

Title: Narrative in cancer research and policy: voice, knowledge and context

Sarah Atkinson

Centre for Medical Humanities, Durham University, DH1 3LE, UK

Tel: +44 191 334 1871

Fax: +44 191 334 1801

Email: [s.j.atkinson@durham.ac.uk](mailto:s.j.atkinson@durham.ac.uk)

Sara Rubinelli

Department of Health Sciences and Health Policy

University of Lucerne and Swiss Paraplegic Research, 6207 Nottwil, Switzerland.

Tel: +41 41 939 65 80

Fax: +41 41 939 65 66

Email: [sara.rubinelli@paranet.ch](mailto:sara.rubinelli@paranet.ch)

\*Corresponding author

## Abstract

*The potential applications of narrative within medical practice are attracting increased interest. In particular, personal narratives afford rich insights into how encounters with cancer and the associated provision of care are experienced, understood and represented. Such first-person accounts are practically useful in indicating improvements to cancer care and politically significant in providing a means to enable the patient voice and legitimising experiential knowledge alongside a biomedical paradigm. However, personal narratives are necessarily and always constructed in particular social and political contexts and through existing 'meta-narratives' relating to cancer, health, illness and a flourishing life. The paper first examines work on personal cancer narratives to critically review the opportunities for narrative within cancer care. We then reflect on the crucial role of meta-narratives of cancer as framings within which personal narratives can be both enabled and constrained.*

Keywords: Narrative, experience, personal, identity, resources, humanities, political, negotiation

*Short bios of the authors*

Sarah Atkinson is Professor in the Department of Geography and Associate Director of the Center for Medical Humanities at Durham University (UK). She is Elected Member of Council of the Association of Medical Humanities.

Sara Rubinelli is Assistant Professor of Health Communication at the Department of Health Sciences and Health Policy at the University of Lucerne (CH) and Swiss Paraplegic Research (CH). She is National Representative for the European Association for Communication in Healthcare.

## **1. Introduction to cancer narrative**

The Medical Humanities place a main emphasis on the link between narrative and the research and practice of medicine [1] [2]. The conceptual and methodological approaches of narrative have long been central to the scholarship of the humanities, but in recent decades there has also been a 'narrative turn' across the social sciences and medicine [3] [4]. The rise of interest in narrative in medicine rests on two related claims. First, there is increasing acknowledgement that a modern medical practice must include the patient as a partner in their own care. Discussions of patient-centred care, patient-led research and the rise of narrative medicine all attest to a trend for greater attention to the perspective and experiences of patients [5]. Secondly, there is growing acceptance that the practice of modern medicine requires narrative competency as an essential clinical skill for diagnosis and treatment, with a particular emphasis on listening [6]. Thus, narrative offers a potential means by which to access the subjective experience of illness [7] and to empower the patient voice within both medicine and wider society [5] [8] [9].

Research on cancer narratives and the practice of narrative medicine are rapidly growing fields. In this paper, we discuss the contributions of narrative-based research for the care of people with cancer in relation to two narrative scales. First, we introduce and discuss claims made for how narrative-based research benefits care through better understanding of the subjective experiences of cancer patients, with a focus on the notion of biographical disruption. Secondly, we consider the contexts within which narratives are constructed, and reflect on the important role of meta-narratives relating to cancer in contemporary society.

## **2. Personal narratives: legitimising the patient voice**

The broad spectrum of interests in what personal narrative may offer to understanding illness and medical practice is inevitably associated with a competing range of definitions and engagements of and with the concept of narrative. But for the most part, an emphasis on narrative assumes two important characteristics of human subjectivity: first, that human beings are 'naturally narrative', that is that we translate and ascribe meaning to events and experiences through a process of story-telling; and secondly, that these discursive translations are coextensive with experience and identity [9]. It is within these two assumptions that narrative-research on the experiences of living with cancer has gained traction within the practice of medicine.

The role for narrative research and practice in medicine has been strongly premised on an argument that illnesses, such as cancer, disrupt the stories that one tells to oneself about oneself. This process constitutes a biographical disruption in that our personal narratives are seen as an essential part of our self-identity [10]: 'Illness represents change and therefore constitutes a potential threat to maintenance of a coherent self. In this way, illness is understood as a disruptive event.' [11, p. 179]. Frank calls cancer a 'deep illness' which 'casts a shadow over the rest of a person's life' and leaves many 'feeling literally dislocated, no longer fully connected to the ground on which they stand' [12, p. 185]. Living with cancer, then, involves biographical work in renegotiating identity [7]. The role for narrative-based research is to understand how biographical disruption affects lives and identities and how biographical work is carried out in order to design appropriate responses and support. Narrative sources, such as published autobiographies, web-site testimonials or narrative exchanges through support groups, may constitute part of that response by offering resources from which to reconstruct one's personal narrative and identity.

Empirical research and the clinical use of cancer patient narratives have provided rich information from which to improve care delivery and expand the range of support and services available. The inclusion of 'narrative medicine' into clinical practice across a range of medical settings is advocated to enable care that is more personalised and responsive to the needs of patients. Moreover, a narrative focus offers an alternative to patient experience approaches informed by psychosocial oncology in which expressions of negative affect are pathologised into psychiatric categories and treated through medication or counselling referrals [7]. Allowing and enabling patients to tell their own story and work through the elements of their own experiences towards reconstructing their narrative constitutes a very different mode of supporting cancer patients to cope with the shifting relationships to self, close friends and family and the institutionalised practice of medicine; here instead of a focus on the outcome of coping, the focus is on the process of meaning-making [7]. Moreover, the therapeutic process of narrating one's experiences, being listened to and heard is itself performative in creating and recreating the very self that it claims as its origin [12] [13] [14] [15].

The public availability of an ever expanding body of published autobiographical work on living with cancer has to some extent lifted the silence and stigma that once shrouded a diagnosis of cancer, affording more openness within which to express the experiences

[12]. Nonetheless, communication for those living with cancer can be exhausting, especially with close family and friends. The growth of support networks, both physical and on-line, provides the space and relationships within which to undertake the kind of biographical narrative work that the experience of 'deep illness' may demand [16]. Existing autobiographies, support groups, on-line information and support groups, as well as a more personalised, narrative-facing medical practice, all can improve the cancer patients' access to needed resources.

Cancer narratives indicate areas for the health professionals to consider in developing more patient-centred care. Information can help support patient coping strategies and cancer narratives have shown the need for information and support that goes beyond a narrow concept of medical care as the illness experience affects all aspects of patients' lives, including functional capacity, financial strain, and stress on relations with friends and family [14] [7] [15]. Research on cancer narratives illuminates how the feelings of vulnerability from the range of impacts on identity can undermine an active engagement with information exchange. The pathways and timings of becoming more actively engaged are highly variable, suggesting the need to offer opportunities to provide information regularly within the care process [15]. A similar emphasis on the continuity of care and support is indicated by narrative research post-treatment, which supports Frank's description of 'deep illness' in revealing a long-term sense of uncertainty and vulnerability to illness even after an extended cancer-free period [17].

Patient narratives have also facilitated a personalised care through revealing the extent of variation in the meanings and form given to the experience of life with cancer. Researchers have sought both commonalities and differences across patient narratives. Commonalities are observed in terms of abstract experiential concepts such as loss, uncertainty and conflict, embracing or resisting change [18] but endeavours to draw out typologies of narrative illustrate the complexity and diversity. Evans et al. [18] described variation in narratives according to whether they focus predominantly on the factual, the emotional or the moral. In the 'Wounded Storyteller', Frank [8] offered a three-fold typology of published autobiographical narratives, i.e. restitution, chaos and quest narratives. Frank's typology of illness narrative is arguably the best known and most widely referenced (see for example, Jones et al. [19]). Such typologies of narrative form can highlight the diversity of meanings and forms given to the experiences of cancer.

At the same time, typologies can also risk narrowing and to some extent homogenising experience into a few categories. The risk here is of stereotyping the issues that matter to people living with cancer, as illustrated through studies of the gendered experiences of breast cancer. The experience of mastectomy has been assumed to carry particular meanings related to body image, femininity and sexuality. However, narrative-based research reveals that although these themes are discussed, there is little evidence of a narrow or dominant preoccupation with femininity and sexuality. On the contrary, the narrative accounts reveal a wide range of concerns across medical, functional and broader gender concerns, including women's agency as mothers, physical beings and whole and healthy individuals as well as much variation in how these themes are expressed and constructed [20] [21]. Narrative accounts often emphasise that the work of cancer in re-negotiating identity and self can only be understood as a highly situated and relational process and demanding greater research attention to the everyday work of getting by [12] [21].

### **3. Limitations of the personal narrative perspective**

The framing through biographical disruption, in its many expressions, has dominated the uptake of narrative into medical framings and practice. However, there are important critiques of the linked concepts of biographical disruption and narrative beings. Several authors have now challenged the ubiquity of an experience of cancer's biographical disruption, drawing on 'normal hardship theory'. According to this view, diagnosis of a 'deep illness', such as cancer, may be experienced as biographically continuous, rather than disruptive, in a context of lifelong economic and social problems, previous and existing illness or ageing [22]. Moreover, the prior experience of living through hardship may equip these cancer patients with particular resources and skills for managing their illness. A second critique argues that there is an over-emphasis on a cognitive self at the expense of an embodied self. Thus Reeve et al. [23] call for a combined attention to cognitive narratives and embodied feelings and emotions in developing personalised medicine. Whilst these critiques again stress the dangers of homogenising the experiences of cancer patients and the need to listen and respond sensitively to personal cases, they also indicate differentiated experiences of cancer across different socio-economic class, illness histories and other relevant social categories.

Others warn against an over-dependency on narrative research and narrative medicine to redress the ills of a mechanistic and dehumanised medical practice [24]. The current success of narrative within medicine reflects congruence between rhetoric for patient-

centred models and the apparent potential for narrative to enable patient agency. However, narrative is an add-on within the dominant medical paradigm in which humans are conceptualised as first biological and only secondly social or narrative. What-is-more, demonstrating the value of narrative to medicine requires the imposition of quantitative and instrumental logics onto the humanistic approach or the acceptance of this approach based on a vision of humans as ‘the being who thinks their own being’ [24] [25].

Atkinson [26] also warns against an instrumental understanding of narrative as a simple means to access subjective illness experiences. Narratives, as complex acts of speech, are constructed in particular times, places, and draw on shared narrative resources. A further caution to the current enthusiasm for narrative research and narrative medicine challenges the assumption that, as human beings, we are naturally narrative [27] [28]. In an opposite argument to Frank that also draws on his own biography, Strawson contests the claim that all humans are narrative on the grounds that he himself is not. Whilst this argument generates passionate debate, what we may draw from this is an imperative to be attentive to the possibilities of undocumented diversity in relation to narrative and to consider options for alternative non-verbal, non-narrative resources through which those experiencing cancer, may express and explore their experiences, negotiate identity and manage daily lives. Tekla Les, for example, describes how a diagnosis of cancer led her to work through her experiences and feelings in the medium of creative art, specifically creating three-dimensional art in the form of boxes using found objects [29]. And as already discussed, embodied feelings in the cancer experience may not be readily narrated [23].

#### **4. Landscapes of cancer narrative: contextualising the patient voice**

Many of the writers who advocate attention to narrative emphasise the complex and situated ways in which people living with illness such as cancer mobilise a range of discursive resources from their material, cultural and interpersonal contexts [4] [30]. Frank in particular emphasises the extent to which an autobiography is necessarily framed within the norms of reference of the time and place in which it is produced. He additionally critiques the impression often given in narrative and narrative interpretation that ‘imagines the storyteller becoming *alone*’ (30: 138, italics in original). Narratives, then, following Atkinson’s critique [26] are never simple routes into an authentic, subjective experience, but are on the one hand, something of an assemblage constructed from existing resources at the narrator’s disposal and, on the other hand, always a performance, both as a speech

act produced in response to the perceived requirements or opportunities of a given social setting and as creating and recreating identity for the self through the narrative act. As such, narratives may reveal as much, if not more, about the norms and dominant meta-narratives of the social, cultural and political context in which they are produced as they do about the narrator themselves.

The Medical Humanities has given far less attention to the nature of meta-narratives of cancer and cancer related policies than it has to the concerns of biographical disruption and personal narrative. But an attention to the normative framings of the current priorities and policies for cancer care can provoke important reflections by both patients and health professionals on our own narratives and practice. As we discuss below, two dominant and interrelated contemporary meta-narratives of cancer illustrate this point: emphasis on early detection and treatment for cancer and the notion of survivorship. We then respond to the call to attend to what is not said as much as what is said to ask what aspects of cancer are routinely excluded from patient and professional narratives [31].

The combination of increasing numbers of people living with cancer, an ageing population, the identification of new cancer types and the emergence of a plethora of non-governmental organisations championing cancer research, cancer support and cancer-related education has raised public awareness of and greater openness towards talking about cancer [32]. There are fund-raising events, most often effected through a vast array of sponsored sporting activities, marketing of attractive logos and emblems, such as the pink ribbon of breast cancer, and sensitive portrayals of cancer experiences in the popular media. The early writers, such as Sontag, who decried the stigmatising silence surrounding cancer [33], or Lorde, who railed against the normative expectations of performing as a good patient [34], might barely recognise many aspects of the contemporary landscape of cancer in Western societies. But questioning social and political engagement with illness must be seen as an on-going, never ending enterprise [12]. And alongside greater openness and awareness, contemporary cancer care is characterised by two dominant narratives - a drive for early detection, for treatment and monitoring and a celebration of those that have been through cancer treatment as survivors [35] [32]. Hope for a better future in relation to cancer is almost entirely invested into the potential of medical science to develop effective cures. What is almost entirely absent, with the notable exception of lifestyle factors and especially smoking, is an equal attention to cancer prevention and particularly to cancer prevention through environmental



regulation. The early autobiographers empowered cancer patients through their creative understanding of the oppressive narratives of their own day and they continue to hold contemporary relevance: 'refusing to let their stories be summarized by the trope of early detection, writers and activists rewrote the narrative, opening it to a broader critique of representations of health, exclusionary health care practices, painful therapy option, and the uncertainty that surrounds any breast cancer treatment.' (32, p. 346).

Various factors contribute to the dominant emphasis on detection and cure rather than prevention. Shifts in the framing of health more generally have witnessed a greater emphasis on personal responsibility for maintaining and perfecting both body and health [36] [37]. In an individualised medicine, responsibility for cancer prevention is placed squarely with the individual and individual lifestyle choices; regulatory interventions are mostly responsive to long-term pressures, as in the case of smoking, sponsorship and advertising. The powerful pharmaceutical industry is obviously interested in a treatment-based model of medicine, or, at best, a drug or procedure based model of prevention. So whilst the life-affirming events of the contemporary cancer landscape are undoubtedly empowering for many, the ambivalence of corporate sponsorship means, 'the empowered patient – the activist-expert, the survivor – has become institutionalized and incorporated into the fabric of the cancer establishment' [38,p. 107].

Other reasons for focusing less on prevention include the difficulties of proving environmental hazards for cancer, the statistical challenges of small numbers and small heightened relative risks and the powerful interests contesting data and evidence (see for example, the competing claims for legitimate knowledge of environmental cancer risks in Long Island [39]).

The promotion of the term "cancer survivor" constituted a major shift from treating those who had been through cancer as stigmatised victims to heroic survivors, the empowerment of whom cannot be underestimated. Mullan [40] argued that the categories of sickness and cure inadequately captured the long-term experiences of the cancer patient. However, more recently, Bartels, whilst recognising the importance of this linguistic shift for cancer patients, asks if it might be time to revisit the concept to redress two unforeseen negative aspects. The concept of a cancer survivor first ties identity forever to the illness and secondly assumes a shared identity and fellowship within an 'undifferentiated "Cancerland"' [35, p. 238]. The empowerment of survivorship derives from

highlighting that people with cancer are not necessarily dying, but thereby effects what Bartels terms a life sentence of 'we are *a/ways* not dying' (p247, italics in original). Bartels calls for a move away from this powerful narrative to allow people with no signs of recurring cancer the space to represent themselves as cancer-free, even though there is never certainty on this, and thereby 'assign as much value to the ordinary condition of being alive and healthy as we do to the extraordinary condition of staying alive against the odds.' [35, p. 250].

## Conclusions

The inclusion of cancer patient narratives within modern medicine brings a number of important benefits to the provision of care including greater responsiveness to a wide range of patient needs, awareness of the diversity in experience and support and empowerment of patients as partners in their own care. Caution is needed to avoid simplistic, homogenising typologies of narrative and of stereotyped assumptions of needs. Cancer patients may benefit from a wide range of narrative resources from which to negotiate and assemble their identities including the process of telling their own stories, the performance of which can contribute to such biographical work.

Whilst the uses of narrative within medical care are very welcome, narrative can also contribute to the broader debates in contemporary medicine and public health and in considerations of what it means to be human. First, narrative can be more than an add-on, but rather a way of thinking about what human beings may be. Secondly, not all humans are necessarily narrative and other forms of support may be more appropriate. Thirdly, narrative privileges cognition at the expense of embodiment and embodied feelings. Fourthly, an emphasis on biographical disruption can conceal the social inequalities which render the experience of cancer for some a biographical continuity. Finally, we call for greater attention within cancer narrative research to the meta-narratives of the contemporary landscape of cancer care. In giving attention to dominant meta-narratives such as that of cancer care and the parallel absence of environmental reference, we give explicit attention to possible limits on the narrative resources available to the majority of cancer patient in building their own illness narratives. Meta-narratives offer a valuable ground for the analysis and evaluation of narratives as they can inform and frame cancer patient experience, health professional engagement in service provision and, ultimately, the phenomena at the basis of health policy.

## Acknowledgements

The authors thank the European School of Oncology (ESO) for their generous support to the task force on Medical Humanities through which this paper has been produced.

Sarah Atkinson is supported through a strategic award from the Wellcome Trust (Grant WT086049: Medicine and human flourishing).

## REFERENCES

- [1] Martignoni, G, Grignoli, N, Di Bernardo, V, Malacrida, M, Bernegger, G, Barazzoni, M, Malacrida, R. Medical Humanities: a question of style. 2012 (ESO TF Med Hum supplement – details and pages to be completed)
- [2] Schiavone, G, Boniolo, G, Annoni, M, Chiapperino, L. Constructing the Medical Humanities gaze. 2012 (ESO TF Med Hum supplement – details and pages to be completed)
- [3] Hurwitz B, Greenhalgh, T, Skultans V. Introduction. In: Hurwitz B, Greenhalgh T, Skultans V, editors. (2004) Narrative research in health and illness, London: Blackwell; 2005, pp. 1-20
- [4] Thomas C. Cancer narratives and methodological uncertainties. Qual Res 2009; 8: 423-433
- [5] Shapiro J. Illness narratives: reliability, authenticity and the empathic witness. Med Hum 2011; 37: 68-72
- [6] Goyal RK, Charron R, Lekas H-M, Fullilove MT, Devlin MJ, Falzon L, Wyer PC. 'A local habitation and a name': how narrative evidence-based medicine transforms the translational research paradigm. J Eval Cli Prac 2008; 14: 732-741
- [7] Mathieson CM, Stam HJ. Renegotiating identity: cancer narratives. Sociol Health Ill 1995; 17: 283-306

- [8] Frank AW. The wounded storyteller: body, illness and ethics. Chicago: Chicago Press; 1995.
- [9] Woods A. The limits of narrative: provocations for the medical humanities. *Med Hum* 2011; 37: 73-78
- [10] Hutto DD. Narrative and understanding persons. *Roy I Ph S* 2007; 60: 1-16.
- [11] Reeve J, Lloyd-Williams M, Payne S, Dowrick C. Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health* 2010; 14: 178-195
- [12] Frank AW. Tricksters and truth tellers: narrating illness in an age of authenticity and appropriation. *Lit Med* 2009; 28: 185-199
- [13] Skott C. Expressive metaphors in cancer narratives. *Cancer Nurs* 2002; 25: 230-235
- [14] Kameny RR, Brearison DJ. Cancer narratives of adolescents and young adults: a quantitative and qualitative analysis. *Child Health Care* 2002; 31: 143-173
- [15] Van der Molen B. Relating information needs to the cancer experience. 2. Themes from six cancer narratives. *Eur J Cancer Care* 2000; 9: 48-54
- [16] Yaskowich KM, Stam HJ. Cancer narratives and the cancer support group. *JHealth Psychol* 2003; 8: 720-737
- [17] Woodgate RL. Life is never the same: childhood cancer narratives. *Eur J Cancer Care* 2005; 15: 8-18
- [18] Evans M, Shaw A, Sharp D. Integrity in patients' stories: 'Meaning-making' through narrative in supportive cancer care. *Eur J Integr Med* 2012; 4: e11–e18
- [19] Jones T, Cohen F, Shapiro J. Minding the gap(s): Narrativity and Liminality in Medical Student Writing. *Lit Med* 2012; 30: 103–123

[20] Langellier KM, Sullivan CF. Breast talk in breast cancer narratives. *Qual Health Res* 1998; 8: 76-94

[21] Schutlz JE. (Un)body double: a rhapsody on hairless identity. *Lit Med* 2009; 28: 371-393

[22] Sinding C, Wiernikowski J. Disruption foreclosed: older women's cancer narratives. *Health* 2008; 12: 389-411

[23] Reeve J, Lloyd-Williams M, Payne S, Dowrick C. Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health*, 2010; 14: 178-195.

[24] Bishop JP. Rejecting medical humanism: medical humanities and the metaphysics of medicine. *J Med Hum* 2008; 29: 15-25

[25] Petersen A, Bleakley A, Brömer R, Marshall R. The medical humanities today: humane health care or tool of governance? *J Med Hum* 2008; 19: 1-4.

[26] Atkinson, P. Illness narratives revisited: the failure of narrative reductionism. *Sociol Res Online* 2009; 14 (5) 16 doi:10.5153/sro.2030  
<http://www.socresonline.org.uk/14/5/16.html>

[27] Strawson G. Against narrativity. *Ratio* 2004; 17: 428-452.

[28] Strawson G. Episodic ethics. *Roy Inst Ph S* 2007; 60: 85-116.

[29] Tekla Les, J. When spoken words fail. *Lit Med* 2009; 28: 200-214

[30] Frank AW. Illness and autobiographical work: dialogue as narrative destabilization. *Qual Sociol* 2000; 23: 135-156

[31] Charmaz K. Stories and silences: disclosures and self in chronic illness. *Qual Inquir* 2002; 8: 302-328.

[32] Gardner KE. Disruption and cancer narratives: from awareness to advocacy. *Lit Med* 2009; 28: 333-350

[33] Sontag S. *Illness as metaphor*. New York: Farrar, Strauss and Giroux, New York, 1978.

[34] Lorde A. *The cancer journals*. Argyle NY: Spinsters Ink., 1980.

[35] Bartels EC. Outside the box: surviving survival. *Lit Med* 2009; 28: 237-252

[36] Galvin R. Disturbing notions of chronic illness and individual responsibility: towards a genealogy of morals. *Health* 2002; 6: 107–137

[37] Miller P, Rose N. *Governing the present*. Cambridge: Polity Press, 2008.

[38] King S. *Pink ribbons, Inc. Breast cancer and the politics of philanthropy*. Minneapolis: University of Minnesota Press, 2006.

[39] Diedrich L, Boyce E. 'Breast cancer on Long Island': the emergence of a new object through mapping practices. *BioSocieties* 2007; 2: 193-218

[40] Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med* 1985; 313: 270-3.

