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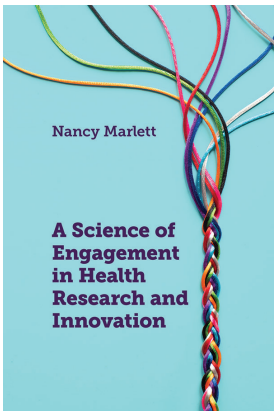

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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ISBN 978-1-77385-733-6

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Narrative as Data Science: Turning Stories into Real-Life Data

Highlights

- The power of story in identity, community building, education, social innovation, and health-related community business
- Stories, narratives, and metanarratives
- Narrative in medicine
- Using narratives for building trust, research priorities, data collection, interpretation, and implementation
- Discourse analysis of stories in autobiography
- A narrative data science

While seeking to test the feasibility of co-research in Chapter 2, we discovered that narrative methods unleash the power of stories as reservoirs of experiences and expertise that are essential to peer research. Stories allowed us to explore existing theory and create a storied method for co-design, data collection, analysis, interpretation, and innovation. Consistent use of story identifies and explains shared concerns and explores potential solutions and actions that are meaningful to patients and communities. The challenge has been how to make narrative meaningful to health professionals and researchers who favour itemized, standardized, and aggregated evidence.

The chapter begins with Rita Charon (2001, https://doi.org/10.1001/jama.286.15.1897), a pioneer in narrative medicine, who has been instrumental in calling attention to medicine's need to find more humble, respectful ways to see health from a contextualized, patient's perspective. A narrative gaze invites healthcare into an intersubjective dance, populated by patients, healthcare providers, and families in their relationships. This opens the door to using stories to explore present and past experience along with possible futures as suggested by Duncan Campbell (2015, https://onthewards.org/bother-listening-patients/).

While coded language and siloed health publications protect power and professionalism in research, there is the growing pressure to democratize science by making room for voices of those who live with, care for, and support patients and their families. Patients are the only new partners in open innovation in science (OIS) initiatives that don't have an existing research methodology or understanding of science. It is therefore important to consider the need for narrative research methods, especially those that have been co-designed and tested with them. Narrative, in this time of new social media platforms that are familiar to patients, can and should be part of how we gather and understand data that is relevant to patients and the public.[1]

Medical sociology and psychology already have adopted narrative, and this chapter could not have been written without the inspiration of researchers who experienced health concerns and used narrative. Using dual roles to explore how direct experience enriches and informs scholarship. Dr. Art Frank, a sociologist at the University of Calgary, wrote about his experience with cancer in *The Wounded Storyteller* (2013), which encouraged academics to explore narrative. Kay Redfield Jamison, author of the autobiography *An Unquiet Mind* (1997), produces academic and popular books that brought new light to bipolar disorder through a patient lens. New research directions such as narratives of change (Wittmayer et al., 2015, http://www.transit-socialinnovation.eu/content/original/Book%20covers/Local%20PDFs/181%20TRANSIT_WorkingPaper4_Narratives%20of%20Change_Wittmayer%20et%20al_October2015_2.pdf) and narrative foresight (Finkler & Leon, 2019, https://doi.org/10.22323/2.18050202) provide democratic, participatory, and action research perspectives and structures to address the surge of potential of narrative approaches in citizen and personal science.[2] This work informs the creating of a theory of engagement in this book.

A Peer Research Approach to Narrative

People tend to lose their personal stories when confronted with serious illness. As patients, they quickly become socialized to new stories about who they are now, as 'the patient.' They view their new identity through clinical and illness

1 Take some time to visit/revisit Chapter 2, which chronicles the development of an integrated narrative methodology for co-design and co-production of health research with participant co-researchers.

2 Before beginning this chapter, you might take time to link to "Losing Our Stories" presentation in PRISM (Koczker et al., 2015, http://hdl.handle.net/1880/109949) that explores the insidious loss of personal stories and identity when people become part of the mental health system. Look at the results and discussion as an example of how compliance and becoming your diagnosis was challenged by a common story of reconnecting.

stories and language that reinforce standardized labels and practices about their new identity. These patient stories are adopted and embodied because they open the door to the clinical pathways that define expectations, roles, relationships, and life goals. People see themselves as their diagnosis and healthcare roles. This loss of personal stories not only changes the content of stories, but the characteristics of stories also change.

Patient stories lose their individuality and singularity as they become absorbed in their care pathways. Peer research reclaims the importance of patient perspective as an active participant in the decisions about what they experience or would hope to achieve. The use of stories as data reclaims a patient voice that makes these authentic health research partnerships possible by describing a patient perspective of main concerns that invites engagement in potential solutions. Stories can be full stories or fragments of stories, using research methods that incorporate personal and shared stories, metaphors, songs, pictures, films, advertisements, or common slang or sayings, in person or online.

New practices emerging from artificial intelligence and machine learning identify patterns and make decisions but require data from real-life patient perspectives. Just as physician narratives and notes made significant advancements when added to machine learning, so too will direct patient experience data increase the power and usefulness of machine learning about patient experience. The final result will be patient-informed algorithms for treatment options. This movement is enhanced through examples such as Zamplo https://www.zamplo.org that are creating platforms that combine online research, patient access to research to data platforms and treatment options while opening the gates to patient networks.

Strengths of Narrative

The following summarizes some of the reasons why stories are essential to research about patient experience.

- Stories make sense of illnesses with links to healing.
- When you listen to a story, you process the action as if you were the actor and this increases memory.
- Stories look back, process the present, and forecast options of what could be or should be.
- Stories start in chaos, and in the telling and retelling make sense out of confusion.
- Stories can make ideas that are complex seem doable.
- Stories are windows into traditions and cultures that are hard to access.
- Finally, stories are subversive; they expose official stories and, in doing so, counter dependence, vulnerability narratives.

The Role of the Researcher in Narrative Research

We begin this section with a discussion about the basic shifts in researcher roles that are necessary when the decision is made to engage patients and communities in research using narrative methods. My PhD study began in the midst of fierce debates over appropriate roles for citizens in participant or partnership research as part of civil rights movements. For example, in *Women's Words* (Gluck & Patai, 1991, https://doi.org/10.4324/9780203819371), Etter-Lewis stated that women should tell their own interpreted stories, while in the next chapter, Katherine Borlan, a folklorist, cautioned that researchers needed to maintain responsibility for research integrity by re-telling community stories through an academic lens. Mishler (1996) used the term 'critical research' to challenge researchers to enhance the opportunities for those studied to gain awareness and improve their status. Mishler, in the same text, suggested a continuum of shared interpretation strategies in narrative research:

1. The researcher analyzes and interprets narratives on their own, with no contact after data collection.
2. The researcher has the subject verify the transcripts.
3. The researcher completes the project and shows it to the subjects for verification.
4. There are opportunities for separate roles for narrators and narrative researchers.
5. The researcher and the subject enter into an ongoing dialectic about meaning and arrive at a joint product.
6. The researcher is the scribe representing stories told.

None of these accurately reflected the nature of our roles at the beginning of the original research to test the feasibility of co-production, but our research relationship grew into partnerships, which reflected point number five above. The partnership was built on a shared commitment to move beyond the moral imperative of engagement, to learn how to create a relationship at all stages that would combine rigour, experience, and meaning for both me and the co-researchers. Within these relationships, peer research is seen as an interaction controlled by role expectations. If the roles are not discussed openly, participants are left to construct their own roles as narrators, telling stories based on their assumptions about what the researcher was looking to find.

Experience with peer research reinforced the need to include a process of negotiating roles and expectations as outlined in Chapter 3. I needed to be clear about why I was committed to the research, what co-researchers could expect of me, and how we would handle challenges. This also included what

co-researchers wanted to know about why they had been chosen, disclose how they saw themselves, and their concerns and hopes in light of the risks, costs, and potential benefits. Without this foundation, there are risks for each party, left to guess about what was adequate when they were finished and what the results meant.

In Canada, we see this through the powerful participatory and action research done by trained peer researchers within the HIV/AIDS community (PAN, n.d., https://paninbc.ca). In narrative methods, roles of peer researchers and participant co-researchers are more easily balanced. The natural peer partnership between researchers and participants significantly reduces the ethical and scientific challenge of imposing theory on vulnerable populations. At the most fundamental level, enabling stories of role expectations to be shared enables peer research to use stories to share ideas and concerns.

This reflects narrative therapy where the person is encouraged to explore different endings to entrenched problematic stories. In peer research the same is true when peers share stories and, in the process, come to understand the problems and possible alternative outcomes.

How Narrative Improves Health Research and Care

Stories impact not only our ability to process information, but how to use and remember stories (Zak, 2013, https://greatergood.berkeley.edu/article/item/how_stories_change_brain). The innate or hard-wired biological power of stories works as follows. When your brain detects the beginning of a story, the auditory cortex becomes active. Then the left temporal cortex, the language cortex, becomes engaged and filters out complex and distracting language to focus on the story. By the time the frontal and parietal cortices become involved, we are literally engaged with what's happening in the story as neurons respond as if we were enacting the story in person.

As we hear stories they are translated into personal ideas and experiences in the brain. This process is called 'neural coupling,' where experience told in the story is mirrored by the same experience in the listener's brain. Speaker-listener neural coupling underlies successful communication. Emotionally charged stories release the neurotransmitter dopamine that ensures that memories remain relevant and accessible. These neurological patterns have spawned new transdisciplinary research and science used in business and marketing, social change at the organizational and political levels, education, and therapy, but it has not penetrated the shields around health research.

We see the evolution of narrative in health research beginning in 2014, when the *Lancet* called attention to qualitative research to broaden the scope of health research and to become more cultural, humanistic, and holistic. The

increasing presence of wellness theories, such as salutogenesis, honed interest in narrative research to capture personal stories of success. The World Health Organization (WHO) Health Evidence Network produced a report on the cultural contexts of health and the use of narrative research in the health sector (Greenhalgh, 2016, https://www.ncbi.nlm.nih.gov/books/NBK391070/). This report focused on how qualitative evidence from narratives has been deployed in the health sector and to what effect. Within the scope of policy and planning, the report highlighted strengths and limitations of using narrative to identify shared values and meaning related to culture in the following:

- Individual accounts of illness.
- Case study narratives of health organizations and systems.
- Cultural narratives where stories are embedded in master narratives of disadvantaged or displaced communities.
- Policy discourses that drive action.
- Shared narratives.

The report concluded, "In recent years, researchers have recognized both the ethical and the scientific challenges of imposing their own research framing (e.g., a particular theoretical lens) on the voices of the vulnerable" (Greenhalgh, 2016, para. 9). They suggest that phenomenology, co-design approaches, and community-based participatory research open opportunities to employ naturally occurring narratives and online communities, broadening the options to include narrative in health research.

There is increasing support for narrative research as an adjunct to quantitative research to support patient-oriented research and policy evaluation and innovation. Data storytelling (Nugit, n.d., https://www.nugit.co/what-is-data-storytelling/) has been called the last 10 feet of research, where it creates a coherent and compelling narrative to share data results.

Levels and Types of Stories as They Relate to Health Research

There are three commonly understood types of stories that operate at the personal, group, and societal or organizational level.

This section describes how personal stories take on the power of community narratives when they are shared. These narratives then grow into master or metanarratives or discourses that challenge dominant professional and institutional discourse. The research of my thesis revealed three significant levels: personal stories, narratives, and metanarratives or discourse. This is depicted in the following example.

> Henry Enns, a founder of Disabled People's International, connected with groups of disabled people around the globe by encouraging sharing personal stories of the challenges of living with disabilities. These painful and embarrassing stories, when shared in groups, led first to dark humour and then to the realization that the challenges were not about their personal or group inadequacies but about the common lack of institutional planning to make access to funding, buildings, and services a priority. Personal stories led to shared and compared stories that identified stories with meaning for the group. These then led to stories about power, oppression, and emancipation.

Stories: The Level of the Individual, Personal Accounts of Events

The term 'story' has ancient roots in most languages, most frequently, a form of 'historia' to describe a form or way of sharing experience: a tale, information, stained-glass windows.

> *A story is a report, description, account or a telling,*
>
> *either true or imagined,*
>
> *of an event, incident, occurrence or something that happened, is happening or could happen*
>
> *that has not been widely known or previously told.*

In most northern countries, a story includes a beginning that sets the context of the story, the plot or sequence of the events, and an ending that indicates the impact and consequence of the story. This provides a framework for collecting, transcribing, and interpreting stories. This structure presents stories as data for analysis that can be shared, compared, and combined with other stories. Mishler cautions that our "attempts to validate people's intentions or personal truth inserts our theories into personal stories. Traditional research practices often obscure relationships . . . and disrupt the individual's attempts to make sense of what is happening to them and around them" (Mishler, 1986, p. 120).

I realized that it was impossible for me to represent the life world of a co-researcher during my thesis. My interpretation of a co-researcher's personal stories coloured my understanding of what was happening. I learned that the story in vivo, in the person's own voice, provided direct insight into possible

categories, priorities, codes, and possibilities for using the same basic story to convey many meanings depending on the intention and outcomes expected.

A young man with AIDS may tell or interpret stories from the perspective of gay men as a group, a person with terminal illness, a young person living on fixed incomes with ongoing needs for support, a person stigmatized and alone, or someone living in a large city. He may share much in common with each of the groups he represents. In peer research, the peer connection creates the context (type of group above) and the co-researcher contributes within this shared view of the world. He is clear about himself as a producer of knowledge within the shared context.

Narratives: Stories of Shared Meaning in the Group or Community

The meaning of narrative comes from the Greek 'gnare' or meaning. Narratives are the way human existence is rendered meaningful to others. Stories take on value and meaning as they are shared and repeated in different contexts, with different people, for different purposes. Stories become narratives of expertise and potential futures.

A peer research focus group comes together to share common experiences and in the process the group creates narratives of their collective understandings. The process of sharing, analyzing and interpreting individual stories develops narratives in research in the same way people who share common experiences create narratives that create collective understandings of their fears and concerns, experience, and aspirations. They connect the past to the future through shared stories in the present.

Narratives are triggers of action research, they identify common concerns, explain what is happening, and explore alternative outcomes and actions to challenge dominant restrictive discourse. The following story from my time at Greenbank demonstrates this.

I was working with the founder of Greenbank to code data in a story about professionals who tried to take over Greenbank and move Gerry to 'disabled jobs' within Greenbank. I had named the story 'Carpet Bagging' because they were opportunists looking to take over. He was very offended by my assumption that he was considered weak because he was disabled and countered with the titles of 'Playing Coach' and 'Taking Back Power.' After much debate, we agreed that the meaning in the story was 'Expect Takeover Attempts by Those in Power.' The eventual title spoke of a relationship wherein innovators needed to expect takeover bids and be prepared. It was not a threat but a fact of doing business, as social innovation threatens those in power.

The above discussion created new meaning and made future analysis lively and collaborative. In the end what mattered was that the title (the code for the story) had changed to bring action and power to the overall storyline of Greenbank. It demonstrated how important it was to clarify the meaning of individual stories to make room for potential change narratives.

The seniors in the *Grey Matters* study (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/) were motivated to confront geriatric and gerontological narratives of loss, 'downhill slide,' decrepitude, and burden of care. They were looking to challenge these healthcare narratives, and in their research, they found narratives of strength through common stories of expertise and knowledge, not deficit and loss. Their stories spoke of the importance of family and community strength during war and depression that prepared them to be resilient, resourceful, and political. These narratives were slogans of emancipation and defined who they were and could be in society. They feared for young people who lacked opportunities to test their abilities and build resilience. These findings seemed to challenge geriatric and gerontology professionals when presented at conferences.

Narratives also create the impetus to change in healthcare practice. Charon's 2017 work on narrative medicine motivates physicians who are interested in making a difference to restore medicine to a more holistic and humane partnership with patients. She does this by sharing common stories of relationships, insight and foresight

To summarize, emancipatory narratives tend to capture the struggle to overcome prejudice or marginalization, and in the process, these narratives challenge the power of accepted professional or political discourse. A narrative is a story with a purpose—it conveys something new or different from the expected patient story. Collective stories suggest new roles and relationships in the way we see ourselves and relate to each other.

Master Narrative or Metanarrative: Using Emancipatory Narratives to Challenge Systemic Discrimination

The story of Terry Fox and the Run for the Cure became an example of a Canadian metanarrative. He courageously challenged cancer by running across Canada, and in the end, cancer won. His story of courage in the face of a common enemy spurred generations of Canadians to run for the cure. This discourse is seldom understood in countries where only winning counts. We all need heroes, especially those heroes that are part of us—imperfect, struggling, but with determination and focus. We want people to look up to those who are like us.

Master narratives operate at the organizational and societal level to define, share, and hold power. These master narratives become dominant discourses

when they justify political control through policy and procedures that restrict the independent action of those who fall within their authority. The power held by experts and the systems that support them became a target of early emancipatory social science that studied the language of the power holders to lay bare the means of oppression. Discourse analysis became the tool of critical theory and emancipatory science to understand metanarratives, especially in academic programs such as feminist, racist, Indigenous, and disability studies that are devoted to social change. They use action research to confront power through new ways of doing, organizing, framing, and knowing through narratives and metaphors that reinforce innovation and action.

To date, health systems have been relatively immune to these challenges because their power holds the promise of access to life-saving information and care. Early emancipatory narratives in health identify why change is needed by unpacking the systemic forces supporting dependence and marginalization. They also locate who has the power and how change can be promoted. This is the message of Chapters 9 and 10 of Section 3, which is about systemic analyses of healthcare discourse from two perspectives: systemic discrimination and collective empowerment. They create alternate realities by challenging the norms, values, and beliefs of the dominant discourse and, in the process, devise alternative futures and the social innovations for change that focus on the use of narratives as community development practice (De Fina & Georgakopoulou, 2008, https://doi.org/10.1177/1468794106093634).

These emancipatory and change narratives move the question from 'what is' to 'what if' to 'what might happen next' (Wittmayer et al., 2015, http://www.transitsocialinnovation.eu/content/original/Book%20covers/Local%20PDFs/181%20TRANSIT_WorkingPaper4_Narratives%20of%20Change_Wittmayer%20et%20al_October2015_2.pdf). Individual stories of both oppression and empowerment, when shared, become narratives, and these narratives motivate change and become master narratives that challenge oppression and incite collective actions.

Narrative Data Methods Support Social Change Using Peer Research

I was privileged to be able to teach narrative therapy to graduate students, and it informed my approach to teaching and emancipatory science. Narrative therapy revolutionized psychotherapy just as narrative medicine revolutionized clinical practice by encouraging new stories and productive scripts to build courage, curiosity, and competence.

All social innovators in the new social movements study used narratives to disrupt stigmatizing master narratives by using their experience as examples of new stories of liberation and emancipation. Henry Three Suns used Native wisdom traditions to inform Indigenous child welfare; Gerry Kinsella adapted the root metaphor of David and Goliath to challenge systemic discrimination of persons with disabilities; and Dame Cicely Saunders used Christian liberation theology to frame stories of dignity in dying. The integrated narrative co-design and research methods then informed peer research methods.

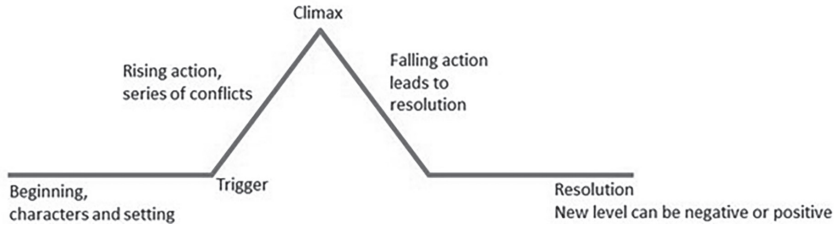
- Peer research with seniors championed narrative focus groups and interviewing methods that consolidated the importance of sharing stories in peer research. At the same time, I was teaching the use of stories in social construction to find common scripts in autobiographies that reconstructed identity after illness and disability.
- During co-design of PaCER peer research, patients shared stories to understand problems and find solutions. This was surprising to the early research teams who partnered with us, because they had believed that patients experience mainly vulnerability, loss, trauma, and deficit. They had not heard a different patient perspective of problem solving and wellness that promotes stories of experience, expertise, strength, insight, and problem-solving competence.

The Elements and Nature of Stories

In peer research, we search for methods that promote iterative data collection, analysis, and interpretation to create a more streamlined and simplified approach. Narrative data promoted both participatory practices and constant comparison. Narratives generally follow two basic patterns.

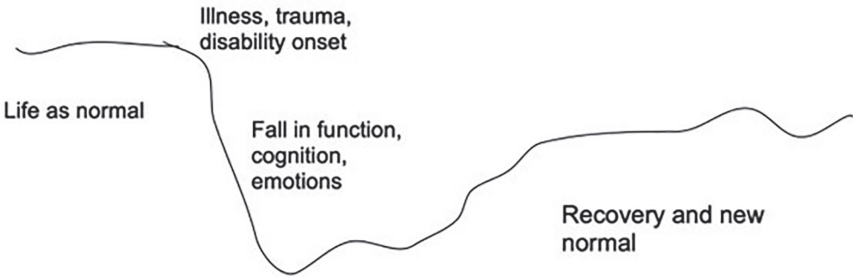
The first is the traditional wide upside-down V that begins at the bottom left with the setting of the story (the who, what, when, and where). The trigger starts the story and as the line goes up, we see the conflict or problem (the trigger that starts the story) and then the rising action. At the top of the V, the climax explains or resolves the trigger, and we have the falling action and the moral lessons learned to return to normal or a new normal at the bottom right. In healthcare the climax tends to focus on healthcare intervention.

Figure 7.1 *Typical Pattern of Stories*



In health research, we tend to see an upside-down V. A story begins with a line that depicts everyday life, then a downward slope that depicts the experience of health problems. The slope can be gradual or steep, smooth or rocky, but most frequently it levels out as the person begins an upward climb to a resolution. That can include rehabilitation, a new normal, or even finding themself in an improved situation.

Figure 7.2 *Anticipated Pattern of Health-Related Personal Health Journey*

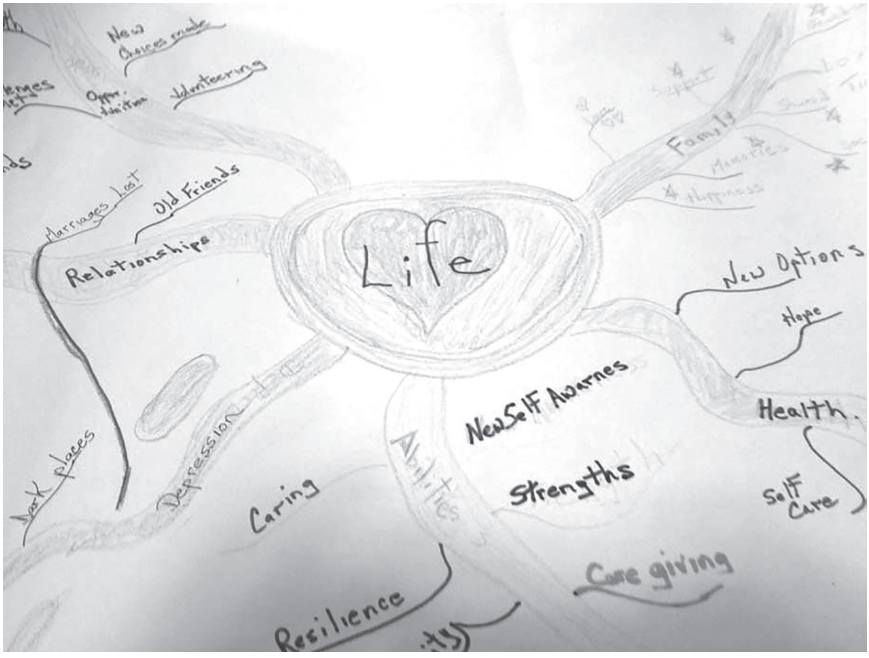


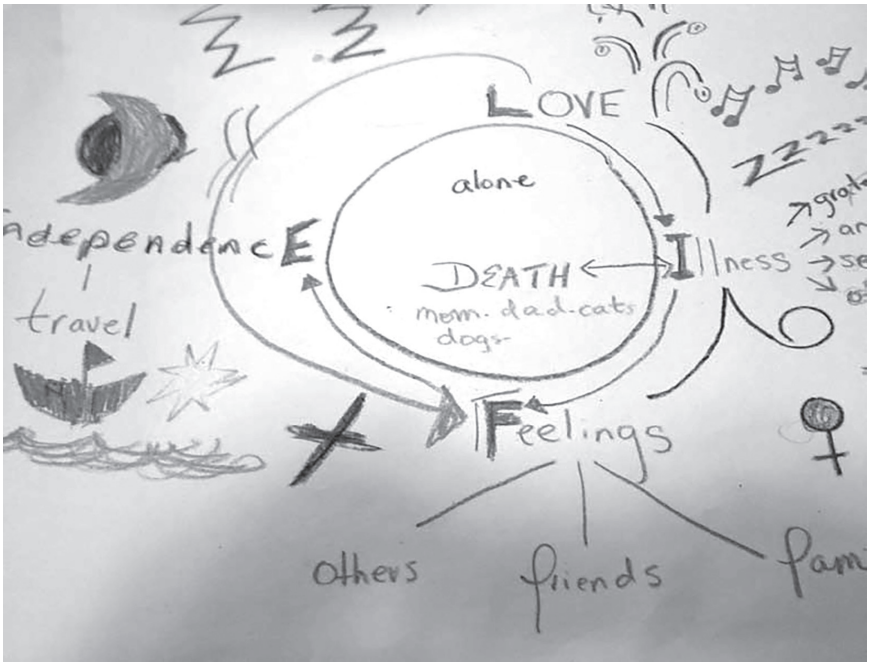
This storyline reflects the dominant story of healthcare that begins with the experience of a patient during the onset of illness, trauma, and loss. When told by healthcare professionals, it is assumed that the patient will engage professionals during this time, who will then diagnose the underlying problem, slow the fall, and provide treatment to recover. The subtext of this healthcare story is one of patient vulnerability and fallibility and the ability of professionals to respond to patient needs and guide them to the new normal.

This does not include those with conditions that arise early in childhood, where the journey has not established a base. Here the goal of the journey is an uphill climb over time, the journey from the bottom of the above figure.

Figure 7.3 is presented to offer a very different picture of a patient story, done by a group of patients living with chronic illness. The story itself was difficult to find because most of the co-researchers and peer researchers involved in the research were at different stages and had different healthcare pathways. The final storyline or theory called upon what had happened, what was happening, and what might happen in a sequence of substories. This created a very powerful storyline of the hidden pathways through chronic illness. The patient story is here presented as a poster that aligns with the clinical story and professional opportunities for engaging patients.

Figure 7.3 *Hidden Pathways Through Chronic Illness*





Hidden Pathways	Patients' voices	Related clinical activities	How health professionals can engage patients
Alien Land	*"[I feared] anger would grasp me and I could easily get stuck in my box."*	Diagnosis	Offer opportunities to ask questions and make connections
Searching for Answers	*"My long days in hospital were spent trying* to *understand this beast that was in front of us. I was convinced that if we educated ourselves about our opponent, we would outsmart him."*	Health promotion, tertiary prevention (lifestyle changes)	Education, validate patient choices

On Your Own	*"This illness is my journey, now that I am on my own. I will be my own counselor and take it into my own hands."*	Clinician's position: "This is the best I can do."	Listen without promises
Searching for Meaning	*"Too often we are overly focused on us. Helping and working with others ... gets us out, moving, thinking and contributing to a more dynamic self"*	Adapt and customize treatment to patient values	Discuss values and obstacles to meeting them
Presenting a New Self	*"I go to counselling ... for advice on how to deal with other people. Because very often it's not how I deal with my disease, it's how other people deal with my disease."*	Follow up	Share health monitoring with patients (patient generated data)
Not the Boss of Me	*"I am the expert of me. [I told my doctor], 'You do not understand! You aren't dealing with the illness!'"*	Co-led team	Work with the patient and other team members

Note: Credit: Zelinsky, S., Marlett, N., & Shklarov, S. (n.d.), Hidden pathways diagram. Source: Banerjee et al., 2013, http://hdl.handle.net/1880/109953.

This theory creates a series of hidden pathways, with each stop along the way a chapter of regaining control of a chronic condition. The dynamic feature of the patient pathways is the dynamic representation of increasingly autonomous destinations as chronic conditions, health, and relationships change. This patient research of chronic conditions creates new options to support shared decision-making between patients and health providers as indicated in Figure 7.3.

Peer research storytelling in a group captures the ability to respond to past, present, and future storied destinations. At the end of each interview or research group, participant co-researchers are invited to identify and analyze the stories that were told with the peer researchers. This ensures that stories

are complete and bring new meaning to what co-researchers have learned from telling the stories. It is also possible to apply the properties (the who, what, where, and when) to inform the nature of their journey: the places, the type of professional providing care, a contact with a peer in the situation, a similar feeling, a strategy.

Common Types of Stories from Peer Research

This leads to looking at the types of stories that are told in peer-to-peer settings:

- Health-related survival stories, where the threat is identified and attempts made.
- Esteem stories, where overcoming health problems are celebrated.
- Personal growth, where the opportunities and challenges lead to the capacity to try new things.
- Action or adventure stories about a quest to find an answer, take control, be a different you.
- Mystery stories, where you and others look for answers.
- Comedies, where threats and low self-esteem are challenged by unexpected positive experiences.
- Journey stories that track stages in recovery or acceptance of disability or death.
- Teaching stories that describe how new ideas and skills can be achieved.

Elements of Stories Told by Patients for Patients

We now look to the similar structures of stories as used in research. Stories are composed of major elements: the title, context, the incidents, plot, consequences, and meaning. These elements form the basis of the story format used in most narrative research.

The **title** of the story names (codes) the story that has meaning to the teller of the story (in vivo code). Titles often change when stories are shared, and in the end the title of the story acts as a major theme of what happened, is happening, or could happen.

The **context** includes properties that define the nature of the story, the actors, the places, the social situation. Properties are identified by who, where, when, and other questions that categorize stories.

The **plot**, the movement of the story is a sequential accounting for the actions of a single story, but elements of the plot may become known from other

stories and thus can be used in several plots. This allows for detailed understanding of the movements within the trajectory of the story through the focus on properties of how, why, and then.

The term **incident** can refer to short abstractions of actions that include actors, actions, and outcomes. These incidents provide a bridge between grounded theory and more traditional thematic analysis. Grounded theory, especially participatory grounded theory, is adept in using and comparing incidents that can be analyzed using properties of narrative.

The **ending, consequence, outcome, or moral** of the story marks the end of a story. It tells what has been learned in the telling of the story and may suggest the beginning of the next story. The ending marks at least a partial resolution of the situation that triggered the story as indicated in the diagrams of story frameworks above.

Narrative peer research uses a **standard story template** to explore a story's properties during data collection, managing data, data analysis and interpretation, and theory. The template promotes iterative story presentations that evolve from personal stories to shared/collective stories that act as narratives. The format remains the same, but the nature of the incidents evolve from personal to collective stories and, in peer research, to scripts for action that challenge systemic discrimination, policy triggers, or social innovation.

The following is an example from Indigenous co-researcher Henry Three Suns. He is talking about how sports and competition allowed reserve students to learn how white society worked.

The first transcription is typical of many transcripts here, presented using a transcription that captures the speech rhythm that reinforces the intention and meaning by starting a new line with each pause in speech rather than traditional transcriptions that force grammatical structures onto oral data.

> *We were exposed to other schools in high school*
>
> *Mostly white schools*
>
> *In sports and the like*
>
> *And we were led to believe that you could be as good as the other person*
>
> *And we won a lot of high school matches*
>
> *And to prove to ourselves that we could do well*

One of the prides of my life is the provincial basketball championship

We won

That was an accomplishment

You get appreciation from the province and the family.

(Henry Three Suns; Marlett, 1996 thesis data)

Notice how the following list is presented as incidents of the above content that occurred as Henry and I discussed his initial story. The language used is Henry's but reflects an initial analysis of what the story contributed to his work.

In high school we got to know white kids

Coaches said we could be as good as them

We won many high school games

We won the provincial basketball championship

I was proud of our success

The province and our families appreciated our achievements.

These incidents could then be sorted into different categories of 'learning about white society,' 'competing in sport,' and 'new ways of being together.' In the final theory, these incidents led to a category of 'Indian Briefcases,' which spoke of a time when Blackfoot members who had learned about white ways began to negotiate with those in power. His grandmother laughed as he tried to work with white officials, saying "you just have to use white people to practice on until you can figure it out."

In later narrative peer research with seniors, the peer researchers used the template while listening to the tapes to fill in the story template, which avoided full-text transcripts. This made it easy to record incidents within the template and allowed them to compare the stories using the templates to combine and rename stories as they were shared.

The value of the use of incidents as individual units of analysis is that they can be detected and recorded directly as focus group, interviews, and observations stories. The incidents can be written verbatim during data collection and then shortened during analysis and interpretation. Incidents are easily

recognized by participants but remain private when reported in categories and quotes that are recognized both by participants and effective in oral presentations and publications.

Metaphors Act as Stories to Explore Meaning

There are five main types of the figurative language—metaphors, similes, personification, hyperbole, and symbolism—that provide ways to understand meaning within stories. Metaphors are the most commonly used tool by citizens and were common as patients struggled to explain their experiences and their expertise. They represent meaning and values when there are few words to explain what is happening. Metaphors can suggest actions, feelings, outcomes, or expectations, and are treated as incidents. "My body was limp like a rag doll after the accident," or "I felt warmth, like sunshine that sinks into me."

Root metaphors are used to find a way to make sense of how our lives are changing. "Life is like weather," "I think like a computer," "I seem to have become my electric wheelchair." Root metaphors can introduce shifts in understanding over time. "I remember my childhood as a time of sunshine and clear skies," or "I can only try to avoid the hurricanes of my bipolar life." In this way, metaphors are windows to worldviews that lie beneath the surface of competing worldviews, which might stifle or negate possible change. These worldviews are often held in our most protected and often unconscious levels of thought.

Common metaphors are often captured in slogans and sayings. "Black lives matter," "nothing about us without us," or "ban the bomb." They are found on plaques, social media, graffiti, and are particularly useful online or in health settings. They often capture the goal, the outcome, or the expectations of marginalized people.

Metaphors provide the data for deep analysis and questioning during research and the participant co-researchers should be invited to explain the metaphors they use in relation to the research being done. Metaphors uncover sources of institutional bias and examples of unexpected success.

Emerging Directions in Narrative Analysis Suggest a Framework for an Integrated Narrative Science in Peer Research

This section attempts to locate the use of narrative in peer research compared to an exciting narrative framework for qualitative narrative research by Roest et al. (2021, https://doi.org/10.1186/s12910-021-00691-7). The original four quadrant process proposes a four-step narrative analysis to guide research projects.

- The first cycle of analysis is **in vivo coding** to capture incidents within stories. This relates to the use of the story template in peer research to locate incidents within the context, plot, and consequence of stories. In vivo coding is the first level of analysis of data collected during observations, interviews, focus groups, and online patient self-help platforms. The structure of the template enables analysis to move through all four cycles as stories are combined and divided as concepts are identified.
- The second cycle of analysis employs features to **interrogate incidents**. In peer research features are related to properties used in classical grounded theory, but the intent and outcome is similar. Peer research focuses on properties that relate to each stage of the research:
    - SET: Co-design of the main concern, properties of who, where, what happened, and what then. These help categorize concerns for prioritizing the focus of the proposal.
    - COLLECT: Iterative data collection and analysis to inform the main concern to search for possible solutions. Properties include who, what, where, when, why, and why now, then.
    - REFLECT: Choosing the best solution to the main concern that is feasible and important to patients using properties. Properties include how the story relates to the main concern, why it works, what is anticipated if it was implemented, and who would implement it and how.
    - INNOVATE: The properties now shift to implementation, such as who will conduct the design of the solution, what is needed to ensure it is EDI compliant, who will pay for the solution, how will costs be covered.

- The third cycle of analysis relates to context of the analysis, by consolidating themes through the various forms of data collection and analyses. In peer research, constant comparison is inductive in that the findings of each step decides the direction needed to extend or challenge the findings until a best solution from a patient perspective is found for the main concern of the research. The equivalent analysis in peer research begins with COLLECT and continues through REFLECT and INNOVATE in an attempt to tell the story of the iterative process and how each step informed the final solution.

- The fourth cycle of the Roest cycle is the synthesis in light of the research question and what has been learned about the methods and the research findings. This cycle in peer research takes place early in the process as the peer research team becomes part of the sponsored research team, sharing emerging findings and challenges. As the REFLECT process identifies how the research informs a patient perspective of a solution to the identified main concern, there is an opportunity to reflect on the narrative data processes informing the research and how it builds bridges to implementation from a patient perspective.

The above exploration of peer research and the qualitative narrative analysis methodology of Roest highlights the shared importance of in vivo incidents and the use of features or properties as analytic tools to interrogate incidents and stories to capture what has happened, is happening, and what could happen. It solidifies the action nature of peer research that focuses on patient concerns and solutions. It also highlights the use of a standardized template to facilitate analysis in peer research that also maintains the integrity of stories to support the evolution of in vivo codes as part of iterative analysis.

In the final chapter, it was finally possible to complete a narrative form of analysis that maintains the integrity of the story as data, method, and theory throughout the engagement strategy of SET-COLLECT-REFLECT. It has not yet been tested, but it builds levels of analysis by using story properties from individual stories of personal concerns that captures the power of story. The next stage encourages sharing stories through the power of narrative to capture concepts that have meaning at the level of the group. The final stage uses past concerns, the current understandings, and potential action-based stories that aspire to suggest potential solutions as the collective expertise of patients who are willing to share stories to make a difference.

The End Goal of Narrative

"Sharing stories to make a difference" was first coined by an Indigenous community researcher as a way to define what PaCER research meant to her community.

The end goal of narrative is to produce stories that are so powerful that they hold narrative truth. For example, the following tale by Dame Cicely Saunders, founder of the modern hospice movement, is an example of a challenge to the existing health discourse for dying patients. In an infectious and gentle manner, the challenge is implied, not shouted. The medical discourse of loss, fallibility, and dependence is challenged through a simple story:

> *Always I remember Helen's laughter. She had a delicious sense of the ridiculous, and especially of the ridiculousness of her own crippled body. She neither pitied it nor hated it—there it was and, like everything else in life, could be laughed at. From behind the curtains came muffled giggles from the nurses, from the bathroom came quite uncontrollable laughter.* (Cicely Saunders, 1988)

Helen's story challenges most of the stereotypes of severely disabled people—the lack of respect for their condition, the sadness of disability, objectivity and non-involvement of staff. This one small story undermines medical, professional, and charity discourses about disability. Stories such as these challenge prevailing oppressive discourse by presenting a very different story of joy and friendship that clashes with what might be approved.

Shared stories often tell about the strengths of patients and communities, in contrast to the weaknesses implied by the dominant medical discourses. For example, those who were part of the new social movements thesis had been defined by political and professional labels or experiences—patients, disabled, prisoners, Aboriginal peoples, that defined how they were distinct from general society. Collective stories as narratives and metanarratives of emancipation are about challenging power, risk. This enables us to combine individual and collective strength to achieve collective action. The following two collective stories are examples:

> *There is a great deal of camaraderie among disabled people*
>
> *Telling stories and laughing at themselves*
>
> *I don't think that really happened until the grassroots movement got off the ground*
>
> *When the professionals were involved*
>
> *You just didn't tell jokes about how crazy it was to be in a wheelchair*
>
> *But now we tell all kinds of stories*
>
> *Even jokes about sexual feelings*
>
> *The professionals thought it disgusting*
>
> *That created a certain sense of community*

Of bonding among the group by challenging professionals

(Henry Enns, Disabled Peoples' International; Marlett, 1996)

All story types have the potential to be emancipatory when they share themes of personal competence, purpose, or contribution. It is about finding and sharing inner authority and finding our preferred roles. This empowerment shines in the comment from Debbie (D), a trainee and apprentice trainer at Greenbank training centre in Liverpool, UK.

N (Nancy). Did you find a difference between the disabled and non-disabled staff when you first came to Greenbank?

D. Yeah. I didn't trust anyone who was able bodied.

N. Are you like that still now that you're becoming staff?

D. I'm less likely not to trust anyone but I'm not blind anymore

When Gerry says 'come on you, you can do that', I know now that he's pushing it

You know, I think he's not exactly me

He may be close

Like what I can do in a chair

The disability and the handicap

But he's not a woman and doesn't have the same problems

(Debbie, Greenbank; Marlett, 1996)

Advances in Narrative as Part of Innovation

The use of stories in innovation needs stories of what might happen, what could or should happen. These are the stories of anticipated and hoped-for futures. If you are interested in this field, recent developments in narratives of change provide exciting ways to use this chapter to understand social innovation by identifying hoped for, anticipated, and feared futures (Wittmayer et al., 2019, https://doi.org/10.1016/j.futures.2019.06.005). The narrative approach above can also be used in design thinking. There are already many narrative or

storied methods being used for user story mapping, projects defined by stories and standardized epic story formats to track progress during prototype testing in design thinking.

Stories and narrative analysis continue to evolve in health research as this manuscript expands to include social innovation in health. New narrative opportunities in design thinking can also be used in qualitative and peer research. These methods are expanded in Chapter 11.

Summary

Stories are the way people share experiences of health and healthcare. Patients with direct experience across settings, transitions, professionals, levels of care, and organizational structures are able to study and share stories of expertise and hope for futures that lead to narratives of change. The ending to a peer research story becomes a practical theory that is useful and meaningful for patients, the public, health systems, and health research.

We realized that the use of narrative methods overcame many of the obstacles that made classical grounded theory seem difficult, lengthy, highly conceptual, and open-ended. The systematic use of stories challenged these assumptions. The major question is perhaps not if patients can conduct classical grounded theory, but if classical grounded theory analysis and practice benefit when simplified through the use of a narrative methodology. Just as Glaser and Strauss (1967) predicted, grounded theory can be done effectively by those without extensive disciplinary training, and we came to believe that the use of narrative made grounded theory even more plausible as a force for social change. Stories and their analysis provide the link between classical grounded theory and the science of engagement.

Questions for Discussion

1. Select one of your favourite stories about a health-related incident. Think about how it began as a story and may have informed narrative or metanarratives that you now hold. Share your findings with others.
2. Write your personal experience in a story template and, if you are intrigued, conduct a basic narrative analysis using the set of questions to identify properties.
3. What obstacles do you see in using narrative in the research you have been involved with? Where do these obstacles come from and how could narrative be adapted to support inclusion?

4. What similarities do you see between narrative medicine and peer research? Have you encountered narrative medicine or therapy in your training or practice?

Resources

- For those interested in a practical guide to the use of narrative, this lay report by Mitchell and Egudo (2003, https://apps.dtic.mil/sti/pdfs/ADA421725.pdf) is short and comprehensive. This can be used as an extra resource that is designed for frontline workers.
- Narrative foresight becomes necessary when creating narratives for social change, as explored by Wittmayer et al. (2019, https://doi.org/10.1016/j.futures.2019.06.005).
- There are other practical reasons for health researchers to engage patients in peer research using narrative. At the foundational level, narrative methods have made inroads in quality improvement research (Greenhalgh et al., 2005, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1744090/pdf/v014p00443.pdf), and there is an increase in patient experience collections that capture personal and family stories:
    - "Why Study Narrative?" (Greenhalgh & Hurwitz, 1999, https://doi.org/10.1136/bmj.318.7175.48)
    - "Database of patients' experiences (DIPEx): A multi-media approach to sharing experiences and information" (Herxheimer, et al., 2000, https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(00)02174-7/abstract)
    - For an example of how medical facilities are incorporating social media into their online resources, see Sunnybrook Hospital's Video Library (n.d., https://sunnybrook.ca/content/?page=youtube-video-library)

1. Narrative Analysis of Autobiographies: An Example

The following case book summarizes the elements of student research done on over 100 autobiographies to learn how to analyze citizen stories to understand the process of personal growth and resilience due to illness and loss.

Table 7.1

Summary of the Elements of Student Research on Autobiographies

Topic	Variable	Data collected and analyzed
1. The stories		
	Title for the story	The title represents the story. It often includes the words of the storyteller. The title stands for the action and results of the story.
	The trigger of the story that disrupts the equilibrium	Loss, challenges, unexpected support, threat to income. *It was my first day and I was excited to wear my new shoes to school.* *Betty had been admitted again because her weight had dropped to 87 pounds.*
	The context of the story, the characters	*When I started grade one, my mother walked me to school to make sure no one would make fun of me.* *Betty, on her 21st birthday, is sitting in her bleak hospital room with her dad, thinking that this may be her last birthday.*
	The plot	List of incidents recorded as what happened.
	The consequence of the plot	The outcomes, changes in direction and role.
Topic	**Variable**	**Data collected and analyzed**

Table 7.1 (*continued*)

2. Discourse analysis of the stories selected		Unpacking the language of the author
	The tone of the language	Emotional, descriptive, abstract, professional, advocacy. Look for
	Pronouns used	The social structure and scope of the story. 'I' is considered to indicate agency, whereas 'me' is considered to be passive. 'We' is an indicator of connection, 'he,' 'she,' and 'they' are active, whereas 'him,' 'her,' and 'them' are passive.
	Active and passive verbs	Study of agency, location of the agency (locus of control).
	Metaphors and figurative language	Finding the root metaphors in the text. A plant metaphor is considered an indicator of growth, and therefore suggested agency. Black dogs are seen as a sign of being controlled by negative influences.
	Developing simple scripts	When (the trigger) *When I am in a crowd of people I don't know.* I (summary of the plot) *I try to close in and get to the edge.* Then (the consequence) *I can figure out how to get away.*
3. Interpretation		Summary of what the student had learned about patient experience from the analysis and how the scripts depicted the trajectory of personal experience.

2. Narrative Analysis Used to Uncover the Social Reconstruction of Self After Health and Disabling Condition

The author of this excerpt was a student in the narrative analysis class. It has been revised to remove any identifying information.

Table 7.2 *Story Analysis Workbook*

Story Analysis Workbook Inquiry into scripts of recovery and resilience: An inquiry is a structured set of questions leading to novel and personal answers. Learners own their knowledge and gain confidence in their critical-thinking capacity.
Reference for Autobiography: Roney, L. (1999). *Sweet invisible body: Reflections on a life with diabetes.* New York: Henry Holt and Company, LLC.
Short 200-word book report: Lisa Roney writes of how being diagnosed with diabetes at age twelve has affected her life. She describes the constant attention diabetics must pay to diet, exercise, and the constant balance of high and low blood sugar. She voices how diabetes infiltrates all aspects of her life. Through her autobiography, Roney hopes to reach out to other diabetics, inform others about the implication of a chronic disease and also validate her own story. Her struggle and life experiences lead her from a young girl trying to be brave to a defiant teenager challenging authority, a college student pretending diabetes doesn't exist, a battered lover defined by diabetes, and then her having found her place as a writer. Throughout the book, Roney knows that her experiences and choices have brought her to where she is, but as is the case throughout much of her narrative, she finds it hard to break out of the control she requires in order to risk any of herself to others. Through her uninhibited recounting of her life, Roney exposes herself, provides an intimate look into the world of a person with diabetes and provides hope for others.
Data collection: Chronological story chain. Each story is summarized as a Story that is a comprehensive incident recounting a story with intent, context, what happened and the consequence
1. Title: Grandpa's moral story (pp. 5–7) Description: Grandpa tells the story of how his brother Russell lost the tips of his fingers to a young Lisa, who hears the moral of perseverance and overcoming horrible events.

Table 7.2 (*continued*)

2. Title: Hershey haze (pp. 18–24) Description: Vaguely aware that she is not well, but too tired to do anything about it, 12-year-old Lisa waits for her mother to come home and return the doctor's call, which confirms that she does have diabetes.
3. Title: Able to take care of yourself (pp. 26–31) Description: Lisa finally learns to inject herself by practicing on a candy striper first.
4. Title: It's okay, I'm brave (pp. 44–46) Description: Lisa's rolling veins cause problems for a nurse who tries to take her blood, but fails and cries due to the pain she has caused Lisa, who tells her, "It's okay. Really."
5. Title: Out of lines (pp. 50–53) Description: Unfairly made to do lines, Lisa copies out an excerpt about strict teachers really being afraid; this earns her more lines that she uses to continue her protest.
6. Title: Role reversal (pp. 62–64) Description: While they are hiking, Lisa's brother, who usually looks out for her on hikes, becomes dehydrated and needs Lisa to take care of him.
7. Title: Soda of hope (pp. 69–72) Description: Coming home from a high school trip to Mexico, Lisa is falling into insulin shock from lack of food and is saved by the sodas that all the Mexicans hoping to cross the border had to sell before they found work.
8. Title: Just a drunk tourist (pp. 85–90) Description: Traveling alone in Venice, after hiking, Lisa shares drinks with Australian women and her glucose drops. Too proud to ask for help, she stumbles around Venice, humiliated by others' reactions to her condition, until she finds her hotel.
9. Title: Allies in a train of normals (pp. 91–93) Description: Lisa is embarrassed about testing her blood in a train car, until the elderly man across from her turns out to be a diabetic as well.
10. Title: Mary's Marvelous Diner: Everyone welcome (pp. 97–104) Description: Mary's Diner was a safe haven for college students to work, where staff and customers alike were comfortable regardless of their shortcomings and Lisa could work and not feel set apart.
11. Title: Cheater, cheater, ice cream eater (pp. 125–128) Description: While visiting her uncle and aunt, who constantly monitor her eating, Lisa sneaks some ice cream while her aunt is out, and is caught by her cousin whom she perceives as disgusted by her behaviour.
12. Title: Running with indifferent rose (pp. 154–156) Description: Lisa's new exercise partner continually changes plans and shows no regard for the structure Lisa needs to regulate her diabetes, so she decides to exercise alone once more.

Table 7.2 (*continued*)

13. Title: Fear of blindness is blinding (pp. 165–168) Description: While proofreading for a law firm, Lisa experiences visual problems related to hyperglycemia and reflects that fearing blindness misled her into art studies rather than following her passion for writing.
14. Title: Learning by lightning (pp. 174–177) Description: One of her favourite teaching moments - during a storm her students were restless so she abandoned her plan and just let the students write while she felt the power of language.
15. Title: Practically perfect Panos (pp. 202–211) Description: Panos accepted her diabetes and created a want for monogamy in Lisa, but they had little in common and he disagreed on the nature of fidelity, eventually giving her an STI.
16. Title: Bill destroys belief (pp. 212–219) Description: Long-term relationship with Bill, who cheated uninhibitedly, lied and raped her, leaves Lisa jaded and wondering if her diabetes made her think she had to put up with this kind of treatment.
17. Title: Trapped, fighting and paralyzed (pp. 242–248) Description: Lisa describes recurring nightmares where a sniper holds her hostage and she won't escape alive, and others where she is rushed by a man who never hurts her but she cannot move, and ones when she yells at people in her life that she is angry within waking life but can't communicate with.
18. Title: Cheating Craig for control (pp. 266–267) Description: A new roommate already found to take her place, Lisa's planned move falls through. Craig offers to work it out together, but Lisa's name is on the lease and she refuses to leave.
19. Title: Cassie is witnessed (pp. 279–283) Description: Lisa's cat Cassie is diagnosed with diabetes, and as she gets worse, her life is worth fighting for, from Lisa's perspective. When she passes away, Lisa takes comfort in the fact that Cassie was known and thus lived fully.
20. Title: Safe and loved with Sally (pp. 292–295) Description: After four years alone, Lisa lives with a roommate again and is worried Sally will start to hate her, but Sally regards Lisa's quirks with affection.

Choose five key stories from the trajectory above and repeat the following analyses for each story. Copy the templates for each story.

Table 7.3 *Sample Analysis of Plot and Structure of Key Stories*

Sample analysis of plot and structure of key stories
Able to take care of yourself (this is the title of the story) The beginning. The context (the who, when, where) Lisa, as a teenager in hospital with diabetes is faced with learning how to inject herself before she can leave the hospital. The nurses and her family try everything.
The middle: The plot (what happened in clear, concrete steps)
1. Lisa's mom went to an American Diabetes Association support group meeting where one mother spoke of her teenage daughter who still refused to give herself injections.
2. Her mom tells her that she is not leaving the hospital until she can give herself her own shot.
3. Lisa practices on oranges but struggles with the idea of self-mutilation and of something "alien invading the body."
4. Every nurse on the floor tries a different tactic, but after days, patience is wearing thin.
5. Finally, a candy striper cuts the deal that Lisa can try it on her first if she does it on herself immediately after.
The ending: Lisa does the needle on the candy striper and then finds it much easier to do it on herself than on someone else.

Table 7.4 *Sample Discourse Analysis of Language in Key Stories*

Sample discourse analysis of language in key stories—abbreviated Select a passage from each story that captures the emotion or movement of the story.
1. Underline individual words that jump out and write them down here. Read your words aloud and write about the nature of the words, what they tell you about the author (who is the author here – victim, colleague, expert, etc. and how do the words generate sympathy, justify anger, etc). Look at the familiarity of the words, how they fit together, are they concrete or abstract, raw or sophisticated, strong or gentle, intimate or aloof. Airy, braced, warm, jerks, dim, rivulet, frightened, tensed, hurting, flesh, recoiled, squeezed, scarlet, imprints, bruises, swelled, angry, puncture, relief. The nature of the words is one of battle. She starts out bracing herself, frightened. Then there is the attack – hurting, flesh – and the retreat – recoiled. The aftermath is told – squeezed, scarlet, imprints, bruises, swelled, angry, puncture – and the final verdict is passed – relief. In this story, Lisa is a warrior on trial. She is being put to the test in a battle of wills. Her unwillingness to break the integrity of her skin and the need to permeate that barrier so she can learn to take care of herself are in conflict. She knows she must overcome her willingness and the generals are present to witness her battle and judge her bravery. The words she uses are strong and very sensual. This highlights the emotional as well as physical struggle she is experiencing.
2. Circle pronouns as connections and indicators of agency. Count the number of each type of pronoun and comment on who each pronoun (I, we, they, she, it, etc.) represents. Me, my: 6 times – represents Lisa I: 9 times – represents Lisa *The story shifts from me/my to I after Lisa has gotten the needle in and can now take it out.* Her, she, and herself: 8 times – represents the candy striper Everyone: 1 time – represents her parents and a floor nurse

Table 7.4 (*continued*)

3. Record verbs as indicators of agency. Are these verbs active or passive? Indicate agency for verbs as indicated: Technique – evaded – Lisa (the technique is in control) active Lisa – braced – side of my right hand (she is mobilizing her hand) active Lisa – planted – needle (using different mediums, first her hand and now the needle, she is acting upon the candy striper) active Giving the needle – take – time (In the story the wording is "This seemed to take forever…") active Dim – going – vision (This verb is passive) Sweat – running down – back (she has no control over her body) active Candy striper – sucked – air (awareness of the candy striper acting is established) active Candy striper – tensed – her arm (though this verb is active, it goes on to say in spite of herself – implying that she was not in control of her actions) Lisa – hurting – candy striper (Lisa is now the one acting directly upon the candy striper) active Lisa – pulled – syringe (there is a shift back to the medium of the needle) active Lisa – recoiled – herself (Lisa withdraws herself, now that she is finished the needle her focus is once again on her own body) active Lisa – squeezed – her left hand (Looking at the candy stripers arm after, Lisa again looks at the effects of the medium between her and the candy striper, in this case her hand) active Lisa – withdraw – needle (still the candy striper is not mentioned – the needle is) active Bruise – swelled – candy stripers arm (The actual wording does not mention the candy striper here, but the angry puncture wound) active Though the author is using very active and vivid verbs here, her role in the affair is very passive. She is rarely in control of the events that are happening beyond her own body. It is her hand that grips the arm and the needle, but her role in puncturing the candy striper's flesh is minimalized through the prominent role that the needle takes on.
4. Purpose / motivation for telling this story at this point in the book. Look to changes in power, establishing new roles, etc. This is one of the first instances where Lisa really talks about losing control. She has just been diagnosed, but previously was vague about what was happening to her. Now that she knows that she has diabetes, suddenly she is powerless. Whether or not she wants to invade her body with a needle is irrelevant – if she wants to live, if she wants to leave the hospital, she must overcome that barrier. This is where her battle with diabetes begins.

Table 7.4 (*continued*)

5. Sample metaphor analysis Read the autobiography to find mention of metaphors. Often metaphors are implied and hidden. Metaphors often point to ideas of concern, strong emotion or confusion.
Metaphor
"The state of the weather seems comparable to my blood sugar levels – some days it makes exercise outdoors impossible, but most of the time it's just something to take into consideration." (p. 149).
"I envisioned a silent monster always after me with an eraser; some days it didn't make much progress, but others I would be going home with barely more than my toenails. During the evening and night, my real self would regenerate, but if I had been erased down to my toes that particular day, then I might have to go in to work the next morning still missing my head or my hands. That gave the eraser demon a jump start and the cycle might go through a horrible phase where I couldn't restore myself and so hardly knew myself, barely felt that I existed." (p. 168).
Is there an underlying root metaphor to the book? For example, does the person use weather, plants, animals, machines, places as the underlying metaphor and how does it shift during the course of the book.

3. Playing Out Scripts

This exercise creates a space to think about the final step in understanding personal truth—the wisdom that the person has to offer from their journey through disability and health concerns.

While people tell individual and unique stories, they do so with recognizable underlying scripts that provide the structures for what roles they play and what they expect of others. Once you have identified common scripts in your text, take these scripts back to the data set of 20 stories to see which stories are told from these common scripts. Identify other scripts in your 20 stories. If possible, take your script discoveries to other stories in your autobiography to find other scripts.

As you begin to understand the purpose of the script (agency and self-regard) you can begin to understand the path taken by the author in finding meaning through adversity.

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