therapies when people enter the hospice.

This is an interesting example for researchers of a study that, from the beginning, situates the data within a wider theoretical framework. It is a well-written paper, with a clear structure that enables the reader to follow the conceptual development of the findings. The method of sampling, data collection and analysis are clearly described and the findings linked to data.

Greenhalgh, T. (1997) The conker tree. *British Medical Journal*, 315, 1315.

Status of author (s)	General practitioner
Nationality	UK
Type of Author (s)	Professional: Practitioner
Study/Text	Auto/biographical accounts of end of life
Type of text	Personal experience: Autobiography
Type of study	Review/Reflection
Whose perspective	Health practitioners
Intended audience	Practitioners
Keywords	Health practitioners (Doctors); Older women; Reflection; Resentment;

This brief, absorbing, and poignant story is of a General Practitioner's (GP's) Saturday surgery and an unexpected home visit, that interfered with the planned afternoon outing with her children. The description is vivid, conjuring a scene and drawing the reader into the GP's feelings of resentment and the thoughts of her children, as time passes by and the possibility of the promised outing with them recedes. It is not possible to say much more about the story without spoiling its impact on the reader. However, as the narrative unfolds, we are presented with a story within a story, and are ourselves changed by hearing and reflecting on it.

This narrative is an example of how a brief reflection on our own story as practitioners and researchers, as well as on the stories that others tell, can impact on us and change our experience and our view of the world. It stands alone as a reflective account of an experience of a GP making a home visit. It also provides researchers with material for interpretation [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this], and a comparative text against which other reflective narratives can be set.

Hok, J., Wachtler, C., Falkenberg, T. and Tishelman, C. (2007) Using narrative analysis to understand the combined use of complementary therapies and bio-medically oriented health care. *Social Science and Medicine*, 65, 1642-1653.

Status of author (s)	Academics in University Departments of Complementary Medicine, Public Health and General Practice
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narrative analysis: End-of-life/Palliative care
Type of text	Research: Primary
Type of study	Case study
Whose perspective	Carers
Intended audience	Academics
Keywords	Bio-medicine; Collaboration; Complementary and Alternative therapies; Meaning; Patient-practitioner relationship; Poetic

This study is part of a larger multi-disciplinary study exploring stakeholder perspectives on the use of Complementary and Alternative therapies (CATS) and bio-medically orientated health care (BHC). The paper presents a case study of one person's experience, drawn from 40 cases perceived as 'exceptional'. It is the narrative of a middle-aged widower telling the story of his wife's use of complementary therapies alongside her bio-medical treatment, although the authors emphasise that the focus is actually on his own experience.

Following Riessman (2002) [and Riessman, 1993, in this Bibliography], the researchers examined the fully transcribed text for 'narrative acts'. Their approach was broader than Labov's (1982) analysis upon whom they also draw. In the text, they identified 'evaluation clauses' in which the narrator stands back and shares their interpretation of the meaning or the 'point' of each of the 14 narrative acts. Two of these narrative acts were chosen as 'performance' for further exploration as they contained rich descriptions of events central to the overall meaning of the narrative. The focus of analysis was on the structural and thematic components, the linguistic features, phrases and recurring themes as well as the appeals to the audience. Gee's (1991) theory, about the nature of speech and the underlying assumption of its poetic nature, informed the organisation of the transcript into stanzas, each of which comprise groups of clauses based around one particular topic. The stanzas were then grouped into scenes and given a title. Temporal order was maintained.

The authors draw on the Cochrane Collaboration's definition of complementary and alternative therapy (CATS) to identify the difficulties of defining therapies into distinctive sectors. They suggest that people do not make the same dichotomous division between CATS and BHC as the medical profession, for whom there may be different purposes for their use. Rather, BHC may remain an important frame of reference for the patient's use of CATS, and the narrative identifies the importance given to both scientific evidence and personal experience. Within BHC provision, there may be a variety of views about CATS,

and successful communication between a carer and an 'open' rather than a 'closed' BHC provider may be experienced as a shift in the hierarchical relationship. Where communication was felt to be poor, the narrative highlighted a number of negative metaphors that were used to describe the BHC practitioners, and the carer narrator forewarns of the forthcoming problems in lack of dialogue and the unwillingness of the BHC provider to acknowledge evidence for the efficacy of the CAT. This is contrasted with a second BHC provider whose observations appear to support those of the narrator. The authors acknowledge that it would have been valuable to include the perspectives of those BHC providers involved, and they hope to do so in the wider study [for an example of this, see Abma (2005), and Brannström et al., (2005; 2006) in this Bibliography].

This paper is valuable to researchers as an excellent example of a study using narrative analysis. The background discussion on narrative is clear and accessible, and the authors provide a detailed summary of the analytic methods and process from data to interpretation.

It is a useful study that describes patient/carer experience of trying to work for their own health or that of another, and the tensions that can arise between patient/carer and Health practitioners.

Hydén, L-C. (1997) Illness and narrative. *Sociology of Health and Illness*, 19, 1, 48-69.

Status of author (s)	Academic based in a University Social Work Department
Nationality	Sweden
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Study of the phenomena of narrative
Type of text	Theoretical: Sociological
Type of study	Review
Whose perspective	Researchers
Intended audience	Academics
Keywords	Bio-medicine; Emplotment; Frank; Health practitioners (Doctors); Life history interview; Narrator/listener; Robinson; Standpoint/Positions; Typology of narratives;

This is a clear, well structured, and accessible paper that helps situate the genre of illness narrative research within a historical context. In doing so, the author identifies useful ways of categorising narrative, considers the contribution these can make, describes problems associated with the organisation of illness narratives, and discusses the social context of telling and its influence on the narrative.

Hydén identifies a number of changes during the 10 years under consideration. Firstly, there has been a shift in the focus of social science studies, from the clinical gaze of the medical profession and the biomedical model of disease towards a focus on illness and then suffering in different social contexts, which has contributed to strengthening the voice of patients. Secondly, there has been a shift in emphasis from interest in what lay 'behind' the narrative to a focus on the narrative itself. Thirdly, the use of narrative in medicine and illness has changed: *thematically* from the clinical practice experience of doctors and

the biomedical conception of disease to the experience of the individual's experience of illness and suffering, with increasing importance being given to the study of chronic illness and problems of identity and disruption; *theoretically*, moving from the periphery to a more central position in social science research, and *methodologically* with an increasing awareness of situational factors in the construction of narrative, particularly the interaction of narrator and listener. Hydén argues that an exploration of the different definitions of narrative reveals that the most common theme is that it is distinguishable from the surrounding discourse, and that it has a beginning, a middle, and an end. The life history interview is an example of an alternative, less demarcated type of narrative in which the end is unknown, but which, nevertheless, involves the narrative emphasis on the ordering of events and an association with change. Hydén suggests that it is this aspect – the location of illness as a disruption to the foundation of life in which conceptions of what is changeable have to be revised, calling into question the experience of continuity - that makes illness narratives interesting. Narrative provides a forum in which to construct a new context that situates the illness and the surrounding events in time and meaning; that is, in the biographical framework of a personal life.

However, Hydén's view of the formal aspects of the typography of narratives – the relationship of the narrator, the narrative and the illness - differs from others in the field such as Frank (1993; 1994; 1995) whose clarification of narratives typify an understanding of illness (in this case as '*restitution*' '*chaos*' and '*quest*') in relation to a person's life, and Robinson (1990) who identified life trajectories in illness narratives (in this case as 'stable', 'progressive' and 'regressive'). Hydén sees these as limited genres based on a meta-narrative of illness, rather than on the inter-related aspects of narratives.

In contrast, Hydén's typology of illness narratives reflect the interrelated positions of their formal aspects: *illness as narrative* in which narrator, illness and narrative are combined in one person, reflecting the central role that narrative plays in the personal experience of the illness as well as the meaning made of it; *narratives about illness* in which knowledge and ideas about the illness are conveyed, and *narrative as illness* in which suffering derives from an insufficient capacity to narrate, that is, for any number of reasons the person is unable to express experience. How a narrator defines their illness narrative - from one of two diametrically opposed perspectives of illness and health, and how it is to end - is the struggle that characterises illness narratives. The co-construction of a narrative between the narrator and listener is helped by literary and cultural conventions, for example, that of culturally embedded genre and narrative techniques. The problematic 'lack of ending' in chronic illness makes it difficult to articulate into a meaningful whole, and this is enabled through the active co-creation of Mattingly's (1994) 'emplotment', a particularly useful tool in therapeutic work. Illness narratives occur in different social contexts which influence form, presentation and interpretation and, within these contexts, can: accomplish transformations in the experience of illness, and illness from an individual to a collective phenomenon; be used, in the event of chronic illness to reconstruct a life history and to explain and understand illness; be used as a strategic form of interaction to assert personal identity.

The value of this paper lies in providing a helpful overview of the historical context for the genre, as well

as an alternative typology of narrative in which to a researcher can situate other research studies as well as their own work.

Johns, C. (2004) *Being mindful, easing suffering: Reflections on palliative care*. London: Jessica Kingsley.

Status of author (s)	Hospice based practitioner (Nurse and Complementary therapist)
Nationality	UK
Type of Author (s)	Professional: Practitioner
Study/Texts	Auto/biographical accounts of end of life
Type of text	Personal experience: Autobiography and Poetry
Type of study	Review/Reflection
Whose perspective	Health practitioners
Intended audience	Practitioners
Keywords	Boundaries; Complementary and Alternative therapies; Dignity; Dying; Ethics; Health practitioners (Nurses, Palliative Care); Hope; Mindfulness; Reflective practitioner; Reflexivity; Standpoints/ Positions; Suffering; Writing;

This book is based on Johns' practice experience, recorded in a journal, between September 2000 and September 2002. It is a 'treatise on mindful practice' working with people facing death and dying, that attempts to answer questions about what makes a difference to suffering and how to become more skilful in practice. His narrative reflection is set in a context of both a research and a development tool, and in his position as a nurse, complementary therapist, and Buddhist, working in a hospice. Johns describes the writing as a research process, in particular the 'researching self as a process of self-inquiry and transformation' (p. 9) through reflexive narrative, and he argues for this as a form of disciplined research methodology that reveals nuanced facets of suffering and his response to it, unavailable in other forms. The book is in 3 parts, although Johns suggests that they need not be read in chronological order.

In Part 1: *Mindful practice*, Johns begins his narrative by situating it in the context of palliative care and Mindful practice. Firstly, he raises questions about some of the words used in the definition of palliative care, and then situates his own practice in *easing suffering* – the existential, complex aspects that cannot be observed, but which arise out of a person's world view – and *nurturing and healing the growth of the other* – helping them to find meaning by revealing the managing self, and enabling them to contemplate new ways of being in the face of life-threatening illness. He then elaborates implicit dimensions by giving his own meanings of '*spiritual*' – that aspect of work which he considers a way of being rather than a technique, and which, although difficult to define, nevertheless, permeates his text – and '*self-growth*' – the opportunity provided by caring for transforming the self, in Johns case, through his experience with patients and in his Buddhist practice. The facets of Mindful practice are also described, including the ability to pay attention to the present, and to bring wisdom rather than knowledge to events that are not pre-judged, but judged on how they present themselves. Prior theories and experience inform, but do

not present the practitioner with prescriptive action. Johns then makes an apologia for his assumptions and the possibility of his distorted reflections, which, he says, may be difficult for readers to accept, before exploring the dimensions of journal writing and its value to reflection, notions of confession, and the benefit of guidance through dialogue and of dialogue with literature. Each of these cohere within and through his narrative, and Johns reflects on his own unfolding drama through its various stages in times, and in style.

Part 2: *Being Mindful, Easing Suffering* forms the bulk of the book and is Johns' attempt to answer the question 'What is it to be with a dying person?' It is written in chronological sequence through dated diary entries, and tracking individual patients. Through this narrative, reflections on his own work, actions, motives, and thoughts in relation to others, and through descriptions of another's story as it interfaces with his work, Johns describes the co-construction and inter-relationship of illness/carer experience. He also reflects on the meaning of inter-subjective experience, challenging assumptions of rationality, and questioning meanings of words such as 'empathy' and 'caring'.

Throughout the text, although Johns includes his relations with families and with other staff, his reflective narrative focuses mainly on his work with patients. He introduces over 40 patients, some of whom, as they die fairly soon, are only mentioned on one occasion, whilst others, such as Iris, span the whole period in which Johns is writing. He draws on Ben Okri's (1997) idea of *narrative transgression* that breaks normative assumptions, and of story tellers as 'reorganisers of accepted reality', which he uses to reflect on his own position as a practitioner and how he narrates the lives of those he encounters. For example, Mary has an odorous buccal tumour and is dying. He sits with her, holding her hand and offering his presence when others find it difficult to do so. He says he honours her and her struggle, in the face of adversity, to die with dignity. He also provides the dialogue that occurred subsequently between himself and his students who challenged his narrative position. Through these stories, Johns gives insight into the patient's practical worries, fear, sorrow and descent into death, but also into what it means to be a practitioner in this setting. He raises, and tries to answer, questions about boundaries - between practitioner and patient, between practitioners, and between the hospice and the community - and about the use of self in this context. He also explores from a Buddhist perspective, the nature of suffering, what it is to be at ease in order to ease, how to help those who appear not to respond, and how much helping arises from his own need.

In this Part, Johns uses patient stories as a vehicle to describe Buddhist teaching and Bach flower preparations, although these are also reflected back into the person's story. His language contains a number of metaphors, such as the 'dance' between himself and his patient, himself as the 'ferryman' aiding transition into death, and he draws on his own or others' poetry through which he explores feelings. He also has what he calls a dialogue with literature - academic, autobiographical, spiritual, professional, and poetic - to help frame his thoughts as he reflects on an aspect of the patient's story, or his own actions. He also raises - through stories - the ethical problems in which practitioners find themselves, for example, about who has or has not been told they are dying, and he considers the place of diagnosis

in relation to hope.

Part 3: *Postscript: Reflection from a Buddhist perspective* is a brief chapter written by another person who reflects on Johns' text.

This book offers researchers a contemplative narrative in its own right, describing one practitioner's thoughts and experiences and his search for meaning as he works so closely with the dying. As a result, it is also available for analysis [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this]. In addition, it offers researchers an example of reflexive writing that might be useful for their own fieldwork.

Johnson, A. and Bourgeois, S. (2003) Essence of caring for a person dying. *Nursing and Health Sciences*, 5, 133-138.

Status of author (s)	Academics in a University School of Nursing
Nationality	Australia
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Auto/biographical accounts of end of life Usefulness and impact for health care practice development and service improvement
Type of text	Personal experience: Autobiography
Type of study	Case study
Whose perspective	Carers
Intended audience	Academics and Practitioners
Keywords	Dying; Pain; Philosophy of care; Quality of life

Through the narrative constructed by one of the authors in her role as family member, this study explores the nature of caring for a person dying at home and for their family. Four examples of this individual narrative are provided and discussed through the lens of the philosophy of palliative care. The WHO (1990) definition of palliative care is used to examine the impact of care in context.

The first narrative extract, which described a party that the author's mother had wanted to take place, was used to illustrate the need of a dying patient to continue with normal life events. The discussion that followed identified the reservations that a carer can experience about a dying person's capacity (wellness), and the need of a dying person to say farewell to extended family and friends, whilst at the same time, living until they die. The second narrative described a worrying period in which 'Mum' was in pain. The discussion emphasised the importance of symptom control and management, and described the feelings of desperation when this is not forthcoming. The third example related to the struggle of a dying person to maintain independence. It highlighted the extent to which carers may experience difficulty in managing physical care, especially when there is deterioration. This extract was also used to identify the importance of the dying person's role maintenance – in this case of a mother caring for her daughter. The final extract highlighted the ever-presence of the dying person within the family. The authors' final

discussion argued that these extracts inform a philosophy of palliative care within which family support is seen as important as patient support.

This is an unusual paper drawing on one author's experience to explore the essence of caring, and the importance of support for those caring for the dying at home. The selected portions of narrative give some insight into these, including the experience of the dying person and the family needs and dynamics, although the points raised in their discussion were not always directly extrapolated from the text provided. No methods of analysis were described, although the authors argued that further research into the needs of families experiencing palliative care is required, and that the use of narratives is a helpful vehicle for developing greater understanding. For this reason, the paper has limited value to researchers beyond the narratives themselves, although the discussion is useful in its own right.

Jordens, C. F. C. and Little, M. (2004) 'In this scenario, I do this, for these reasons': Narrative, genre and ethical reasoning in the clinic. *Social Science and Medicine*, 58, 1635-1645.

Status of author (s)	Academics in a University Centre for Values, Ethics and Law in Medicine
Nationality	Australia
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory Using narrative analysis: Illness experience
Type of text	Research: Primary
Type of study	Narrative
Whose perspective	Health practitioners
Intended audience	Academics
Keywords	Cancer; Ethics; Identity; Spoken policy genre; Typology of narratives;

Based on a study that explores values in clinical situations, the authors build a case that supports their differentiation between the wide variety of written and spoken genres under the rubric 'narrative' to discern an, as yet undescribed, 'spoken policy genre' which gives insight into the process of ethical thinking and identity construction through language.

In their background discussion, the authors identify the applications of narrative analysis to research as concerning: the nature of clinical reasoning; the nature of clinical ethics (narrative ethics); and understanding individual and collective forms of identity. They clarify the purpose and structure of 'story genres' of narrative:

- *recounts* which construe experience as *expected*; and the following that construe experience as *out-of-the-ordinary*;
- *narratives* which portray the struggle for equilibrium;
- *exempla* which describe moral judgement;
- *anecdotes* which share a reaction with the audience;

- *observation* that construes personal responses.

They also delineate genres other than stories as:

- *expositions* presenting one side of an argument;
- *explanations* that explain something;
- *discussions* that explore two-sides of an argument;
- *explanations* that explain something;
- *descriptions* describing something; and
- *procedures* providing step-by-step instructions.

Ten clinicians involved in treating and managing colorectal cancer were interviewed. The interview prompt question was 'Tell me how you came to be a doctor (or nurse, etc), and how you came to specialise in your particular field of work'. Interviews were fully transcribed, originally in 'playscript' (according to the turns of the speakers), and then later reformatted according to the transitions of one spoken genre to another. Analysis was undertaken using NVivo, where spoken genres were coded. Three interviews contained recursive patterns for which there were no coding categories. This uncoded material was re-analysed, an additional code created for a 'spoken policy genre', and the coding exercise repeated across all interviews. Twenty-two further instances of the spoken policy genre were identified. A frequency distribution of final coding was undertaken.

Policy as a spoken genre is distinguished from other genres by the middle stages of 'Scenario, Policy; Rationale', although like other genres these may be preceded by an Abstract summary in advance, and followed by a Coda that re-contextualises the policy in on-going discourse. The *Scenario* orientates the listener to situations construed as recursive, rather than to persons or events; the *Policy* stage identifies the practical way forward or routines of clinical work in the particular circumstances; and the *Rationale* gives the reasons for proceeding in this way. The examples given in the paper clarify a number of features that imply an accumulated clinical experience of a situation, and which contribute to differentiating policy from other spoken genres. These include the sequential location and frequency of the event, spoken in the present rather than the past tense, concerning categories of persons rather than particular individuals.

The authors describe spoken policy genre as an important feature of clinical discourse whose function is to regulate behaviour, enabling clinicians to manage the recurring disruption of clinical work. Their discussion draws on Aristotelian ethics to suggest policy genre as the unfolding of *practical wisdom* in speech, and as the *enactment of professional identity*. In the former, policy genre is identified as the means of negotiating values and action in particular complex, ethical circumstances, occurring in speech (what it is about) and in rhetoric (what it is doing). In the latter, identity is considered as something performed or enacted rather than experienced, in which speech genres form part of a repertoire for the performance or enactment of identity. The authors argue that, where a display of identity is called for, the spoken policy genre is the appropriate choice. They identify genre analysis as a means of understanding moral reasoning in terms of staged social processes, and they build on the differences identified between the language of clinical practitioners (for which spoken policy genre was identified as the most common

non-story genre) and lay people (who narrate as subjective story tellers) to suggest ways of bridging the communication gap that these differences create.

This is a useful paper for researchers for a number of reasons. Firstly, it provides a very helpful background to ‘genre theory’. Building on their previous work, of a theory of meaning in the context of both situation and culture in which a number of analytic categories were introduced that differentiate between story genres and other spoken genres, the authors provide sufficient details for those who have not read their original work. Secondly, it provides a description of the generic structure of a narrative-style interview (the ‘story stage’ and the ‘weakly structured interview’) that was used to elicit the story from the informant. It is also a helpfully descriptive paper on the process of the development of a new category – the ‘spoken policy genre’ – which it then elaborates.

Kingson, E. R. (2005) *Lessons from Joan: Living and loving with cancer, A husband’s story.* Syracuse, NY: Syracuse University Press.

Status of author (s)	Husband, also Professor of Social Work in a US University
Nationality	US
Type of Author (s)	Lay
Study/Text	Auto/biographical accounts of end of life
Type of text	Personal experience: Biography
Type of study	Review /Reflection
Whose perspective	Carers
Intended audience	Lay and Policy Makers
Keywords	Cancer; Complementary and Alternative therapies; Decision-making; Dignity; Health care policy; Health practitioners (Doctors); Hope; Insurance; Quality of life;

This story is written by Joan’s husband following her death from colon cancer and multiple metastases. Its purpose is to describe Joan’s life, but to also give readers guidance on how to identify and assess treatment options; how to communicate with Health practitioners with whom they come into contact; and how to negotiate with Insurance companies to get the best possible treatments paid for.

Although divided into 7 chapters, the book is essentially written in two parts. The first part provides a chronological account of Joan’s early life, their life together as a family, Joan’s illness, and the events leading to her peaceful death. The story of their life together is underpinned with details of their lives before they met – Eric’s as an ordinary life, and Joan’s as traumatic and bleak. Eric describes a loving marriage and family life and the pleasure they each took in the other, and in their two children. In this part of the text, we are led via sequential headings, such as ‘*The bad scan results day*’ when news of the spread of the cancer to Joan’s liver was given, rather than diary dates. The second part of the book, following Joan’s death, contains Eric’s reflections on this journey. He describes the ‘kindness, courage, and humour’ experienced during this time. Each of these dimensions are elaborated in story,

for example: 'A gift from a parking lot attendant'; 'Opium in a Thanksgiving basket', 'Friends you never wanted to meet – at least not this way', and 'Joan's last words'. He also describes the final six months of Joan's life in more detail.

Joan is described as proactive, and early on had set a limit on her treatment possibilities, opting for quality, rather than length, of life. The metaphors that Joan rejected include 'fighting her cancer' and 'battling', which she construed as fighting against herself. She felt there was no sense in which she could gain control over her cancer or cure herself, and resented the victim-blaming subtext of many self-help books. Nevertheless, she was amenable to both Western and Eastern approaches and complementary therapies. As time goes by, these set limits to treatment evaporated, and even until quite close to death, Eric continues to search for new possible options. He refers to the 'trade offs' and how their definition of quality of life changed over time as hope, but not expectation for more time, was maintained.

As a couple, they had insight into the health care system to which their position of having Insurance - acknowledged as privileged - gives them access, and which they were able to use to their benefit. The story describes their engagement in an extensive amount of research. At each consultation, Joan and Eric arrived well-informed, with an extensive list of often quite technical questions based on their research to date. The doctors do not appear to have been threatened by their extensive research, and they appear to enter into dialogue based on this research about the value and benefits about treatment options. Eric acknowledges their humanity and the nature of the difficult work of health care providers, and he describes how he thanked them for giving them bad news sensitively. To enable them to make decisions about treatment options and health care providers, they spoke to medical friends who acted as mediators of decisions and advocates working on their behalf, and they searched the Internet, including exploring drug company websites. Details of some of the drug options are given in the Appendix. They also wrote a considerable number of letters to their doctors and their Insurance company and copies of these, together with some of their Doctor's letters, are enclosed in the Appendix as a form of template for readers to use. In addition, Eric wrote to pharmaceutical companies requesting new, and often untested, drugs under the 'compassionate use' protocol. He estimated that these negotiations with Insurance companies and Health practitioners took between 3-6 hours a week.

This is a thoughtful and reflective account, both of the person who has died and their dignity within illness, but also of a husband's own deepening pain and suffering. As well as a text in its own right available to researchers [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this], this auto/biography is richly descriptive of the maintenance of hope in the face of reduced options. An undercurrent of different types or aspects of hope - both of the couple but also of the oncologists - and how these change over time, are available to researchers. It also provides researchers with an illness experience set within a specific US health care system, where access to a number of Consultant oncologists is relatively easy, and the working relations between patient, family and doctor, as well as doctor to doctor appears respectful. The texts of the letters provide researchers with insight into a Insurance-based health care system which gives access, to those who can afford it, to good quality care without long waits, and

to many doctors with whom they speak often. It also gives an insight into the lengthy negotiations with Insurance companies, and the types of letters that were written to the Insurance companies to ensure the highest possible level of reimbursement. Finally, it gives insight into academic life in the US that made it possible for Eric to spend so much time supporting Joan through this time. This is an interesting book to read alongside Charon (2000), Myers (2000), Mishler (2005), Tomlinson and Tomlinson (2005) and Byrne (2006) [in this Bibliography]. It is an example of Frank's (2002a) extrospection [see this Bibliography], where story is used, not only to describe personal experience, but to locate and reflect upon that experience in the wider context of care systems. In this way, it stands as an example of Frank's (2002) notion of re-enchantment, linking personal troubles to public issues.

Laungani, P. (2003) Therapeutic strategies for coping with a life-threatening illness: A personal testament. *Illness, Crisis and Loss*, 11, 2, 162-182.

Status of author (s)	Senior Research Fellow, Manchester University
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Auto/biographical accounts of illness
Type of text	Personal experience: Autobiography
Type of study	Case study
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Anger; Coping; Dying; Fear; Health care; Health practitioners; Hope; Pain; Polymyositis; Psychology;

This paper focuses on the experience of coping in the face of chronic debilitating and life-threatening illness. It includes a moving account of the author's diagnosis and illness, although this is not the main focus of the paper [written about elsewhere in *It shouldn't happen to a patient: A survivor's guide to life-threatening illness. London: Whiting and Birch, (1992)*]. This paper describes both a move towards, and a personal journey through, means of coping with a chronic, debilitating, and life-threatening illness. Laungani offers the reader a 'view from the bed' of different professional groups with whom he came into contact, as well as the rules he devised and utilised to help him cope with the painful predicament in which he found himself. He subtitles his paper: '*A personal testament*' and, despite his theoretical background in psychology, it remains a personal reflection on the trajectory of illness, recovery, and what it means to face dying sooner rather than later.

Laungani's seven rules, and their corollaries, are clearly explained: focusing on what can be done rather than what cannot; recognising the uniqueness of one's own illness; accepting pain as part of the human condition; finding activities in which one can become absorbed; seeing the funny side of things; not worrying about events which are out of one's control, and creating room for hope in one's life. He suggests that these seem rather like the techniques used by Cognitive Behavioural Therapy, but argues that these rules arose from his own 'self-help' experience rather than from outside, and his descriptions

of how he came to develop each 'rule' provide vivid insights to the meaning and experience of chronic illness and what it means to face debility and death.

Like Craib (2003) [in this Bibliography], this paper provides researchers with an academic's description of, and intelligent reflection upon, personal and painful experience. In addition, it is useful for researchers as a text available for analysis [see O'Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this].

Little, M. and Sayers, E-J. (2004) While there's life ... hope and the experience of cancer. *Social Science and Medicine*, 59, 1329-1337.

Status of author (s)	Academics in a University-based Cancer Survival Project
Nationality	Australia
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narrative analysis: Illness experience Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary and Secondary
Type of study	Mixed methods
Whose perspective	Patients and Carers
Intended audience	Academics and Practitioners
Keywords	Cancer; Death salience; Fear; Hope; Illness; Meaning; Mortal extreme experience; Narrator/listener; Self; Standpoints/Positions; Survival;

This paper reports on a mixed method, qualitative study of narratives concerned with instances and expressions of hope. It forms part of a wider study of experience of cancer. There were four data sources: interviews with 15 survivors of different types of cancer; interviews with 3 partners/carers of cancer survivors; published accounts of survival of bone marrow transplantation for leukaemia; and a detailed account of the experience of dying from prostate cancer (Broyard, 1972). The analysis was undertaken using Grounded Theory and Narrative Analysis methods of Kleinman (1981; 1988), Hawkins (1993), Mishler (1995,1996), Mattingley (1998) and Jordens et al., (2001). For more details the reader is referred to an earlier paper [Little and Sayers (2003) although this is not fully referenced in the paper].

The first discourse in which hope can be narrated is one of *hope for life over death*. This is based on the possibility of a cure that may need to be transformed, if this is not forthcoming, into the *hope for the formulation of meaning* for the life that is ending, and for a good death. Within this discourse, death is not certain only a possibility, and there will be a point at which the participant moves away from, or further towards, the probability of dying. In those who move further towards this probability, death salience is the awareness that *this* experience is the experience of dying. Nevertheless, the authors identify that this will still be present in those surviving, even though it may take time to emerge. This reflective, and

uncomfortable, awareness of the possibility of death involves, at times, unexpressed or unacknowledged feelings of fear, as well as the knowledge of the reality that this process will have to be lived through again, with death eventually being the only possible outcome. The post-survival phase, whilst one of relief, also involves other feelings such as distress, and may present some with a challenge to meaning in a life. However, for others, their post-survival project may be one of *restitution* to the valued order of their prior life, or to a *heroic* development of it. The second discourse in which hope can be narrated is the discourse of meaning in a life, a hard-working narrative that denotes the purposeful attempt to create meaning out of chaos. The study also identifies the breeches that can occur, as a result of illness, between the 'deep' and 'social' self, which may create difficulties for the survivor. These arise as a result of death salience and awareness of the discrepancies between the 'ideal' self, the 'ought' self, and the 'actual' self.

It is through the clarification of these positions that the authors are able to situate the complexity of observer-participant relationships in which there may be competing discourses, or discourses at odds with each other, as the survivor changes. In the transition from illness to recovery, that is, from the first to the second discourse, a number of clashes can arise. There may be different feelings about an unusual openness that had occurred during the illness that now feels difficult or inappropriate to one person, the carer may now feel they want to focus their attention on their own needs, or there may be differences in the post-illness need for a return to 'normality'.

This is a well-written, carefully structured, paper that uses the data creatively to identify the different and competing discourses in the *mortal extreme experience* of cancer. It presents an interesting discussion of the ambiguities of the emotion of hope expressed through the discourse of both the 'participant' and the family members 'observing' the experience of a life-threatening illness, in this case, cancer. It identifies that the mobility of hope determines a variety of discourses and that there may be a clash, both within an individual and between the person with cancer and their family and friends, in quite serious ways. This paper offers researchers a useful basis for exploring the narratives of hope in illnesses other than cancer, and it also provides helpful insight into the complexity of feelings in relation to hope that surround cancer patients and their families, during their illness, and as they move closer to or further away from the probability of death. It also provides researchers with useful methodological insights, including into research relationships.

Mason, C. (2002) (Ed.) *Journeys into palliative care: Roots and reflections*. London: Jessica Kingsley.

'Status 'of Editor	Social Work Manager, St Joseph's Hospice.
Nationality	UK
Type of Editor/Authors	Professional: Researchers, Academics and Practitioner
Study/Text	Auto/biographical accounts of end of life
Type of text	Personal experience: Autobiography b. Biography
Type of study	Case study
Whose perspective	Health Care practitioner
Intended audience	Academic and Practitioner
Keywords	Culture; Dying; Ethnicity; Health and Social care practitioners; Reflection; Reflexivity; Technology; Writing;

This edited book was written in the context of the approaching centenary of St Joseph's Hospice, London. Whilst there is a brief discussion on the nature of palliative care, the main emphasis is on the narrative accounts of how the practitioners came to be involved in working in palliative care settings, and a reflection on what influenced them to do so. The starting point for all narratives were three questions: 'What are the roots of your interest in palliative care?', 'What route did you take into the discipline?', and 'What has been the effect of your particular journey on the work you do with the dying and grieving?' The reflections are located in theoretical and disciplinary frameworks chosen by the 9 contributors, with the Editor book-ending the text with a reflection and an overview of the basic emerging themes.

Christina Mason in *Basic themes* (pp. 15-31) introduces the book with an exploration of these themes. The question of communication and its importance in healing is highlighted, and the issues of role modelling in medical education and the impact of high technology on communication explored. The UK-based General Medical Council's major amendments to the medical curriculum as an attempt to ameliorate the communication difficulties are discussed, including the introduction of medical humanities whose perspective is to enable students to understand the perspective of patients, connect with them through their shared humanity, and examine motivations underlying professional practice. Reflective practice is explored and the role of the development of awareness and insight foregrounded. The myth of Chiron is used to elaborate the role of the 'wounded healer', the use of self through listening, sharing our humanity, living with uncertainty and mystery, the power of love, and the power of stories.

Louis Heyse-Moore in *Medicine and Palliative Care: The bronze serpent* (pp. 32-50) offers a range of personal musings on different patients he has encountered in his palliative medical practice, and their relationship to aspects of his own life. He raises questions about medical training and its place in the development of it as the objective, logical conqueror of death, and in wondering about why and how some patients enter a remission and others do not, he identifies the paradox of having expertise and knowing little.

Julie Franklin in *Early challenges in palliative care from a social work perspective: The gift of serendipity* (pp. 51-61) situates her own experience alongside the development of hospice and specialist palliative care social work, and to social policy and wider social movements. Her personal reflections consider the impact of training, working with the dying, but also the serendipity of life's events and the opportunities that arise as a result.

Robin Trewartha in *On becoming a practitioner: The view of a psychologist* (pp. 62-79) describes his journey relating this to his work with people who have experienced major loss, including asylum seekers, and with people who are dying. He draws on the 'driver' idea of Transactional Analysis, and identifies the ways in which personal discovery and reflection on these aspects have been brought to bear on his work with people.

Gillie Bolton in *Explorations in creative writing: I re-charge myself from experience* (pp. 80-98) tells of the value of listening to our own stories, how stories of how others telling stories can help, and the story of herself as someone helping others tell their story through writing. Bolton emphasises that reflective practice writing is reflection enabled through the process of writing, rather than reflection documented in writing.

David Oliviere in *Learning in palliative care: Stories from and for my journey* (pp 99-118) offers insight into how culture and ethnicity can be sources of loss of place and identity, and how the loss of a pet can have importance and meaning. The place of these experiences in informing his work with children who have been bereaved are explored, and excellent examples provide insight into this challenging work..

Lois Pollock in *Accompanying the dying: The spiritual perspective* (pp. 119-134) considers the transitions in her life to reflect on spirituality and its impact on her work, in the UK and overseas, with marginalised people, with the bereaved and accompanying those who are dying. In describing her work with Graham, Pollock identifies a number of existential questions that challenge people who are dying, as well as those who care for them. She elaborates the 'right' of the dying to a sense of hopefulness, and to purpose in life.

Gordon Riches in *The loss of children: Thinking the unthinkable* (pp.135-153) offers both a personal and a sociological reflection, and – more than other contributions – explicitly raises a number of questions for researchers, about the place of their own biography and how this is managed. He provides an interesting reflection on the relationship between his own story, the story of others, and the story of the dead, especially deceased children, and their continuing influence on the lives of their relatives. Riches urges us to listen to the stories of bereaved people to help us recognise the fragility, and preciousness, of life.

Christina Mason in *Reflections on my roots and personal journey* (pp.154-164) describes her own roots and routes into palliative care, and how the influence of illness, politics, spirituality, and education have informed her work. In particular, she describes the loss of her daughter and, although not without criticism,

identifies the benefit that psychoanalytic psychotherapy brought to her.

Kevin Yates in The nursing perspective: Pain is the breaking of the shell that encases your understanding (pp. 165-175) is a moving reflection on his own bereavement experience and how it influenced his work. His insights are themselves encased in a light humour that seems to situate them all the more in their poignant reality. His description of his own loss of a much loved older brother and his journey through bereavement are written with clarity, and he makes important links between this, his professional practice and professional practice in general to negate the statement ‘there is nothing more we can do....’

Finally, *Christina Mason in Overview (pp. 176-181)* draws together the four common themes that underpin the contributions as: the outsider; the wounded healer; the use of the self; and working with the dying, and invites the reader to reflect on their own personal and professional story by providing a number of follow-up questions for personal or group use.

This book is valuable as a text in its own right and useful as background as a source of data for researchers interested in the narrative of professionals in palliative care [see O’Brien and Clark (2006) in this Bibliography for a critique on the ethics of this]. Whilst the style of each narrative differs, they offer insight into different aspects or dimensions of the relationship of professionals to patient experience, as well as their experience of patient experience. Taken together, they represent a body of experience influenced by suffering and provide insight into its place in influencing decisions about practitioners’ life and work. How the distress of the work is managed and integrated offers researchers some insight into ways that might be helpful to them, as researchers, in palliative care and end-of-life issues.

Maxwell, T. L., Passow, E. S., Plumb, J. and Sifri, M. D. (2002) Experience with hospice: Reflections from third-year medical students. *Journal of Palliative Medicine*, 5, 5, 721-727.

Status of author (s)	Academic practitioners in a University Department of Family Medicine
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Usefulness and impact for health care practice development and service improvement Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Grounded theory
Whose perspective	Health practitioners
Intended audience	Academics and Practitioners
Keywords	Bio-medicine; Dying; Hope; Hospice care; Medical education; Patient-doctor relationships; Reflection; Standpoints/Positions; Technology;

This paper describes a study based on the reflections of third-year medical students following their hospice placement experience. Maxwell et al., contextualise the hospice visits for 3rd year medical students with an increasing interest in palliative care, and an emphasis on experiential education. As part of a 6-week rotation in the Department of Family Medicine, medical students spend 1 week visiting community venues during which they spend a day accompanying a hospice nurse on home hospice visits. Prior to this option, a lecture and a discussion on the concept of a good death for the patient, family and physician is provided. Following the visit, students write a reflective assignment on an aspect of their community experience. Half of every block (10-12) of students write about their hospice experience. Forty-nine reflection papers, of between 1-2 mostly single-sides, were examined. A thematic analysis of content using a constant comparative method was used.

Students, who had had little experience of death and dying, expressed initial apprehension at the forthcoming visit to what they thought was 'a place' for the dying. They anticipated that it would be depressing, and were surprised by the normality of the lives of patients.

Seven themes were identified:

1. *The value of hospice and the support role of the hospice nurse/team*, including an awareness that patients had not 'given up', but had been empowered to actively chose the option of dying at home,. They understood that the supportive work of the hospice nurse was psychosocial as well as physical, and they identified the excellent communication skills that the nurse displayed. They also viewed the work as inspiring and rewarding, rather than depressing;
2. *Value of empathy*. The visit presented some students with a challenge to their previously held view of a patient-doctor relationship as best devoid of emotion. They were able to witness the importance of showing emotion and listening, and how seeing individuals in the context of their own home contrasted with seeing patients in the clinic;
3. *The distinction between acceptance and resignation*. During the visit, students were able to revise their understanding of these positions by seeing how people had chosen to opt for a quality of life, rather than a life prolonged at the cost of comfort;
4. *The changing face of hope*. They identified how this can reflect a present position, rather than a future (im)possibility, assisted by hospice care that is not equivalent to doing nothing, but which enables patients to reflect on life;
5. *An understanding of death as a natural event*. This included the realisation that dying people were not different from themselves, they were still able to be active in their own life, and that accepting and embracing death, as a part of life, has value;
6. *The quality of family caregiving in the home*. The home visits expanded the students perceptions of their role in caring for all members of the family, by giving them insight into the emotions and family dynamics away from the clinical setting, as well as some of the difficulties that caring for the very ill and dying presented;
7. *Role of the physician in the care of the dying*. The hospice home visit helped them to consider their responsibilities, by expanding their view of this role to include communicating with the family and offering their presence, as well as symptom management and active treatment. It also helped

them to understand the limits of aggressive treatments.

The authors were unable to conclude on the value of the visit itself, as those who did not find it valuable may have written their assignment on another type of community visit. Nevertheless they were able to reflect on the value of the assignment as providing insights into how students viewed this aspect of their rotation, which included a deeper understanding of dying as a natural process, that professionalism does not depend on detachment, and their responsibility as a physician – in the face of potentially limiting value of technology - in supporting patients needs and priorities. They argue that hospice experience could be incorporated into many programmes, in order to offer a perspective on the familial and socio-cultural dynamics in health and health care, and to serve as a balance to the prevailing focus on aggressive treatment. Lastly, they argue that reflection, rather than didactic pedagogy, may be crucial to training related to death and dying.

This paper provides researchers with insight into a useful methodology – that of using naturally occurring reflective narratives – as well as the value of this reflection on medical education programmes.

McPherson, G. and Thorne, S. (2006) Exploiting exceptions to enhance interpretive qualitative health research: Insights from a study of cancer communication. *International Journal of Qualitative Methods*, 5, 2, 1-11.

Status of author (s)	Academic practitioner/Professor in a University School of Nursing
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Usefulness and impact for health care practice development and service improvement Using narratives analysed with qualitative methods: Illness experience
Type of text	Theoretical: Research methods
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics
Keywords	Cancer; Evidence-based practice; Exceptions; Hope; Outliers; Theoretical sampling; Truth;

Through the example of a cancer communication qualitative research project, this theoretical paper focuses on the dynamic concept of ‘exception’ – labelled in quantitative research methodology as ‘outliers’ - and its value in prompting new conceptualisations and uncovering assumptions. McPherson and Thorne draw on Miles and Huberman’s (1994: 269) definition of outliers as ‘discrepant cases, atypical settings, unique treatment or unusual events’, and their central argument is that analytic capacity is deepened, and the credibility and utility of the research intensified, by paying attention to the contrary variations within data rather than glossing over them. This is particularly relevant in the study of clinical settings where

negative or exceptional cases enhance insight into their complexity.

McPherson and Thorne begin by exploring the concept of exceptions, or outliers, identifying first how these are managed in quantitative research. Here they are eliminated from analysis because they might have a significant influence on what is otherwise known about the phenomena as unlikely to be correct. Furthermore, rather than simply discard the outlier, questions such as whether this arises from a mistake in measuring or recording are asked of each instance. They then suggest three reasons why the problem of exception has received less scrutiny in qualitative research. Firstly, they argue that the study of the social is less governed by the laws and principles of the material, and secondly, that exceptions can be written out of the data set by interpretive manoeuvres. The third reason, to which they give most attention, is the misconception that the researcher has unilateral privilege as an 'interpretive instrument' on what constitutes meaningful and relevant data. This lack of scrutiny has meant that what is 'seen' by a researcher from a particular perspective has not been subject to analysis. McPherson and Thorne then briefly describe their qualitative cancer communication study, designed to search for deeper principles that will offer guidance to cancer care practitioners. Their analysis was organised around three themes in each of which occurred exceptional observations: the sense of 'being known'; discourses associated with numbers (statistical representations and numerical information) linked to the subjective experiences such as hope; and outcomes of communication, understood as benefit or harm.

In the first theme, human connection seemed a central ingredient. However, exceptions to wanting to be known – those for whom technical engagement is most reassuring, for whom human touch and emotion is disconcerting, and for whom being known is less important than the technical business of knowing – led them to consider 'being known' in a different way that asked questions about, and incorporated, gender, culture, age, and prior life experience in authoritative relationships and health care settings. In the second theme, the 'self-evident' findings of the value of access to information were challenged by the exception of those for whom information can be too much (too detailed, intense, or overwhelming). They argue that, as a primary discourse, information cannot be distinguished from hope-building, and too much information may generate despair. Whilst not having a solution to the problem this presents health practitioners, upon whom the onus of detecting signs of this difference in their patients rests, McPherson and Thorne suggest it challenges researchers not to foreclose on their analysis or thematic understandings prematurely. In the third theme, they explore, through the presence of exceptions, the problem of the competing conceptualisations of outcomes. Positive attitudes are considered sufficiently potent to play a critical role in cancer care outcome. However, alignment with ideas of responsibility for illness and recovery is experienced by some as demeaning and patronising [see an example of this in Kingson (2005) in this Bibliography].

McPherson and Thorne then turn their attention to the insights to be gained from exceptions. They argue that exceptions are important in making a contribution to the discernment of what is knowable about a phenomenon, thereby enabling a rich and complex portrayal of it. This is enhanced by the attention to, and interrogation of, exceptional observations. They explore and critique the assumptions within which

qualitative researchers enter their studies, including the perspective taken, the questions asked, the purpose and worth within the theoretical structure of an applied health care orientation. In the case of their own study, they identify the assumption of possible discernible truths 'out there' and upon which patterns and themes shed light, and that aspects of communication have importance for the well-being of cancer patients. The assumptive framework was derived from an existing evidence base, and serves to shape what will be encountered. They argue that the value of searching for, and using, exceptions contributes to strengthening qualitatively derived inquiries, and the failure to attend to these will have untoward consequences, particularly in generating comprehensive conceptualisations from oversimplified interpretations that exclude greater understanding.

McPherson and Thorne pay particular attention to the impact of disregarding diversities. They discuss methodological decisions of sampling as the means of addressing the way assumptions may shape these, and raise a number of challenges, including: the oversimplification of the invocation of 'data saturation' arising in the search for evidence of universal, rather than diverse, human experience; the reliance on published reports utilising small samples, and offering 'thin' thematic descriptions; and the increasing justification for the use of small sample sizes by a reliance on the explicit numeric suggestions found in the research literature taken out of the methodological context in which they were intended. They argue that a smaller sample size in their own study of 200 would have excluded unusual observations and led to a less sophisticated analysis and less 'truthful' findings. In reflecting on their study, they confirm the value of sampling diversity in order to generate and exploit exceptions that contribute to understanding complexity - an issue that they consider particularly important in researching within the health care setting.

In 'befriending our outliers', McPherson and Thorpe highlight the importance of the health care setting as this is where the discourse around the role of qualitative research and evidence based practice - with the inherent tensions between universals and particulars - is manifest. They identify that there are implications for both exceptional individuals and instances if the universal commonalities were elevated to 'truth'. This perspective is unavailable to quantitative researchers who - in trying to understand the whole - use what McPherson and Thorne describe as constructed categories of meaning, numeric representation of complex phenomena, and artificial population groups. They contend that these instruments reduce, fragment and sterilise human health relating from the context in which it occurs. What attention to exceptions creates, they argue, is not a competing reality, but one in which the acceptable contexts and conditions of evidence-base practice - as a majority opinion - becomes understood. They draw on Sandelowski (2004) who argues that qualitative health research is making contributions to the notion of evidence in a number of ways, including to its original intention of transferring knowledge to individual cases, and it is in this capacity that qualitative research creates opportunities for challenging assumptions and interpretations in order to extend understanding, and tests the degree to which findings make a meaningful contribution to evidence-based practice.

In conclusion, McPherson and Thorne see exceptional observation as contributing to the quality of

qualitative research as a complementary genre to quantitative studies in evidence-based practice. They suggest that they provide a 'heuristic' device to challenge theory and assumptions, and oversimplified conclusions. As a result, they advocate vigorous application of theoretical sampling that accounts for the variation inherent in the phenomena, and presentation of findings that attend to subtlety, variation, and depth. They also argue for analysis that seeks to conceptualise complexity within an organising structure. Such studies provide nuanced, subtle, and complex evidence and, in this capacity, provide a humanising force within the dominant ideology.

This paper provides researchers with a line of argument for the value of qualitative studies in health care settings, accentuating the contribution of these to evidence-based practice. That this value is predicated on paying particular attention to exceptional observations - only possible through adequate theoretical sampling - is a reminder to researchers of their responsibilities.

McPherson, C. J., Wilson, K. G. and Murray, M. A. (2007) Feeling like a burden: Exploring the perspectives of patients at the end of life. *Social Science and Medicine*, 64, 417-427.

Status of author (s)	University Research Department and School of Nursing, and a Hospital Rehabilitation Unit.
Nationality	Canada
Type of Author (s)	Professional: Researcher/Academic and Practitioner
Study/Text	Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Phenomenology
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Burden; Cancer; Coping; Decision-making; Equity; Hastened death; Hope; Interpretive Phenomenological Analysis; Physician-assisted suicide; Self;

This study, situated in social psychology theory, explores the perception of being a burden on others, termed a 'self-perceived burden', at the end-of-life. McPherson et al., identified that less attention has been given to the care recipients sense of being a burden on others, although they identify a number of studies in which there is evidence that this is an important problem. They cite a number of studies in which self-perceived burden appears to influence treatment and end-of-life decisions, including euthanasia and physician-assisted suicide. Their sample included 15 patients (10 women and 5 men), aged between 42 and 78 years with advanced cancer, who had expressed feelings of being a burden during the course of their clinical care. With one exception, all patients lived at home with different levels of dependence. Patients were interviewed for approximately 1 hour at home, and these were tape-recorded and transcribed. Data were analysed using the process of Interpretive Phenomenological Analysis described by Smith (1996) and Smith et al., (1999).

Three categories emerged within which there were a number of sub-categories:

1. *Concern for others*: This included 5 sub-themes of specific burdens that participants felt were imposed on others:
 - *Physical burdens*, arising from the attention carers paid to the participant's physical needs, such as managing household tasks, assistance with daily living, different levels of personal care, meeting appointments, help with eating, and managing medication. This aspect was experienced as particularly difficult if, in the case of a female participant, it was undertaken by a man;
 - *Social burdens*. The self-perceived burden was situated in the context of the carer's other responsibilities, for example, for child-care or work, and of the financial burden that may be imposed if leave from work had to be taken. It was also taken in the context of the restriction on the carer's social activities, and the potential impact on their marital relationships;
 - *Emotional burdens* arose from a complex mix of empathy for the carer, anxiety about adding to their burden, and worry about the impact of their illness and death on the carer and wider family;
 - *Future concerns*. The uncertainty of the future – itself a worry for both parties – created anxiety about the possibility of the increasing strain on carers, or their additional responsibility for decision-making;
 - *Aftermath* included worries about the effect of their death on the carer and wider family.
2. *Implications for self*. This included three sub-themes:
 - *Emotions*, including guilt and regret at the hardship others endured on their behalf, sadness at being the cause of hardship, and frustration and anger with themselves for being unable to do more. Sadness and mourning were also experienced for the loss others would experience on their death;
 - *Self-blame* for developing cancer and for being accountable for the hardship of others;
 - *Self-concept*, including the many changes and a sense of failure and disappointment, occurring as a result of the loss of control, independence, and their future social roles.
3. *Minimizing burden*. To minimise their sense of being a burden, participants used a variety of strategies:
 - *Alleviating burden to others*. Attempts to minimise the effects of their illness included a number of *problem-focussed* strategies, including:
 - *Being active in their care*, through developing new routines, taking a load off their carer, and making a meaningful contribution to their relationships;
 - *Concealing need*, by foregoing their own needs to protect their carer from distress, and trying to do as much as they could for themselves;
 - *Managing the needs of others*, including talking about feelings and offering reassurance through discussion on issues, including the impending death and its consequences;
 - *Making preparations* by talking about decisions, putting plans in place, and having contingency plans made;
 - *Desire for death*, including through considering hastening their own death to relieve the

burden.

- *Reducing perceptions of burden to self* involved a number of *emotion focussed* strategies, including:
 - *Cognitive avoidance*, which involved avoiding thinking about the burden they were placing on others;
 - *Resigned acceptance*. Reconciling their own needs and their culpability for creating hardships on others was difficult and, in the absence of choice, was a position to which they made gradual acceptance;
 - *Positive outlook*, emphasising aspects such as strengthening their relationship, and feelings for one another;
 - *Entitlement*. A sense of entitlement arising from reciprocity, based on past care to caregivers, diminished a sense of burden.

In their discussion, McPherson et al., emphasise the inter-relatedness of the two major categories, and the evocation of distressing emotions that affected the participants' sense of self-worth and psychological well-being. The role of feelings of dependence and an increasing incapacity to meet obligations resulted in feelings of loss or failure, and a disruption of self-concept (Charmaz, 1983). The alleviation of this was helped by a number of coping strategies, and the authors locate this in the *equity theory* of Walster et al., (1973; 1978), in which individuals strive to maintain equity in social relations between benefits and contributions. Individuals with advanced disease may be less able to restore an inequity balance through reciprocity and, as a result, resort to other means such as an unwillingness to ask for help. Psychological equity (Hatfield and Sprecher, 1983) requires a reframing of the perceptions about a situation.

In their conclusion, McPherson et al., argue that the definition of 'self-perceived burden' (Cousineau, et al., 2003) upon which they have drawn should be expanded to encapsulate the emotions and effects of terminal illness on this perception. They also suggest modifying it to accommodate the idea that dependency is not necessarily a factor contributing to self-perceived burden. In acknowledging the limitations of the study, they argue for further research across different care-giving dyads. They also indicate the relevance for health practitioners of attuning to the expression of burden in their patients.

This qualitative study provides researchers with an example of how narrative research can shed light on less accessible meanings of an event. It is also an example of a study that situates the findings within a broader theoretical framework, and the value of doing this. Finally, it makes explicit recommendations for the improvement of practice.

Mishler, E. G. (2005) Patient stories, narratives of resistance and ethics of humane care: A la recherche du temps perdu. *Health 9, 4, 431-451.*

Status of author (s)	Professor of Social Psychology in the Department of Psychiatry, Harvard Medical School
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory Usefulness and impact for health care practice development and service improvement
Type of text	Theoretical: Research methods
Type of study	Discussion paper
Whose perspective	Researchers
Intended audience	Academics and Practitioners
Keywords	Emplotment; Ethics; Health care policy; Health practitioners; Medical education; Patient-practitioner communication; Resistance; Social inequality;

The paper focuses on what Mishler considers to be a lack of connection, in both practice and research, between two ethical dimensions: an approach grounded in the *humane care ethic*, and the *ethic of social justice*, concerned with inequalities and access to health care. Its purpose is to generate discussion between patients, practitioners, educators and researchers about practice, research, and ethical standpoints.

Mishler begins with a story of patient resistance that serves to exemplify three features. The first concerns the tensions in the power relations between professional groups, and between patients and practitioners, that arises from a refusal to accept practitioners efforts. The second feature concerns the way in which patient action – as constituting an account of ‘who’ a person is – enters the stories folklore of family and friends. The third feature concerns the way in which this resistance is characterised as ‘non-compliance’ in the practitioner literature, which Mishler argues, excludes the context in which a refusal of treatment takes place. Mishler had argued elsewhere (2004) that there is a disconnection, arising as a result of a lack of attention by practitioners between the macro-ethics of social justice (the impact of social inequality on health and access to care) and the micro-ethics of the interpersonal action of humane care. His remaining puzzlement, at the narrow framing of humane care that excluded reference to the impact of inequality and its effects on patient vulnerability from studies of the clinical relationship, provides the impetus for this discussion. He then draws on Stone-Mediatore (2003) to ask questions about the role of a ‘*marginal experience*’ narrative of resistance in destabilising ‘ossified truths’ and on what might be learnt by situating patient stories in this category, and about the impact of humane care on theoretical development, and on an ethic of social justice.

Mishler begins his discussion with a brief history of the recent growth in interest amongst practitioners,

researchers, and educators in patient stories. One solution to the problem of patient dissatisfaction with what is experienced as dehumanised care and often expressed in these stories, includes a return to more humane care in which health practitioners would listen to patients. This moral imperative resulted in changes in medical education and clinical research which attends to features of patient-practitioner communication. Whilst Mishler acknowledges that this was productive, it focussed on individual interactions, and failed to contextualise the ethic of humane care with the wider health care system and the structural sources of inequality. The notion of 'humane care' also has a recent history as a theme in medical education and clinical practice. Mishler's (1984) early work on the discourse of medicine identified how physicians controlled the flow of the clinical interview, and concluded with his encouragement to investigators to 'interrupt the voice of medicine' by withholding their reliance on the assumptions and practice of medicine through which to develop their categories. He argues that this was critical for the development of humane care, and in turn health care would require physicians to listen to the stories of patients' illness and their lifeworld meaning. But it is this recommendation that Mishler feels has gained less attention. Mishler chose his opening story of non-compliance as it exemplifies an interruption of the medical voice, in which support from other practitioners as well as family and friends - communicated through ordinary, everyday, language - enabled the patient to maintain her marginal resistance. It is in recognising this function, Mishler argues, that a deeper conception of the ethic of humane care may be understood. Mishler then turns his attention to the issue of suppressing narratives of resistance. He situates this discussion in questions about the sociocultural construction that defines what can appropriately be brought to encounters (the rules), and about which events belong in the category of humane care and which do not. In particular, he identifies Waitzkin's (1991) micropolitics of medical encounters as the mechanism for suppression that keep experiences of social inequality out of the clinical encounter. The power relations between patients and doctors (generating patients fears of being abandoned or harmed) mean that resistance finds outlets in Scott's (1990) protective practice of 'hidden transcripts', rather than in displays of opposition. It is to these discourses that Mishler urges researchers and educators to look.

Mishler then suggests that including this category as significant in studies of patient-practitioner communication are important ways in which narratives of resistance can be recovered, and he argues for a wider conceptualisation of humane care that takes account of people's experiences of resistance to their social circumstances. He presents some examples that show attempts by individuals to recontextualise, reconstitute, and repair their body, self, and world, but notes that not all the examples make specific recommendations for clinical practice. He presents examples of more recent attempts to engage critically with patient stories, including Charon's (1998) invitation to medical students to keep parallel charts on their patients, and Mattingley's (1998) story of 'narrative emplotment' in which an occupational therapist and a Spinal Cord Injury patient negotiate a 'hopeful therapeutic plot'.

Finally, Mishler considers what he and his colleague have termed 'solidarity work' (Mishler and Steinitz, 2001), that describes an alliance between researchers and respondents, which enables a collaboration on studies that would contribute to shared political aims. He identifies the paradox that this alliance is

problematic because the relationship with persons is already pre-structured by, and beholden to, the medical system who grant access to the socially constructed category of 'patient'. One solution, Mishler suggests, is to reformulate topics by expanding the focus from the diagnostic interview or illness episode to a fuller investigation, tracked over time, of the person's illness and treatment experience, including the many types of health care practice, and to enable patient and practitioner viewpoints to stand side-by-side.

This is an interesting paper that has important implications for researchers. It challenges researchers to contribute to the interruption of the medical voice, and to situate their research in the wider concept of humane care that takes account of the sociocultural contexts within which the stories are narrated, and to which they give insight.

Moss, B., Parr, S., Byng, S. and Petheram, B. (2004) "Pick me up and not a down down, up up": How are the identities of people with aphasia represented in aphasia, stroke and disability websites? *Disability and Society*, 19, 7, 753-768.

Status of author (s)	Academics: University-based Researchers, now working freelance, and Practitioner based in a Communication Disability Charity
Nationality	UK
Type of Author (s)	Researcher/Academic and Practitioner
Study/Text	Using narratives analysed with qualitative methods: Illness experience
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Aphasia; Ethics; Identity; Internet; Stroke; Workshops;

This paper describes the issues pertaining to identity and narrative. It forms part of a wider 2-year study that explored how people with aphasia use the Internet to access information, and the representations of identity within Internet-based technologies. In their Introduction, Moss et al., identify aphasia as a largely invisible disorder that can affect any or all of the modalities of language and communication impairment. It arises as a result of a stroke or head injury and, despite spontaneous improvement or improvement as a result of speech therapy, it can present long-term impairment of either or both processing and production of messages. As a result, it can be profoundly isolating and disabling, and requires the support of methods such as *total communication*, which involves the use of many forms of visual, verbal- and non-verbal methods that ensures communication is well-paced, streamlined and verified, and involves combining speech with drawing, gesture, writing.

Thirteen people with aphasia, comprising 6 men and 7 women, aged between 25 and 76 years, whose onset of aphasia varied from between 20 months and 10 years, were recruited through the Communication

Disability Network (Connect). The degree of the severity of impairment, and their familiarity with, and use of, the Internet varied. Accessibility to all aspects of the project was considered, and included a number of strategies, for example, some participants were paid as co-researchers and undertook a number of roles such as interviewing candidates for the research post, and joining the advisory group. To ensure access to communication support, participants met in 3 small groups for approximately 90 minutes, once a week for a period of 30 weeks. The sessions were divided into two parts, and to support full participation, the researchers used *total communication*. The first part of the session, in which comments and insights were audio-taped, involved a collective group activity facilitated by a researcher. Using a laptop with a screen projected onto the wall, each group gave directions as they surfed the web and negotiated specific websites. In the second part, participants continued, individually or in pairs, to explore websites. Detailed fieldnotes were kept of the methods, routes, and strategies used, and the difficulties experienced. Whilst many sites were explored, the main focus was on 9 aphasia, stroke and disability sites, 7 of which were UK-based, and the remaining 2 were Australia- and US-based. These sites offered a variety of avenues for contact, including personal accounts, chat forum, message boards/penpals and guest books.

Three dimensions of presentations of identity in aphasia-related websites were explored.

1. *The tone, content, and narrative voices of the websites*

The participants identified a number of issues, including that some websites were written *about* aphasia for family members or health practitioners, rather than *for* those with aphasia; they felt alienated by some sites that used medical jargon or other inaccessible language presented in an impenetrable way, or recommended telephone or text contact. They also became fatigued by protracted searching through poorly designed sites. Furthermore, some disability sites appeared to be targeted at young people with motor impairments, and included aspirational language, such as striving for recovery and battling adversity, with which they did not always concur.

2. *Individual narratives and group members' reactions*

Participants found that individual accounts on charitable websites appeared to mirror the organisational narrative. They were dense, lengthy and complex, leaving participants wondering if they had been ghost written or tidied up. The organisational themes were also detected in many of the personal accounts, but participants also recognised the experiences related in the accounts of poor treatment and a lack of awareness. They were also encouraged by these accounts, whilst feeling that the contextual reality of the impact of aphasia, and how these were adapted to or overcome, was not always told.

3. *Constructions of personal narratives by participants with aphasia*

This began two-thirds of the way through the project, and raised a number of issues for participants, including the difficulties in writing honestly when there was family tension and disharmony; or fear that their now very isolated life would make monotonous reading. Motivation for what their webpage contained varied, with some wanting to pass on wisdom and offer support, and others to write more personal accounts of their story. The design also varied, containing written and visual forms, and some, but not all, elected to construct their pages without editing. In the study, the visibility of the 'voice' of those with aphasia is a central theme, and the paradox - of working with

the participants to create a webpage that expressed their own authentic account, and in which the production was controlled by them, but that ends up with no tangible evidence that there is a communication impairment – is highlighted. The authors' identify the resulting replication of the previously criticised stylistic traits of sites.

In their discussion, Moss et al., reiterate the issues related to self-expression, but also give further consideration to the ethical and practical issues involved in ensuring the implications of writing a webpage were transparent to the participants. They also discuss the different realities of communicating visually face-to-face, compared to linguistically through the 'levelling ground' of the Internet - a medium that appears to offer a sense of privacy and safety. Nevertheless, Moss et al., argue that the Internet can have wider ramifications for those with aphasia, where a largely invisible communication impairment is made more visible through this medium but, at the same time, this invisibility makes it difficult, as a result of conventions and unspoken rules of the Internet, to conceive of a rightful place for them on it.

The paper concludes with a more positive view of the value of narrative on the Internet as a way of expressing identity, and Moss et al., were seeking further funding to allow them and their co-researches to develop more visual and non-text based techniques to inform service users, providers and stakeholders about the work of Connect.

The study is of value to researchers in a number of ways. It adopts an interesting methodology that is concerned with both the narratives of the participants and the narrative accounts on the Internet and links to O'Brien and Clark (2006) in this Bibliography.. The study also gives insight into the sensitive nature of some research, and it is a reminder of the necessary arrangements that need to be in place to minimise the threat to research participants (Lee, 1993), and to make research accessible to, and inclusive of, participants. One outcome of the study was the development, based on participants' recommendations, of a collaboratively designed website *Aphasiahelp* (www.aphasiahelp.org), and this stands as a powerful reminder to researchers of the emancipatory, and ethical, nature of research.

Myers, G. E. (2002) Can illness narratives contribute to the delay of hospice admission? *American Journal of Hospice and Palliative Care*, 19, 5, 325-330.

Status of author (s)	Academic University School of Medicine
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Usefulness and impact for health care practice development and service improvement
Type of text	Research: Secondary
Type of study	Discussion paper
Whose perspective	Patients and Health practitioners
Intended audience	Practitioners
Keywords	Culture; Decision-making; Dying; Frank; Health care policy; Hope; Insurance; Medical education; Quality of life; Typology of narratives;

Drawing on a number of studies, this paper focuses on the critical factors of cultural interpretations of illness, mediated through illness narratives, in understanding delays in hospice admission.

In the introduction, Myers sets out the problem of how difficult it is to correlate specific illness narratives with specific effects, arguing that it is not necessarily the conscious, but rather the sub-conscious, narrative of speech that might be most active. He suggests that rather than helping to create meaning and ameliorate chaos and distress by reconnecting personal experience to personal story, some illness narratives increase the chaos and fragmentation of life that can accompany terminal illness. This occurs because prolonging the denial of the terminality of the illness, and distorting the character of the person's future, denies access to supportive relationships.

Myers outlines a number of issues that contribute to the delays in accessing supportive end-of-life care.

1. In the US, the health Insurance company, Medicare, imposes the conditions of a prognosis of 6 months or less and that the patient will forego curative treatment, on those seeking hospice care. This shift in treatment goals may be resisted by the patient, their family, and physician until the reality of death is undeniable. However, late admissions to hospice care means there is insufficient time to establish supportive relationships;
2. Frank's (1995) *restitution* narrative – the dominant illness narrative in the US - presents two problems, Firstly, the concept of hope for a cure, implicit in this narrative, may result in a lack of information or misinformation about end-of-life care. Thus, hope for a quality of life until death, is excluded. Attempts to educate the public and health practitioners about hospice care have not changed the pervasive resistance. Secondly, the *restitution* narrative resists the notion of terminality, which contributes to delayed hospice enrolment and a miscalculation of the time left available in which to complete unfinished business. Myers argues that the desire to support or maintain hope results in physicians giving overly optimistic or vague prognoses, resulting in patients not considering themselves to be candidates for hospice care. Myers argues that this

compromises crucial end-of-life tasks, and the possibility of transforming hope for a cure to a hope for quality of life until death. For this, he suggests, the *quest* narrative, with its model of journey, would be a more fitting one to adopt.

Myers then turns his attention to the cultural resistance to alternative narratives. He draws on Janoff-Bulman and Timko's (1987) view of the positive and optimistic North American assumptive world – that in a benevolent world individuals escape negative life events; that in a just world people get what they deserve; and individuals are worthy of good things happening in their lives – to argue that the *restitution* narrative protects core assumptions. It restricts the narrative choices that includes transforming hope through a different illness narrative that calls this assumptive world into question, and is capable of acknowledging terminality and sustaining hope. He then considers an alternative- the *quest* narrative – that embraces mortality and supports a transcendent concept of hope in which the end-of-life is something to be lived. He argues that a shift in narrative from *restitution* to *quest* would enable patients to obtain the benefits of living until their dying and the acceptance supportive care, and to become meaning-makers in the face of their own death.

Myers concludes by arguing that illness narratives affect experience of illness and decision making, but also planning for the future including whether or not hospice care is accepted. The consequences of *restitution* narratives for patient, family, and physician are emphasised and he calls for further research into effective teaching methods in medical education that enable students and physicians to analyse their own assumptions, and be open to changing their operational illness narratives if these appear to be limited.

This is a useful paper for researchers. It provides interesting background in which to embed other papers [for example, Kingson (2005) and Payne (2007) in this Bibliography] and it provides an interesting insight into consequences of illness narratives and how these are culturally embedded. It makes a number of useful references to other studies, and is an example of how Frank's typology can be used in a secondary analysis of data.

O'Brien, M. and Clark, D. (2006) Online narratives about living with motor neurone disease: A quantitative analysis. *British Journal of Neuroscience Nursing*, 2, 8, 410-414.

Status of author (s)	Academics: University College Research Fellow and a Professor of Sociology, CECo, Lancaster University
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Study of the phenomena of narrative
Type of text	Research: Primary
Type of study	Descriptive statistics
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Ethics; Internet; Motor Neurone disease;

The study explores methods and procedures for retrieving Internet-based illness narratives of people with Motor Neurone disease (MND), and it identifies the characteristics of those who share their narratives. It provides a brief introduction to the function and importance of illness narratives and how they can be obtained, before exploring electronic narratives of illness. Sixty-four sites were eventually identified, with narratives ranging from a single page to 45 chapters detailing a 2-month period of a man's experience from diagnosis to his death. At the start of the study, information available within the public domain at the time of data collection was identified through a scoping exercise. Initial searches, made through Internet search engines and MND association information sites, revealed a large volume of sites of which many were not relevant. As a result, a four-stage process of assessment was initiated. A more focussed 'snowballing' approach within a limited number of websites provided links to 1363 personal websites, MND chat rooms, and newsgroups. Subsequently, 988 sites were eliminated as either duplicates or inappropriate to the study, 278 as inaccessible, and 33 as not meeting the inclusion criteria. The remaining 64 were downloaded and archived. A content analysis of the author's demographic details was undertaken.

Within the posted narratives, 73% were written by men, who are both more susceptible to MND and who produce more illness narratives than women. Narratives from the US and Canada represented 77% of postings, compared to 15% from Australia and New Zealand, and 8% in Europe. This may be accounted for by limiting the search to English-speaking sites or to those with English translation. Of those that gave details of their occupation, 20% were posted by manual or unskilled workers, 16% by members of the armed forces or emergency services, 10% by professional writers, 8% by engineers, 6% by health practitioners, 6% by business professionals, 6% by IT workers and 4% by sportsmen. The youngest author was 20 years old and the eldest was 65 years old. Fifty percent of the narratives were written by those who were aged less than 40 at the time of diagnosis, despite the peak incidence of MND as being between 50-70 years old. The narratives spanned experience from 1960 to 2005, with 57% of authors being diagnosed during the 1990s.

This is a most useful paper for several reasons. Firstly, it constitutes a useful source of information about those who write Internet-based narratives on their experience of MND, and it is useful to read alongside Moss et al., (2004) in this Bibliography. In addition, whilst the proliferation of ‘blogs’ makes this a challenging enterprise for researchers contemplating such an activity in a different field of illness, this paper provides some useful advice and guidance, including that the erratic nature of their availability means that researchers must ensure the material is secured. Ethical issues are considered and the authors identify the differences between the use of ‘unsolicited’ material from personal websites (that is, posted in the public domain and termed ‘passive analysis’) and Internet-based data collected through active intervention by the researcher. In the latter case, it is argued that informed consent should be sought. Useful information on a systematic sampling strategy is provided, and the importance of a log of activity and data management is identified. Lastly, as the authors argue, these narratives constitute a rich source of previously unavailable data from a wide cross-section of society.. They are often contemporaneous reports reflecting current feelings and, because they are un-edited, the intensity and poignancy of the writer’s words can be viewed in their raw state [see Moss et al.,(2004) in this Bibliography for further comment on this].

Payne, S. (2007) Living with advanced cancer. In M. Feuerstein (Ed.) *Handbook of Cancer Survivorship*. New York: Springer, 429-446.

Status of author (s)	Help the Hospices Chair/Professor of Palliative Care and End-of-life, CECo, Lancaster University
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Usefulness and impact for health care practice development and service improvement
Type of text	Research: Secondary
Type of study	Discussion paper
Whose perspective	Patients and carers
Intended audience	Academics and Practitioners
Keywords	Bio-medicine; Cancer; Decision-making; Health practitioners; Hope; Identity; Patient-practitioner communication; Resilience; Standpoints/ Positions; Survival;

The focus of this paper is on the unpredictable and uncertain experience of cancer survivors - those increasing number of people who live with advanced disease for some time before they die. The paper draws on accounts of cancer patients, and contextualises this experience in the theoretical and empirical literature on coping with loss, change and uncertainty, as well as in the public health agenda.

Payne begins with a review of the social and anthropological literature in which to situate living with advanced cancer, and to discuss issues of identity and social role, and the problematic simultaneous positioning of cancer patients between the world of the ‘healthy’ and the world of the ‘patient’. She then

moves the discussion to a consideration of the construction of health, illness, sickness, and disease, and identifies the paradoxical features that are present for cancer survivors, including the uncertainty and unpredictability of the cause, course, and outcome of the disease. The complex problems for those living with advanced cancer are also identified, including the uncertainty of the nature of symptoms (for example, permanent or temporary, cancer-related or 'normal'), the heightened vigilance, the feelings of loss of control over body and life, the impact of fatigue on social roles and relationships, and the change in appearance and body image. This latter is linked to cultural influences on the bodily presentation, as well as on the presentation of individual identity.

Social role and identity is then elaborated by further consideration of the psychological and sociological literature on coping with loss, change, and uncertainty. The respective approaches are outlined, before Payne discusses their relevance in the context of advanced cancer. The complexity and multiplicity of social roles have a number of implications for those living with advanced cancer, including the threat to self-esteem that an inability to maintain these may make, and/or the opportunity it provides for a reappraisal of life. The complex negotiations and interactions between patients and their family and friends, as well as between health practitioners are illuminated in two study examples, in which patterns of communication become evident. The role of comparison with others in creating the 'cancer patient' identity is also highlighted; a status which has implications for every aspect of the person's life.

Payne then turns her attention to the question of how patients cope with advanced cancer, and she situates this discussion in a broader framework of the processes of loss and change to which people with advanced cancer are subject. These may include changes in, and loss of, functional ability and the anticipation of further loss, including of life. She identifies the question - under-represented in the research literature - of what allows people to cope so well with survival, and the dimensions of personality, hope, and the reframing of goals and priorities, are considered. Payne draws on the narratives of people with the experience of living with advanced cancer, and health practitioners, to gain greater insight. She argues that patient narrative accounts provide rich details of their lives and decision-making, and express the need to make sense of the traumatic events, to create and renew constructions of themselves, and to express dimensions of the experience of hope. An example of a narrative analysis shows how the experience of illness is creatively managed by both patients and practitioners to maintain the possibility of hope. In contrast, the narratives of doctors – the most productive and dominant voice in palliative care accounts - framed patient experience in a biomedical discourse, and Payne identifies the paradoxical tension in this, between patient autonomy and choice, and psychologically-based expectations about 'right' ways to express emotion.

The last group to whom Payne gives attention are family caregivers, for whom there are important implications. Family caregivers are more likely to be within-generational, rather than inter-generational who, as well as providing daily care, are being relied upon to manage the consequences of advanced disease. Although this can be a rewarding and satisfying relationship, the role may result in reduced social and recreational activities, financial hardship, and involve problems such as stress, isolation,

exhaustion, and physical injury. The complexity of this role may not be fully understood by health care providers, and Payne identifies that there is little evidence for effectiveness of services to support families carers, for whom services may not fully engage. She ends this section with suggestions for topics for further research.

In her conclusion, Payne identifies the framing of people with advanced cancer, within the general palliative care literature, as that of 'dying' rather than 'surviving', with a tendency to identify pathology rather than the adaptation and resilience that many cancer survivors demonstrate. With an increase in interest in extending palliative care principles to all cancer patients, she argues for a review of new models of care such as those emerging in less-well resourced countries such as India.

This paper provides a useful overview of theories that have relevance to the experience of living with advanced cancer. The discussion also offers researchers a broad view of the issues involved for those living with cancer.

Pearlman, R. A., Hsu, C., Starks, H., Back, A. L., Gordon, J. R., Bharucha, A. J., Koenig, B. A. and Battin, M. P. (2005) Motivations for physician-assisted suicide. *Journal of General Internal Medicine*, 20, 3, 234-239.

Status of author (s)	Health practitioners and Academics in University Departments of Medical History and Ethics, and Health Services, Anthropology, Psychology, Psychiatry, and Centres for National Centre for Ethics in Health Care, and Biomedical Ethics.
Nationality	US
Type of Author (s)	Professional: Researcher/Academics and Practitioners
Study/Text	Usefulness and impact for health care practice development and service improvement Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Burden; Control; Dying; Fear; Hastened death; Identity; Pain; Physician-assisted suicide; Quality of life; Suffering;

This study focuses on the accounts patients gave for their pursuit of physician-assisted suicide (PAS). Readers are directed elsewhere for a more detailed account of the study, including the participant characteristics and the outcome towards hastened death (Back et al., 2002). However, they indicate here that the sample comprised 60 participants who discussed 35 cases of those considering pursuing PAS and their family members. Five investigators undertook 159 semi-structured interviews with the participants

over a period of 4 years (1997-2001). These were conducted at enrolment, and then at approximately 3 monthly intervals until the patient's death. Families of on-going and historical cases were interviewed between 2 and 4 times. Interviews were taped and fully transcribed and all transcriptions were read by all members of the research team. Analysis was undertaken using content analysis methods in which primary codes were developed to classify sections of transcripts. The checking and cross-checking of transcripts, the allocation of codes, and the resolution of coding disagreements is described. In addition, the estimate of life expectancy that had been given was assessed, and evidence for major depression sought.

The research identified 7 common influential issues within 3 inter-acting categories:

1. *Illness-related experiences*, including:
 - *Feeling weak, tired, and uncomfortable*. Symptoms or treatments had become unacceptable, interfered with functioning and quality of life, caused suffering, and were expected to get worse, resulting in the patient's identity and sense of self being undermined;
 - *Pain and/or unacceptable side-effects of pain medications*, which became unbearable, pre-occupying, or consuming;
 - *Loss of function* - to read, socialise or care for themselves - that was no longer possible to accommodate, intertwined with physical changes, acted as a marker of the transition towards death.
2. *Sense of self*, including:
 - *Loss of the sense of self* – eroded through dying, and the loss of the ability to maintain aspects of life that gave it meaning and defined an individual. Dependence and being cared for was experienced as an assault on the self and the desire for control;
 - *Desire for control*, and its loss feeling intolerable.
3. *Fears about the future*, including:
 - *Fears about the future quality of life and dying*, sometimes based on past experiences, for example, of pain associated with other conditions, but also anticipating a loss of control, functional ability, being a burden, and a loss of a sense of self;
 - *Negative past experience with dying*, of a loved person.

In their discussion, the authors identified the prolonged period of time over which patients consider a hastened death, during which benefits of living and dying are assessed. They identified that diagnosis, pain, and a lack of access or care, were not cited as motivations. Rather, the two key features appeared to be desire for control and a sense of self, and hastening death was a way to minimise the damage or stop the process of their potential loss of these through treatment or illness. Depression and hopelessness also did not feature greatly amongst participants, although the authors acknowledge that fears about the future quality of life and dying reflect a negative expectancy about the future. The existential suffering involved in dying, loss of integrity, function, and control appeared to threaten the social construction of life's meaning.

They conclude by drawing several implications from their study. Firstly, that health care providers

understand more fully the holistic illness and dying experience of their patients, and that these are assessed repeatedly in order to tailor care to the patients changing experience. Secondly, that the motivating issues, outlined in the research, form the basis for an on-going discussion with patients about their fears, and that requests for hastened death should generate evaluation of motives and an attempt to ameliorate suffering.

This is an example of a well considered and well-resourced study. It identifies a number of important themes from patient narratives that have value to researchers in other studies on suffering and desire for hastened death. It also identifies ways in which findings can be transformed into recommendations for practice.

Riessman, C. K. (1993) *Narrative analysis*, London: Sage.

Status of author (s)	Professor of Sociology and Professor of Social Work, Boston University.
Nationality	US
Type of Author (s)	Professional: Researcher
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Research methods/Narrative
Type of study	Review/Reflection
Whose perspective	Researchers
Intended audience	Academics
Keywords	Narrative analysis; Research methods; Truth;

This is an excellent, clearly written, and well-structured introductory text for anyone considering undertaking narrative analysis. Riessman is an experienced researcher and PhD Programme Director, and she has also undertaken a number of studies involving narrative analysis.

Riessman begins by identifying differences between narrative and other forms of interpretive analysis, and outlining a number of theoretical contexts that need to be considered. Her discussion ranges from identifying the decisions that need to be made about how a person's experience is represented in the five stages of the research process from what she calls '*attending to experience*', '*telling about experience*', '*transcribing experience*', '*analyzing experience*', to the final stage of '*reading experience*'. Her theoretical discussion of narrative structures and forms of narrative are elaborated and clarified through interesting and diverse examples from three research studies, each of which adopt a different analytic approach. The ways in which these different forms 'create' meaning are compared and critiqued, using three questions by which each are assessed in terms of their success.

Having presented some examples of narrative analysis, Riessman provides a brief outline of how to 'do' narrative analysis, describing how to transcribe interview data into a text for analysis. Attention is also paid to the thorny question of validity and reliability, and she identifies aspects of trustworthiness

(persuasiveness, correspondence, cohesion and pragmatic use) as appropriate alternatives. Riessman's writing style is clear and lucid. Her arguments are well-presented and the structure of the book makes the complex dimensions of narrative analysis easy to follow. It provides a good basis from which to move into a more detailed and theoretical narrative research literature.

Riessman, C. K. and Mattingley, C. (2005) Introduction: Toward a context-based ethics for social research in health. *Health*, 9, 4, 427-429.

Status of author (s)	University based academics
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory
Type of text	Theoretical: Research methods/Narrative
Type of study	Review /Reflection
Whose perspective	Researchers
Intended audience	Academics
Keywords	Bio-medicine; Ethics;

This paper is the Introduction to a Special Edition of the journal *Health*. This Edition arose as a result of a number of important questions, generated at a UK conference on narrative-based medicine, concerned with ethical issues such as informed consent, confidentiality, and who 'owns' the stories collected during research. These questions were interpreted as indicative of a medico-centric, rather than social, model of research which has had an increasing influence on health care research, but which ignores social science and feminist models that challenges inequalities between the researcher and the researched, and rests in on-going negotiation. The Special Edition was a way of addressing some of these issues.

Senior researchers were invited to contribute to the Edition, in which narrative has important place. This is for three reasons. Firstly, narrative research focuses on personal experience and is a primary vehicle for understanding this. Secondly, narrative has a particular role in studies of illness and disability as a call for exploring lived experience. Thirdly, they play a significant role in critiquing and rethinking ethics in which the uniqueness of a situation, rather than a context-free ethical framework, is taken to guide action.

Although very brief, this Introduction raises an important argument that is of value to researchers in considering the ethical aspects of narrative research. It is also an example of how interesting and challenging arguments can be situated in short, focused, essays.

Romanoff, B. D. and Thompson, B. E. (2006) Meaning construction in palliative care: The use of narrative, ritual, and the expressive arts. *American Journal of Hospice and Palliative Medicine*, 23, 4, 309-316.

Status of author (s)	Institute of Palliative Care, Sage College
Nationality	US
Type of Author (s)	Professional: Researcher/Academic
Study/Text	About narrative methodology: Theory Usefulness and impact for health care practice development and service improvement
Type of text	Theoretical: Narrative
Type of study	Discussion paper
Whose perspective	Health practitioners
Intended audience	Academics and Practitioners
Keywords	Health practitioners; Identity; Meaning; Ritual;

In this paper, Romanoff and Thompson closely link the two concepts of narrative and ritual to consider them in relation to meaning-construction in palliative care.

Their paper begins with a broad discussion on humans as meaning-makers and story-tellers, and is then situated in a palliative care context, in which the disruption created by a life-threatening diagnosis requires a revision of the assumptions that have guided experience. They draw on the increasingly widening literature that signals the importance of meaning construction, but they note the use of disparate definitions of meaning-making that has resulted in conflicting findings. They also note that, whilst some people have a world view or belief structure, not all individuals following diagnosis find positive meanings that enable them to assimilate tragic life events. In relation to illness, Romanoff and Thompson argue that meaning construction is both a process and an outcome, and to enable patients and families to construe meaning, palliative care teams need to enter a conversation free from pre-conceived ideas, including of a beneficial outcome.

Romanoff and Thompson then turn their attention to the value of narratives and stories as forms of meaning construction and as an act of healing. Their focus is particularly on narrative as a social act in which the listener becomes an integral part of story creation, and they suggest that the capacity to develop a coherent story of illness or loss that gives meaning or purpose to the narrator's life is restorative and healing. They emphasise the importance of the curious, interested, attitude of the listener in eliciting narratives, and the requirement that the listener sets aside their assumptions and experiences to attend to the meaning of experience for the narrator. This includes the use of questions that elicit examples and the deeper meaning of events, but may also include forms other than direct conversation to elicit narratives, such as the use of objects or art-based approaches.

Turning their attention to rituals, Romanoff and Thompson describe their function as serving to reaffirm

social ties, make changes in identity, generate meaning, and manage crises. In relation to serious illness, Romonoff and Thompson suggest that rituals can serve three healing functions when illness disrupts the familiar ways of being and self-understanding. These include: vehicles for transformation of meaning; creating bridges for psychosocial status transition; and affirming family and community connections. In their discussion, they expand the ritual repertoire of palliative care beyond the familiarity of practitioners with funeral and bereavement rituals, to suggest ways of facilitating informal and formal ritual activities. They also suggest ways in which the family can be helped to create a story, not only of the person who is ill, but also of their experience of this illness.

Whilst this paper is directed towards practitioners in palliative care, it is nevertheless useful for researchers. It provides an interesting, if brief review of literature, and the advice it offers palliative care practitioners in terms of the importance of creating the conditions that enable people to describe their stories, apply equally to narrative researchers. Finally, it provides a useful background to, and argument for, the value of narrative as a means of meaning-construction.

Smith, B. and Sparkes, A. C. (2005) Men, sport, spinal cord injury, and narratives of hope. *Social Science and Medicine*, 61, 1095-1105.

Status of author (s)	Exeter University-based Qualitative Research Unit,
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narrative analysis: Illness experience
Type of text	Research: Primary
Type of study	Mixed methods
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Active listening; Bio-medicine; Body; Emplotment; Fear; Frank; Hope; Men; Spinal cord injury; Suffering; Technology; Typology of narratives;

The purpose of the study is to illuminate the experience of hope definitions of disability in men who had suffered a spinal cord injury (SCI) through rugby football, and, drawing on Frank (1995), to illustrate the Western cultural narrative types that frame their narratives of hope.

Fourteen white, working class, men aged between 26 and 51 years, who had sustained their SCI between the ages 16 to 35 years, were sent an invitation to participate in the research. This included a questionnaire that sought their brief demographical details, and asked if they would agree to be interviewed. Over the period of a year, each participant was interviewed three times at home, using the stance of an 'active listener'. The interviews were transcribed and subjected to a structural analysis which identified a particular narrative type by focussing on the distinct structures that held the narrative together, and a content analysis in which central themes or instances of categories and the relationships

of categories, were sought.

Linked to the work of Frank, three types of narratives of hope were illuminated:

1. *Concrete hope and the Restitution narrative.*

Within this narrative, concrete hope was the most dominant form, and linked to themes of medical cure through technology and the restorable body-self. The examples provided of this type of narrative elaborate their relational and social dimension, for example, in the created and negotiated process of therapeutic and other social encounters in which narrative resources (particularly those of the medical model) were made available. The discussion further elaborates aspects of this narrative, and Smith and Sparkes consider the dimension that involves ignoring the uncertainty of a cure arriving on time. They argue that the concrete narrative may be precarious and more problematic than the specific emplotments suggest and, as this can also be denied, a future of possibility and potential is constrained. Whilst Smith and Sparkes identify the beneficial and problematic nature of this narrative, they argue that problems can arise for individuals when the narrative of restitution and the hope of a particular kind of body is not appropriate.

2. *Transcendent hope and the Quest narrative*

In this narrative, suffering is met head on, disability and impairment is accepted, and a use for it sought. This narrative includes a hope that it is not orientated to an outcome, but is rather open to the possibility of, as yet unknown, sources of meaning and value. It reframes disability as a challenge and as having potential for other ways of being. This narrative provides what the authors call a narrative scaffolding, through which the self is restored, and body-self relationships are differently valued, and this potential is enhanced by access to counter-narratives that provide alternative maps and different emplotment about impairment and disability. This affirmative mode of disability has transformative and therapeutic possibilities for both individuals and communities. The discussion focuses on how this counter-narrative displaces restrictive storylines through its potential to help and challenge the sanitised and distorted presentations of the research evidence of medical care. This narrative contributes to the expanding the cultural repertoire of stories, and points to an alternative form to concrete hope. The problems of transcendent hope are also highlighted as those of potentially romanticising disability, depicting disabled people as a homogeneous group, and creating expectations, both individually and culturally, about how people manage disability. Nevertheless, they argue, it offers the possibility of adapting to an uncertain future, and enhancing their own and others experience as they inhabit, construct, and develop, different body-selves over time.

3. *Despair and the Chaos narrative*

In this narrative, life is never imagined to get better, and the stories, lacking narrative order and plot, are chaotic. One consequence may be despair and loss of any hope, in which a conviction that life is over, and hope for a worthwhile future is lost. In their discussion, Smith and Sparkes draw on Frank's arguments that the self can gradually be reclaimed from the narrative wreckage through story-telling, to argue for opportunity and support for those whose voice and story SCI has taken. Whilst getting out of the chaos is to be desired, Frank (1995) emphasises the importance

of affirming the chaos story by people who can bear the fear that it provokes. Their discussion focuses on the way in which the boundaries between able and disabled bodies are patrolled - legitimising and defining acceptable stories of hope.

The authors conclude with a reflection on the nature of their findings, and the questions that remain concerning the processes in which the participants were drawn to one, rather than another, narrative type and kind of hope. They also question whether the expectations of research interviews and other encounters, and of able-bodied people influences how respondents talk about hope, if they are to maintain relationships and secure professional support.

This paper, which links to Sparkes and Smith (2005) [in this Bibliography], is of value for researchers. It provides a detailed discussion on Frank's narrative types and forms of hope upon which researchers can draw. It presents findings that are interesting in their own right, as well as an example of how findings of a study can be situated alongside theory.

Sparkes, A. C. and Smith, B. (2005) When narratives matter: Men, sport, and spinal injury. *Medical Humanities*, 31, 81-88.

Status of author (s)	Exeter University-based Qualitative Research Unit,
Nationality	UK
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narrative analysis: Illness experience
Type of text	Research: Primary
Type of study	Narrative
Whose perspective	Patients
Intended audience	Academics and Practitioners
Keywords	Active listening; Body; Frank; Hope; Identity; Spinal cord injury; Standpoints/Positions; Time; Typology of narratives;

The focus of this paper is to explore how specific narratives shape the experience of men with Spinal cord injury (SCI), and help to reconstruct their body/self relationship over time. The paper focuses on the way these stories, whilst unique to the teller, are social creations that draw on the available cultural, social, stock of narratives. The sample included 14 working class men, who suffered SCI and were disabled through playing rugby football. Data collection methods and analysis are not provided in this paper; rather, readers are referred to Smith and Sparkes (2005) [in this Bibliography]. Nevertheless, they indicate that the men, aged between 26 and 51 years, were sent an invitation to participate in the research, which included a questionnaire that sought their brief demographical details, and asked if they would agree to be interviewed. Over the period of a year, each participant was interviewed three times at home, using the stance of an 'active listener'. The interviews were transcribed and subjected to a structural analysis which identified a particular narrative type by focussing on the distinct structures that held the narrative together, and a content analysis in which central themes or instances of categories and

the relationships of categories, were sought.

Sparkes and Smith situate the bodies of these men within Frank's (1995) notion of the disciplined and narrating body, and the narratives that shape individual experiences within his definitions of 'restitution', 'chaos' and 'quest'. Each of these narratives are linked to a sense of hope.

- The *Restitution* narrative and *Concrete hope* - the return to health and ability - was framed with sporting or war metaphors, including ideas of 'fighting to make a comeback' linked to the possibilities of: a medical cure for SCI; winning as being cured of disability; the enemy beaten; and the body the battleground. In this narrative, the self in time is constructed in a philosophy of the future, although this takes different meanings as the narrative shifts between three time tenses: *past in the future*; *present in the future*; and *future in the past*. Time is also expressed as a scarce resource - a commodity - in terms of SCI being defined as temporary (waiting time) and the effects of SCI being time-consuming. This metaphor sustains a sense of concrete hope, with the outcome of recovery and cure to a *restored* self.
- The *Chaos* narrative and *Despair* - a view that life will never get better - is seen by Frank (1995) as the inverse of restitution narratives. These stories lack narrative order, and are without causality or sequence. The life in chaos is described through metaphors of 'choking', being in 'solid darkness', and the self as an 'object'. In this narrative, time is defined as an *empty present*. Drawing on Crossley (2000), time is experienced as a stream of overpowering events and, because people are afraid of disappointment, they make no plans or commitments for fear of the future. Thus, meaning and coherence in life is lost and time caves in. In this narrative, the time tense is the *future in the present*; a present in which the narrator is trapped and a future is undesired because of the imagined chaos. These metaphors and time tenses are framed by a static view of life, and operate in a narrative that leaves little sense of hope. This sense - that one's life is over - is described by Freeman (2003) as a *narrative identity foreclosure*.
- The *Quest* narrative and *Transcendent hope* contrasts with the restitution and chaos narratives by facing suffering head on, and accepting and living the experience of impairment. What is sought (quested) may not be clear, but involves the belief that something can be gained from the disrupting experience; that life is a journey in which the narrator is 'reborn'. The tragedy story-line is rejected, although the difficulties and complexities of reconstruction are not minimised. As a result, descriptions of the difficulties of the 'distance travelled', or the 'obstacles', 'barriers', 'the rocky road', of 'covering a lot of ground', having 'moved forward' and being 'off track' occur. The metaphoric aspect is also emphasised, in that it is through stories and dialogue, rather than solitude, that the point of lives may be found. Thus, this metaphor involves the advice and guidance of guides, and is therefore, essentially a social process in which time is reclaimed, but which also recognises and accepts that human life is fragmentary, unpredictable, contingent, and beyond control. It is accepting these that gives life immediacy - time tenses include the *past in the past*, the *present in the present*, and the *future in the future*. This narrative embraces *transcendent hope* which, according to Barnard (1995), involves a person being open to the possibility that reality will disclose as yet unknown sources of meaning and value. Disability is

reframed as a challenge and, within a vista of possibility, a *developing self* emerges; a self over time that is open to change.

Sparkes and Smith conclude that these narratives energise or impose structure on the life, and they raise questions about how and why men are drawn into one type of narrative rather than another.

The paper presents researchers with a very useful elaboration of Frank's (1995) narrative types, aided by the narratives drawn from their own research. It elaborates hope in a way that can be used alongside others [for example, Benzein (2001) and Elliott and Olver (2007) in this Bibliography], and it is a good example of a narrative analysis that raises questions for health practitioners, and the type of support they may need to give to those holding particular positions on hope.

Terry, W. L., Olson, G., Ravenscroft, P., Wilss, L. and Boulton-Lewis, G. (2006) Hospice patients' views on research in palliative care. *Internal Medicine Journal*, 36, 406-413.

Status of author (s)	University Faculties of Health and Education
Nationality	Australia
Type of Author (s) (s)	Professional: Researcher/Academic
Study/Text	Usefulness and impact for health care practice development and service improvement Using narratives analysed with qualitative methods: End-of-life/ Palliative care
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics
Keywords	Decision-making; Dying; Ethics; RCTs;

This study describes the views of hospice patients on research in palliative care. The authors cite a number of ethical problems that have been considered impediments to including terminally ill people in studies, including their impairment by disease or treatment to give consent, needing to spend time with their family, and their supposed vulnerability to unrealistic expectations of benefit. The authors challenge these assertions as they make a number of claims about the terminally ill for which, they argue, there is little evidence to support. The sample included 22 patients (13 women and 9 men) of a palliative care service, whose ages ranged from 28 years to 90 years, and who were deemed able to give informed consent. Patients were approached by a member of staff on admission. No patient refused to participate, or needed more than the allotted 24 hours in which to make a decision. All participants are now dead, and the authors give the time that separated the interview from death as varying between 24 hours (5 people), 48 hours (9 people), and 105 weeks (8 people). Interviews lasted between 19 and 74 minutes, using open-ended pre-determined questions. The interviews were recorded and transcribed, and an analysis drawing on the principles described by Altheide and Johnson (1994), Wolcott (1994), Mishler (1996), and Froggatt (2001), were used.

Two areas were identified:

1. *The value of research and the value of participation*

The reasons patients gave for their wish to be involved included:

- *Utility* – a reference to giving something back to their family and community, and to do something of enduring value;
- *Validation* – a chance to be seen as more than a dying person, and to participate in meaningful activities to the limits of their capacity;
- *Assurance* – that health care workers pursue new knowledge to improve care, including care for the terminally ill. To not do research implied not be committed to their care.

2. *How research should be carried out*

The practical aspects of research included:

- *What research should be undertaken*: Patients were most interested in research on cancer, but more specifically on aspects of palliative caregivers;
- *How the request to participate should be made*: Patients identified their preference to be approached by a doctor or nurse involved in their care;
- *Consent*: Rather than be too distressed by their illness, patients identified a freedom, that comes with the knowledge they are dying, to express themselves without reservation. Furthermore, patients indicated they would only participate if it did not prolong their deaths;
- *Impact on families*: Participation was valued as enriching family relationships, by offering an opportunity to affirm their autonomy by deciding independently of their family to participate, and to help families understand that their terminally ill family member was able to make decisions. Patients considered the possibility of behavioural side-effects important, but that the doctor, whose role it was they felt to explain the research to the family, would discuss this possibility as well;
- *Randomized controlled trials (RCTs)*: Whilst active comparator RCTs were likely to be acceptable, patients did not want to participate in placebo controlled RCTs;
- *Delivery of information*: Verbal information and discussion was preferred to written information, particularly in view of their fatigue and other physical changes.

In their discussion, Terry et al., conclude that the sample of terminally ill patients did not share the dominant concerns regarding research in palliative care, and that the practical and ethical difficulties of researching in this area are overstated. They comment on their small sample to suggest that these people, who bring a perspective to the debate, are entitled to have a say. Furthermore, they deserve consideration in their own right, not simply because they were expressed by a dying person. They argue that patients valued research because of what it implies about care of the dying, as a key to improved care, even if they themselves would not benefit, and as an objective and humble approach to knowledge – a characteristic their professional carers needed to express.

Terry et al., then turn their attention to ethics to suggest that stakeholders objecting to patients participation as if they were incapable of speaking for themselves is ethically problematic, and they challenge the notion

of researchers' decency or propriety of intruding on patients as the language of taboo. In this discussion, based on their patients' views, they challenge guidelines of ethical research, derived from Jonas (1969) that participants should share the goals and values of researchers; a position that excludes the dying. Furthermore, the desire by their patients to be approached by a doctor or nurse they trust, rather than the investigator, is impossible as it contravenes the Declaration of Helsinki. The authors were troubled by the unwillingness of patients to enrol in placebo-controlled RCTs, but wondered if careful explanation might make this more acceptable. They conclude by arguing that active comparator RCTs may need to be the design of choice in this setting, but acceptable robust methods will need to be designed.

This is an interesting paper, providing researchers with the arguments put forward in the thoughtful narratives that justify the inclusion of patients in palliative care settings participating in research. As such, it is an interesting study that has implications, not only for the practice of care, but for the practice of Ethics committees and researchers. Although the authors did not remark on this irony, the problems identified in the literature that palliative care patients cannot give consent in their own right was enacted in this study, where informants were 'judged' whether or not they were to be able to do so, although it is not clear by whom.

Tomlinson, J. and Tomlinson, M. (2005) *The luxury of time*. London: Pocket Books.

Status of author (s)	Patient and husband
Nationality	UK
Type of Author (s)	Lay
Study/Text	Auto/biographical accounts of illness
Type of text	Personal experience: Autobiography
Type of study	Case study
Nationality	UK
Intended audience	Lay
Keywords	Body; Cancer; Fear; Pain; Running; Suffering; Survival; Time;

This book is a joint enterprise between Jane, who developed breast cancer, and her husband Mike. It follows the events of their lives from just before the time Jane found a lump in her breast to her receipt of the Helen Rollason Award at the BBC Sports Award ceremony in 2002. The narrative begins in 2000 at this Award ceremony, and then returns to 1990 when the events that led to this point began to take shape. The account is structured sequentially, and the narrative alternates between Jane's voice and Mike's. At times, the two narratives speak of the same event, but mostly they both take the story forward, each person describing their own story/perspective of the next event in the narrative in a 'leap-frog' style.

The focus of the narratives are, nevertheless, dominated by the cancer. For Jane, the experience is of uncertainty and ambiguity of the meaning of symptoms, and the subsequent uncertainty about whether to take them seriously is highlighted. Her fears and resentment, and the experience of pain and the effects of chemotherapy, are described, alongside the, at times, intense pressures created through juggling

work, young children, illness, and meeting the needs of a partner. She conveys a sense of suffering, not only from the possibility of facing death and having to leave her young children, but also through the effort to live and carry on with her family and work relationships, the work itself, and keeping the household going. In this way, it makes visible the respective perspectives of the ill and the not-ill people involved, including the tensions and conflicts of interest, the demands and feelings of lack of support, often present in gender relations but exacerbated in the face of a life-threatening illness. It is, therefore, not solely a story of illness, it is also the story of a family-based relationship, and it identifies the extent to which each one of a couple face different things – for Jane the possibility of life being extinguished, needing attention and reassurance, and for Mike the fear of the possibility of life alone bringing up their children, and a desire to be as normal as possible.

The book is unequally distributed between the experience of illness, which lasted for the greater part of the time period. This approximately 8 years comprises a quarter of the book, with the remaining three-quarters of it describing the approximately two years in which Jane and Mike begin to run and compete in events. The focus of this narrative is on strengthening the body for the race, despite the constancy and presence of pain, and a life foreshadowed by the certainty of death and the uncertainty of when and how this would occur. Time and its weight/wait become more evident following Jane’s terminal diagnosis of metastasised secondaries. The setting and achieving of goals pass by.

This is a useful for researchers as a text in its own right, providing a descriptive chronicle, rather than a reflective account, of the experience of cancer and its impact on a couple. It is also available for analysis [see O’Brien and Clark, (2006) in this Bibliography for a discussion of the ethics of this]. Furthermore, it has an interesting relationship to Frank’s (1995) ‘*restitution*’ and ‘*quest*’ narratives that is worthy of exploration. It is also an interesting book to read alongside Myers (2000), Kingson (2005) and Byrne (2006) in this Bibliography.

Ville, I and Khlal, M. (2007) Meaning and coherence of self and health: An approach based on narratives of life events. *Social Science and Medicine*, 64, 1001-1014.

Status of author (s)	Academics: National Institute of Health and Medical Research/ Demographic studies.
Nationality	France
Type of Author (s)	Professional: Researcher/Academic
Study/Text	Using narrative analysis: Life events
Type of text	Research: Primary
Type of study	Ethnography
Whose perspective	Patients
Intended audience	Academics
Keywords	Agency; Coherence; Coping; Meaning;

This paper is based on a study which is itself part of a wider project to study the role of life-events in

biographical stories (Ville and Khlal, 2004). It focuses on the way in which narratives of meaning and coherence are organised, and it forms the basis of further work towards a more appropriate tool to assess meaning and coherence from narratives of life-events. The sample included 26 women and men, aged between 51 and 73. The main study draws on several approaches to emphasise agency and subjectivity to produce a 'thick analysis' in three stages:

4. Sequenced to understand cause and effect relationship (Young, 1987);
5. Turning points/epiphanies (Denzin, 1988);
6. Structural categories (Labov, 1982) to analyse 'plot'.

The interviews, of (average) 2½ hours duration, were transcribed to include non-verbal signs.

The authors argue that meaning and coherence of self are not intrinsic dispositions that precede action, but are products of socio-cognitive work on self-narration. As a result, they suggest that there is a need for a replacement of empirically-based instruments, in a yet to be constructed tool, that assesses meaning and coherence as reflected in the narratives of life-events.

Through their analysis, they identified the characteristic of causality as the main dimension that demonstrated variation between narratives. These variations included the *strength* of the causal relationship between events, the foundation of this causality, and the transversality, that is, the extent to which the cause of an event was related to other events. Each of these dimensions contributed to, or impeded, meaning-making and contributed to an integrated coherence or to an incomplete coherence, and to a low level of integration of the event into their life narrative. In addition, they identify the 'saliency' of a singular event – an event that is not smoothed into the whole narrative and, as such, is indicative of a lack of coherence. In the '*fantasy causality*' the particular cause of an event appears to have no rational foundation, thus giving it a 'fantasy' dimension, but this nevertheless does not appear to interfere with the coherence of the narration. Narrators were able to convey positive feelings, and the authors identified that in these 'fantasy' narratives, emotion was mediated by language which, they suggest, in functioning as a distancing from emotion, may have a role in coping. In the '*absence of link*', an event is not embedded in the network of causality, despite the potential for a causal link, and this confers an unpredictable nature upon the construction. In these incomplete coherent narratives, emotion was expressed more through non-verbal channels than through language.

The authors make several challenges to the objectivist orientation of stress research, including raising questions about: the use of qualitative interview data to regroup compatible events into investigator-defined meanings and levels of severity, that is, into hypothesised, acontextual constructs and psychometric tools; the direction of the causality of relationship between meaning/purpose in life as a determinant of well-being and health or as a consequence of specific action such as an outcome of a given programme; and the empirical basis of 'sense of coherence' assessments. Their argument rests on the notion that mediation between life-events and state of health requires an active agent - what Thoits (1994) calls a 'psychological activist' - often ignored within these models.

The study is well-constructed, the methods articulately described, and the purpose of this particular

paper contextualised in the larger study. Although the focus of this paper is concerned with meaning and coherence of self and health, it is, nevertheless, valuable in the context of end-of-life and palliative care as a basis for reflection for two reasons. Firstly, as a paper overall, it raises a number of questions about the empirical basis for 'sense of coherence' and 'meaning' assessment tools as well as the orientation of stress research, and this could well be applied to a number of end-of-life and bereavement assessment tools. Secondly, it uses examples of narratives of end-of-life and bereavement through which to demonstrate narratives of coherence and incomplete coherence.

This is a clearly written paper on a set of complex ideas that need reflection, and the paper is well-structured to support this. It is of use to researchers for three reasons. Firstly it is an example of the use of narrative as a method to examine agency and it illustrates the place of agency in creating meaning and coherence. Secondly, it presents an example of a research method through which to do this, and thirdly, it demonstrates how complex ideas can be written.

PART 3 : REFERENCES

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APPENDIX 1: ANNOTATED BIBLIOGRAPHY LITERATURE ASSESSMENT FORM

Study/Text	<ol style="list-style-type: none"> 1. About narrative methodology a. Theory b. Study of the phenomena of narrative 2. Using narrative analysis a. End-of-life/Palliative care b. Loss and Bereavement c. Miscellaneus (e.g. Life events) d. Illness experience 3. Auto/biographical accounts of a. Illness b. end of life 4. Usefulness/Impact for HC practice development and service improvement 5. Using narratives analysed with qualitative methods: a. End-of-life/Palliative care b. Loss and Bereavement c. Miscellaneous d. Illness experience
Type of Author	<ol style="list-style-type: none"> 1. Professional: Researcher/Academic 2. Professional: Practitioner 3. Lay
Author/Date	
Status of author	
Keywords	
Intended audience	<ol style="list-style-type: none"> 1. Academics 2. Practitioners 3. Lay 4. Policy Makers
Nationality	
Type of text	<p>Research: a. Primary b. Secondary</p> <p>Theoretical: a. Sociological b. Psychological c. Research methods d. Narrative</p> <p>Personal experience: a. Autobiography b. Biography c. Poetry</p>
Type of study	<ol style="list-style-type: none"> 1. Grounded theory 2. Phenomenology 3. Ethnography 4. Review /Reflection 5. Discussion paper 6. Case study 7. Longitudinal study about changing concerns in older women's lives 8. Mixed methods 9. Descriptive statistics
Whose perspective	<ol style="list-style-type: none"> 1. Patients 2. Carers 3. Both 4. Health practitioners 5. Researchers
Focus of study	
Sample size	
Methods of Narrative analysis	
Findings/ Accessibility/ Critique	

APPENDIX 2: KEYWORD INDEX

FEELINGS

Anger	Anonymous, 1994; Byrne, 2006; Craib, 2003; Ferrell, 2006; Laungani, 2003;
Coping	Brown and Addington-Hall, 2008; Bury, 2001; Laungani, 2003; McPherson et al., 2007; Ville and Khlal, 2007;
Dignity	Byrne, 2006; Charmaz, 1999; Johns, 2004; Kingson, 2005.
Fear	Brannström et al., 2006; Byrne, 2006; Craib, 2003; Laungani, 2003; Little and Sayers, 2004; Pearlman et al., 2005; Smith and Sparkes, 2005; Tomlinson and Tomlinson, 2005;
Hope	Anonymous, 1994; Benzein et al., 2001; Bingley et al., 2008; Brown and Addington-Hall, 2008; Byrne, 2006; Elfick and Head, 2004; Elliott and Olver, 2007; Johns, 2004; Kingson, 2005; Laungani, 2003; Maxwell et al., 2002; McPherson et al., 2006; 2007; Myers, 2002; Payne, 2007; Smith and Sparkes, 2005; Sparkes and Smith, 2005;
Pain	Anonymous, 1994; Benzein et al., 2001; Bingley et al., 2006; Brannström et al., 2006; Byrne, 2006; Charmaz, 1999; Frank, 2002; Johnson and Bourgeois, 2003; Laungani, 2003; Pearlman et al., 2005; Tomlinson and Tomlinson, 2005;
Suffering	Anonymous, 1994; Brown and Addington-Hall, 2008; Bury, 2001; Byrne, 2006; Charmaz, 1999; Charon, 2004; Ferrell, 2006; Frank, 2002; Johns, 2004; Pearlman et al., 2005; Smith and Sparkes, 2005; Tomlinson and Tomlinson, 2005;

ILLNESSES/CONDITIONS

Ageing/ Older women	Feldman, 1999; Greenhalgh, 1997;
Aphasia/Stroke	Moss et al., 2004;
Cancer	Abma, 2005; Anonymous, 1994; Benzein, 2001; Bingley, et al., 2006; Byrne, 2006; Craib, 2003; Elliott and Olver, 2007; Jordens and Little, 2004; Kingson, 2005; McPherson et al., 2006; 2007; Payne, 2007; Tomlinson & Tomlinson, 2005;
Dying	Abma, 2005; Andersson and Öhlén, 2005; Anonymous, 1994; Benzein et al., 2001; Bingley et al., 2006; Bolton, 2004; Brannström et al., 2005; Craib, 2003; DelVecchio Good et al., 2004; Elfick and Head, 2004; Elliott and Olver, 2007; Ferrell, 2006; Garnet, 2003; Johns, 2004; Johnson and Bourgeois, 2003; Laungani, 2003; Mason, 2002; Maxwell et al., 2002; Myers, 2002; Pearlman et al., 2005; Terry et al., 2006;
Heart failure	Brannström et al., 2005; 2006;

Motor Neurone Disease	Brown and Addington-Hall, 2008; O'Brien and Clark, 2006;
Polymyositis	Laungani, 2003;
Spinal cord injury	Smith and Sparkes. 2005; Sparkes and Smith, 2005;

PALLIATIVE CARE AND END-OF-LIFE ISSUES

Bio-medicine/ Futile care/ Technology	Bury, 2001; DelVecchio Good, et al., 2004; Ferrell, 2006; Frank, 2006; Garnet, 2003; Hok et al., 2007; Hydén, 1997; Mason, 2002; Maxwell et al., 2002; Payne, 2007; Riessman and Mattingley, 2005; Smith and Sparkes, 2005;
Complementary therapies	Abma, 2005; Garnet, 2003; Hok, 2007; Johns, 2004; Kingson, 2005;
Decision-making	Brown and Addington-Hall, 2008; Charon, 2004; Elliott and Olver, 2007; Ferrell, 2006; Frank, 2002; 2006; Kingson, 2005; McPherson et al., 2007; Myers, 2002; Payne, 2007; Terry et al., 2006;
Identity/Self	Bingley et al., 2006; Bury, 2001; Byrne, 2006; Charmaz, 1999; Frank, 2002; Garnet, 2003; Jordens and Little, 2004; Little and Sayers, 2004; McPherson et al., 2007; Moss et al., 2004; Payne, 2007; Pearlman et al., 2005; Romanoff and Thompson, 2006; Sparkes and Smith, 2005;
Meaning	Andersson and Öhlén, 2005; Atkinson, 1998; Benzein et al., 2001; Brannstrom et al., 2005; 2006; Frank, 2002; Little and Sayers, 2004; Romanoff and Thompson, 2006; Smith and Sparkes, 2005; Ville and Khlát, 2007;
Physician-assisted suicide/ Hastened death	McPherson et al., 2007; Pearlman et al., 2005;
Quality of life	DelVecchio Good, 2004; Ferrell, 2006; Johnson and Bourgeois, 2003; Kingson, 2005; Myers, 2002; Pearlman et al., 2005;
Survival	Brown and Addington-Hall, 2008; Byrne, 2006; Ferrell, 2006; Little and Sayers, 2004; Payne, 2007; Tomlinson and Tomlinson, 2005;
Time	Bury, 2001; Byrne, 2006; Charon, 2000; DelVecchio Good et al., 2004; Sparkes and Smith, 2005; Tomlinson and Tomlinson, 2005;

PRACTITIONER ISSUES

Health practitioners	Anonymous, 1994; Frank, 2006; Craib, 2003; Laungani, 2003; Mason, 2002; Mishler, 2005; Payne 2007; Romanoff and Thompson, 2006;
Health practitioners (Doctors)	Bolton, 2004; Charon, 2000; 2001; 2004; DelVecchio Good et al., 2004; Greenhalgh, 1997; Kingson, 2005;

Health practitioners (Nurses/Palliative care nurses)	Abma, 2005; Brannström et al., 2005; 2006; Ferrell, 2006; Garnet, 2003; Johns, 2004;
Medical education	Charon, 2001; DelVecchio Good et al., 2004; Maxwell et al., 2002; Mishler, 2005; Myers, 2002;
Patient-Practitioner communication/relationships	Bury, 2001; Frank, 2002; Hok et al., 2007; Maxwell et al., 2002; Mishler, 2005, Payne, 2007;

PRACTITIONER/RESEARCHER ISSUES

Boundaries	Charmaz, 1999; Frank, 2002; Johns, 2004;
Ethics/Moral distress/Moral life	Abma, 2005; Atkinson, 1998; Brown and Addington-Hall, 2008; Charmaz, 1999; Charon, 2001; 2004; Ferrell, 2006; Frank, 2000; 2002; 2002a; 2002b; 2006; Johns, 2004; Jordens and Little, 2004; Mishler, 2005; Moss et al., 2004; O'Brien and Clark, 2006; Riessman and Mattingley, 2005; Terry et al., 2006;
Reflection/ Reflexivity	Atkinson, 1998; Bolton, 2006; Brown and Addington-Hall, 2008; Frank, 2000; 2002; Greenhalgh, 1997; Johns, 2004; Mason, 2002; Maxwell et al., 2002;
Writing	Bolton, 2004; 2006; Charmaz, 1999; Charon, 2001; Feldman, 1999; Ferrell, 2006; Johns, 2004; Mason, 2002;

NARRATIVE INQUIRY/METHODOLOGY

Emplotment	Hydén, 1997; Mishler, 2005; Smith and Sparkes, 2005;
Standpoints/ Positions	Abma, 2005; Charmaz, 1999; Frank, 2000; 2002; 2002a; 2002b; Hydén, 1997; Johns, 2004; Little and Sayers, 2004; Maxwell et al., 2002; Payne, 2007; Sparkes and Smith, 2005;
Truth	Atkinson, 1998; Bingley et al, 2008; McPherson and Thorne, 2006; Riessman, 1993;
Typology of narratives, inc Frank (F), Kelly (K), Robinson (R)	Abma, 2005 (F); Bingley et al., 2006 (F); Brown and Addington-Hall, 2008 (F); Bury, 2001 (F) (K) (R); Hydén, 1997(F) (R); Jordens and Little, 2004; Myers, 2002 (F); Smith and Sparkes, 2005 (F); Sparkes and Smith, 2005 (F);

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