



A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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ISBN 978-1-77385-733-6

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Negotiating Co-research: A Theory and a Method for Empowering Stories

Highlights

- International case studies of new social movements
- Research devoted to finding a way to make co-research work
- Grounded theory research to find theory and a method
- Integrated narrative theory of data collection, analysis, interpretation, and theory
- Case-based or idiographic theory and theory of new social movements

The goal of this chapter is to share the research that led to the emergence of an integrated narrative, grounded theory research method. This was done in partnership with founders of new social movements, as part of my PhD at the Open University in the United Kingdom. This was a case study of six new social movements that enabled the incubation of methodology. Each of the six founders committed to the co-design and co-production of a new research approach suitable for peer research. The resulting method informs grounded theory research to adapt the peer research method of the science of engagement (SoE).

This chapter was first published as partnership research in *Doing Health Promotion Research* (Thurston et al., 1998, out of print). It is adapted here with the permission of the editors. The impetus for the research came from the Calgary Association for Independent Living (CAIL) that introduced me to peer support self-assessment and goal planning as part of action-based research. It helped me understand peer support as a potential model for peer research. In spite of much skepticism from my PhD supervisor and committee, I decided to use co-research where I was a peer in the study because of my work as a social innovator that the co-researchers saw as equal to their work in social innovation.

Research Partnership in Co-research

Co-research introduces new research roles to the study of social innovation, which, according to Conger (1974, <https://doi.org/10.1111/j.1467-9833.1974.tb00448.x>), is “a new procedure, organization or law that changes the ways in which people relate to themselves or to each other” (p. 26). This study addresses a subset of social change—innovations that influence people’s ability to realize personal and group emancipation.

I set out to explore social innovation in ways that would inform traditional power imbalances in research. While conducting the research, I had the opportunity to visit a number of universities to present seminars on my work. I spoke to sociologists, educators, psychologists, and discourse analysts. While most were intrigued by the research, they had strong reactions to the idea of working partnerships with people who were the focus of the research. Reactions were far reaching, from threat to academic freedom if co-researchers were equal partners in the interpretation of data, to the abdication of academic responsibility. On the other hand, feminist researchers I spoke to considered full partnership a fond but elusive dream.

The study took place in several settings in the UK and Canada, with people who had experienced a social change that had an impact on their personal lives. Most co-researchers were involved over a period of three to four years. British partners included Gerry Kinsella, founder of Greenbank College; Dorothy Birtles of the Quaker Prisoner Befriending Scheme; Dame Cicely Saunders, the founder of the modern hospice movement; and David Brandon, Director of Mind UK. Canadian partners included Henry Enns, co-founder of Disabled Peoples’ International, and Henry Three Sons from Siksika Family Services Corporation. They and the people involved with their social innovations offered living laboratories of the study.

Through hours of interviews, site visits, and sessions with their families, staff, and clients, they became researchers of their own experience. We were able to document how they, as equal partners, found ways to collect, analyze, and interpret their data. In the process, we uncovered knowledge that was meaningful, both for an academic audience and the new social movements studied. In a way, we lived social innovation, as we explored new partnership roles for both myself and the founders.

I chose to use grounded theory as the general framework for the study because I anticipated that the methods used to study social innovation would have to evolve and expand as the study progressed. After an extensive recruitment and preparation process, we started with a fairly traditional qualitative interviewing approach, using feminist principles and ethnographic processes, which encouraged an open sharing of ideas and reciprocity.

We soon encountered serious difficulties as the transcripts, and the forms of analysis posed barriers to partnership. The founders felt increasingly alienated. Although we spent time together, most of the work was my work trying to figure out how to do co-research. The use of conceptual abstractions as themes distanced the participants from their own material, because many of the themes arose from my background and reading as a psychologist.

When I sat back to analyze what was happening, it seemed that we kept talking because neither I nor the others knew when we were finished. I began to imagine that we were trapped in a force field defined by collecting, analyzing, and interpreting data without a way to stop. My feelings about the search for the meaning were coming close to those of expressed by Rommetveit (1987, <https://doi.org/10.1080/00201748708602111>) in discussing the plight of the enlightened layperson struggling to make themselves understood within the games of research: “[The participant’s] initial pride turning to despair and alienation while I as the scholar of human communication pursued the trade with scientific rigor, formal elegance and academic success within the convenient fiction of joint construction of meaning.”

I came face to face with reality, as stated by Gluck and Patai (1991, <https://doi.org/10.4324/9780203819371>): “Narrators typically are not true partners in the process. Whatever control they exercise during the interview, when they are able to negotiate the terrain, usually ends once the session is completed” (p. 2). Gluck and Patai go on to assert that, although narrators are occasionally consulted prior to publication, the interviewer/scholar maintains control over “the work of framing, presenting, interpreting, analyzing and making the work public” (p. 3). They conclude that feminist scholars contribute to the collectivity of women, but their actual practice has maintained the real separation between narrator and interviewer.

As we discussed the difficulties we were experiencing, it became apparent that the participants had particular strengths related to understanding the nature of partnership research. They had agreed to participate in the study after understanding the scope of the research, their role in negotiating topics, and their role in the use of the material. The participants were high profile people with much to lose, and the topics covered could be potentially damaging—both personally and professionally. They needed assurances that their information would be treated with respect and their ideas not squandered. The first change was to move away from conceptual abstractions and psychology-based theory and agree to base our work within a shared language of everyday experience. We also needed a process whereby we could capitalize on the implicit expectations of our partnership so that we could shift expectations and goals. It seemed logical and natural to consider a social contract that could help us clarify the steps to be taken.

Table 2.1 *A General Social Contract Framework for Co-research*

	Give	Get
<i>Co-researcher: content expert</i>	• Information and personal perspective on topic	• Respect and involvement • Useful data that can be shared with others, especially peers and community members
<i>Co-researcher: academic expert</i>	• Values contribution of participant	• Participant information and perspective on the topic.

The contracting process was adapted from a training contract for the Adaptive Functioning Index (Marlett, 1973). It created the opportunity to openly discuss activities, interaction, quality standards, and products and end points. We negotiated next steps and options, instead of being limited to one prescribed research process.

Rather than trying to negotiate a contract for the entire research, we negotiated our roles throughout each task of the research. These tasks occurred within four general and interconnected stages in the research process: data collection, data analysis, interpretation, and theory generation and dissemination. The negotiation at each stage began by defining and agreeing to the tasks at hand. We could then define our respective roles in relation to the specific research task, the anticipated product of each task, and how each of us would know when the process was finished. From this, we could also judge the quality of our work in completing the task and the product that resulted. This was a verbal process, captured on tape, and this is available in the transcripts for reference.

1. Data Collection

Data collection was an easily identified process because most of the co-researchers had been interviewed in the past and were familiar with evaluative research. They were comfortable with the different methods used to collect data in the study—interviews, observations, use of documents—and, thus, the data collection contract held no surprises.

The purpose of the contract, as illustrated in Table 2.2, was to secure relevant and accurate information. In this, the researcher provided the opportunity and means for the participant co-researchers to explore and discover, in order to learn about themselves and the topic. The participants committed to explore and share their experiences and ideas within their limits of trust and safety. I, as a co-researcher with experience in social innovation, contributed when it facilitated and expanded the scope of the data. Any agreements to disclose information were governed by the balance between the benefits and the inherent risks to the participants.

Table 2.2 *A General Social Contract for Data Collection*

	Give	Get
<i>Co-researcher: content expert</i>	• Commitment to explore and disclose information on topic	• Opportunity to be part of research • Opportunity to discuss one's experience • Recognition of experience • Respect and acknowledgement of expertise • Understandable data
<i>Co-researcher: academic expert</i>	• Knowledge about research related to the topic • Willingness to discuss process • Preparation of transcript and data summaries	• Opportunity to explore topic with an expert with direct knowledge • Self-awareness as a researcher

Every effort was made to establish and maintain an informality in collecting data. Co-researchers set the pace and were free to expand on topics or issues that they felt were important. It was common for the co-researchers to ask questions and for me to share my experience and material from my research experience with marginalized groups. The founders were asked to comment on the process and whether they felt safe and comfortable with the information disclosed. If a topic was too sensitive, it was removed, deferred, or approached in alternative ways. In all instances, participants were invited to include others in data collection to explore alternative perspectives. For some co-researchers, this meant the casual involvement of a spouse or family members; for others, formal group interviews with co-workers and the people directly involved in the social invention were arranged. Interviews took place in a location chosen by each participant, usually at the site of the organization. Interviews were taped throughout the entire research process to provide a record of the evolving methods. The final product of the data collection stage was the transcript.

Transcribing our first co-research interviews from taped interviews, field notes, and documents almost derailed the co-research and my thesis. The first transcripts were formal texts that left participants alienated and reluctant to engage in analyzing the transcripts. Similar concerns have been raised by feminist researchers Doucet and Mauthner (2006, https://www.researchgate.net/publication/251770477_FEMINIST_METHODOLOGIES_AND_EPISTEMOLOGY).

Co-researchers felt the words in formal text didn't look like their words and this was embarrassing to them. I had taken their words and ideas and made them mine, as I attempted to impose grammatical structures. The written record seemed barren and alien. All founders felt that I had appropriated their experience, and they were relegated to confirming my record of their lives.

Using Glaser and Strauss's (1967, http://www.sxf.uevora.pt/wp-content/uploads/2013/03/Glaser_1967.pdf) call to experimentation in grounded theory, I spent eight months trying various transcription methods with the co-researchers. I wrote in various styles of texts, prepared short summaries of key points, used various linguistic formulae that translated the spoken word to speech acts, drew annotated pictures of constructs, and, in desperation, I even resorted to writing free verse.

Then, late one night, I plugged in my transcription machine and slowed the speed. I just began typing and lost myself in the unfolding stories. As I listened, I typed and hit the return button each time I heard a pause, for no other reason than that it seemed a sensible way to avoid run-on lines. I typed naturally, often keeping time with the tape recorder, and, after a few hours, I looked at what I had created and smiled. Rather than listening for content and sentences, I listened to the rhythm of the speech and the intonation of the speaker. When I read it back, I suddenly realized that I was listening to the person talking 'text'—the breath, the pause, the hesitation had created speech on paper. The following is a short example of the method for transcribing in which Gerry was talking about bus transport at Greenbank:

It took 10 minutes to load a trainee
not particularly good on her feet
He (the bus driver) had to use the lift
and I said
are we talking about the same person
she could go up the steps at the side of the bus
(driver) said no she can't
and her mother is adamant that she can't
I said okay, I'll go with you
and I went out

and the parent came out and was about to say my daughter can't
do it

and I said

alright Mrs. Jones we don't need you here right now

in a tone that means I don't want you here

it's not a school

this is an exercise that management needs to do

and the kid is bemused as anybody

it could have been one of those tearful experiences

the upshot was that the exercise was completed

she got on the bus.

I've had dozens of these where people assume they can't do
things because people tell them they're disabled.

This transcript maintains its conversational character and the integrity of ideas as separate but connected. Without punctuation or a constructed sentence structure, it reads with the rhythm of speech. One of the co-researchers called it research poetry. When the speaker is talking about familiar concepts, long, run-on sentences appear because the speaker doesn't need to think, but when the speaker is concerned or searching for answers, short lines appear. In our transcripts, the visual appearance and the rhythm reflected individual characteristics. When more than one person was included, each person could be identified by the visual footprint of words on the page.

In essence, the story tells itself in the person's own voice. The reader gains what the person is saying in a direct way that doesn't need interpretation or presentation. This maintains respect and reality, and, in doing so, enhances the overall outcome. The connection between memory and the rhythmic patterns seemed to draw in the co-researchers—they could easily locate ideas in text. We could recall the conversations, and, most importantly, each person commented that they could hear themselves in their story. They heard their own rhythm rather than the rhythm imposed by the transcriber who had produced the transcripts.

The problems of written representation have been associated with the power of ownership in research. Written text becomes owned by the researcher instead of belonging to the speaker. This speech transcription shifts power to the narrator.

The speech transcription method is included here because it provided an important breakthrough in the extension of partnership beyond the interview. Transcripts were produced using a technique designed specifically for the study. This created a written representation of oral conversations.

This speech-based procedure for creating transcripts enabled the co-researchers to own their transcripts as part of an ongoing oral interaction. This enabled us to 'play' and engage with the data longer. The social contract of data collection was considered complete when participants saw and felt comfortable with their transcripts.¹

Listening to recordings and making notes or filling in story templates creates support for the reluctance of grounded theorists to produce transcripts that may inadvertently subtly change the meaning of thoughts in conversation. It also made me more confident in the transparency of the text form of our experience instead of relying on attempting to create written text.

It was interesting that as PaCER shifted to qualitative research using thematic analysis, they also returned to transcribing interviews and focus groups. In the final chapter, we introduce a new integrated narrative science that uses story templates to organize data from recording throughout the stages of research, and this may encourage a return to data that captures real-life experience of co-researchers in ways that reinforce the language used by co-researchers.

2. Analysis

The definition of, and contract for, analysis proved to be the turning point of the study. After much study and discussion, analysis was defined as examining and breaking data into small pieces or incidents for grounded theory constant comparison. In this, the whole story and the elements of the story were considered incidents. Each incident of data was studied to find similarities and to sort the data into categories. The purpose of the contract was to ensure reliability of the information that had been gathered and sorted, to ensure that the elements or

1 Note: Not even this simplified speech process was enough to engage seniors from *Grey Matters* (Marlett & Emes, 2010) in transcribing data. They used a story template that enabled them to listen to the tape and insert what was happening in the stories into the story template. This provided a bridge between data collection and the first stage of analysis of taking data apart into pieces or incidents that can be studied for meaning. The story template has since become the basic data format for collecting incidents.

units were complete and correct. Table 2.3 represents the framework for the analysis contract.

Table 2.3 *A Contract to Sort Data Units into Categories*

	Give	Get
<i>Co-researcher: content expert</i>	• Verification of correctness and completeness of the data • Agreement on elements in the data, their groupings and order	• Security that information is not distorted or changed • Involvement in data analysis
<i>Co-researcher: academic expert</i>	• Preparing data and templates for analysis • Opportunity to involve participant co-researchers in analysis	• Visibility and verification of the data • Co-researcher perspectives on the connections in the data • Security in the elements and their integrity

After working with the transcripts in the form of whole stories and short word phrases in order to identify concepts, it became clear that the time required became excessive. We agreed that I would take the responsibility to prepare the data into units, so that we sort them into categories. The end product was a collection of incidents sorted into categories with preliminary names from the data.

The search for methods of analysis was a six-month quest to find a collaborative way to work with the transcripts that respected the co-researchers and enabled the analysis to reflect an authentic negotiation of meaning. Conceptual and thematic analysis, life-course analysis, conversational analysis, structure analysis, movement analysis, and antecedent/consequent analysis were all tried, but none fostered the ability to co-research. Each felt like I was retelling their experience in a foreign conceptual language. They felt alienated, abandoned, and frustrated. Eventually, shared stories composed of common experiences were chosen as the foundations of analysis because co-researchers could relate to stories and work with them.

The negotiated contract for analysis was complete when all the relevant information (transcripts, observations from the site visits, interviews with collaborators, and documents) were represented in story units. The initial story chains were constructed using cards enabling the co-researchers, and those they chose to be involved, to see and work with this initial stage of analysis

more easily. The stories were summarized by title, page reference, a summary, and a brief list of incidents of experiences. Participants were invited to add stories that had been missed, combine or separate stories, or delete stories that were not relevant to the topic. It enabled creativity and the notion of playing with experience in the process of ensuring thorough analysis.

The processes were open, concrete, and transparent, and led to productive and comfortable working relationships. Both parties knew what was expected and when the task was complete. Co-researchers had come to feel a certain security in the handling of their stories because they could see and understand each of the steps in the process. They came to believe that their information was respected, that there was a deliberate search for truth and that their stories would not be distorted.

The following section is a summary of some of the more successful methods used with co-researchers in this stage of analyzing their data. The process of sorting and comparing incidents to create categories is considered under interpretation.

Options for Analysis

1. Short Story Summary and Initial Codes of Categories

We began creating notes in the transcripts that identified potential stories in the margins. We named each story (a title) and included a summary of potential themes. We used this process for all data. These stories grew to become chains that created a chronology of stories. Stories from different data sources could be added into the story chain from interviews, groups, and documents. The innovators maintained their ownership of these short stories and story chains. The following is an example of several stories from a story chain of the Greenbank training centre:

- **Debbie comes to Greenbank (field note):** From a chat with Debbie while writing a European Union report about Greenbank. Professionals had convinced Debbie that she would never work anywhere but in a sheltered environment. However, she came to see herself as a competent and creative worker.
 - *Themes: stigma, labelling, external control, new hope.*
- **Bus and Mrs. Jones (Gerry transcript, p. 16):** Interview with Gerry and the bus driver. Gerry sidelines a mother who is limiting options for her daughter; Gerry asserts that the daughter will be able to get on the bus.

- *Themes: control of external power, risk, power, power balancing, staff training for expectations, belief and confidence*
- **Crooked eyed joiner (article in newspaper and field note 17):**
General chat in the lunchroom with a group of staff. Gerry noted that a trainee jerks when cutting, not because of physical disability but because he is blind in one eye. The trainee adjusts the angle of the work so he can see and performs well.
 - *Themes: a peer notices problem missed by a professional assessment, native cleverness of peers, staff training, belief and confidence*

Over 90% of the data was included in this type of chronology of stories, which we defined as any temporally and thematically connected series of ideas or incidents. We entered the short story notes onto small cards, to compare each story and to sort into categories of like stories. We worked with the story chains to fill in the gaps, find duplicate or related stories, look for patterns and create analysis for common stories. This process was in keeping with classical grounded theory and necessary for the social contract.

2. Antecedent Consequence Analysis

We experimented with different ways to express the short stories in a more expanded fashion that captured action, direction, and change. The most extensive of these was antecedent/consequence analysis of events to flush out the stories. The following is an example of the analysis of antecedent and consequences in the Bus and Mrs. Jones transcript noted above:

- Implied actors: *Gerry, Mrs. Jones, bus driver, and daughter*
- Condition: *Dispute over time taken to load trainee on the bus triggers Gerry to set up a session to witness the loading process*
- Activity: *Assessment of the loading process to identify parts where difficulty was noticed*
- Tactic: *Interrupt Mrs. Jones before she has a chance to voice her option—change focus to transportation difficulties, not the daughter*
- Consequence:
 - *Daughter is bemused and vulnerable*
 - *Parent is sidelined*
 - *Staff is chastised*
 - *Daughter gets on the bus and is proud of herself*

This analysis was incorporated into the analysis of the story template that consisted of the beginning, middle, and end. The shift to a more simplified format made it easier for novice researchers to understand and use.

Figure 2.1 *Story Template to Record Stories in a Quick, Visible Format from Audio Tapes, Flip Charts, or Observations*

Story Template		
Title		
Researchers	Date	Project
Context (the who, where, when, and what was happening of the story)		
The trigger that starts the story (the action, idea, or event that disrupts the flow)		
The plot of the story (and then . . . and then . . . and then) simple steps in the unfolding story		
1.		
2.		
3.		
4.		
5.		
The consequences or ending of the story		
What did the teller learn about the topic or her/himself		
What did you learn and how does it relate to the concern or question		
What next steps are suggested		

3. Interpreting Stories: The Search for Meaning

During data collection and analysis, we worked to capture historical truth. Historical truth lies in a story that is recounted by those who have lived it. Historical truth is truth as seen, experienced, and recalled. We had done this

through the honest and comprehensive documentation of actions, events, ideas, and feelings. Now we had to deal with narrative truth wherein the story is true regardless of its historical veracity because of the meaning the story conveys to others (Spense, 1982, <https://doi.org/10.1080/21674086.1982.11926984>). In the search for narrative truth, the stories were no longer products in and of themselves but were tools in an ongoing interpretive process that used the stories to uncover topic-related information. We defined ‘interpretation’ as the process of finding relationships between the stories that added to our understanding of the intention, purpose, or impact of the topic.

This following section addresses constant comparison and coding using incidents, which includes stories (small action statements of what’s happening) and descriptions of experience (what was it like).

In my experience with quantitative, evaluative, and social action research, the scope of the interpretation was predetermined by the method used. None of these experiences seemed relevant to the work we now faced. While our roles had been different and discrete in the search of historical truth, we were now fellow observers and interpreters, as we moved beyond documenting stories to understanding the topic through stories. We had to create our respective roles and rules of conduct as we went along, as represented in Table 2.4.

Table 2.4 A Social Contract for Interpretation

	Give	Get
<i>Co-researcher: content expert</i>	• Understanding of context—place, time, actors, history, culture • Increased options for understanding meaning • Seeing commonalities or categories in stories	• Increased understanding through reframing events and experiences • Personal awareness of social innovation • Sorting experience to find common themes
<i>Co-researcher: academic expert</i>	• Process for identifying various perspectives of categories • Recognition of co-researcher’s life worlds and impact • Process for making sense of experience	• Contextual and social validity • Fresh insights • Dense categories • Options for theory • Novel process for interpretation

In this contract, we move from stories to categories of stories through a sorting process. There are two goals related to negotiating roles—social validity

and contextual validity. Social validity was enhanced because the process and the product were personally meaningful to the founders of the organizations they created. The contract also framed the tasks of interpretation within our respective experience. Contextual validity was a term that I coined to recognize the underlying meaning inherent in context (historical, social, personal, and cultural). For example, the results of a study of mother/infant interaction would take on particular meaning if the study was conducted in an intensive care nursery and a very different meaning if the study was conducted within the home. When the context is identified, readers have important reference points that ground their understanding.

The tasks involved developing methods that capitalized on the strength and breadth of our combined experience and complementary perspectives. The benefits of partnership during interpretation were great. The co-researchers had an opportunity to reframe their experiences according to a number of perspectives, including their history and their culture. The academic researcher broadens the interpretive base so alternate meanings are recognized and integrated into the final products.

My role included the development of methods and procedures that would engage both of us in a shared search for meaning. The co-researcher's role was to approach each exercise with openness to different perspectives and to identify as many interpretations as possible. We began by discussing what each of us brought to the process of interpretation by looking at our experience with the categories. We also discussed how our shared experience extended the boundaries of possible interpretation to include our combined personal, social, cultural, and historical perspectives. This process also helped me define the potential for generalizing our interpretations.

As we started to work with stories, I was unprepared for the openness, mutuality, and reciprocity that ensued. It was as if the stories had created a familiarity and trust that made it possible to understand our research roles at a new level. The following transcript is taken directly from a tape of the interpretation session, and therefore not presented in the usual transcript format. It is included to identify the partnership that enabled the case study to proceed.

G: *At the beginning, I must confess that you were asking questions and I was wondering if my rabbiting on would give you any information that would be of any use to you at all, and then I stopped doing that very early on. I was constantly thinking about what I'm saying and what meaning it may have to your research. It might have been a botched-up job.*

- N:** *You know, I don't think researchers realize just how much people do just that –that people are trying to give us what we want. I think that may be the reason why so much research is shit. We never sit down and say "this is the area I'm interested in" and be honest with you. You end up spending your time guessing what my agenda is.*
- G:** *It's almost like bedpan syndrome. You've been interviewed by so many professionals who are wanting to prove a theory. Not really searching for new stuff by wanting to prove a theory and you see that when somebody's eyes start glittering or their voice changes –it says "yeah, tell me a little more about that" and you think "oh shit, I've got it right haven't I" and then you get the disappointment in their eyes and you think "oh now I've done it." That wasn't happening 'cause I quite enjoyed telling you my stories, to be quite honest.*
- N:** *There were times when I thought I should be directing it more. I finally thought it's time to just watch where this goes. There were pages where all I got to say was an "um."*
- N:** *One of the stories that I wanted to interpret with you is a story that happened a long time ago and it will be a challenge to get back into it. I'd like to talk about what roles we might take in this. I'll need to be guided by you.*
- G:** *OK, lead us into it. There's so much in my mind, let's start with the story and see what comes out.*

(Gerry and Nancy, interpretation tape, 1991)

The short story chronology and the story template identify story-based categories for more detailed analysis and interpretation. The following describes the elements of the story template as used in interpretation.

Title

The title represents an aspect of the story that sets it apart from other stories; the naming of the story is akin to its birth. Story becomes an entity when it has a name that acts as a specific code for the entire story. The title suggests how the story will be recalled, shared, and changed. It, in effect, bridges from story to narrative because of the shared meaning.

We learned that the person or persons who label the story owns the story. Even when I chose words from the transcript that I felt honoured the narrator, my act of naming presented problems. In the beginning, the co-researchers either capitulated and gave the story to me or we engaged in a struggle for power in naming the story. Once we realized the power of ownership, the ensuing naming ceremony developed into a kinship between us.

The title is in fact the theme of the story in most cases and as such titles represent stories as incidents.

Context

This is generally the beginning but can be scattered throughout an interview. It combines the who, what, when, and where of the story. It follows from the much-loved phrase ‘once upon a time.’ The context sets the stage, outlining what was happening when the story began and the triggers that initiated the story. The context collects the properties and characteristics of the story that are used to understand categories by looking at the common properties. The following is a summary of the properties that are used in interpretation:

- Who is the teller of the story? A young Indigenous woman.
- Where does it happen? A young Indigenous woman in the emergency department.
- When does it happen? A young Indigenous woman in the emergency department in the early morning.
- What’s happening? A young Indigenous woman in the emergency department in the early morning having difficulty breathing.

The following example from Greenbank led to an important breakthrough in understanding the importance of place as a context in understanding stories. Over 100 stories from Greenbank were sorted into piles according to where the story took place. Four locations were identified:

- Greenbank, the former special school that was taken over by persons with disabilities to start a training co-op.
- Smithdown, the downtown commercial enterprise that houses shops, a wheelchair factory, and a whole food restaurant.
- Past places such as special schools, hospitals, and in foster care.
- Westfield, the proposed and contested site of expansion and direct competition with professional services. While Westfield failed to materialize, a recreation centre was built instead.

Place or ‘where’ is just one of the features of story analysis that can lead to categorizing stories and incidents. Categorizing by place was the key in the development of understanding how the environment created consistent psychological spaces that were reinforced by common stories or narratives. It also provided an overall theoretical framework for the social enterprise that was called Greenbank.

The questions related to who, what, where, when, how, and why are not just context, they are a powerful tool in interpreting stories. In grounded theory, which is not narrative by nature, similar tools are called properties—qualities or characteristics. From a narrative analysis perspective, this would relate to the question, ‘what is happening here?’ This questions the story as an incident, happening, action, or metaphor.

Plot Analysis

The plot consists of actions or incidents, listed in order, from the context to the outcome or consequence. By analyzing the plots of similar stories, it is relatively easy to study what is happening in the story. There are common plots in literary analysis, such as tragedy and comedy. There are also specific tools that capture the overall movement. This represents movement analysis that tracks the conceptual movement from a story template.

Consequence

The consequence demonstrates how the flow of the overall story had altered by the end. It identifies what the person learned (the moral of the story), and how relationships, roles and even organizations seemed changed because of the events of the story. The consequence also includes the ‘what next’ question, to identify sequence and related stories.

Underlying Scripts or Action Scripts

The following interpretive tool was developed in the student research of autobiographies and is added here as a powerful tool to capture theory. Stories are captured in what became known as script analysis. Categories are described in a short story script that can inform theory.

The context, plot, and consequences can be used to sort stories into underlying scripts. Scripts are, in effect, another way to represent the narrative themes or categories of the research. For example, constructs in grounded theory research are often written as gerunds, or action phrases such as ‘looking for safe spaces on the bus.’ If the researcher is using narrative methods to complement grounded theory, the following action script can be extracted from the context, plot, and consequence. The movement of the overall story can then be tracked through these script titles.

- The context begins the script with the phrase ‘When I . . .’ that captures the trigger of the story.
- The plot describes the action or generalized plot through the steps outlined in the story. This begins with the pronoun ‘I . . .’
- The consequence, the expected outcome of the script begins with this phrase ‘And then I . . .’

The following is an example of a common script used by trainees at Greenbank. Trainees labelled this the ‘give it a go’ script.

Script title: Give It a Go

When I am afraid because I don’t know if I can do what is expected of me.

I remember that Gerry and other trainees felt unsure, but they tried.

And then I just give it a go and try again and again just to see what happens.

This was a significant script for Greenbank because it removed the role of reward or failure in learning. It introduced a script that allowed trainees to experiment, without the overlay of more traditional approaches that often carry the fear of failure.

The interpretation that emerged from the above transcript about the bus and Ms. Jones and similar stories became narratives or collective stories of the group that set expectations of what might happen and, in the process, explained how to respond to new situations.

For example, a young disabled woman approaches a ramp and a door and is met by a visitor, who offers to help by pushing the chair up the ramp and opening the door. The young woman uses a common tactic of Greenbank and says clearly ‘Thank you, but no, I am quite capable of trying this on my own.’ She asserts herself and the visitor (in this case, me) is sidelined and bemused.

4. Theory

The definition of theory, a set of ideas that explain practice or experience, includes the tasks of making theory for sharing and comparing results with other theories. There would appear to be three main audiences for theory, depending on the purpose of the research:

1. **The community of academic peers**, who judge and reward the researcher by academic standards. I was concerned about this audience because the final product had to speak to an interdisciplinary academic community that represented often conflicting standards. This paper is an example of an interdisciplinary and multisite academic product.
2. **Practitioners who seek knowledge to improve their practice** and who will judge the theory by its applicability and usefulness. The concepts of empowerment and change are particularly relevant to human service professionals who seek new ideas to keep abreast of changes in technology and policy.
3. **The target population**, who judge the quality of the theory according to its relevance to their personal, social, and economic lives. This audience is represented by people who were impacted by the systemic discrimination they encountered, prior to the new social movements that sought to redress the power imbalances. The stories of each of the new social movements were prepared to recognize both systemic oppression and the empowerment now possible through the new social movements.

The social contract for the research, however, only addresses the target group for each of the case studies. In keeping with this, each case study received a report of the research, with a theory of what was learned about the new social movement and its founder. As such, it is ideographic and specific. There is no expectation that the findings apply to other similar situations.

The social contract for theory was designed for three audiences: usefulness of the theory to those who live the experience; implementation and impact for those interested in improving practice; and theoretical integrity for academic audiences (see Table 2.4).

The negotiation of the theory building process as part of the social contract freed us to interact and explore ideas in an open partnership. Most co-researchers felt they were part of the process; they were not being studied but had embarked upon a joint journey of discovery. The relationship was time limited and governed by the task at hand, but dependent upon us as people, ready to risk and experiment. It seemed natural to see the relationship as a partnership that recognized the sophistication and willingness of participants to be part of social science research. Partnership research provided an opportunity for role empowerment by making role expectations explicit within a process that authenticated the contribution of each of the parties. The improved clarity in the

relationship increased the rigor of the research, opened new options for shared knowledge, and, hopefully, improved the quality of the research product.

We attempted to create an integrated narrative strategy and to understand the role of founders of emancipatory social movements. Examples of the theories are presented below.

An Integrated Narrative Strategy That Is Both Emancipatory and Rigorous

This research was an example of co-research where each partner shared their experience of social innovation. One was the expert of the case being studied and the other a researcher searching to understand the role of the expert in social innovation. The following is a short summary of the narrative strategy or theory of method presented as consecutive research actions.

- **Co-design: Population identifies stories of a social problem that is a priority to the group.** Consult individuals, leaders, and professionals who have experience with the topic to identify categories of concerns and select a general concern or topic for study from the stories they tell.
- **Build trust** in the process through a formal or informal social contract for each step to understand roles, expectations, and when the goal of each step is completed.
- **Use iterative cycles of storytelling** to collect and analyze/explain the social problem to identify possible actions.
- **Explore methods for capturing stories that are compatible with the ways of knowing of co-researchers** (observing, interviewing, documents, and media) that allows co-researchers to tell stories.
- **Organize story incidents**, using recording and notes, to complete story templates.
- **Produce a story chain** of incidents to ensure that all relevant stories are accurate and included.
- **Constantly compare** incidents/stories about experiences, problems, actions, emotions, and thoughts, sorting them into rough categories.
- **Name or code emerging categories** as new data challenges the category and force it to divide or combine with other categories.
- **Test emerging categories** until one emerges as the best explanation of the social problem. This might be a common story that becomes the core category.

- **Arrange all categories into a theory or strategy of action** based on stories that explain the problem. Note: at this point, there is a distinct difference between general qualitative research that is conceptual and action-based narrative research.
- **Share and compare** with dominant narratives of similar social problems.

As the main feature of co-research, narrative builds on the power of story to build and support partnerships in sharing, refining meaning, and sharing the results of research.

An Idiographic Theory of the Role of Founders of New Social Movements

Grounded theory is considered to be substantive but situational. In this study the idiographic or situational theory was the explanation of the founder's role in their social innovation. Each is organized within the context of the situation and the root metaphor or way of thinking of the founder. The following are several examples:

- **The theory of Greenbank** is based on the metaphor of place. Recruits who were disabled came from medical and social institutions that defined both their deficits and needs for care. They came to Greenbank, a place of peer support and mainstream training with the expectation that they would learn new skills and graduate. Graduates either became trainers or moved to mainstream businesses run by Greenbank or other competitive options. There was always a new idea to chase and a program to build.
 - Gerry Kinsella, the founder, was a hero in disability sport who challenged the existing systems that stigmatized disabled people. His root metaphor was the playing coach—he coached staff and trainees alike to take risks, support each other, and aim high. He did this while inspiring trainees through building new facilities and programs, political and business successes, and sports. His way of thinking could be summarized as 'give it a go.' He is the quintessential social entrepreneur.
- **The Quaker Prisoner Befriending Scheme's** theory is grounded in the teachings of the Quaker movement, specifically, the importance of gaining trust through personal advocacy and passion for a cause. We also learned about the importance of grassroots supporters.

Dorothy's personal mission was to build life-sustaining connections and contributions among volunteer befrienders who committed to share daily experiences with those who have been disappeared (imprisoned without trial) for their beliefs. The theory outlines the power of everyday connection through letter writing when there is no power and almost no hope for liberation. It is here that the power of stories is clear—to connect, inspire, and bring joy in the absence of hope.

- Dorothy is clear and persistent about the horror of torture that must be faced and studied. Her challenge is simple—when we do nothing, we too share the guilt, brutality, and secrecy of hidden, invalidated people and thus contribute to the potential success of terror.
- **Siksika Nation's traditional child welfare**, based on the metaphor of 'The People.' The context of Henry Three Sun's history and the development of a traditional approach to child welfare provided a chance to learn about what has been called the Sixties Scoop. The innovative combination of Indigenous and white ways provided an opportunity to track the journey from the 1950s to the 1990s that told the story of rapid destruction of traditional values and the eventual reclamation of two-eyed seeing. The stories resonate with colour, sound, symbols, and images. The following theory is presented as a summary marked by decades:
 - 1950s: **the Sundance**, a traditional gathering of the clans to celebrate the harvest through dancing and rituals, while gathering to govern and plan. The colours were yellow for the autumn sun under blue skies, the sounds were the drums and singing.
 - 1960s: **Bad Medicine**. The change is the introduction of alcohol, bars, and loss of ritual and governance. This leads to family breakdown and child isolation. The 'white' government places neglected children into white families. The colours are red and black, the sounds are of loud country music, and the metaphor is the local smoke-filled bar. He is isolated because he is not part of change and turns to Elders for guidance.
 - 1970s: **Silent Funerals**, a cold time of dying and the death of tradition, the family, and community. The colour is cold white of winter, the sound is silence, and the metaphor is the internment of the coffin. Henry's work was to support tribal

members to become Indigenous social workers, in order to reverse the trend of ‘scooping children.’ These social workers activate the natural supports within clans to refocus on family capacity.

- 1980s: **Briefcases.** Blackfoot negotiators took on the ways of white power brokers to defend and reclaim the rights of Indigenous peoples. Henry speaks about how they studied policy and worked to identify gaps and obstacles to equitable policy and funding. Trusted insiders provided insight into provincial and federal policy. The theme was briefcases and Western business suits with colourful Indigenous emblems, the sounds are the measured sounds of negotiation.
- 1990s: **The Siksika radio station,** the use of Western technology to reclaim traditional communications. This is used not only for sharing stories but community input into planning and governance.

Combining Cases: A Theory of the Role of Innovators in New Social Movements

After all seven cases were completed, I eventually was able to create a combined theory of the role of innovators in new social organizations by conducting a separate analysis of all of the new social movements. It combines the initial role of the founder as both storyteller and activist.

This activist role was embedded within the target population as a trusted ally who challenged the status quo of the dominant system and, thus, was able to make a difference. Their emancipatory stories were shared within the target population and inspired members to imagine what they might have done in the past or might do in the future. This leads to more emancipatory narratives that buttress the new movement’s reputation. Not only does it buttress the reputation, it creates a shield against the continued force of dominant discourses of vulnerability, difference, deficit, and deviance.

Over time, a meta narrative emerges that is able to effectively challenge the dominant discourse of society. Examples include the following: dying with dignity and legacy, businesses run by persons with disability, Indigenous support of families, international disability rights that impact not only at the local but national levels. These meta narratives call forth both community support and professional attempts to take over or absorb the innovative features of the organizations related to the new social movements. Many new social

movements are taken over, but the ones that grow and survive share some common features that were apparent in the founders who took part in the study:

- Understanding and skill of storytelling to mobilize new aspirations and roles that challenge dominant discourses of vulnerability, deficit, and marginalization.
- The persistence and energy of the founder to continue to challenge the system and represent the population.
- Organizational skills to enable the new social movements to grow and to become recognized.
- Continuing ability to respond, adapt, and innovate.
- The ability to secure champions who can speak for the movement from the dominant society.
- Remaining alert to sources within the system that are likely to challenge, take over or compete with the movement.
- Use of media, publicity, or publications.

The data from this study continue to inform the development of peer research and social innovation. In particular is the concept of a shield of new roles that protected the members of new social movements from dominant and powerful forces. The majority of the founders were subsequently honoured in their country for their innovation.

Summary

This has been a short summary of case studies chosen to explore the breadth of social innovation and innovators. This was a grounded theory study with two goals: find ways to engage as equals in data collection and analysis, interpretation and theory building, and understand the role of founders in new social organizations.

Story emerged as the framework to enable a variety of methods to engage founders of new social movements as equals. This understanding is the consistent feature of peer research and peer support programs in the disability community and health systems as it emerged through research with seniors and finally with PaCER.

This narrative has enabled work with Indigenous communities and marginalized populations who have strong histories with story and the power of story to bring people together to find meaning in everyday experience and challenge systemic discrimination.

Questions for Discussion

1. What was your understanding of narrative and story prior to reading this chapter?
2. Which cases related to your experience and how did this influence your understanding of the integrated narrative method or the importance of new social movements?
3. Which of the methods used made you uncomfortable, and which might you consider studying in more depth?
4. Are you aware of any new social movements in healthcare or cultural studies including disability and mad studies?

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