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Developing narrative research in supportive and palliative care: the focus on illness narratives

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The phenomenon of the 'illness narrative' is well-documented, in the last 25 years, of increasing interest to researchers in health and social sciences. Personal stories about the experience of facing the end of life also have an established history of particular relevance for palliative care clinicians. In this article, we review and describe a range of narrative analysis approaches that may be of use in palliative care. In particular, we distinguish between qualitative analysis applied to narratives and narrative analysis as a method. We discuss the potential benefits and challenges in the use of narrative research methods as a means to deepen our understanding of patient, carer and health professionals' experience, and to support improvements in end of life care policy and practice. *Palliative Medicine* (2008); **22**: 653–658

Key words: illness narratives; narrative research methods; supportive and palliative care research

Introduction

Giving time and space to patients' oral histories and their stories of the end of life experience has a long tradition in hospice and palliative care. Reflecting this practice, the last 25 years has seen an increase in narratives written by healthcare professionals about their experiences of caring for people facing death.¹ There has also been a remarkable growth in stories written by patients and carers about their personal experiences of illness portrayed in books, magazines, on the internet, on television, in film and radio drama.² Both the patient and healthcare professionals' stories have much to teach us about living with life-limiting illness, suffering and the experiences of care. These developments are testimony to the importance of narrative and storytelling in the world of supportive and palliative care. Recognizing this trend, the Cancer Experiences Collaborative (CECo)³ has chosen narrative research methods as one of its three research themes.⁴ This paper offers an introduction and review to some key narrative research methods currently used or being adapted for use by those engaged in palliative care research.

Dame Cicely Saunders was an inspirational advocate recognizing that the importance of ensuring time was made to listen to the patient and their family caregivers.⁵

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Her approach demonstrates the inherent advantages, both practical and humane, in attending to the central message of patient and carers' stories in terms of improving our understanding of an individual's total needs and finding ever more effective ways to support people at the end of life.⁶ As she observed:

The search for meaning, for something in which to trust, may be expressed in many ways, direct and indirect, in metaphor or silence, in gesture or symbol or, perhaps most of all, in art and the unexpected potential for creativity at the end of life. Those who work in palliative care may have to realise that they, too, are being challenged to face this dimension for themselves.

p. 1601

Valuing the patient's story is, though, only the start of the engagement of palliative care with narrative research methods. Another important part of the process is to make narrative research work for palliative care. Thus, there is distinction to be made between the well-documented value of the narrative as a way for palliative care clinicians, patients and carers to communicate their practical and esoteric experience at the end of life and the development of narrative research methods that will help us gain more insight into those lived experiences by exploring these narratives from the various different angles made possible through narrative analysis. The telling of stories has been a vital currency of reporting the experience of end of life care over the last 50 years.^{7–9}

Since the early 1980s and the start of the contemporary movement in illness narrative research with the work of medical sociologist Michael Bury,¹⁰ social psychologist Elliot Mishler¹¹ and doctors like Arthur Kleinman,¹² there has been a steady, though somewhat, gradual increase in interest and use of narrative methods in palliative care research.¹³ The CECo proposition is that research designed to capture and explore these stories can inform changes that have potential to improve practice and policy in hospice and palliative care.

Working from the basic premise of the relevance of narrative research in palliative care, in this article, we outline some typical narrative research methods and designs, noting how these have evolved from general qualitative research. In particular, we distinguish between qualitative analysis applied to narratives and narrative analysis as a method. Some examples of narrative research used in palliative care situations illustrates where the approach seems to be appropriate and effective, for instance in helping to identify underlying issues for patients and those involved in their care. Some of the benefits and challenges of using narrative research methods are identified.

Narrative research: a definition

The telling of stories is an integral part of human social communication – occurring in all types of textual, verbal, nonverbal and creative expressions – as a means to describe, reflect, share, to perform or entertain.^{14,15} In this context, we define the term ‘narrative’ – often used interchangeably with ‘story’ or storytelling – as a form of expression recognizable as a story, i.e. “discourses with a clear sequential order that connect events in a meaningful way” p. 26.¹⁶ Based on time, stories are typically recollections of events with an identifiable ‘storyline’ or ‘plot’ having a beginning, middle and end.^{17,18} Even a single sentence can be enough for us to identify narrative/story as opposed to the account being a statement or a series of related or unrelated facts, a set of instructions or comments. Story is one of the most significant mediums through which we define and shape our cultural and personal interactions. We live within and by the stories that we affirm and re-affirm throughout our lives from early infancy. Our personal and shared stories are a crucial and integral ‘modus operandi’ of human life, a means through which we define our lives, our identity, culture and society. Researching stories told verbally, in writing, music or art has become a specialist methodological field within qualitative research methods. The growth of narrative approaches to data collection and analysis has opened up a range of innovative ways for researchers to access and capture social and cultural experiences.

Storytelling, in general, appears to be sparked by experiences of a ‘breach’ or ‘disruption’, however minor, in our usual patterns of life.^{19,10} Stories, therefore, gain a particular relevance at times of life transition or change, seemingly as a way of ‘sense-making’ or attempting to re-shape and manage the shifting ground of our lives. Cheryl Mattingly²⁰ notes that the suffering of illness and facing death tends to ‘demand’ the story: “It is the one liminal place within the human condition that calls for sense making and this often takes narrative form” p.1. Illness narrative research recognizes that the apparently commonplace phenomenon of people ‘telling their illness story’ is often a way in which they integrate their symptoms into a new sense of self or personhood. Gareth Williams²¹ refers to this as ‘narrative reconstruction’. He is one of several sociologists who focus on the way the personal stories appear to mitigate the loss of self-identity arising from the experience of illness or disability. Thus, the illness story may arise from a hope to enable a re-establishment of a continuity and sense of self, even in the face of death.^{22,23} In some cases, the telling of one’s illness story proves to be an opportunity to find a politicized ‘voice’ and raise public awareness of issues.^{24,25} Several sociologists who succumbed to life-threatening illnesses themselves have combined personal experience with sociological interpretation.^{26,27,23} These accounts, in a similar way to those written by healthcare professionals facing serious illness and death, potentially raise the profile of narrative research and provide an impetus in encouraging others in the field to develop narrative research methods and skills.

Narrative research

It is important to distinguish between qualitative analysis applied to narratives and narrative analysis as a method. In the former, general methods of qualitative analysis such as thematic, discourse and conversation analysis may be applied to the interpretation of narratives as well as other sources of data; while in the latter specific, analytic techniques have been developed devoted to narratives alone. In this article, we will concentrate on the latter types of narrative analysis methods as shown in Table 1.

Narrative research methods aim to explore the meanings within individual narratives and gain a general overview of subjective experiences. There are certain features that distinguish narrative research methods within the broad field of qualitative methodology. Narrative research only deals with stories (in any media), and research is specifically designed to work with or to generate stories. For example, Charlotte Linde’s theory of ‘narrative coherence’,²⁸ described below, is developed to examine particular aspects of the content, structure and form of life stories, as distinct from the structure of com-

Table 1 Example of some key narrative analysis methods used in healthcare settings: type of analysis and process

Key data analysis foci	Type of analysis	Analytic process
Content of narratives	Life-grid time lines	'Life-grids' or 'timelines' of key biographical events: a technique developed by Atkinson, provides quantifiable, descriptive content, facilitates recall and exploration of the life story
Structure/form of narratives	Structure/form	Six separate elements identified by Labov and Waletzky: subject summary, information about situation; what happened; what it meant to the narrator; how it ended; looking at the event from present perspective.
	Holistic (similarities and links with genre approaches)	Holistic analysis as described by Mishler, and in more detail by Lieblich, <i>et al.</i> , uncovers effects and experience of socio-cultural-economic factors in the narrator's life. The story is seen as a performance with the narrator reworking events as part of a process in which the story may fulfil different functions (depending on purpose) e.g. sense making or therapeutic.
Content/form/structure of narratives	Biographical-Narrative-Interpretative-Method (BNIM)	Highly formalized version of structural/form analysis developed by Wengraf for application to life-story interviews: examines structure and connections between different versions of the same biography
	Coherence	Developed by Linde: cultural and historical context of personal stories are examined via the descriptions and expressions of the narrator's 'system of beliefs and relations between beliefs'. These 'narrative linkages' explored by identifying the causal connections the person draws on when e.g. recalling early childhood/specific events.
	Genre	Developed by Frank: identifies the 'genre' or literary 'form' of the narrative, borrowing archetypal categories from literature, such as 'comedy, tragedy, satire, or epic'. Analysis includes noting the presence or absence of different genres and comparative differences in ways a narrative engages with genres. Can explore underlying meanings of the narrator's experience within their socio-cultural context.

mentary, descriptive interviews or everyday exchanges. Narrative analysis encompasses a number of techniques that offer differing levels of engagement with narrative data. Different typologies and data collection techniques developed by health and social science narrative researchers all work around the three key aspects of narrative content, structure and/or form. Table 1 provides a summary of some key narrative methods.

In comparison, general qualitative analysis methods may also be used to engage with sources of data that have a narrative structure. For example, 'thematic analysis' discourse analysis and conversation analysis, all commonly used qualitative methods, are often used to explore narrative texts or interviews. Identifying the 'genre' or literary 'form' of the narrative borrows archetypal categories from literature, such as 'comedy', 'tragedy', 'satire' or 'epic' can be used within a thematic analysis to build a greater depth of understanding of the ways people process and make sense of their experience. Content analysis of key themes in a published literary illness narrative, for example, provides a very different level of engagement with the text when compared with a discourse analysis 'micro-examination' of the pattern of narrative structure and form in oral storytelling, such as use of language, pauses and intonation.²⁹ Content analysis encompasses a range of methods concerned with 'what is said' and 'thematic' analysis, which examine descriptive content, chronology of events and word usage. Identifying different ele-

ments in text allows the researcher to examine unexpected 'snapshot' intertextual stories that for example, in short segments of story within a longer qualitative interview or text.¹⁶

Returning to specific narrative analysis methods, Arthur Frank²⁶ developed the life-grid method to identify three categories specifically arising from illness narratives; 'restitution' (all can be restored), 'chaos' (all is lost) and 'quest' (deeper meaning will arise from suffering). This kind of genre analysis enables a comparison of the different kinds of direction and experience described in stories of illness journeys or trajectories. Researchers like Brett Smith and Andrew Sparkes³⁰ have built on Frank's original thesis highlighting the potential for such analytic strategies to broaden and develop illness narrative theory in ways that support improvement in understanding patients' needs. Such broadening of our knowledge may ultimately influence healthcare policy and practice.

Biographical accounts and stories of daily experience have stimulated the development of a range of specific narrative analytic methods that use differing amounts of content, structural and form analysis.³¹ Narrative coherence, life-grid timelines and 'biographical-narrative-interpretative-method' (BNIM),³² are methods by which researchers can explore and interpret the illness and end of life experience from the perspective of a person's life as a whole, within their socio-cultural context. Robert Atkinson's 'lifeline' approach, for instance,

categorizes a story as 'regressive' (a deteriorating situation) or 'progressive' (a situation of achievement and success).³³ There are other methods that are designed to actively work with storytelling that arises from the creative arts. The aim is to interpret the 'performance' of storytelling in terms of, for instance, how people make sense of their experience in relation to their everyday lives; gain new perspectives on the event or series of events; express a political or personal point or facilitate a therapeutic process by sharing the experience of traumatic events.³⁴

Examples of narrative research methods in palliative care

To date, research in palliative care falls into two main categories: firstly, studies using general qualitative research designs to thematically analyse narrative interviews and other data sources, and secondly, studies utilizing specifically narrative designs derived from one or more of the narrative research methods listed in Table 1.

An example of qualitative research using thematic narrative analysis focused on content is well-illustrated by Anne Grinyer, who conducted an extensive in-depth diary-based study with parents of children who as young adults had suffered terminal illness. Parents taking part in the study were invited to share a written story of their experience of their child's illness.³⁵ At the time of the study, many of the young adults had already died. Some parental accounts had been written in diary form at the time of their child's illness and eventual death; other parents wrote retrospectively about these events. Grinyer's thematic analysis of these narratives uncovered a range of experience, complex underlying issues and feelings about the impact of such a tragedy on the parents, their relationship with their child, other members of the family, friends and relatives. According to Grinyer,³⁶ there are certain circumstances in which participants may value the written narrative compared with an interview in that it allows the option of how and when to reflect on their experience (in this case most were writing narratives on the death of their son or daughter). Given that this such painful recollection, the ability to select the moment (which may be during a sleepless night), the length of time devoted to the task (which may be minutes or hours) and not to have to anticipate in advance of an interviewer's visit that he/she will feel able to engage with the account at a particular moment in time, may make writing an appropriate method.

In a remarkably detailed 'micro-examination' of the concept of 'hope' in the end of life stories of patients and the healthcare professionals caring for them, Jaklin Elliott and Ian Olver³⁷ (2007) use discourse and conversational analysis. They examine the ways patients and profes-

sionals use 'hope' as a noun and as a verb in the speech patterns and word usage of the stories they collected through semi-structured narrative interviews. They uncover various underlying and subtle differences in meanings of hope between patients and their healthcare professionals that suggested useful and different ways of thinking about and discussing hope with patients as they face death. Elliott and Olvers' study resonates with an earlier similar study by Miles Little and Emma-Jane Sayers, who drew out the discourses of hope between patient and healthcare professionals and noted that the verb 'to hope' gives patients more 'meaning in life' and autonomy.³⁸

An increasing number of qualitative studies explore the stories of nurses working in palliative care settings use, methods that facilitate the interpretation of their experiences. These approaches draw on the theory of phenomenological hermeneutics and aims, through written and spoken stories, to uncover feelings and thoughts about the intricacies of the person's everyday experiences. Margareta Brännström, *et al.* (2005) for instance, found this method enabled getting a clearer understanding of the complexity of day-to-day issues that arose for nurses working in hospice.³⁹

Narrative research in action: benefits, challenges and validity

There is an ongoing debate around how clinical and sociological research views the 'validity' and usefulness of patient narratives, which draws on long-running philosophical, social theory debates about 'what is truth' in narrative text. As Riessman¹⁵ notes, this is a "thorny problem in narrative research" p. 21. But, as Ricoeur argues in his extensive theorizing on the relationship between text and our perceptions of truth as expressed in stories, the narrative is transformative, an opportunity for reflection about events – connecting the surface history of the narrated events with personal reactions infused by cultural and individual meanings. He thus draws out the complexity of the narrative for both the narrator and the reader, noting that the reading of the narrative adds yet another dimension, "the same story can be read in different ways because it is multi-layered" p. 298.⁴⁰ Riessman,¹⁵ drawing on similar sociological debates on validity, suggests that fundamentally "narratives are interpretative and, in turn, require interpretation" p. 22. She argues that "a personal narrative is not meant to be read as an exact record of what happened not is it a mirror of the world 'out there' concluding that this is the case precisely because narratives are always located in discourses (e.g. scientific, feminist, and therapeutic)" p. 64.¹⁵

In terms of the validity of narrative and qualitative research, Margarete Sandelowski and Julia Barroso⁴¹

argue that this kind of research does have validity, being based in real world experience and as case-orientated data is generalizable from the perspective of that representative sample. They do insist that to maintain and develop valid and valued qualitative and narrative research, researchers must be alert to the basis of their knowledge construction and the claims made as a result of interpretation of research 'findings'. Although the intricacies of the debate raised by Sandelowski and Barroso go beyond the remit of this short discussion paper, it is important to note these challenges and debates around the perceived value and evaluation of narrative research.

The point argued by narrative theorists is that the study of narrative/storytelling is by default less about accessing factual account and more about understanding the meanings that individuals' create and live by. Narrative analysis is 'valid' only where the truth status of the accounts analysed is regarded as irrelevant. The accounts function as a sense-making exercise for speakers, regardless of whether they are 'true' depictions of some other reality or not. Narratives have a complex and creative set of functions, which as Barbara Czarniaswka⁴² suggests, are firmly based in our social lives. Stories are an extraordinarily rich medium, acting to interpret and make sense of events, infused with multi-layered meanings, arising from and expressing personal, socio-cultural experience. Narrative research, rigorously conducted, can offer a lens through which we may gain a more nuanced understanding of end of life experiences. Trisha Greenhalgh,⁴³ a strong advocate of narrative approaches in medical education and social science-orientated health research makes this very relevant point: "Storytelling is not unscientific. On the contrary, a creative imagination is the scientist's greatest asset and is also the essence of competent clinical and moral decision making" p. 818.

Conclusion

Listening to patients' narratives has a well-documented history in palliative care, advocated by pioneers in the hospice movement such as Dame Cicely Saunders, who stressed the importance of attending to the stories of patients and their caregivers. The increase in illness narratives research on the part of social scientists is reflected in a growing interest in narrative research methods in palliative care. This trend is acknowledged in the current CECO initiative that draws on narrative research methods as integral to building research capacity in supportive and palliative care.

This article has identified and explored two different approaches: general qualitative research that focuses on narrative and specific narrative research methods. We have given some examples of how these approaches have

been developed and applied in healthcare in ways that highlight their potential value in palliative care research. Narrative research is an innovative specific approach in the field of qualitative methodology dedicated to ongoing development of rigorous analytic methods to better understand individual and cultural experience. Palliative care clinicians and researchers have the opportunity to build on a wide range of narrative research methods with potential to inform and improve healthcare policy, medical and health sciences training and practice.

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- 3 The Cancer Experiences Collaborative (CECo) brings together five UK universities led by Southampton with Liverpool, Lancaster, Manchester, and Nottingham. CECO has an opportunity over 5 years (2006–2011) to build research capacity in supportive and palliative care, by developing new research initiatives, resources and networks. Funding is provided by five partner organisations through the National Cancer Research Institute (NCRI) Supportive and Palliative Care (SuPaC) research collaborative scheme. CECO works through collaborating university-based research teams focusing on three key themes; innovative approaches to complex symptoms; planning for the care of older adults towards the end of life; and narrative research, as a methodological focus for all the themes. <http://www.ceco.org.uk/>.
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