

Original Article

Narrative Research Methods in Palliative Care Contexts: Two Case Studies

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Abstract

Narrative methods have played a minor role in research with dying patients to date, and deserve to be more widely understood. This article illustrates the utility and value of these methods through the narrative analysis of semi-structured interview data gathered in a series of interviews with two terminally ill cancer patients and their spouses. The methods and findings associated with these two case studies are outlined and discussed. The authors' contention is that an analytical focus on the naturalistic storytelling of patients and informal carers can throw new light on individuals' perceived illness states and symptoms, care-related needs, behaviors, and desires. In addition, the juxtaposition of two cases that share a number of markers of risk and need at the end of life illustrates how the narrative analysis of patients' experiential accounts can assist in uncovering important distinctions between cases that are of relevance to care management. *J Pain Symptom Manage* 2009;37:788–796. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Terminal cancer, cancer patients, palliative care, narrative research, narrative analysis, informal carers

Introduction

Narrative methods have played a minor role in research with dying patients to date, and deserve to be more widely understood. The

The U.K. Economic and Social Research Council (ESRC) is acknowledged for funding the re-analysis of the interview data using narrative analysis methods (Ref: ESRC RES-000-22-2031).

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Accepted for publication: May 7, 2008.

methodological credentials of narrative research methods in the social sciences are now well established,^{1,2} and it is recognized that this qualitative research subgenre has much to offer to health and clinical sciences.³ This article illustrates the utility and value of such methods through the narrative analysis of semi-structured interview data gathered in a series of interviews with two terminally ill cancer patients and their spouses. The methods and findings associated with these two case studies are outlined and discussed. The authors' contention is that an analytical focus on the naturalistic storytelling of patients and informal carers can throw new light on individuals'

self-identities, their perceived illness states and symptoms, and their care-related needs, behaviors, and desires. In addition, the juxtaposition of two cases that share a number of markers of risk and need at the end of life illustrates how the narrative analysis of patients' experiential accounts can assist in uncovering important distinctions between cases that are of relevance to care management.

In both case studies, interviews were conducted in the last few weeks of the patients' lives, as part of a study on place-of-death preferences of 41 cancer patients in northwest England in 2001–2003 (hereafter referred to as the primary study, details of which are available elsewhere^{4–6}), with full National Health Service (NHS) Ethical Committee approval. The narrative analysis of the interview data reported here arises from a secondary data analysis project currently underway, funded by the United Kingdom's Economic and Social Research Council (ESRC) and approved by Lancaster University's Ethics Committee, entitled *Narratives of Living and Dying with Cancer: Sociological Perspectives* (PI: C. Thomas; Ref: RES-000-22-2031).

The secondary analysis involves revisiting the primary study's interview data and applying narrative analysis methods, as opposed to the traditional cross-sectional *content* or *thematic* analysis method used in the primary study.⁷ This narrative analysis exercise is closely associated with the authors' participation in the narrative research theme in the British *Cancer Experiences Collaborative* (CECo). The CECo is a five-year program (2006–2011) funded by the National Cancer Research Institute (NCRI) in the United Kingdom, involving five English universities. CECo works through collaborating university-based research teams and focuses on three key themes: 1) innovative approaches to complex symptoms; 2) planning for the care of older adults toward the end of life; and 3) narrative research methods in supportive and end-of-life care (see <http://www.ceco.org.uk/>).

Methods

The Interviews

All the interviews in the primary study were sensitively conducted by a researcher

experienced in entering into conversation with seriously ill cancer patients and their informal carers. The semi-structured conversations explored patients' and carers' experiences, with the interviewer paying particular attention to the meanings that these experiences had for the respondents themselves. Interviewees were gently steered toward the following themes: cancer diagnosis and the course of the illness; experiences of medical treatments, care systems, and health care practitioners; the impact of the illness on the lives of self and others; the meanings, emotions, and practical challenges tied up with having cancer; sources of support; and preparations for the "where, when and what" of end-of-life care. Interviews took place in patients' homes, at a time of mutual convenience, and were audio-recorded and fully transcribed, with participants' permission. Interviewees soon felt "safe" and able to speak openly and naturally; less-guarded demeanors were adopted as the interviews progressed, and opinions and evaluative assessments were more readily expressed.

Narrative Research

Narrative research is a subgenre of qualitative research methodology in the social and health sciences, and now constitutes a set of related approaches that are applied and taught in many contexts,^{8,9} particularly in studies of illness experiences in the United States and United Kingdom.^{10–12} The sine qua non of qualitative methodology in general is a commitment to seeing the social world from the point of view of the individual social actor. It purposively deals in "the subjective" in social context, in seeing through the eyes of one's research subjects, and demands a high degree of interpretative training and skill on the part of the researcher. Interpretative skill requires reflexivity, that is, a trained ability to critically reflect upon, and make evident the "whys and wherefores" of data collection and analysis, and thus, the construction of knowledge.^{13,14} As a qualitative research subgenre, narrative research is especially relevant to examining the ways in which an individual's self-identity is challenged and changed through the impact of traumatic life events, such as being diagnosed with a chronic or terminal illness. This is because self identity, under all circumstances, is narratively constructed. In

the words of the social psychologist Elliot Mishler, a long-standing advocate of narrative methods at the Harvard Medical School, identity development is an interpersonal process involving the telling and retelling of stories about the self to others: "... our identities are defined and expressed through the ways we position ourselves vis-à-vis others along the several dimensions that constitute our network of relationships" (p. 16).¹⁵ Mishler's interview-based narrative research led him to note that when people experience unplanned changes or unforeseen events in their lives they "... reshape and reconfigure their identities—always works-in-progress—either through efforts to maintain a sense of continuity with their previous mode [of being] or by changing direction" (p. 60).¹⁵ Mishler's words suggest strongly that narrative methods have the potential to occupy a valuable place in both research activity and clinical practice in end-of-life care, especially in case comparison.

Narrative research methods invite people to talk, or write, about their experiences in a naturalistic storytelling fashion. There is now a large literature on the data collection techniques that can be used.^{1-3,16,17} Semi-structured interviews, such as those reported here, represent an excellent vehicle for data collection in this tradition, facilitating the generation of "insider" accounts of sequentially lived experiences. What patients and carers recounted in their interviews took multifaceted storied forms. Like other human beings in almost any social context, their "talk" constituted storytelling and involved the ongoing crafting of experiences and self-identity, with the following key elements and illustrative statements:

- the recounting, in loose temporal order, of events and encounters with people and organizations (e.g., "then I was asked to see another doctor, so I went to the other hospital clinic and ...");
- the communication of reactions and feelings (e.g., "I felt awful about that, because I wasn't expecting it...");
- the explanation of reactions and feelings (e.g., "you know, I'm not the kind of person who just sits back, I like to be in control of what is happening to me...");
- the expression of assessments and evaluations of what had occurred (e.g., "well, I

thought that behavior was really dreadful, wouldn't you agree...?")

It is important to note that interview talk is always co-constructed, involving a dialogue,¹⁵ and makes use of metaphors and other everyday grammatical devices. It is marked by variations in style and mood, shifting, for example, from gravity and sadness to light-heartedness, humor, or playfulness. The interlocutors make assumptions about what "goes without saying," because the discussion is based on some shared fundamentals: language, "common knowledge," and known cultural contexts. However, dialogic "checking out" can be frequent, for example, "Do you know what I mean ...?"

The narrative analysis of interview transcript data, or other narrative material, can be approached in different ways, focusing mainly on the content or the form of the text data. However, both content and form are of interest to most narrative analysts. This variety of approaches is helpfully reviewed in the CEC context by Bingley et al.¹⁸ On matters of academic rigor and methodological validity, all qualitative research methods are guided by a set of well-established rules and procedures,^{19,20} not explored here due to space constraints.

Our narrative analysis focused on the narrative threads that ran longitudinally through the two case study interview transcripts, together with the relationship between these storylines. This alerted us to how particular excerpts, such as those presented later, fit with other parts of an interviewee's life story as narrated during the interview as a whole. This compares with the traditional cross-sectional thematic analysis technique⁷ used in the primary study, wherein sections of text in the interview transcripts were broken up into themes and sub-themes that could be grouped together *across* a whole dataset. Different, although complementary, research findings have been generated by these contrasting methodological approaches to the analysis of a common patient interview dataset. This can be illustrated by making a comparison between this article and an earlier published article that reported on patients' place-of-death preferences.⁵

Narrative Analysis: The "River" Allegory

The approach to narrative analysis adopted here might best be conveyed and shared by

the use of a simple “river” allegory, developed by the first author. This approach draws upon the narrative research pedagogy of Elliot Mishler,¹⁵ Jane Elliot,² and other leaders in the field.

This allegory suggests that the interpreter of the data engages with the interview text as if he or she were an observer of a stretch of river flowing past, but soon disappearing out of sight. The observer wades in, looking downstream, and attempts, with rigorous attention to detail, to discern and explain the river’s currents as they move by. The visible section of the river provides strong clues as to the strength and interweaving character of the currents: tributary streams run into the river and exert their influence; rocky and sandy sections of the landscape are traversed and cut through; materials carried along from the river’s unseen reaches upstream are deposited; and the river babbles past in places or moves sluggishly by in others.

Like the river itself, the life subjectivity captured in words on a page is a force in creative motion. And like the river observer, the interpreter wades into the “word data,” and endeavors to make sense of the storylines or narrative threads that run longitudinally through the text; these are the “currents” that convey meaning and contextual detail. To discern and explain the storylines, the interpreter empathetically studies both their content and their form, making use of information shared on: the impact and influence on life and self of other people, present and past (the river’s tributaries); the social and cultural landscape that is “lived,” present and past (the terrain traversed by the river); the events and experiences that are perceived by the narrator to be of significance (the material carried and deposited by the river as it passes by). The way that words are put together and expressed, with, for example, laughter or tears, is of significance to the interpretation of meaning (the sounds and appearance of the water).

Results

The Case Studies

The two case studies selected for inclusion have a number of shared characteristics: tumor type, age, spouse carers, family structure, middle-class socioeconomic status, northern England location, long-standing and mutually

supportive marriages. Both couples received support from specialist palliative care services (both patients used the same inpatient hospice for symptom control services), including home visits from nurses that all interviewees referred to as “Macmillan nurses,” and general practitioner (GP) and district nurse care; both couples made use of the local cancer psychosocial support services. These similarities allow distinctive longitudinal themes to surface more clearly in the narrative analysis of the interview data.

Case 1 (K5). A 67-year-old woman, whom we shall call Anne, was in the final stages of life with colorectal cancer when she was referred to the study. She lived with her husband, “Peter,” in a village location, and was fully aware of her terminally ill status. The couple had two adult daughters, one of whom resided nearby and the other far away; both daughters are reported as being very supportive. Peter, a former business manager, had become his wife’s main informal carer, although the long-standing, traditional sexual division of labor in the household meant that he had had to learn new domestic skills quickly, such as cooking. Three interview episodes took place in Anne’s final months: one with Anne separately (1.5 hours), one a few weeks later with Peter separately (one hour), followed immediately by a joint interview with Anne and Peter (1.5 hours). Anne died in an inpatient hospice, as she had planned.

Case 2 (K1). William, as we shall name him, was aged 67, and knew that he was dying of colorectal cancer. He was an independent-minded businessman who had rarely consulted a doctor during his healthy and active working life. He and his wife, “Jane,” had four supportive adult children, two of whom lived close by and offered a source of practical assistance, and two of whom lived far from home. Jane took time off from paid employment and extended her domestic duties to care for her seriously ill husband. The couple was interviewed together once (2.5 hours), and Jane participated in a lengthy post-bereavement interview (1.5 hours). William died at home, as he had wished, but Jane recounts a “difficult” home death experience for all concerned.

Narrative Threads

There are many narrative threads of relevance to palliative care professionals in the two case studies. The inpatient hospice and preferred place-of-death storylines are the focus here. In both cases, these storylines interweave with others, particularly: the disease and its symptoms; service usage and experience; self-identity; marriage and family relationships; employment histories; and the deaths of others.

Case 1. In her first interview, Anne explains that she refused further chemotherapy treatment when she was informed by a doctor that cure was no longer possible. She favored “quality of life” for whatever time remained. Her storytelling displayed certainty and determination about the decisions that she had made, and would yet make, which included being as open as possible with everyone around her about her unfavorable cancer prognosis, especially with family, friends, neighbors, and people who knew her in the village shops. A word she uses repeatedly is “accept”: “I’m not depressed about it, I haven’t got down, upset about it. I just accept it.” As the interview unfolds, the content and form of Anne’s narrative reveals that this acceptance theme, and her desire to be open with others, is the means by which she works hard to continue her life-long project of caring for the family, that is, of supporting and looking after other people; this is at the very core of her self-identity. She refuses to abandon this identity in the face of worsening symptoms and impending death, and remarks, with ironic humor, that she has already tried to minimize the anticipated distress of family and friends by planning her funeral service:

Anne: I am very fond of hymns and I don’t want all this “Abide with Me” lark... As I said to my family, I want more of a celebration, I said “You’re very lucky to have had me [laughter], I don’t want you mourning me.”

Anne had decided that she would die in the local inpatient hospice for the same reasons:

Anne: And I said to [the Macmillan nurse] right away, “I want to go in the hospice. I don’t want my family to have to look after

me here [at home] ... I really don’t ” ... They [the hospice staff] know how to cope with the medication. And my husband has actually said the one thing he can’t cope with is me in pain. So it’s better anyway. But, I mean, he didn’t say that until after I made the decision, and he’s alright with it....

Anne’s strong conviction that the local inpatient hospice would be the best place in which to die is further explained by a narrative thread that comes to the surface periodically about the death of her sister, over a decade earlier, in the first and second interviews. Indeed, this storyline also illuminates Anne’s determination to be “open” and “accepting.” Anne had never been close to this “very difficult” older sister, but had found herself in the position of carer when the unwell sibling had moved in and was diagnosed as terminally ill with cancer. Anne describes having helplessly witnessed her sister’s “screaming” as pain worsened, and her feeling of relief when she was taken into a local inpatient hospice, where the death occurred some weeks later (this was at a time when the hospice was run by a religious order, and patients might stay for some weeks). Anne came to know the hospice well through her frequent visits and involvement in the care arrangements (making tea and other tasks). The hospice was described as “wonderful,” and Anne joked that she had “booked her place.” The inpatient hospice option met both of her life experience-based requirements: controlling pain and any other problematic symptoms that she thought would be inevitable, and relieving the caring and suffering burden that would be placed upon her husband and daughters.

In his separate interview, Anne’s husband, Peter, confirms Anne’s conviction:

Peter: ... her personal hygiene I can cope with, I think—but it depends what it looks like at the end, but that’s, she doesn’t want me to have that. She would say, “I’m going to the hospice,” and there’s no way I could stop her. When she says she’s going, she’s going—so—until then, I can cope.

In her final interview a month later, Anne’s condition had worsened markedly; she tired easily, was breathless, and commented on the

“fuzziness” that accompanied the morphine. But her independent and determined spirit was still much in evidence, as was her desire to engage in housework and “normal” activities. Anne returned once again, without prompting, to her hospice narrative theme, something obviously much in her thoughts, and of great importance to her calm state of mind and expectations:

Anne: [The hospice...] giving you the quality, I think, of life. They controlled my sister's pain just like that. I mean, she was screaming with pain at home and we went the next day and she was sat in a chair at her bedside — uncomfortable, that's all. So I think, probably, the pain control which gives you a better life towards the end, I think, or even, you know, if you go in for a week to sort the pain control out, they do that. That would be helpful probably, in both pain control and getting you used to the place, if you haven't been before, you wouldn't feel quite such a stranger when you went in, would you? At least, I thought that, but I didn't feel a stranger [when I went in for day care], even though it was 13 years ago. That sort of atmosphere they have, yeah.

Anne did die in the hospice she knew, as she had planned. After reflecting upon her narrative, one wonders, with much disquiet, what would have happened to both Anne and her family if an inpatient hospice bed had not been available when “the time came.”

Case 2. In their joint interview, William and Jane talked at great length about William's colorectal cancer diagnosis, and the repeat chemotherapy and radiotherapy treatments that had followed. As their interlaced narrative threads unfold, one thread of great significance to both William and Jane comes to the forefront: once William had been informed by doctors that it was no longer a question of curative interventions, he had independently and determinately taken the decision to refuse further treatment options, including an ileostomy and additional chemotherapy. Specialist palliative care services had thereafter come into play.

William: I mean the great difference was that mine was not recoverable and therefore

you're really only talking about two things—quality and length of life, and it was going to kill you at some point ... It's gone fairly well, but we're cognisant of the fact that, um, it could get into second gear tomorrow, and, you know, be all over in a month, so to speak.

The narrative analysis of this joint interview transcript reveals that the interview event itself offered both William and Jane a meaningful opportunity to talk to each other, once again, about how difficult it had been to turn down the treatments and advice offered by oncology physicians and to move into the realms of “palliative care only.” With the benefit of hindsight, Jane expressed the view that William's decision, although an extremely difficult one for her and other family members to accept at the time, had been both “brave” and “right”: a better quality of life had ensued, and for an unexpectedly extended period of time.

William's pride and independence of mind, clearly displayed as biographical constants in the interviews, came to the forefront once again in a storyline about an episode of inpatient care in a hospice for drug assessments. This narrative theme was opened by Jane in the first interview, and emerged again in her post-bereavement interview. In short, William had disliked, strongly, his experience of staying in the hospice, and had consequently changed his place-of-death preference from inpatient hospice to his home setting; Jane promised him that she would honor this change of mind. It was not a question of the quality of care in the hospice, which the couple insisted had been excellent. Rather, William found the hospice profoundly depressing, and hated being positioned adjacent to dying people. Both Jane and William questioned the wisdom of a policy that mixed patients in this way:

Jane: William's visit to the hospice was really for palliative care, to assess his drugs, and the building and the staff and everything were absolutely superb. But sadly, the people like William going in for respite or palliative care are in with people who are very, very terminally ill and about to die — instead of it being in a separate block where you're having your palliative care and you're walking

about and, if you like, upbeat, and as you are at home, even, with your single room. You're made very aware of the last stages of the sort of illness that you've got. William came out quite depressed and down — well, he described it to the GP this morning as a bruising experience. He found it very, very depressing, and yet the care was superb.

William: Oh, there was absolutely nothing wrong with the care.

In her post-bereavement interview, Jane tells, in great detail, the story of William's final weeks and days, culminating in a difficult death at home. It was a story of the unavailability, at critical moments, of both key health professionals and appropriate drugs. These resources were necessary to manage William's growing physical and mental distress:

Jane. ... he went into a little frightened shell ... his eyes were sort of staring in fear, you know. We never found out why the syringe-driver didn't work, and why that mistake [about a particular drug] had been made.

Jane and the adult children had struggled to calm William's distressed state, to keep him physically safe, and to make him comfortable. Jane now carried the painful memory that he had remained agitated and unwilling to talk until his last breaths. Her post-bereavement narrative is testimony to how emotionally and physically demanding and draining it can be, perhaps inevitably so, for family members to assume primary responsibility for the cancer patient dying at home. Her storytelling is full of references to how "good" and "caring" some, though not all, of the nurses and doctors were who visited the house, but highlighted the fact that, in the final analysis, the care responsibility was hers:

Jane. There was support, but you didn't get 24 hour support, and toward the end I needed it ... I needed [help] because of the lifting, I couldn't do the toileting and the lifting, you know. And if you've got somebody who's very prudish and very private like William was, he wasn't going to let the family do it. Fortunately he was unaware that it was [our son] that was helping me towards the end, at least he may not have been, but he'd gone past that stage where he could object. But earlier on in

those weeks he wouldn't have wanted his daughters or his sons to have done it. And when the nurses went away there was only me. So it was, it was a privilege to be able to keep him here and do as much as we could for him. But I didn't feel we managed it very well. I felt it left him often quite vulnerable to injury, and lacking in the adequate support to keep him totally comfortable, you know.

The legacy was that Jane lived with a mixed residue of pride and guilt, the latter overlaid by the death of her own father soon after.

Discussion

We see that the narrative analysis of the interview data in these two case studies offers an innovative and clinically informative way of accessing the personal worlds and perspectives of patients and carers in end-of-life scenarios. Like stepping into a river and studying the currents and their antecedents, these biographical storylines' approach to the analysis of interview talk has enabled a revealing light to be thrown onto the life-patterning and contemporary manifestations of individuals' behaviors, convictions, beliefs, desires, purposes, and intentions—in the face of challenging symptoms and life's closure. Thus, Anne's apparent capacity to cope so successfully with cancer and its symptoms, and her steady determination to die in an inpatient hospice, can be more readily appreciated and explained by paying analytical attention to the interwoven narrative threads that convey her self-identity and current perspectives, such as those associated with her domestic and family-centered life course, and with her close witnessing of a sister's dying days. Similarly, the narrative analysis of the words spoken in William and Jane's joint interview, and in Jane's post-bereavement interview, uncover dimensions of the complex circumstances and personal identities that led, first, to William's refusal to accept further treatments suggested by oncologists, second, to his distressed and distressing death at home, and third, to the legacy of pride and guilt carried by Jane as she attempts to rebuild her life after loss.

In addition to illuminating the individual perspectives and needs of patients and carers,

we suggest that the narrative analysis of interview data can also pose important questions for policy and clinical practice. This assists in setting an agenda for further qualitative or quantitative research, including quality-of-life surveys. In the two cases examined here, questions raised include the following: Should inpatient hospice stays for drug assessments routinely separate the patients involved from others who are actually dying, or would such a practice fly in the face of the palliative care ethos? Should care for the dying in home settings make 24-hour nursing care, at critical moments, an absolute requirement, rather than a desirable “extra”? Such questions are at the cutting edge in palliative care in many countries. Moreover, Case 2 draws attention to an important area of clinical practice that merits further research: the acute emotional difficulties that patients and their families may encounter when deciding whether or not to resist further treatments offered by oncologists, and thus, to make the transition to palliative care. The case studies have also strongly suggested that the use of narrative methods in a clinical context with individual patients has the potential to develop a necessary evidence base to further support the clinical care of individuals with complex and multifaceted identities. That is, the use of narrative methods in clinician–patient relationships can assist in bringing to light the “core selves” of individual patients and their informal carers.

A comparison of the two cases featured here also serves to suggest the need for caution when using standard scales, or other epidemiological instruments, which categorize individual patients and generate group aggregates. The two cases appear very similar when marker variables are employed: Anne and William shared tumor type, disease stage, age, and many key social characteristics, and yet, their attitudes toward the dying in the local inpatient hospice could not have been more at variance, for reasons tied up with formative experiences revealed in their own, and their spouses’, storytelling. Thus, narrative analysis of in-depth research interviews with patients and carers, or clinical practices that make use of narrative methods, can help, in a unique fashion, to uncover and make sense of finer grained distinctions between cases—distinctions that are necessary for maximally effective palliative care.

Our claim is that in these ways, and no doubt in others, narrative methods represent a valuable addition to the palliative care repertoire. The narrative analyses of suitable data generate new knowledge that can complement knowledge generated either in routine clinical discussions with patients and carers or in more traditional qualitative approaches to analyzing interview datasets (i.e., cross-sectional thematic analyses), or in quantitative research in palliative care settings. That is, the “storylines” or “narrative threads” approach opens up fresh and humane ways of accessing the life worlds of seriously ill and dying patients, and their close companions. Of course, researchers and practitioners must recognize that narrative methods share the logic and limitations of other qualitative research methods in the interpretive paradigm, and they cannot be used to generate answers to research questions that demand large samples, numerical data, and statistical techniques for data analysis and generalization. Moreover, compared with some other qualitative research methods, narrative methods are particularly time-consuming and case-focused. Nevertheless, this article suggests that narrative research methods have a great deal to offer health and social care professionals in palliative care. These methods can be readily shared and learned in academic and clinical contexts, as the United Kingdom’s CECo program is currently demonstrating, and should be welcomed into the palliative care fold.

Acknowledgments

The authors would like to thank the patients and families who participated in the primary study.

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