
“Lives at Risk” Study: Philosophical and Ethical Implications of Using Narrative Inquiry in Health Services Research

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Abstract

Narratives ascribe meaning to individual experience and life events through a process of storytelling. Storytelling provides a context for understanding illness and health by mirroring life back to the self while at the same time disseminating personal inner thoughts of the storyteller out to the wider world.

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This chapter will examine the contribution, meaning, and value of narrative inquiry within a health services research context. In so doing, it considers one specific case study, the “Lives at Risk” study, discussing some of the philosophical and ethical implications of narrative inquiry as it relates to this case.

Introduction

This chapter examines the contribution, meaning, and value of narrative inquiry within a health services research context. In so doing, it considers one specific case study, the “Lives at Risk” study (described in detail later in the chapter), discussing some of the philosophical and ethical implications of narrative inquiry as it relates to the case.

What Is Narrative Inquiry?

People have been telling stories (also known here as narratives) about how they live and what that means to them as a natural human response to life. A narrative inquiry approach within a health services research context has emerged relatively recently, from within the broader field of qualitative inquiry in social and human sciences. In other fields, such as education and sociology, narrative inquiry is much more familiar. Narrative inquiry, as a research method, has been said to contribute to knowledge development as a means of information transfer:

...lived and told stories and the talk about the stories are one of the ways that we fill our world with meaning. (Clandinin and Rosiek 2007, p. 35)

Narrative inquiry is considered to be a form of storytelling (Frank 1995, p. 19). In this sense, the process of *telling* offers insights for the researcher into the social phenomena being considered, while adding to our understanding through the storyteller’s (or research participant’s) approach to presentation. Narrative inquiry, most typically, uses qualitative data collected from personal stories, autobiographies, journals, letters, interviews, and photographs to develop greater knowledge and understanding of the meanings people attach to their lives (Connelly and Clandinin 2000) and their sense of identity and selfhood (Ricoeur 1992). The uncovering of subjective truths by engaging with a variety of texts may produce a richer and more holistic understanding of the lived experience (Ricoeur 1991; Wiggs 2011) as opposed to considering individuals as “social variables” that can in some way be measured (Maynes et al. 2012, p. 16), apparent within impersonal statistical analyses.

Narrative inquiry data can be collected over a brief or extended period of time and can contribute to the development of broader understanding of what it means to be human within a social setting, as well as narrower understanding of an individual’s personal experience (Connelly and Clandinin 2000; Nettelbeck 2008).

Understanding the experience of the research participant through narrative presentation allows the health services researcher to gain an "insider view" (Wang and Geale 2015, p. 2). The researcher aims to develop a deeper understanding of health issues as experienced by participants (Green 2013) and through the participants' own, enhanced self-awareness (Skultans 2000), while at the same time acknowledging participants' own subjectivity during the process of data collection, interpretation, and presentation of stories (Wang and Geale 2015).

Narrative inquiry, to reiterate, is principally an approach that seeks to identify, represent, and share knowledge and the experiences of others as they may apply to a range of different social phenomena. In effect, the process of telling a story enables knowledge to be transferred from the storyteller to the listener (Frank 1995, p. 19) while allowing meaning to be bestowed in the form of a collective narrative of a particular life experience (Bruner 2003). Knowledge transfer relies heavily on the storyteller's private memory and the moment in time in which the story is told, as much as it does to and the meanings assigned to it. Narratives are often interpreted and reinterpreted by the teller and the audience in light of their own perceived values, identity, and positions of power, where they can exercise choice on aspects of narratives with which they wish to identify and those to which they feel less affinity. Research participants are often clear about which aspects of their narratives are likely to resonate with a particular type of audience and so adjust them accordingly. Cathy Kohler Riessman (2008, p. 3) summarizes this by saying:

...a speaker connects events in a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take-away (sic) from their story. Events perceived by the speaker as important are selected, organised, connected and evaluated as meaningful for a particular audience.

Kohler Riessman also helpfully outlines the many uses of narratives, from constructing individual and group identities to initiating social action and giving voice to those who are least heard. However, Frank adds a note of caution, stating that the process of telling stories, although beneficial, could affect the research participant in some unforeseen and "dangerous" way (Frank 2010, p. 71), a point which the researcher should be aware of at all times when engaging with participants. Thus, narratives are not "static entities," and they should be understood as part of an ongoing dialogical relationship between storyteller, listener, and audience (Riessman 2008; Frank 2010).

Analyzing Narratives

Storied lives are far from autonomous constructions or reconstructions of stand-alone experiences. Rather, they should be understood in terms of relational and situational experiences, referencing existing social, political, and cultural events and encounters that forge an identity for the self. Individual personal narratives are

often located within these larger meta-narratives of social experience, in order to make meaningful sense (Atkinson and Rubinelli 2012).

Connelly and Clandinin (2006, pp. 477–487) have developed a conceptual framework consisting of narrative “temporality,” “sociality,” and “place” for supporting the analysis and reporting of others’ narratives in a more precise way. *Temporality* can refer to the timeframe being described within a story and the way that time impacts on the telling of the story. Temporality also refers to the changing nature of stories as told, in order to make the most appropriate meaning of a person’s life, for as Carr (1986, p. 76) indicates, “we are composing and constantly revising our autobiographies as we go along.” In so doing, the future emerges from the understanding of various iterations of a person’s narrative. Such temporality refers not only to the storyteller’s life but also to the places, objects, and events in which encounters and experiences are contextualized.

Sociality refers to the way personal and social experiences interplay in the shaping and delivery of stories, while *place* or the context of stories takes us beyond the personal aspects of experience to the context within which the story took place and the social conditions most relevant to that context. Marmon Silko (1996) emphasizes the importance of recognizing that physical boundaries are inextricably linked to the experiences that take place within specified places and that there is a need to recognize physical boundaries surrounding the context within which events in stories unfold in order to fully understand the meaning of the narrative. Connelly and Clandinin (2006) describe all three concepts as important contributing factors that shape meaning-making and personal association.

Landman (2012, p. 30) sets out four levels of analysis in support of Connelly and Clandinin’s (2006) conceptual framework. These are:

1. The linear level (relating to the sequential nature of storytelling and the basic structure of the narrative)
2. The relational level (what the story reveals about relationships between storyteller and listener)
3. The emotional level (conveying the storyteller and listener’s feelings and subjective understandings of an event)
4. The analytical level (where the researcher reflects on the collected material)

Landman suggests that by underpinning the conceptual framework with these four levels of understanding, it is possible to guide researchers in making sense of how stories are told. Bruner (2003, p. 114) also illustrates this point when he says:

...the ways of telling and the ways of conceptualising that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for not only guiding the life narrative up to the present but directing it into the future.

Bruner (2003) identifies that in analytical terms, obtaining knowledge through narratives that are told, heard, and recreated for research purposes is an inherently

interpretative process. Not only do the individuals providing their narratives “filter out” information that they consider superfluous, but the researcher then filters out information that is not clearly aligned with the research purpose, research question, or overall endeavor for the purpose of clarifying the complex experiences, perceptions, and events they are hoping to interpret.

Unraveling Epistemological Questions that Arise from Narrative Inquiry

We turn next to the necessity of unraveling wider epistemological questions that can be bound up with the researcher’s appreciation of others’ narratives, in order to pass on knowledge about the personal experiences of others from a health services research perspective.

By considering philosophical and epistemological questions linked to narrative presentation, we can consider not only the story as told but also the nature and scope of the knowledge acquired, resonating with the need to appreciate that there are multiple ways of not only studying but also knowing the social worlds of others.

The research participant and the researcher, who are actively engaged in a narrative inquiry, directly affect the scope of knowledge acquired and, as a result, our understanding of social phenomena and the construction at a macro level of our social worlds. Bruner, cited in Charon and Montello (Charon and Montello 2002, p. 4), speaks of the epistemology of narratives as follows:

Telling stories is an astonishing thing. We are a species whose main purpose is to tell each other about the expected and the surprises that upset the expected, and we do that through the stories we tell.

Bruner claims that narrative inquiry is an instrument for collecting knowledge about experience, but that the collection of knowledge is not enough in and of itself. Rather, knowledge that is gleaned needs to be situated in a broader landscape to facilitate a deeper understanding of ontology, exploring truths embedded in what we come to know, as well as the way in which knowledge has been constructed. The cornerstones of narrative inquiry set out by Connelly and Clandinin (2006) may offer a framework for specifying certain dimensions of *new* knowledge to which Bruner refers, in as much as they support the passing on of knowledge and subsequently its reconstruction by others. Thus, re-situating stories and experiences within the social, political, and cultural fabric of society allows human endeavor to flourish.

The first cornerstone of Connelly and Clandinin’s (2006) framework, “temporality,” relates to the notion of continuity and change, envisaged within events, conversations, and individual thought, that then becomes the subject of the inquiry. As these are all in a state of flux, it is the job of the researcher to collect insights into the research participant’s associated past, present, and future expectations, to develop a more comprehensive view of how they make sense of their world.

The second cornerstone, “sociality,” focuses on the notion that in any given experience, event, or situation, people are always interacting with one another as well as simultaneously managing their own views and experiences of what is happening. Individuals’ feelings, hopes, opinions, and moralities, suggests Connelly and Clandinin (2006), may influence how the researcher will interact with the participant and, as such, are as implicit in shaping understanding and the retelling of stories. Moreover, the role of the researcher cannot be removed from how the narrative develops in form and content, because the relationship becomes integral to the disclosure of the narrative and in turn informs the context of disclosure. Simultaneously, social conditions, as referred to by Connelly and Clandinin (2006), can influence both the storyteller and the listener and can shape what is said and what is heard.

Clandinin and Rosiek (2007) have considered the wider philosophical issues surrounding narrative inquiry by referring to the way the researcher can be affected by conflicting narratives in their own academic and personal worlds and how this can then impact on the research process. While the researcher can offer information to the narrative audience about their own views, experiences, and personal position, this nevertheless creates an additional challenge for how stories are managed, interpreted, and represented.

Connelly and Clandinin’s (2006) final cornerstone, “place,” refers to the abstract, imagined, and recalled places within which events take place. In epistemological terms, while the events being narrated are crucial to meaning-making, knowing the worlds of others, according to the positive or negative associations that the storyteller bestows on them, is also essential. Thus, meaning must be extracted to imply not only context-building but also symbolic association, and the researcher must consider the best way to contextualize the impact of place within the interpretation of the narrative and the way it is reported.

Not all researchers choose to, or indeed are able to, grapple with the more complex philosophical challenges of understanding the epistemological and ontological dimensions of narrative inquiry. However, Connelly and Clandinin’s (2006) three cornerstones offer a useful framework for guiding researchers who wish to do so.

Pinnegar and Daynes (2007, p. 7) recognize that researchers must undertake a difficult personal transition if they wish to conduct philosophically appropriate and ethically driven narrative inquiries that take into account “the blurred genres of knowing.” They refer to the need to explore “narrative turns” (2007, p. 7) in the timeline of a researcher’s own conduct, suggesting that the “narrative turn” refers to:

... a change of direction from one way of thinking or being toward another ... in the process of designing, studying, and engaging in inquiries. (Pinnegar and Daynes 2007, p. 7)

In this respect, it is the researcher’s own motivation that influences the stories being told and the stories being heard. As a result, the researcher needs to consider her/his own responsibility and ethical stance, beyond the mere collection of the

research participant's story and the writing and dissemination of outputs. The researcher is embedded in the research process, in the shaping of telling, in the recollection and retelling of others' lives, and in the context of health and illness narratives.

With this in mind, we turn to Frank's (1995) categorization of patients' illness narratives as:

1. *Restitution narratives*, in which the storyline or "plot" involves returning in the narrative presentation to a previous state of health. For researchers working with those living with chronic illness, listening to stories of a long recovery can be both inspiring and intimidating.
2. *Chaos narratives*, in which all life events are in a state of flux and subject to change. For researchers, others' illness narratives can reveal vulnerability, futility, and impotence (Frank 1995) and can be difficult to hear.
3. *Quest narratives*, in which illness is seen as a journey (both spiritual and secular). Quest narratives may serve to instill within the researcher an appreciation of a narrative ethic of illness or, as Ricoeur defines it, "living a good life" (Ricoeur 1992, p. 172) for all concerned.

The categorization of stories, according to Frank's typology above, the process of analyzing stories according to these categories, and the impression that these stories make on the researcher require the extrapolation of meaning attributed to the researcher's own perceptions of temporality, sociality, and place. Narrative inquiry, in other words, is affected by:

the differences in people's experienced meaning, the stories they tell about this meaning and the connections between storied texts and the interpretation of those texts. (Polkinghorne 2007, p. 471)

Ethical Implications in Conducting Narrative Inquiry

In the pursuit of gaining new understanding in a health services research context, as the section above begins to explain, interesting ethical dilemmas can present themselves to the researcher. These relate to both the nature of understanding and the researcher's responsibility in the creation of new knowledge. Firstly, the notion that a narrative is socially constructed by both the research participant and the researcher, and then reconstructed by the researcher alone, indicates the existence of an unequal relationship and consequently an unequal distribution of power. Accordingly, it is important to acknowledge that while stories can become "research data," the dynamics of the situation and context of the collected narratives can change.

Secondly, because of the dialogical nature of storytelling (Frank 1995, p. 19), research participants may feel obliged to "say more" than they would ordinarily, in

order to uphold a conversation and build a trusting relationship with the researcher. The researcher must be aware of this and manage the situation carefully.

Thirdly, the researcher may respond to the dialogical nature of the relationship with the research participant, by becoming emotionally engaged not only with what they hear but also with the individual involved. As a result they may overlook or overstep the boundaries between the researcher and the researched, as laid out by the researcher's code of ethical practice. Some participants may be overcome by their emotions during narrative presentations, and a plan should be in place to manage such a situation should it arise (Wang and Geale 2015).

Fourthly, the researcher has a responsibility to the research participant to conduct research according to institutional codes of ethical practice and research principles (e.g., see British Sociological Association Code of Ethics, Academic Governance Protocols (British Sociological Association 2002)) and thus uphold an ethical relationship in studies involving narrative inquiry. This is pivotal to ensuring data are collected, analyzed, and disseminated appropriately. Finally, while it is well recognized that informed consent processes take place at the outset of a research study (Estroff 1995), in a narrative inquiry study, it is important for the researcher to appreciate the extent to which they are crafting the finished product and to consider whether there is a need to return to the research participants with their work before disseminating it more widely.

While attesting to the value of narrative inquiry, we also need to be aware of opposing arguments that question the value of narratives. Strawson (2004), for example, argues that the narrative model of meaning-making is not commonly experienced by individuals:

there are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative. (Strawson 2004, p. 429)

Strawson (2004) suggests that the explicit assumption that humans are happy to narrate by nature undermines those, and may even cause undue harm to those, who do not consider their experience of life in narrative form. Atkinson and Rubinelli (2012) suggest there are ways of overcoming such concerns, by offering alternative, "nonnarrative" approaches to meaning-making (such as creating art). These allow individuals to explore their personal and social experiences and give meaning to such experiences.

Narrative Inquiry in Action: The "Lives at Risk" Study

Having considered some of the ethical and philosophical issues associated with a narrative inquiry approach in a health services research context, the chapter now turns to narrative inquiry in action. The "Lives at Risk" study provides a case study to illustrate how the authors used the method reflectively, while taking into account the research participant's story, the context for storytelling, and the environment in

which patients' narratives were told. The case highlights both the specificities of the research study (its aims and research questions) and links the outcomes of the study through the concepts of "temporality," "sociality," and "place," the three cornerstones of narrative inquiry already outlined in this chapter (Connelly and Clandinin 2006, pp. 477–487).

The "Lives at Risk" study which, among its defined study objectives, aimed to improve the quality of service delivery for patients with breast cancer involved two cohorts of women: (1) women who had undergone treatment for one or more episodes of breast cancer and were being managed by an oncology unit and (2) women who were determined by clinicians to be at a genetic risk of breast cancer, but had never undergone treatment for breast cancer.

This study used bio-photographic qualitative data collection methods. These are methods of a visual and textual nature that can be considered as discrete elements, corroborative elements, or combined elements in a study. These methods used discretely or in combination can provide rich data that aims to add to our understanding of patient's personal experiences, and in this case textual and visual narrative materials were considered in terms of what it means for women to live with the "risk" of developing breast cancer or further cancer episodes. Study participants were asked to create "Books of Experience" as Stage 1 of the study. These were scrapbook-style, large, blank, spiral-bound books which were provided to enable women to present their narrative experiences in visual and textual formats. Participants were asked to present key aspects of their experience, such as being seen by an oncology consultant for risk assessment and risk presentation or being seen by a genetics specialist to discuss risk in relation to familial links with breast cancer and to relate these aspects of experience to the shaping of their own beliefs of what it means to be living a life "at risk." The research team provided a brief outline of six predetermined themes that the research sought to explore in order to support women's completion of the "Books": (1) risk assessment; (2) tests, treatments, and drugs; (3) impact on life; (4) support and care; (5) time periods; and (6) future expectations.

On completion, the "Books of Experience" were collected and considered by the research study team in accordance with the predetermined thematic areas of interest. Bio-photographic elicitation interviews were then conducted, as Stage 2 of the study, with each woman, who used the interview time to feel at liberty to interpret the Book's narrative for the researcher. Bio-photographic elicitation interviews also provided the opportunity for participants to convey the symbolism of described events, experiences, and images in more detail. The interview data encouraged the research team to explore how women responded to their own narrative presentations, once finalized.

The method of collecting bio-photographic data from the "Books of Experience" alongside the bio-photographic elicitation interviews provided women with the opportunity to clarify the disordered nature of real life for themselves and for the researcher and to highlight those areas that specifically related to their health and illness. The study findings illustrated that, irrespective of the independent nature of narrative creation, the researcher's role in the facilitation and collection of

narrative material enabled them to extract and forefront specific aspects of information. Furthermore, the research team's interpretation and involvement in the co-creation of these narratives was influenced by their impressions of the women's stories and the women's approach to narration, which would, in turn, influence how they engaged the reader or audience with the study outcomes.

Before reporting on the interpretative process and the findings generated from the "Lives at Risk" study, it is important to expand on the research study team's reflections of their influence in this narrative inquiry. It is also important to explore the associated impact of this on the representation of study participants' narratives. In this particular study, taking the notions of "temporality," "sociality," and "place" into account, the study team recognized the importance of the chosen context (a medical hospital environment) and the plethora of relationships within and beyond that context that shaped participants' experiences.

The research team identified that several aspects of the study researcher's own identity were significant in the collection and interpretation process. For example, the ethnicity of study participants was predominantly white Welsh, with only one patient from a non-white Welsh background, who, in addition, had recently relocated from England to Wales. The ethnicity of the study researcher, however, was Welsh-Asian, and the researcher thought that this might have influenced both the openness of the encounter and the development of rapport between researcher and study participant. Furthermore, the researcher clarified her role during the narrative inquiry and emphasized to study participants her nonclinical background and knowledge. The positioning of the researcher as a nonexpert among study participants contributed to developing equitable researcher-participant relationships and facilitated informal conversations around the retelling of experiences and events. The research team readily acknowledged that articulating a narrative can be influenced by the researcher's presence, the aims of the research itself, and how comprehensible the narratives might be.

The research team also acknowledged that the study researcher may have arrived at a different interpretation of the narratives in the "Books of Experience" and interviews than the team, following discussions during group analysis meetings. It is well documented (Bruner 2003; Riessman 2008; Maynes et al. 2012, p. 16) that narrative inquiry involves a process of shared meaning-making for the storyteller, research team, and audience in a social environment that is shaped by historical, cultural, and political or theoretical viewpoints. The "Lives at Risk" study team adopted a peer-group analysis approach to the "Books of Experience," which involved both study researcher and analysis team discussing their interpretations together through ongoing narrative analysis meetings during the whole study. Team meetings were extensive and undertaken to create an analytic research conversation by the wider team which, over time, helped hone down the data and clarify key issues arising.

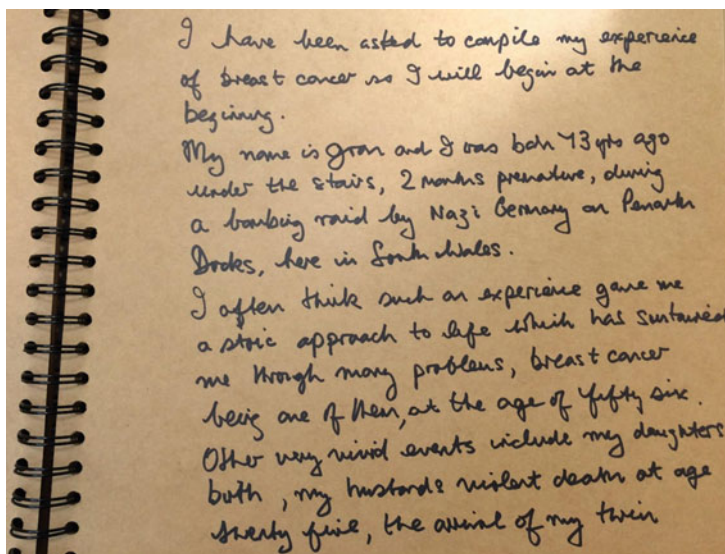
The following section outlines the study findings within the conceptual framework of Connelly and Clandinin's (2006, pp. 477–487) three cornerstones of narrative inquiry, supported by Landman's (2012, p. 30) four levels of analysis (linear, relational, emotional, and analytical).

Temporality

In the "Lives at Risk" study, women's narratives were strongly linked to their own personal and social discoveries and experiences, to which others have alluded (Maynes et al. 2012, p. 16), as well as their health and illness stories. There was a sense among study participants that they were struggling to take control of the transience of health and illness experiences, as they tried to ground their experiences in a more controllable, less quickly paced and less fleeting, reality. They did this by, for example, recording appointments meticulously, recording events in a diary, and counting the number of days taken off from work due to ill-health. The "Books" enabled women to create a longer-lasting legacy in some respects than might otherwise have been the case, bearing witness to their fear, pain, and regaining of health, and for this they were entirely grateful. The bio-photographic method allowed them to capture moments in time which enabled them to slow down the pace of their lives, securing moments that could, in effect, be bound and stilled between the pages of their "Books." The "Books," in essence, became not only active witnesses to these women's experiences but also evidence of moments in time and points of reflection, within which women could communicate their innermost thoughts about "who they were" and "how they lived" (Reissman 1993; Elliott 2005; Riessman 2008).

The "Books" became both creative elements and significant elements of their illness narratives. During their creation, they represented particular moments of ill-health and good health to which individuals attributed meaning. Women explored their own identities and considered how they could live with the risk of breast cancer and to what extent were they willing to renegotiate their identity to either accept or reject their current state of ill-health. According to Bruner (2003), outside the world of chronic ill-health, people are less likely to pause and take part in such conscious efforts of meaning-making.

The intersection between a life without cancer and a life with the possibility of cancer, or the confirmation of cancer, in any given moment in time, was one of the most striking features in these "Books." The temporality of women's sense of well-being was communicated clearly through this mixed media. One moment study participants illustrated and conveyed their wellness in terms of their health and daily routines, and the next they conveyed the chaotic array of emotions they were experiencing, following the news that they had been diagnosed with cancer, or told that they were "at risk" of developing breast cancer, through long textual diary-style transcriptions. Many study participants compartmentalized aspects and events into "before and after" cancer, acknowledging that they would not physically be the same person ever again, indicative of the importance of temporality in their lives. There was also a sense of loss, which was turned, by many, into an occasion for positive action. Women created new narratives of living, thinking, and acting, to fit in with their new identity (Ricoeur 1991). Women used their new-found knowledge, confidence, and skills to share their experience with others. Some aimed to make the most of life by traveling and experiencing new



Extract 1 Temporally Meaningful Episodes in a Patient's Life

social worlds; others raised money for charity or undertook voluntary work. The temporal nature of time also brought on a new appreciation of life to many of these women and of the people they cared for and, in so doing, strengthened family and community bonds. However, this was not the experience for all women, and we would follow Atkinson and Rubinelli's lead (2012) by cautioning researchers against forming simplistic typologies of certain narratives (Atkinson and Rubinelli 2012).

For some women it was important to locate the experience of breast cancer as an episode within their whole life story, in order to gain an understanding of its cause and effect.

As shown in Extract 1 for one study participant, her "Book" helped her to reflect on her breast cancer experience by looking back on "temporally meaningful episodes" in her life (Polkinghorne 1988, p. 1). This study participant sidestepped the medical definition of cancer as a naturally occurring biological formation and proceeded to look for her own meaning for explaining the cause of her cancer. Later on in her narrative, she tried to locate some point in time when she thought her exposure to environmental risks could have caused her cancer.

Sociality

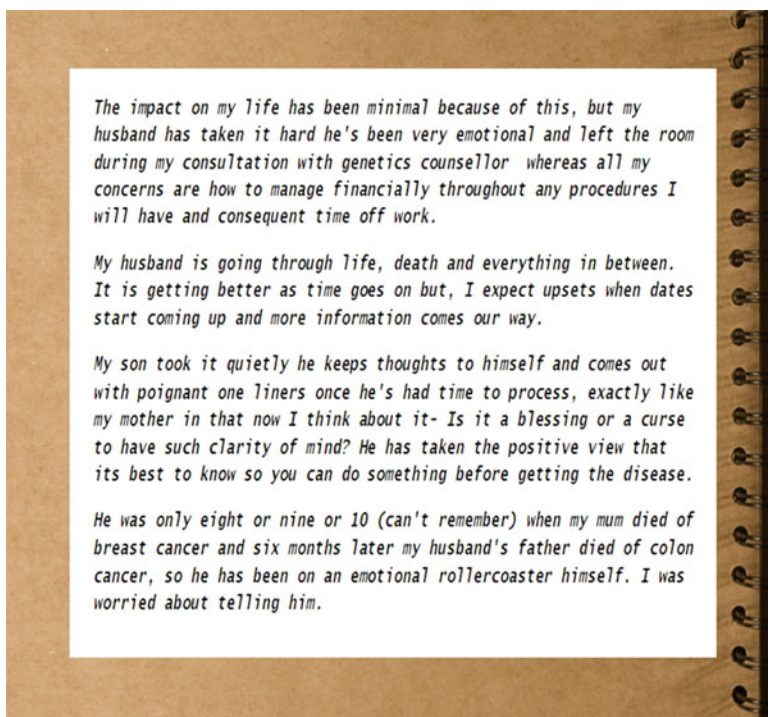
To reiterate, the purpose of the "Lives at Risk" study was to explore meanings attributed to the notion of "risk" among women who had previously had an episode of breast cancer or had been assessed to be at risk of breast cancer as a

result of a genetic predisposition. The research team were surprised that in some instances the topic of "risk" was altogether absent from participants' narratives. Indeed, the study researcher noted that some study participants found it difficult to recall any discussions around risk that had taken place with members of their medical team. In many cases women thought discussions around risk had been based on their relationship with the consultant rather than on any standard practice. In this respect, the consultant oncologist was identified as the individual controlling the disclosure of information, and clinicians were often described as being adept at using their own language, which conveyed both hope and more foreboding ambiguity, which often left women unsure about their future. This view aligns with the literature on the topic (Del Vecchio [Good et al. 1994](#)) which suggests that women seek definitive answers in relation to questions about their mortality, while clinicians appear unable to provide such clarity. Study participants often reported that the statistical probability of risk conveyed by clinicians was meaningless. Many understood it as "numbers and averages" and wanted to know if they had been cured or how long they had left to live. However, for the minority of participants, as the example below indicates, statistics were not meaningless, but meaningful and desired.

I wanted statistics. I wanted figures. I wanted to know my chances . . . the oncologist spent quite a long time asking 'are you sure?' Lots of 'you don't have to, many people prefer not to know, there's no saying which group you'll be in.' I was adamant. He showed me the NHS 'Predict' tool results.

The analysis of the bio-photographic "Books of Experience" and the bio-photographic elicitation interviews highlighted that participants' interpretations of living at risk depended not only on their understanding but also on others' perceptions of these issues, including family members, clinicians, and friends. Study participants reported that the dynamics within their own families and among their friendship groups changed according to the extent to which risk was understood, accepted, and, in some cases, rejected by individuals who shared their social worlds. Women acknowledged a range of reactions from friends and loved ones, some expected and some unexpected, which affected how they managed and lived with their "at risk" classification. For example, some women described wrestling with their own emotions as well as those of others, and acknowledged that this often posed additional distress, sometimes sending them into an isolated and lonely state, when they most needed the support of others.

The extract below, Extract 2, illustrates how this particular study participant played down her own emotional well-being and highlights the challenges she faced in managing the emotional well-being of her family, as they struggled to come to terms with her risk of breast cancer. It is clear from the writing that the participant valued herself in terms of what she could offer others. The study participant used her "Book" to emphasize that social and financial aspects and her family's reaction to her ill-health took precedence over her medical story of ill-health. The ensuing medical interjections are given less importance and

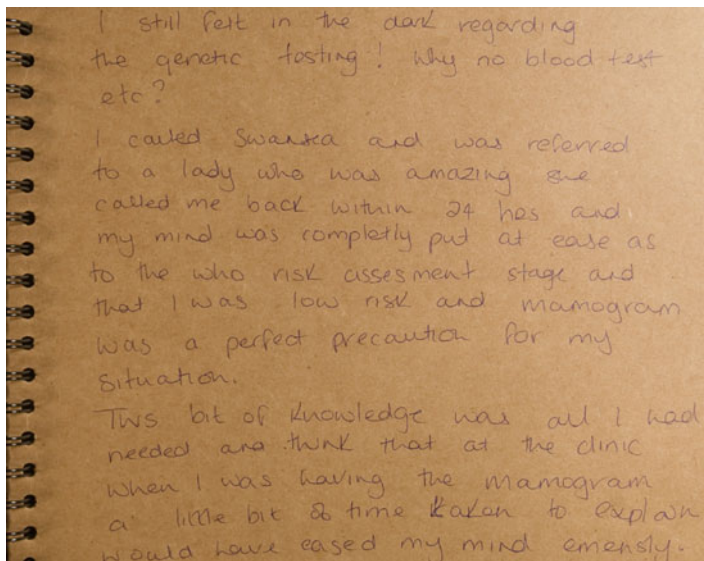


Extract 2 Patient's Concerns for Family Involvement in Ill-Health

thought. This also illustrates the “sociality” of these narratives and provides a useful illustration of Frank’s observation that “ill people are wounded, not just in body but in voice” (Frank 1995, p. 19). Within this one section of narrative, we get a glimpse into this woman’s world and the interconnectedness of experiences of ill-health, juxtaposed by everyday concerns of life, work, and relationships she appeared to be grappling with.

Place

The “Lives at Risk” study participants frequently tried to associate their breast cancer experience with specific physical places they found themselves in, or thought about, or that were personally meaningful. Many study participants referred to their cancer as a “journey,” both metaphorically and literally, in terms of mapping places associated with their illness and care. For example, one study participant described her journey by train to hospital to attend a breast screening appointment as the starting point of her care. The entry into her “Book of Experience” is deeply reflective, and she recollects a strong feeling of apprehension



I still felt in the dark regarding the genetic testing! Why no blood test etc?

I called Swanka and was referred to a lady who was amazing she called me back within 24 hrs and my mind was completely put at ease as to the who risk assesment stage and that I was low risk and mamogram was a perfect precaution for my situation.

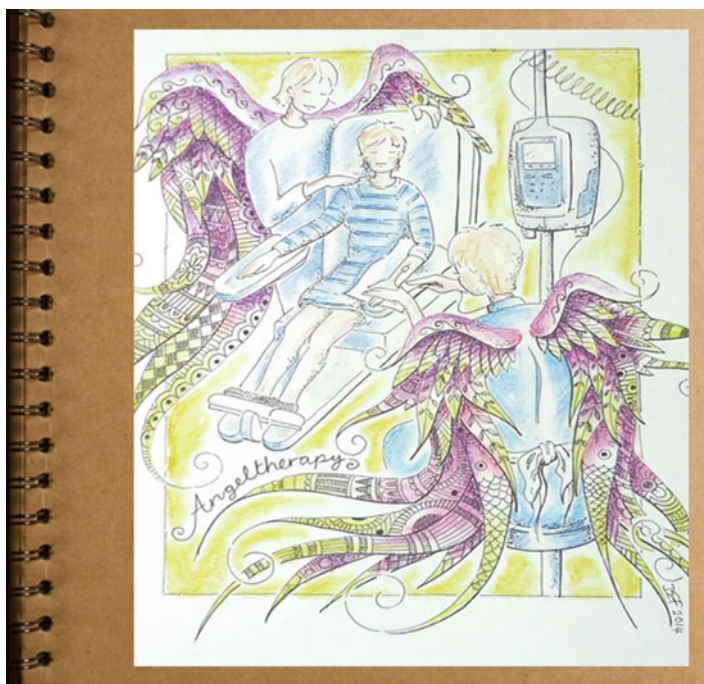
Two bit of knowledge was all I had needed and think that at the clinic when I was having the mamogram a little bit of time Kakan to explain would have eased my mind immensely.

Extract 3 Patient Expectation for Appropriate Professional Support

coupled with disappointment when the medical team unsuccessfully managed her anxiety. She explained that all she required was appropriate information during the care process to stabilize her emotions (see Extract 3).

For many, hospital waiting rooms and treatment rooms were places of dread. In some “Books” these places held silence; in others, silence arose from the emotional and physical impact of going through chemotherapy and radiotherapy treatment. The lack of detail in many narratives about the places where the treatment was conducted may suggest that this was not a salient issue for these women or that women may not have wished to relive the whole experience of treatment over again by writing about those areas. These places were often described in the interviews as painful to recall. Indeed, during one of the interviews, the researcher asked a participant about the treatments she had undergone, and in what appeared to be a desire to maintain agency and control, the women only briefly mentioned her treatment in response. On occasion, treatment and treatment places were redefined to appear manageable and under control. One woman called chemotherapy her “angel therapy” using her own religious beliefs to symbolize illness (Riessman 2000) in this case, in terms of the cure received from angels (see Extract 4).

Finally, study participants reported that they had recreated and revised their views about their future in light of the “philosophical truth” that they had discovered about the fleeting nature of life following their diagnosis. The study team recognized that the “Lives at Risk” narratives emulated the “modernist logic of the triumphant individual-one who has suffered, survived, and surpassed”



Extract 4 Patient's Symbolization of the Illness Experience

(Plummer 1995, p. 34), but also that narratives were interwoven with the making of the self and provided women with the opportunity to consider their future and shape the stories they were yet to experience. Thus, narrative inquiry in this study supported the premise that “there is more than one story to tell” to enable “ethically conscious and thoughtful” conduct toward those experiencing ill-health (Carson 2001, p. 202).

This chapter has laid out a set of philosophical and ethical issues with respect to narrative inquiry, primarily with reference to Connelly and Clandinin's (2006) tripartite conceptual framework of narrative “temporality,” narrative “sociality,” and narrative “place,” refracted through Landman's (2012) fourfold levels of analysis: the “linear,” the “relational,” the “emotional,” and the “analytical.” This form of narrative inquiry has been illustrated through a consideration of one particular case study that used narrative inquiry to ascertain what it means for women to live with the “risk” of developing breast cancer. The “Lives at Risk” study demonstrated how an attention to the interplay of narrative “temporality,” narrative “sociality,” and narrative “place” can reveal profound insights into women's stories of illness, health, and well-being. As a powerful approach to qualitative research, narrative inquiry has the potential to play an important role in contributing to more insightful, sensitive, and humane discourses in the context of health services research.

Summary Points

Narratives contribute to meaning-making and a way of knowing the self.

Narratives mirror the self and allow personal inner thoughts to be conveyed to others.

The storyteller and the listener both influence the formation and interpretation of narratives.

In health services research contexts, the process of narrating and listening to narratives needs to be managed and conducted within clear ethical boundaries.

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