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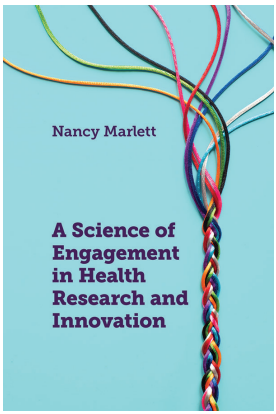

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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An Emancipatory Patient Standpoint Theory: Stories Tell Us Who We Are and Who We Want to Be

Highlights

- Standpoint in everyday decisions
- Feminist standpoint and JEDI principles
- Discovering a patient standpoint as part of making a difference
- Patient standpoint map

As I began writing this book, I realized that the combined patient and researcher roles in peer research resonated with the early dual roles of feminist researchers. Feminist standpoint theory helped me understand the impact on people as they were recruited into patient roles within health systems, just as women were/are recruited into roles by patriarchal systems.

The most dramatic similarity with feminist standpoint theory was the call for research to begin with the experiences within systems. In this I was lucky because of my foundation within disability, aging, and mental health communities that were early leaders of emancipatory movements that challenged health system restrictions and achieved significant success.

PaCER peer research development was fortunate because several health professionals, Jean Miller and Sylvia Teare, were also patients who were part of the first research cohort. They were able to define the distinct difference between patient experience research done by professionals and that done by patients. Jean Miller, an academic nurse who was part of the first cohort of patient researchers, tells her story on YouTube (PaCER, 2017, https://www.youtube.com/watch?v=bR6VnjwupjM). The unique partnership between trained peer researchers and participant co-researchers was able to tap into the social structures of healthcare and the political forces that were present and not apparent to professionals.

This chapter attempts to 'stand on' standpoint theory to prepare a simple emancipatory tool that combines the analysis of systems in Chapter 9 with an emancipatory extension of salutogenesis (Chapter 6) to inform a standpoint theory that enables patients to identify the impact of their experience in their health systems.

A standpoint theory can help identify program and policy characteristics and obstacles to patient ownership of their health and healthcare. It is also useful for communities and patients looking to find alternative ways of dealing with systemic discrimination. As such, it enables people, students, patients, and communities to look at options for change and innovation in existing health systems while supporting innovative community and consumer options.

The theory was incubated through community peer support groups, my thesis, student discourse analysis of autobiographies, and study of *Grey Matters* and PaCER research. Like salutogenesis, it offers an asset-based alternative to the deficit or dependence focus of most healthcare research. The theory is a pragmatic strategy using a map of key psychological spaces in health systems. The following are responses to the patient standpoint theory.

- *The powerful thing for me is that it isn't about being 'positive' in the face of something cruel and terrible, it's about being real and assertive, to have a life in your own hands when so much of the power can be taken away by treatment, illness and even sympathy.* (PWLE reviewer of the chapter)
- *Patients who participate in peer research respond to the safety of a peer-to-peer approach to share their stories. Our group said that 'Telling stories to someone who is like me adds to my knowledge about who I am, and what I know.' In group sessions, participants listen to others and respond with their own stories, and all gain power and control of new knowledge about their lives.* (A note attached to a peer research report by a peer researcher)
- *Through being co-research participants, they describe, explain, or evaluate healthcare experience. Through their efforts, they become knowledgeable agents in their own right rather than the source of information that is held by others. Peer research comes from and focuses on questions that would not otherwise get asked.*

Feminist Foundations of Standpoint Theory

Feminist standpoint theory arose from sharing real-life stories to create a collective identity. In doing so, the feminist scholars legitimized everyday

experiences of women. They created a movement that challenged the male patriarchy, which assumed that women's aspirations were misplaced and their problems were seen as a weakness of nature or character faults (see Borland, 2020, https://www.britannica.com/topic/standpoint-theory).

A patient standpoint theory begins with the basics of feminist standpoint theory that identify and analyze the systemic obstacles in healthcare. A patient standpoint supports emancipatory social science by combining the two key dimensions of empowerment identified in the co-design of peer research: identity and agency. Throughout, it addresses how we are recruited into dependent patient roles and the potential to change these roles to become stakeholders in our own health and healthcare.

The term 'standpoint' in everyday language refers to the stance, perspective, or point of view each of us take about issues, opportunities, and challenges. We likely have more than one standpoint at any one time, depending on what we are doing. These values, beliefs and expectations generally evolve from our history and current circumstances. These standpoints, or life scripts, develop early in childhood, based on family expectations, and they branch out as we encounter and are socialized by the schools we attend, our faith, work, sports, professional training, healthcare, and friendships.

For example, a student in Community Rehabilitation and Disability Studies at the University of Calgary might introduce a case study assignment with the statement: I take a social justice standpoint in that I look to the sources of power that render persons with disabilities subjugated. Nursing students might approach the same case study quite differently: As a nursing student, I would be looking for the impact that disability has on overall health and, in particular, the nursing services that might be required. If I were a business student, I might take a standpoint that enables me to investigate the case study from a cost-effective perspective.

Most of us are not even aware that we make choices and decisions using the values and expectations of family, schools, faith, and work. Feminist standpoint theory linked experience and everyday experience of being a woman (Hartsock, 1998; Heyes, 2002, https://doi.org/10.1353/hyp.2002.0033).

Standpoint theory takes this everyday understanding of roles, relationships, and systems one step further. Marxist theory, said to be the beginning of standpoint theory, encouraged workers to understand and challenge the forces of capitalism. Modern standpoint theory is also grounded in a collective consciousness or identity as the first step to emancipation. By sharing their experience, women recognize the dominant and systemic forces that have shaped the scope and boundaries of their lives. Patriarchal systems, not personal inadequacy, hold women in support roles. Subjugation is the result of

systemic, economic, and social discrimination. Collective understanding of the forces that constrain women creates a collective energy to challenge power imbalances.

Women researchers are also mothers and daughters, and they understand that knowledge generated as peers creates a perspective of women as told by women (Hartsock, 1998). The researchers and academics who were part of the early feminist movement created disruptive feminist research to legitimize the importance of sharing and researching everyday experience through stories. These narratives, in many ways, are like the narrative research methods that evolved in the development of peer health research.

The publication and dissemination of research informed women's experience and called out awareness of systemic patriarchal forces. These courageous women researchers and academics were both insiders and outsiders on a very basic level. They shared the discrimination of all women and also that of women scholars in academic patriarchal systems. They published research about women's oppression to support the need for social change. "We looked both from the outside in and from the inside out . . .we understood both" (hooks, 1984, p. xvii). In turn, the feminist political movement used these publications to motivate women to construct a collective reality to challenge stereotypes of their lives, their potential, and their power (Brown et al., 2004, https://doi.org/10.1111/j.1467-9566.2004.00378.x).

Downing and Roush (1985, https://doi.org/10.1177/0011000085134013) provide an early example of a standpoint theory about women's experience, moving from a passive acceptance of sexism to a greater understanding of the ways in which sexism has affected their lives. The summary of the four points of their work depicts four stages of emancipation:

1. **Passive acceptance** of traditional gender roles and the belief that traditional gender roles are acceptable.
2. **Revelation**, when women question traditional gender roles and how they may have supported these roles.
3. **Synthesis**, when women reject traditional gender roles and judge men on a more individual basis.
4. **Active commitment** sees collective action and a commitment to social change. Women and men are different yet equal.

Finally, Table 10.1 depicts the similarities and differences of feminist standpoint and a proposed patient standpoint theory. This table was adapted from principles and practices of current feminist science to contrast established practices of feminist standpoint theory and early indications of a patient and disability standpoint theory.

Table 10.1 *Feminist Standpoint and Patient Standpoint Characteristics Contrasted*

Feminist standpoint theory	Patient standpoint theory
Study of the production of knowledge and the practices of power.	Study of the production of patient roles within systemic power practices of medicine.
Female identity is defined mainly at birth.	Patient identity is defined by the systems they rely on. These change as health status changes.
Women in diverse cultures are further defined by social determinants.	Patients are further marginalized by gender, poverty, culture, and other social determinants
Women share everyday experience to produce a collective-research-informed voice.	Patients seldom share everyday patient experience. Peer research produces a collective-research-informed voice.
Knowledge owned by women through their natural connections and affiliations.	Knowledge is accessed by patients through social media and access to digital medical information and their interactions with their medical contacts.
Challenge patriarchal values and dominant discourse.	Challenge the impact of labels and protocols that reduce personal values and preferences.
Oppositional conscience names the sources of oppression as a call to action.	Systemic vulnerabilities identified by JEDI are named as a call to action.
Social action to achieve equity and equality, through targeted social movements.	Call to create social action within healthcare through research and alliances.
Range of methods within a critical theory and epistemology of emancipation.	Critical theory and engagement research strategies to draw attention to the need for change.
A political strategy to name and confront sources of patriarchal power.	Political alliances within health transformation teams to increase collective patient voices. Social entrepreneurship alliances to create innovative alternatives.

This comparison highlights the obstacles patients face to increase their control over their health and healthcare. The shaded cells identify the key differences that had to be considered when creating a patient standpoint theory. The first and most difficult is the lack of a consistent patient cohort. Most standpoint theory relates to identifiable groups where the difference is stable and lifelong, such as gender, race, immigration status, or Indigenous heritage. Patients,

however, are defined by their conditions and the services they use. They interact with individualized treatment models that seldom include opportunities to connect with patient peers during their care. Knowledge about health conditions tends to be organized by health professionals, and there is little opportunity for sharing experiences and concerns among patients that might create a shared identity.

Social media and chat rooms have done much to overcome this gap in patient knowledge and identity, and these new connections triggered patient engagement networks. This is nascent, as citizen action groups and health associations are just realizing the importance of patient action, and there are few political avenues to voice concerns and suggestions for change. The examples below from patients who were reviewing this manuscript, however, reflect emancipation.

- *In reading this chapter, I reflect on patriarchal and colonial views on women and other cultures and how they relate to my health conditions. I sometimes feel my present journey is counterintuitive to how I was raised. I'm now examining the matriarchal way in my own culture, the roles we played, and how they were erased by colonialism. I've always felt I was in two worlds, not quite in one, not quite in the other, but then I learned about the concept of two-eyed seeing and I was able to reconcile things and feel stronger in my beliefs as they evolved, and we joke about Big Aunty Energy.* (Patient reviewer of the manuscript)
- *I know as a dialysis patient in my 40s, social media opened up my world to people like me, and, in turn, to patient engagement opportunities.* (Member reviewer of this chapter)

Patient identity is not stable, even for those with substantial and ongoing contact with the health system. Currently, the first goal of emancipatory theory is to recognize and acknowledge a patient's right and ability to question and make decisions about personal health and healthcare. Patients then can identify the systemic practices that reduce or obstruct the ability to notice, call out and challenge these obstacles by seeking out opportunities to share experience with other patients. This is where peer research exists. It enables patients to share their knowledge of systemic discrimination and look for ways to make these known. How to make this knowledge available to others is the last step in the process to a patient standpoint theory.

A Patient and Disability Standpoint Theory

This section draws on parallel research projects. The Calgary Association for Independent Living research supported an informal grounded theory project to explore how members could analyze everyday stories to understand the obstacles they faced and set goals that mattered to them. At the same time, undergraduate and graduate students conducted class research as part of a social construction of disability courses in disability studies. They used a casebook-based narrative analysis to uncover how patient roles were constructed and how they reconstructed patient stories to find a new normal. A number of ideas emerged from student-driven narrative and discourse analysis that was interfaced with real-life peer support experience of telling stories in peer support group sessions. More recently, versions of this chapter about standpoint theory were used in courses related to social innovation and design thinking.

Standpoint theory works with other standpoint theories, salutogenesis, JEDI goals, and the principles and methods of the science of engagement and citizen science to achieve a new understanding of the potential of peer research to support new roles for patients in research, healthcare, and new health technologies.

We start with Jean Baker Miller's (1976) feminist standpoint definition, adapted as a patient standpoint theory:

> *Patients, who are in a subordinate position within a health system, observe and learn what is expected by the system and professionals to navigate the system. Their dependent position is what motivates them to study the system. This perspective is an advantage, and patients with chronic illnesses or disabilities who become adept at learning what professionals need and want to hear use this knowledge to retain or regain control.*

This aligns with the basic theory of salutogenesis, which affirms that

> *patients make choices to use stressors of health systems to build and refine personal, program, and generalized resources and, in the process, develop a sense of coherence using their understanding of their health conditions and their ability to manage stressors to find meaning that builds resilience, confidence, and expertise.*

Standpoint, salutogenesis, and systems theories were not part of the early development of PaCER. These theories gained importance during the development of the science of engagement and the role of peer research in health research and innovation. Standpoint theory evolved as a tool to set goals in

personal well-being and program settings where it speaks to the interaction of identity and agency within programs, policies, and systems. Standpoint builds empowerment through new social roles that address justice, equity, diversity, and inclusion (JEDI) principles that reflect standpoint theory, citizen science, and peer research that should be an essential tool in future health systems and the transformation of current systems.

These situations can be identified by simple narrative analysis of patient and PWLE stories to uncover identity and agency. Through PaCER research, we discovered that when systems support new roles for patients and persons with disabilities, change happens. This innovative partnership created peer research that was listened to by the healthcare system. The SoE and new peer research options may help to guide professional and public interest in patient involvement to achieve health transformation. The following are some examples from the PaCER/PRISM hub at the University of Calgary (https://prism.ucalgary.ca).

- Patients were initially excluded from information about the safe surgery checklist, a tool to improve surgery outcomes adopted by most provinces. Patients were confused by the questions in the survey and this led to stress at a critical time before surgery. The peer research that uncovered this was instrumental in patients being informed as part of the checklist protocol that significantly changed the role of patients in surgery and allowed them to participate in the protocols that impacted the overall compliance with the protocol.
- An arthritis study included both peer and physician researchers as part of a co-research team to develop a patient management app for knee osteoarthritis that met the needs of both physicians and patients.
- Patient input into one-day breast surgery intervention noted significant patient suggestions for more patient-centred education, focusing on preparing for surgery and aftercare.
- Current socialization practices in mental health override patient stories and relationships, and when the findings were shared with professionals, they were more aware of the impact of losing personal stories in their new patient identity.
- A peer research study of parents who deliver still babies showed that they needed to connect with their newly born child and mourn loss in natural ways. This helped professionals respond differently after delivery.

Most health problems occur within health systems that are not aware of the impact their roles, language, practices, and policies have on patients. I tried popular polar archetypes such as Eysenck's introversion (1952), but few included the social ecology of the categories. The following patient standpoint theory was developed so that patients, healthcare providers, researchers, developers, and funders could visualize the patient journey through healthcare systems based on the two characteristics of identity (as a patient) and agency (within the health system).

I had been intrigued by self-assessment and personality theory early in my career, so I selected two current theories: Atkinson's (1974) motivational theory (motive to approach success and avoid failure) and Rotter's internal and external locus of control (1966, https://doi.org/10.1037/h0092976). A current application of Rotter's locus of control addresses the concept of agency or locus of control (Tyler et al., 2020, https://doi.org/10.26686/wgtn.12956984.v1).

The eventual format to create a concept map of patient experience in health systems evolved into a cartesian map informed by these two theories. The quadrants evolved to include four psychological spaces created by the intersection of a horizontal axes of:

- self-regard or identity informed by theories related not only to feeling good and being motivated to approach success approach or avoid failure; and
- internal and external locus of control that denotes personal control and control by external agents and systems.

During an extended series of workshops and peer support sessions, participants chose a story of their experience and identified where the story was located on the grid by plotting where it was located on the horizontal identity grid and the vertical grid of internal and external control. They then proceeded to where on the grid they would like to reach by plotting how they would like to feel (horizontal) and the control they would like to have (agency). This was the inception of standpoint theory as a tool that could be considered a standpoint that included both identity (horizontal) and agency (vertical) directions. Refer to the following YouTube video for a quick lesson on plotting coordinates on a grid (Mathispower4u, 2009, https://www.youtube.com/watch?v=s7NKLWXkEEE).

Staff and members of CAIL were recruited to experiment with the first primitive grids. Members made statements or told short stories about their experiences that were important to them, and they helped each other to plot their stories on a four-quadrant map as a way to analyze how it made them feel.

- First they considered the horizontal axis and identified where their story was located along the axis of feeling good or feeling bad. It was not necessary to use numbers. They just estimated the distance from the neutral centre to the end of the horizontal coordinates. The questions might be: 'How do I feel about myself when I tell that story?' 'Do I feel good about myself or bad about myself?' 'How good?' They used the centre as a transition point where you 'feel just ok,' and the right end is 'better than you have ever felt' and the left side is 'feeling really bad about myself.'
- They then considered where the story was located along the vertical axis that asked the question: 'Where am I? Am I in control of this, or are others in control (internal/external locus of control axis)?' If the 'welfare system rules are in control, how much control do they have along the up and down axis?'
- They then made a mark based on the horizontal and vertical positions. This mark ended up in one of the quadrants that identified where they felt they were at the time of the story in terms of their identity (good or bad) and agency (internal and external locus of control).

They now knew where they stood when the story unfolded. They could then discuss how they felt with language about feelings and their hopes for being in control. They were supporting each other in telling and thinking about their stories. For example:

- When that happened, I was feeling good and in control of what happened (positive identity and internal control)
- When that happened, I was really messed up and I should have known better (internal control and negative identity)
- When that happened, I was not happy with myself, but it was because I was stuck in that group home that wouldn't listen to me (negative identity and external control)
- When that happened, I knew I was doing the best I could and the guys there support me so that I can count on them (positive identity and external locus of control)

This created a natural communication and planning tool for people to understand how their experience made them feel and how much control was in their hands or in the hands of others. The tool also suggested that it might be possible to have control over what happened to them. It was not long before we realized

that this small self-assessment tool was also able to identify the nature of the environments that people lived in.

- Pete had spent most of his childhood in a behavioural unit. When asked about the unit, he was clear when using the tool: *They made me feel like shit, they always noticed how I screwed up, it was like they had shit radar.*
    - This clearly defined feeling bad and not in control; 'they' were in control.

- Joan, talking about living on her own for the first time: *I have my cat and I'm learning to cook, I decide when I go to bed and what I eat for breakfast.*
    - In a situation of being in control and feeling good about herself.

- Megan, talking about her weight in a hospital setting: *I try everything I know to lose weight, but no matter how hard I try I look fat and ugly.*
    - In control and feeling bad about herself.

- Tony, about playing wheelchair basketball: *I was so lucky to meet Jim, I'm now part of the ball team and my life has turned around.*
    - Lucky to be part of a team supported by others and doing well. The team is external control that brings comfort and a positive identity.

This helps people think dynamically about identity and agency that changes with experience. For example, *I am not always a loser who screws up; yesterday I saw a person drop her scarf and I ran to get it and gave it to her.* People on their own or discussing experience with their peers make meaning that challenges the labels they use to describe themselves.

This tool soon became a power for personal change. Individuals could share experiences that were disempowering. They could identify how they wanted to change in a natural environment with peers. We could also use this at the program level. We could see how our expectations and structures created positive and negative roles and relationships. We could also build personal agency (internal locus of control) and self regard (the good-bad axis) by creating different expectations within the program. It was a clear representation of peer support.

> *J was a physically disabled woman who was overweight. She was quite worried about her size and wanted to lose weight, but she*

came from a large family and the only times she was invited to visit was for family meals. Her mother was proud of her cooking and cooked very traditional high-calorie food. She said she felt very bad about her weight and that she placed herself at the negative end of the horizontal axis. However, when she considered the vertical axis, she placed herself as in control, but as she talked about this, she felt she couldn't miss her family meals, and her mother would be very insistent that she ate her food. While this did not change her behaviour with her family, she clearly understood the external force that her family and her mother exerted. J knew she could make the hard decision to take control, and this realization meant that the decision was hers.

The above story was included because it captures what happens when people are trusted to evaluate their own situations, identify possible goals, and then weigh the options. As an emerging standpoint map or grid, it was shared in community settings, practicums, and classes on social construction and capacity building, along with conference presentations and professional meetings with educators, nurses, and psychologists. As these groups experimented with the standpoint grid, the nature of the grid shifted and responded to the different applications.

As I was writing the science of engagement and reviewing both *Grey Matters* and PaCER research projects, I realized that this simple grid was not only a good tool for peer support, but it was, in fact, a standpoint theory to explain the nature of patient and disability experience in the systems they were part of.

A Patient Standpoint Theory

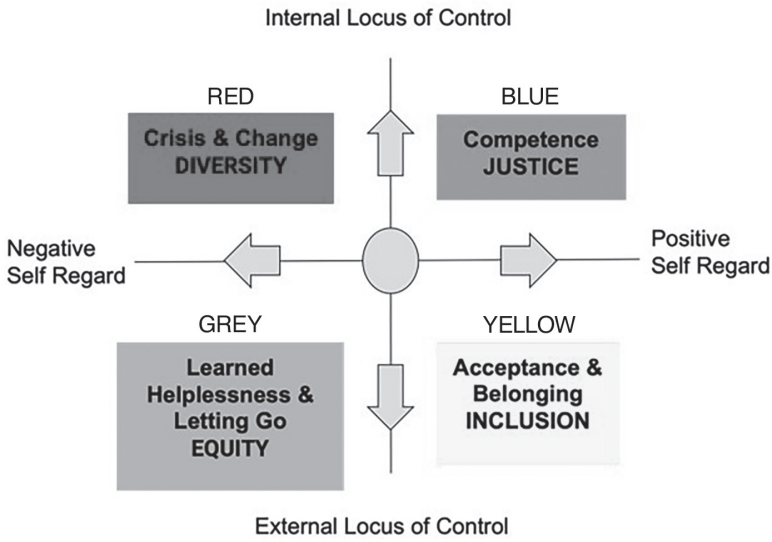
Most standpoint theories start with the process of sharing stories of capacity and oppression that identify strengths and the obstacles that are part of their experiences in systems and relationships that define who they are and what they do to live the life they expect to live. Sharing stories leads to analysis of obstacles and this then leads to identifying ways to resolve the inequalities and collective action to achieve these goals. The standpoint-informed theories use data from real-life experiences to understand and categorize the nature of the oppression and stages of emancipation.

This section deals with patient standpoint theory from a patient perspective that recognizes the complexity and dependence of patient roles in health systems. It also celebrates the power of narrative peer research to challenge

existing barriers to achieve justice for patients and communities and make systems and policies more equitable, inclusive, and diverse.

Figure 10.1 is a basic four-quadrant map with concepts of identity and agency that evolved during workshops with persons with disabilities, seniors, patients, and health and education professionals who were invited to describe their personal healthcare and well-being experiences with healthcare systems and health research. This was done to co design a way to represent healthcare and research characteristics that produced a map with two axes that eventually produced four psychological spaces and four transitions between spaces.

Figure 10.1 *Basic Structure of a Patient Standpoint Map*



Note: Map is based on positive and negative self-regard poles and internal and external locus of control poles. Also included are the related JEDI principles in capital letters.

The map represents the basic four-quadrant grid with the themes and colours negotiated during consultations and tested during the narrative analysis of autobiographies of patients done by students. The quadrant labels can be adapted to reflect specific situations. Each axis can be adapted, by changing the axis labels of identity and agency.

- The horizontal axis represents a positive and negative pole, the poles can also be named good, bad; happy, sad; pain-free, overwhelmed with pain; upbeat, depressed; even the ease, dis-ease continuum of salutogenesis. The horizontal axis represents the balance obtained when a positive or salutogenic theme is added to the focus on illness and trauma.
- The vertical axis represents agency with labels such as: internal or external control of the person's actions; supportive, restrictive experiences; individual or collective agency. This axis of agency is new in health experience research, which has focused on negative or weakened patient characteristics of vulnerability, fallibility, and loss. It brings a salutogenic element to medical research.

When dealing with external control in health situations, there seem to be a number of debates. For example, when overwhelmed with pain or loss that places people in the negative side of the grid, the source of control and power is two-fold. The external control can be supportive and facilitate positive self-regard, or it can be negative and increase avoidance of failure or helplessness. When it is negative, it relates to the JEDI principle of equity and captures the essence of the loss of essential personal or group power.

External control that takes away agency is difficult for patients with complex healthcare needs who may, for a short time, need to let go and let others help or make the decisions when faced with intractable pain and loss. Those who brought this to light felt that it was a conscious decision to prioritize what they could or wanted to be in control of. For them, it was not a learned helplessness but a willing suspension of being in charge for a period of time. A reviewer spoke of having to abide by funding regulations to meet basic needs, even though they restricted her freedom and ability to contribute to her advocacy work. This led to the realization that all quadrants had both positive and negative attributes. For example, 'competence' can be destructive when it leads to burnout. 'Crisis' is also the motivation to change. 'Learned helplessness' can be seen as needed refuge, while 'acceptance and belonging' is both a positive thing and can lead to dependence. This brought new meaning to analysis.

A patient standpoint theory needs to accommodate many layers of power and complexity to represent and benefit from an emancipatory science in systems that are both essential and restrictive. This is one of the intriguing ways that theory opens the door to layered and nuanced experiences and decision-making in healthcare.

Four psychological spaces were identified by analyzing stories told by patients, using concepts of identity and agency. These stories can be captured as

part of peer research from narrative analysis or through discourse analysis of public documents and online social media of programs and policies. An example of using standpoint theory to inform discourse analysis of public documents is included in the Resources section as part of a university course on innovation using the science of engagement theory to analyze systemic discrimination to identify solutions identified by patients.

As you read about each psychological space of the standpoint map, consider how it might be used during co-design or SET to identify a main concern or priority for peer research. Consider also how you might recognize identity and agency, the criteria you might use to compare stories and themes during COLLECT data collection and analysis. Finally, consider how standpoint theory might map themes and categories that relate to the explanation of the main concern of research and point to the potential solutions as part of REFLECT.

Blue: The Competence Quadrant

Table 10.2 *Blue Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Blue—capacity and competence Feeling good and in control Motivated to achieve success (MAS)	Develops where there is positive reward and opportunities to develop resilience Achievement leads to expectations of success	The exaggerated need to achieve and to test oneself Dependence on individual strength The constant need to prove oneself Type-A personality	Look at me Bring it on Learn before acting Don't sweat the small stuff Put it on a schedule Just do it I know I can

The blue quadrant was the first psychological space identified in the study of autobiographies, partly because most autobiographies begin with a chapter about what life was like before the accident, illness, or loss. This represents their anticipated life story and sets the stage for the changes that come with the onset of a disability or health condition.

Blue stories aligned with Atkinson and Litwin's (1960) achievement motivational theory that captures the early work of McLelland on the basic motive to approach success (MAS). This includes the expectation and probability of succeeding. The MAS appears to be associated with the behavioural activation system, positive emotionality, and extraversion that combine in an approach temperament (Elliot & Murayama, 2008, https://doi.

org/10.1037/0022-0663.100.3.613). Many of us live our entire life in this quadrant, living our anticipated life guided by our scripts. It is difficult to realize that this is only one reality, if we have never experienced anything else.

Everyone doesn't have a history of success or a motivation to achieve. Standpoint theory helped professionals realize that their way of seeing the world as a blue standpoint might inadvertently restrict the potential for their students and clients to understand their own place in standpoint and their option to change their identity and agency through finding ways to celebrate their identity and search for ways to take more responsibility.

Living the success of a life expected can present long-term consequences when serious setbacks occur later in life when you have had little chance of building resilience. The concept of errorless learning that was once popular in special education actually harmed children who had experienced failure and had learned to focus on avoiding failure. When faced with a teacher's expectations of mastery, because of errorless learning, children are locked into a struggle between staying safe by avoiding failure. Teachers who expect all children to be able to succeed are soon surprised and disappointed when children who don't respond the way they expect them to. They see these children as not motivated, lazy, and disruptive.

Resilience as Social Capital

In the senior's study of resilience, one of the key findings was the worry that young people don't have opportunities to risk and to fail, and that they will never learn how to be resilient. Seniors had all experienced deprivation and loss as part of two World Wars and the Great Depression. They felt that their childhood experiences had produced a social capital of resilience that could be shared with others as a gift of achievement.

The blue quadrant is important when analyzing programs and policies, because it represents the dominant quadrant of many who are health professionals. It is not uncommon for online program descriptions to be written as if clients were motivated primarily by success, even though the language used to describe patients and clients reflect the goal of compliance—"the good patient."

Red: The Crisis and Change Quadrant

Table 10.3 *Red Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Red—crisis and change High motivation to act to change an untenable situation Feeling responsible for being unwell or in pain	Caught in a negative situation and believing that it is your fault Feeling overwhelmed by the problem Temporary high anxiety, loss of positive self-regard due to illness, negative self-regard, identity and feelings Loss of control in new traumatic or medical situation Survivor guilt	Constant and pervasive tension can lead to dangerous choices and motivations Anger at oneself and others because of fear and hypervigilance about loss	Must get back to normal I need to learn about this problem Naming ceremony Shaming and blaming I know I can How could I do this I must have done something to cause this Anorexia—I hate my body; I can change it by not eating Post traumatic stress—I must control the uncontrollable I must keep control no matter what the cost

The red quadrant is extremely complex and stressful—it is a crisis. The patient considers themself responsible or at fault. It is a double jeopardy situation. This quadrant captures the power of pathogenesis and the challenge of personal agency for a serious problem. We make decisions to stay in control, often in threatening situations that preclude control. The red or 'crisis' space most often comes without warning—accidents, trauma, sudden onset infections, or disease. It is also primarily a temporary space, as people struggle to maintain some control during the onset of problems. This is a high-energy quadrant of crisis with high motivation to return to the blue quadrant. The power of personal threat makes people feel desperate but can also motivate patients to change. They have the option of becoming involved in the technology innovations that are emerging. Access to medical information has made it possible for people to understand their conditions, share experiences, and gain confidence and

motivation to find solutions, or build self-management skills to monitor and manage their healthcare.

Stories in this quadrant were hard to identify in autobiographies because stories are about blame and shame and are relatively short lived. The breakthrough to understanding this quadrant came with a group of undergraduate students studying autobiographies about eating disorders. Not only did they read autobiographies, but they also dove into deep-web anorexia chat rooms to learn more about the RED quadrant. The students also were motivated by the Mental Health Commission of Canada's report that year that had declared anorexia to be the most serious mental illness issue, because of the high rate of suicide. The National Initiative for Eating Disorders (NIED) identified that the mortality rate associated with anorexia nervosa is 12 times greater than ALL other causes of death combined for 15- to 24-year-olds (NIED, 2020, https://www.nied.ca/eating-disorders-in-canada).

The first level of analysis done by students dealt with the inherent danger of being in a negative RED space (the fear of being overweight) without a way to leave the negative space. Students noted that girls and boys who were trapped in a negative space, with an 'overweight' impression of their appearance, withdrew from school, work, and family relationships and many joined deep internet chat groups that promoted losing weight and suicide.

While suicide is a way out, the majority of people in the red quadrant use the motivation to change. The following examples are offered from personal experience and student presentations.

- **Too close to home**. I had been asked to teach the quadrant map to a class of special education teachers by a colleague. She took part in the class discussion until we reached the red quadrant. She slowly moved to the back of the class and crossed her arms. I quickly ended the class and went to her to find out what was wrong. Her husband had lost his job in the downturn of the oil and gas boom. He was a senior executive, used to power and control, and considered that he should be able to overcome this unexpected setback. He spent months analyzing the firing, working on strategies to convince companies that they needed him, looking for comparable jobs, and selling off luxuries. Finally, he seemed to lose hope, became depressed and was found dead by suicide. She was angry with me for not telling her about the dangers of feeling responsible during a sudden change in identity. She felt that if she had known this she could have intervened and prevented his suicide.

- **Yvette's metaphor of an alien land.** This metaphor comes from a PaCER student's contribution to their final report on hidden pathways of chronic illness. It describes the initial impact of adult-onset, life-threatening illness, such as cancer, Huntington's chorea and ALS, as well as conditions considered to be without hope. This is a segment in "Hidden Pathways to Chronic Illness" (Banerjee et al. 2013, http://hdl.handle.net/1880/109953) that captures the impact of negative news over which you have no control:

> You and your family have been away on vacation for two weeks and return to your farm in southeastern Alberta. The sight that awaits you is shocking and surreal. The entire landscape that was once flourishing with undulating green grain fields around the farm is now nothing but fields of pale brown earth with short straw stubble everywhere. As you drive up the driveway toward your home, you are more shocked. The house and outbuildings look starkly naked as there is not a shred of colour visible where the trees, shrubs, and garden that had been lovingly planted. All that remains is a moonscape with some tree skeletons standing in the brown earth and the carcasses of hordes of grasshoppers. This scenario might be similar to those confronted with serious illnesses. Life proceeded as normal, and then one day a huge, foreign landscape was before them.

Most patient experience research does not focus on this quadrant because there seems to be an assumption that the cure for the anxiety and stress of health concerns is to align with professionals who understand how to manage these situations. This is in part due to the individualized nature of healthcare—there are few options for connecting with patients who could provide support for self-help and how to make decisions about care. The fear of losing medical support is often just too great for individuals who would like to be engaged in their healthcare; it is easier to turn control over to professionals.

Grey: The Learned Helplessness and Letting Go Quadrant

This represents a common quadrant in patient experience studies. It is the psychological space that occurs when people feel vulnerable, fallible and lost that supports the need for professional care. Unfortunately, it also has the potential to create long-term dependencies, as people rearrange their lives around the healthcare they rely on.

Table 10.4 *Grey Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Grey—learned helplessness Negative self-regard but it's not my fault History of failure or rejection leads to a motivation to avoid failure (MAF) Grey is also the quadrant of deliberate acquiescence of control when serious or chronic conditions become too onerous to manage. This requires further study.	Giving up control in a negative situation reduces anxiety (move from RED) Externalizing fault and power Compliance with authority Oppressed by stigma and external control through rules and punishment A history in these situations can be hard to change because they perpetuate expectations of inadequacy	People are misperceived as unmotivated, aggressive and difficult when trying to avoid being seen Avoiding failure takes a lot of energy and vigilance This is a quadrant of loss and holding ground. Blaming others, the system, fate, poor health Extended periods of compliance can cause people to withdraw and give up	Don't expect much of me; I'm sick (disabled, etc.), I used to, but now . . . They have it in for me It wasn't worth doing anyway Nobody cares I work all the time just to keep out of sight If only . . .

Grey is the second most identifiable psychological space and is the polar opposite (diagonal) to the blue space of 'competence.' Grey captures Atkinson's motive to avoid failure (MAF) that is the opposite to motive to approach success (MAS, in the opposite blue psychological space). MAF is defined as a relatively stable personality disposition to avoid and anticipate negative impact of failure outcomes. It is the stable response to loss of control of chronic conditions that are often defined in terms of shame, embarrassment, humiliation, and loss of status and esteem (Elliot & Murayama, 2008, https://doi.org/10.1037/0022-0663.100.3.613). This avoidance is seen in the stories of experience of many of the clients and patients who had experienced failure, stigma, loss, and despair. This history results in little control over the probability of failure or success. The MAF may be associated with behavioural inhibition systems and a learned avoidance temperament (Elliot, 2008).

The title of this quadrant, 'learned helplessness,' which was the original work of Roald Nygård (1969, https://doi.org/10.1080/0031383690130112) was adopted during the early stages of development of this standpoint theory during work with the Independent Living Centre of Calgary. It conveys the

systemic discrimination of bureaucracies and educational systems that fostered loss of confidence and reliance on professionals.

This is often interpreted as disruption, low motivation, and avoidance, all of which reinforce the continued need for external control. Teachers often use programs based on positive reinforcement to try to promote achievement, but unfortunately, positive reinforcement often increases anxiety and the need to avoid potential failure.

However, people who have complex and severe medical conditions can see the term 'learned helplessness' as giving up. Learned helplessness also failed to recognize that there are times when the pain is just too great, the loss too hard to ignore. During these times, patients need to unplug and let others take over, to retreat and recover, at least for a while. Therefore, 'refuge,' a new name for this reality was added to the GREY quadrant that doesn't diminish those who end up in this psychological space either as respite or because financial security or access to needed treatment force them to comply with external demands.

The following examples provide dramatic grey situations.

Naming Terrorism

The following excerpts from Dorothy Birtles, the founder of the Quaker prisoner befriending scheme where Quakers became pen pals with victims of terror in prisons. As a co-researcher, she provided examples of extreme external control in a situation that is fraught with death and pain. Both external locus of control and a certainty of torture and death are dramatic and, sadly, still current. Dorothy begins:

> Violence and torture are so highly successful
>
> We need to be shaking in our boots
>
> The pictures, smuggled out from a prisoner are excruciatingly painful
>
> These guards are trained to bring these people to their knees
>
> The lowest possible level of human experience
>
> The sexual things are not there by accident
>
> It's beyond sadism as such
>
> Getting pleasure from terror and pain . . .

This small gentlewoman fiercely believed that all societies are capable of unspeakable terror, but it needs to be faced, studied, and countered. The personal contact through letters, lessened the impact of terror and brought a sense of refuge with each new letter.

Those who end up in GREY because they can no longer fight the systems they rely on represent the need for a standpoint theory to name and challenge systemic discrimination and punitive social policy that restricts personal choice and ignores personal values. It is here that extreme JEDI action is needed.

Yellow: Quadrant of Belonging and Acceptance

Table 10.5 *Yellow Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Yellow—belonging and acceptance Feeling good within a collective psychological space that matters to me New normal	Peer support—finding others like me and adopting the ways of the group Finding attachment among family and friends Spiritual and personal meaning	Vocational and insurance professionals often see patients who don't return to former employment levels as malingering, unmotivated, settling for less, not living up to potential Individuals may become dependent on the support that is provided and may lose motivation to regain more personal control.	Fitting in Sanctuary/peace New expectations My place is here God guides my path

This quadrant has had a low profile in an economically oriented economy where everyone is expected to contribute to production and wealth. It also provides psychological space for living with a purpose beyond employment. This has been a choice for many living with disabilities and chronic health conditions. The patient and citizen engagement movements rely on people who volunteer to make a difference because working full-time may not be possible. Funding sources for basic life and disability necessities use policies that restrict earning and even discourage volunteering as a means of controlling funding.

The yellow quadrant is most uncomfortable for professionals whose work is to ensure that people return to productive employment after injuries or illness. In the past, rehabilitation for adults was focused on vocational rehabilitation that used employment statistics to justify rehabilitation professions and programs as a way to reduce disability benefits.

As a rehabilitation professional, I didn't understand this quadrant because I worked in work-training programs, but I came to understand that yellow was an end goal for many of the people I worked with. I began to worry about my own lack of experience of belonging and acceptance because my life was so filled with work. The yellow quadrant is more than an alternative to employment—it is a space to gain strength and acceptance. It is the space of peer support. It is a realistic goal for standpoint theory. It is here where identifying with 'others like me' can lead to wellness.

That said, yellow is a psychological space relegated to 'othering' those who are defined within charity or as non-productive discourse. The science of engagement will hopefully take up the challenges of contributing without pay to support research in these important and neglected spaces. The following examples are from comments made by reviewers or students developing or using standpoint theory.

- **Balancing a yellow life**. This new normal is where I'm at and happy, and even find that many in my team support me not working so I have the flexibility of volunteering and peer support. However, it's a big thing that I struggle with, knowing that I'm doing the right thing for my physical and emotional health while society as a whole believes that somehow I don't have value or am taking advantage of the system or am lazy, just because my new normal is better for me.
- **Professionals see acceptance and belonging as malingering**. Workers compensation and disability insurance professionals, at a presentation about the standpoint grid, were quite happy to name the quadrants and consider the implications for working with clients in the first three quadrants, but the last quadrant was met with hostility and anger. They felt that a standpoint needed to be about going the full way, not taking advantage of the system, malingering or challenging long-term treatment goals. While I had never related to this quadrant easily, likely because I had worked as a vocational counsellor, I was shocked into reconsidering the value of living a life that had purpose.

This quadrant provides a safe path back to blue, and a standpoint from this quadrant that provides a peer foundation for support groups and a standpoint

that is invoked when those with serious conditions search for meaning to accept their new normal. It is here where identity with others like me can lead to wellness.

A Route Map to Get from One Psychological Space to Another

Standpoint and systems theories were not part of the early development of PaCER. These theories gained importance as the science of engagement and the role of peer research in health research was recognized as a means of addressing systemic discrimination and achieving JEDI principles in healthcare and research. Standpoint also works as a tool in personal and program level where it speaks to the interaction of identity and agency within programs, policies, and systems.

We had learned that autobiographical stories often start in one quadrant, often the blue or 'competence' quadrant and end up in other quadrants, and often ending back in 'competence' or in 'acceptance.' As students continued to map autobiographical stories, we noticed common movement patterns.

These basic movement patterns provided new focus in creating a standpoint map that included transitions from one quadrant to another, and another, and another.

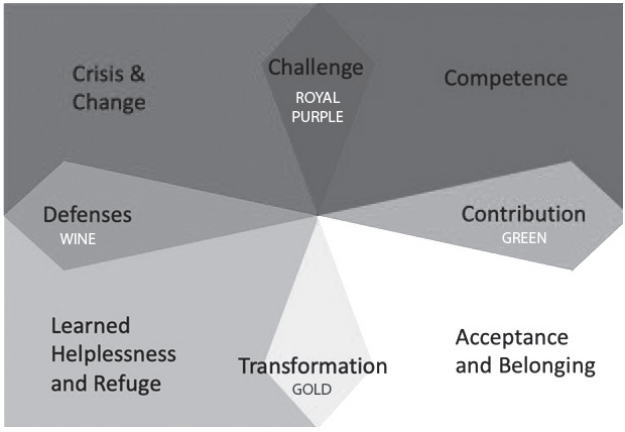
- The movement between BLUE and RED combines the colours to represent the PURPLE 'challenge' transition that sees the experiences associated with illness and disability as challenges to be conquered. It captures the energy and essence of regaining agency as the person achieves a new identity and retains personal agency. This space is the foundation script of sociologist Art Frank, author of *The Wounded Storyteller* (2013, (https://press.uchicago.edu/ucp/books/book/chicago/W/bo14674212.html), who sees this movement as a hero script. This also represents most professional discourse in healthcare where patients are rewarded for complying with treatment. This is a purple health discourse about succeeding by following care plans.
- The movement from RED to GREY produces a WINE colour of 'defence' transition that captures resistance and defense mechanisms employed to protect self-identity and personal agency as long as possible. When it is not possible to overcome the challenges of illness and systemic discrimination and loss, this transition shifts to attempts to defend one's identity and agency in the only methods left, giving up control to others to achieve stability through acceptance of loss and moving to the grey quadrant.

- The next transition from GREY to YELLOW produces a GOLD colour and was named 'transformation' because it includes powerful external forces such as spiritual awakening (gold scripts) and the influence of peers, champions, models, or mentors. This captures the power of inclusion and acceptance from the JEDI principles.
- The final movement from YELLOW to BLUE produces a GREEN 'contribution' transition that occurs when people regain enough positive self-regard to become agents again and use their new knowledge of illness and peer support to regain former roles or find new ones or focus on contributing to others. This captures JEDI principles that rely on accepting difference and diversity as one re-enters everyday living and contribution. It is about claiming the right to be included despite differences.

We now have a basic set of four psychological spaces that reflect health-related experiences, and four transition strategies that point to where people want to move and how to get there. The grid had become an active standpoint theory for training health-related students, professionals, and communities seeking to understand peer support. I then returned to the autobiographies to test out the hypotheses generated by the blending of the colours and realized that the quadrants and transitions depicted most patient journeys. In the past four years, I have also been able to explore the ability of this standpoint theory to support interpretation of peer research using peer research included in the PRISM hub and publications of peer research.

The final coloured standpoint theory is presented in Figure 10.2.

Figure 10.2 *Standpoint Theory Map Using Four Psychological Spaces and Four Transition Actions*



The eight psychological spaces of the coloured standpoint theory map represent an emancipatory patient perspective of healthcare experience. It represents the links between changes in identity, health status, agency, and EDI principles that identify the nature of systemic discrimination.

Transitions as Standpoint Stories of Emancipation

This section describes the four transitions that mark strategies to regain control and a sense of wellness. The study of transitions took up a great deal of incubator space and focused study and research.

The 'Royal Purple' Transition from Crisis to Competence

This transition is the most common motivation and the most frequently used strategy to overcome obstacles and return to life as it was before illness and trauma. This is the transition of patient education, of finding answers and new ways of living to regain competence. This is the hero script in Arthur Frank's (2013) work. It is also a dominant male script.

Sometimes, people become addicted to the emotional satisfaction of conquering health problems, and tempt fate by pushing limits to challenge their power. This is a high-energy transition.

If we consider the EDI principle of difference defined by a change in health status, we see that this transition is about reducing differences to become 'normal' and a way back to their 'just' position (justice). It also is the hero script of conquering adversity and loss.

- Deciding to ignore cancer and win the election, Ed was the leader of a political party and had successfully fought cancer. When he realized that the cancer had returned, he made up his mind to work through the cancer, no matter what the result. He and his party worked out many ways around the fatigue and pain, and Ed continued valiantly defying cancer. Shortly after the election, he passed away but had achieved an unprecedented increase in election wins. He died a man of competence, bravery, and determination, and he achieved his goal and died with the memory of his achievement.
- Terry Fox: The Canadian hero decided to use his remaining time to make a difference by running across Canada, in spite of a painful prosthesis and active cancer. His determination to continue despite major obstacles struck a chord in the Canadian spirit of never giving up. His legacy continues as we respond to his challenge to run for the cure as we continue the fight to beat cancer.

The 'Wine' Transition: Defenses Transition from 'Red' to 'Grey'

There are two routes out of crisis and change, and the "wine" transition is not normally tried until the person has tried repeatedly to transition through the 'challenge' transition (i.e., the royal purple back to blue). Naming and understanding the transition between the red (crisis and change) quadrant and the grey (learned helplessness) quadrant was the last transition to be identified. This transition is seldom recorded in autobiographies or shared with others, apart from the despair and the fear of losing control or power. Much of the search to understand the role of defenses came from focus groups recalling their experience in the 'defense' transition. In groups, they were able to share these stories and enjoy the embarrassment and struggle, but they indicated that they would be reluctant to share these experiences in formal interviews or surveys where they might be identified.

Losing control is often seen as a defect and acknowledged infrequently. However, people caught between an untenable situation (red) and helplessness or loss of hope (grey) live in constant turmoil. For many, the potential loss of control (moving from red to grey) is overwhelming, and it took much reanalysis to figure out what was happening.

People who live with blame, shame, and anxiety protect themselves from new uncomfortable realities through defense mechanisms. I include some of the more widely accepted defenses as examples of some of the strategies that were identified to protect personal control over health and healthcare.

- **Repression and denial.** When faced with a diagnosis or prognosis that causes loss and fear, patients protect themselves and their family by tucking the information away and ignoring its existence. Doctors used to encourage families to hide medical information that might be considered too much for the patient to handle. Many families close ranks and don't let others know about a cancer diagnosis—it becomes a family secret. This was a common defense for men who couldn't cope with the thought of not being able to continue to be the head of household. It is also common with cancer, when a person feels that the only way to protect family members is to hide the diagnosis and continue life as is. Some cultures hide or ignore disabilities or illness, for fear of public shame.
- **Projection.** This tends to be used in situations where others are blamed for causing the problems, diverting attention away from personal responsibility. The process of blaming others is used by patients and by family members who become complicit in blaming

others for family problems, that often include blaming the medical system for lack of action or poor treatment practices.

- **Regression.** With chronic and degenerative conditions, it is easy to lessen adult expectations and enable patients to relate as they might have done when they were children. Those with dementia are often encouraged to live in a past they remember, to make their life happier and less stressful. Similar stories are told of developmentally handicapped adults who are encouraged to continue with childlike activities and avoid situations that might become difficult if the adult were expected to live like an adult.
- **Sublimation.** Unacceptable impulses are transformed into socially acceptable interests, turning negative energy into positive outcomes. This is often seen as a mature defense mechanism that can divert feelings of anger, loss, or frustration into physical activities that create opportunities for new identity in adapted sport, leading peer support groups, mentoring, and writing about experiences. This 'defence' mechanism is not just about avoiding loss of control, but it provides a way to establish new forms of competence or new relationships in the quadrant of belonging and provides another way to avoid the grey quadrant.

Defensive strategies that help deal with the anxiety of being caught between 'crisis' and 'learned helplessness' are significant and provide a temporary reprieve between two untenable situations. This category of strategies is difficult to research through autobiographies or traditional qualitative research, because defenses are not generally shared as coping mechanisms.

The 'Gold' Transition: Transformation

This transition is life changing. It is about finding value and connection that enables us to change negative identity to positive identities through the power of inclusion. Transitioning occurs when people connect to a power source that can counteract the forces of marginalization and subjugation. Finding a higher power, reconnecting with cultural traditions, reading an inspiring autobiography, and disability sports are some of these forces. When connecting with peers, patients realize that they are not unique or alone. People find hope that they might also be able to change their situation when they meet others who have been able to make significant changes in their own lives. This sentiment captures the power of the independent living movement, emancipatory theory, and social disability theory.

The stories from disability and adult mental health celebrate peer support through disabled sport and artistic accomplishments. This includes the independent living movement and clubhouse and the many advocacy and emancipatory groups that exist in this space. This is a collective space of role models and peer support of those who have overcome adversity and use their experience and expertise to support others. This psychological transition is particularly important for health-related conditions because healthcare is primarily an individual experience, and this often makes the power of 'belonging' a new experience that is unexpected and emancipatory.

- **Greenbank program.** Most of the applicants to the Greenbank College came from special schools, specialized institutions, family homes, or group homes for the physically disabled. As such, many came from a grey standpoint. Greenbank College was a place of acceptance and belonging, run by people with disabilities. Gerry himself was disabled, coming from childhood polio to challenge the education provided by the institution he lived in. Greenbank College was founded on peer support and challenged the systems that subjugated and controlled the options available to disabled youth. Originally, I thought that Greenbank represented the blue quadrant of competence, but the stories of competence were more in keeping with the social enterprises that were considered separate from Greenbank: community wheelchair industry; whole food restaurant; and a second-hand store that existed during the research connection. Greenbank was, in fact, an example of gold standpoint theory, providing time and opportunity to share personal experiences of being able to challenge the dominant stories of subjugation through their successes in the training college. This was possible because storytelling was encouraged by Gerry and disabled staff members.
- **Wheelchair sports.** Gerry grew up avoiding being in a wheelchair and struggled to get around with canes and callipers. One evening, he attended a wheelchair basketball competition with a friend and became mesmerized by the power, maneuverability, and grace of wheelchairs. He was smitten with a desire to use a wheelchair and to build wheelchairs for racing. He and a disabled colleague, who was an engineer, designed and manufactured high-end racing wheelchairs and used them in fundraising runs.

- **The god scripts.** In one of the narrative analysis classes, I noticed that many students had chosen religious autobiographies. This provided a unique opportunity, and I asked if the students might like to focus on 'god scripts' in their analysis. With autobiographies covering many faiths and cultures, this became a highlight of the year. The scripts had many diverse and contradictory messages, but the essence remained the same: there are things to learn about life from setbacks; there is a purpose in what is happening; you can handle this.

Connecting with a higher power to find meaning is also a common source of transformation. These 'god scripts' can be as simple as "God wouldn't have sent this illness if he thought I couldn't handle it," or as complex as the need to atone for past life sins in order to move to grace in the next life. These higher power scripts are often minimized by professionals who may be uncomfortable talking about someone's higher power.

The 'Green' Transition of Contribution

This transition is about using the expertise, connections, and understanding that comes with long-term conditions or life-changing events. This is also a key transition in standpoint theory, turning knowledge gained through the collective identity of the gold transition into action in the same way that feminist standpoint theory focuses on collective action to build personal competence. The autobiographies and experience working with the patient standpoint grid also identified the option of moving from a collective sense of belonging to individual action. This was part of Indigenous stories that celebrated the retelling of original stories and living within a community with ancestors and the land, while finding ways to use this new traditional strength and wisdom to declare ownership of their lands and expertise related to reparation of land devastated by climate change, industrial pollution, and degradation.

The key to a green transition lies in the expertise gained among peers and communities as part of the yellow quadrant of acceptance and belonging and the willingness to become active in making a difference. There is a large appetite for champions who have experienced a serious health concern, who then write or speak about their experience. Other patients and PWLE use their influence to become involved in advising and research. These generally begin as a volunteer commitment but are no less valued than moving to paid employment.

The other example of this is the growing influence of peer support. There is a growing movement to invest in training and payment of patients who provide support to others. Some examples of peer support workers include the following:

- Peer Support Canada (https://peersupportcanada.ca) that works with the Canadian Mental Health Association to certify peer support workers.
- A scoping review of peer support workers by MacLellan et al., (2015, https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0141122).
- There is a growing interest in citizen science in health and healthcare. Citizen Science for Health (https://www.citizenscienceforhealth.org) is a broker for health research, looking to find engaged patients as citizen scientists in health research.

In summary, the structures and strategies of the above patient standpoint theory will hopefully evolve as it is used and adapted to various situations. Like the challenge of Antonovsky, the originator of salutogenesis, my challenge to readers, is to use and adapt this standpoint theory to health research and, in particular, peer research.

An Application of Standpoint Theory at the Program Level Using Experience of the Case Studies of New Social Movements

In looking back at the case studies, it struck me that the data spoke to the power of standpoint theory.

- **Gerry Kinsella** was a scrapper, fighting the system in defense of others like him. He was the insider with status, because he was a social entrepreneur, earning money as a business to challenge the oppression of the 'professional disability sector.' His standpoint was the blue quadrant as a media sports hero, setting a standard of competence and achievement for his Greenbank team. Originally, I thought that Greenbank was also in the blue quadrant, but Gerry was an agent of transformation, guiding and encouraging young people who had come from the grey quadrant of special schools and medically based programs into Greenbank, a safe, yellow place of acceptance and learning among peers. Eventually, with training, the young people joined competitive, downtown businesses to contribute to the success of Greenbank by working and mentoring new graduates and, eventually, moving into mainstream lives.
- **Dorothy Birtles** was driven by a personal and a spiritual mission as a Quaker. She reached out to those tortured and often killed in prisons because of their political beliefs. With a simple act of kindness,

she connected caring Quakers with prisoners, writing letters of acceptance and belonging, and sharing the stories of prisoners with their extensive Quaker networks. Prisoner's lived in the deep depths of the grey quadrant, without hope or personal control in the midst of torture and extreme brutality. The befriending scheme was the transforming influence (gold) and a source of comfort. Being part of a story that was larger than torture was emancipating. Prisoners experienced an unexpected source of belonging and acceptance within a yellow quadrant formed by sharing letters between the Quakers and prisoners. For the Quaker correspondents, their normal, everyday, blue existence was plunged into the pain and suffering of the red quadrant, but their work brought them to a new competence and sense of control, not in releasing prisoners but through sharing the power of their stories with others.

- **Dame Cicely Saunders**, the founder of the modern hospice movement and St. Christopher's Hospice. Dame Cicely began as a nurse, an almoner, and eventually a physician and a palliative pain specialist. Her books were written for families and patients, and she expected patients who were dying to write their life's legacy story for the family. She expected them to set aside the despair and helplessness imposed on the dying to take up the challenge to live until you die. Patients came to the hospice deep in the grey quadrant with cancer and other terminal conditions that controlled their lives. This was the only example of patients moving from a grey quadrant directly to a blue quadrant, without going through the other transitions. Most patients died in the blue quadrant.
- **Henry Enns and Disabled Peoples' International (DPI).** DPI is an international social movement that captured the emancipatory promise of the women's movement and all its struggles against systemic discrimination. It was founded by disabled people, who resisted the attempts of the World Rehabilitation Association to control them. Henry was the master storyteller and part of an international coup that located their work at the level of the United Nations and the declaration of the rights of disabled people. This new social movement worked in the same fashion that the feminist movement had. Henry and others travelled the world, meeting groups of disabled people and sharing stories of systemic discrimination and the lack of accessibility and services. They also met with the power brokers in each country, challenging their policies and practices, and building the local capacity to continue

the fight. Within standpoint theory, Henry and the DPI team acted as gold agents of hope and transformation, encouraging those living within neglected segments of society without hope or agency. They helped groups come together and build skills, to become agents of change in their own right. They created a positive collective sense of positive self-regard (blue). In many ways, the original DPI group of disabled men acted like the women academics, as insiders able to bridge to power through their negotiation skills.

- **Henry Three Suns and the Siksika Nation**. Henry had become a social worker to create child welfare solutions that honoured the traditions and family values during the infamous scourge of the Sixties Scoop in Canada. However, he refused to see himself as a change agent. His Indigenous spiritual and collective approach to life opened an interesting translation of the grid. He and one of my PhD students who was Indigenous felt that the blue quadrant represented the dominant white culture; the yellow quadrant was Indigenous, with external forces of ancestors, generations to come, the Creator and the land; grey was the loss of their humanity through alcohol and white ways; red represented the pain inflicted by white ideas of power and wealth. This positive yellow collective existence found a way of living and knowing with white society that reflected a green transition. The changes made in the colours reflected the quadrants of the medicine wheel and this was used in teaching Indigenous students of PaCER.

Summary

This chapter has introduced a new standpoint theory for peer research elements of participatory action research, narrative data, and grounded theory analysis. It creates a bridge between the previous chapters and the final chapter about possibilities for using peer research in new ways in the future.

Questions for Discussion

1. Now that we have completed the chapter, I invite you to return to the "Hidden Pathways of Chronic Illness" peer research project (Banerjee et al., 2013, http://hdl.handle.net/1880/109953) and use the grid to locate the paths in the quadrants. Although there is not a 1:1 match, what pathways can you identify that reflect the psychological spaces (quadrants and transitions) identified in this chapter?

2. This chapter introduces a first attempt at a standpoint theory, grounded in the complexity of healthcare systems. Consider a course you have taken that included theory which was emancipatory and choose a theory to compare with the patient standpoint theory described here. What were the strengths and weaknesses of each of the theories, as applied within a healthcare setting?
3. Plot your own journey through the standpoint theory during a stressful stage of your life. What have you learned about your strengths and emancipation? Or, what might you have been able to accomplish had you known about standpoint as a theory?

Resources

Standpoint Theory as a Tool in Design Thinking as Part of the Science of Engagement

The following resource by Cera Cruise, an undergraduate student in Community Rehabilitation and Disability studies, provides an example of how standpoint is useful in choosing potential goals/innovations for design thinking. It demonstrates how online program descriptions can be used to identify location on a standpoint theory.

Using scripts from three of the health systems related to health professionals who experience moral injury—treatment and diagnosis, community inclusion, and peer and natural support—I used standpoint theory to understand the location on the standpoint grid of moral injury patients at the onset of their moral injury in the red quadrant and the treatment, staff, or programs as they attempted to guide patients to healing and acceptance in the yellow quadrant. The 'end destination' of each system was illustrative of what the system defined as patient capabilities or the blue quadrant. However, in the treatment and diagnosis system, patients were not supported in returning to the blue quadrant, while in the community inclusion system supports were given to those who were in the grey quadrant, therefore excluding those in the red quadrant. Finally, the peer support system supported members in all quadrants, but was uniquely able to facilitate a transition from yellow to blue that the other analyzed systems were unable to do.

Table 10.6 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/Cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"Another coping strategy involves letting the incident overly redefine one's self-concept and identity."	Crisis: Locus of control or agency is internal, while self-regard is negative. This places the person in the red quadrant.
"The patient needs to understand that concealment is understandable but maladaptive."	Control: Here seen as personal control by concealing the problem. The professional encourages the patient to take the advice of the professional and transition to the learned helplessness quadrant.
"Ultimately, the expectation is self-forgiveness and the possibility of living a moral life."	There doesn't seem to be an expectation of moving to competence through contribution; acceptance seems to be the final goal of treatment.
Summary: To heal, one must first give up control, and this program requires the patient to develop a sense of positive self-regard in the face of doing something that they currently see as morally reprehensible. It would have been interesting if the treatment system discussed the power of contribution, beyond the fact that amends can be good but within reason. The limit placed on amending acts suggests that the professional remains in control to decide which acts of amendment are too much. The patient, therefore, can't move from acceptance to competence without the professional willingly giving up control. Program and patient capacity could be increased if the transition of contribution was facilitated or encouraged more.	

Table 10.7 *Community Inclusion Analysis*

Data: Community inclusion https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740 https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/	**Analysis**
"I couldn't tolerate the feeling of failing to give my patients the kind of loving, tender, comprehensive whole healthcare I knew they deserved, but I had no idea how I would pay the bills if I left, and after spending 12 years training to become a doctor—and feeling spiritually called to do so—I couldn't imagine what else I'd do. Rock and hard place. Despair. Helplessness."	Control of their circumstances is external and the patient shares that their negative self-regard was placing them in the learned helplessness quadrant.
"We support practitioners in building a thriving healing practice, as we believe this is necessary to provide the material and organizational resources needed to accelerate the reintegration of psychospiritual work into the healing process and the healthcare industry."	Presumes that having a "thriving healing practice" will increase the healthcare provider's self-regard, and that by being more effective at their job, they will (re)gain a sense of competency.
Designed to diagnose and treat what the shamans call "soul loss," this program is meant to heal you by helping your soul take over as the guiding force of your life.	Brings awareness to patients of the importance of spiritual well-being (self-regard), meaning that patients are presumed to be in the crisis and change or learned helplessness quadrants.
Summary: The Whole Health Medicine Institute's aim is to improve the self-regard of healthcare providers, which it presumes is negative. Giving them the tools to be more effective practitioners, the program assumes that this will move them in the competence quadrant. No resources are specifically mentioned for individuals whose moral injury stems from their own actions; rather, the Institute appears to be catered towards those whose moral injury stems from structural violence—the injury created by social institutions. This leads me to infer that the program may be effective for those in the learned helplessness quadrant, but perhaps not the crisis and change quadrant.	

Table 10.8 *Peer and Natural Support Analysis*

Data: Peer and natural support https://projecttraumasupport.com/	**Analysis**
"Pain is nothing more than a sensation of extreme discomfort, meant to alert you to the need for attention. It is not meant to make you hide or withdraw. Its purpose is to focus your attention."	Crisis is recognized as a temporary position in the plot, leading one to infer that a transition is necessary.
The group provides a forum where openness and honesty are admired and encouraged, under an umbrella of assured confidentiality and anonymity.	Acceptance: The group is the external locus of control that admires the patient for their openness and honesty, encouraging the patient to increase their self-regard
"I feel like taking care of myself is worth it."	Competence: patients sees themselves with positive self-regard and realize that taking care of themselves is an active choice.
"We are in a position to walk in the dark suffering that others are feeling and to bring in the light and love we cannot see for ourselves. We cannot and should not be cutting the cords of the collective just to protect ourselves—we are better than that."	Competence: Contributing to others with a similar journey as a necessity. Locus of control is internal, in that it's an individual decision to contribute to others' well-being.
Summary: Patients come to the group in crisis with low self-regard and an internal locus of control. The group allows them to contribute to the healing of others, therefore lessening their locus of control so that it becomes more neutral and less extreme. Coming to a personal place of acceptance is important to group members, and increased opportunities to contribute to society outside of the group could be innovative for patients and allow them to reach a place of competence. Through growth within, the group patients are able to improve their self-regard and transition from crisis to competence. Some control is given up when they join the group, as they follow the group's rules and experience the group's reactions to their story, showing that acceptance is necessary before competence. Contribution is an important patient role and signals that they are in a position to walk in the dark suffering that others are feeling.	

Co-designing an Emancipatory Standpoint Theory

This section is part of my ongoing memo about emancipation. It is included to depict how grounded theory provides a way to support and document inductive reasoning of social change. It is included as a first-person memo.

Intrigue with power in health and healthcare began for me in a psychiatric unit for aggressive and regressed women. As part of a social innovation called 'Token Economies,' we were able to change the behaviours of these women by providing rewards for 'good' and 'productive' behaviours. In the same institution, I was part of challenging dependent roles of patients by introducing a positive checklist that staff had to fill out and report on. We created a workplace within the hospital by creating realistic employment expectations.

I continued to develop self-assessments and community training programs for disabled adults that built a culture of capacity. This led to changes in institutional programs for profoundly handicapped children, new curricula for the children, and training programs for teachers where none had existed in public education. This position led to designing the Community Rehabilitation and Disability Studies program at the University of Calgary, the first of the Canadian Disability Studies programs that was transdisciplinary and focused on creating leaders in community alternatives and advocate for people with disabilities and their families.

These experiences confirmed my belief that new social organizations could change the way people saw themselves and related to each other. Then I was jolted further from my belief in being able to establish ways to empower people by creating new programs. I joined a new social organization for independent living that challenged my assumptions that social change depended upon professional programs and tools. One of our university students was hired to create a program that followed the principles of independent living, including: changing the environment, not the person; a person with a disability can understand the needs of another; and a person with knowledge and power can make their own decisions. The program accepted all people with disabilities, including those who had lived their lives in institutions.

I was so taken aback by the changes in people's lives that I set out to do my PhD to understand more about how to conduct peer research with social innovators in Canada and the United Kingdom. As I was conducting my PhD, my university students took up the challenge to become engaged in research that looked for the ways people reconstructed their lives after illness, loss, trauma, or disabling conditions. We developed methods to analyze autobiographies. The result of all three simultaneous activities created a first version of standpoint theory. All three activities were about emancipation and created

tools and theory to unpack a standpoint theory that explored a very broad and diverse sector of health.

Incubating a Self-Assessment and Goal-Setting Tool

The director of the Independent Living Centre was a student in the Community Rehabilitation and Disability Studies program, who knew of my early work with Vecova and how we had used a simple tool to help people with limited language make basic decisions and express (positive and negative) feelings. She asked me to help find a way for the members of Calgary Association and Disability Studies (CAIL) to make decisions. She felt that they had been so controlled and diminished by their experiences in institutional care that they had difficulty understanding their strengths and what they wanted to accomplish. We introduced the Vecova yardstick, but it was clear that the linear process was too simplistic. Instead, we decided to add a second axis to create a grid system.

Developing a self-assessment tool for peer support as the beginning of standpoint theory, I had been intrigued by self-assessment and personality theory early in my career, so we tried the following popular polar archetypes:

- Eysenck's (1952, 1966) introversion/extroversion polarity and Atkinson's (1974) motivational theory (motive to approach success and avoid failure), covered in Elliot's *Handbook of Approach and Avoidance Motivation* (2008).
- Rotter's internal and external locus of control have been covered in Tyler et al. (2020, https://doi.org/10.26686/wgtn.12956984.v1). The concept of agency or locus of control seemed to work when combined with the basic positive/negative axis of identity and personal self-regard. The intersection of the map axis became a neutral or transition zone of two bipolar opposites.
- The personal construct work of George Kelly (Cherry, 2023, https://www.verywellmind.com/george-kelly-biography-2795498) supported our goal of creating simple grid structures for basic self-assessments. This interest in grid formats has continued and is currently represented through what is referred to as cartesian mapping, used to map constructs against each other. The above grid as a cartesian map was eventually called a patient and disability standpoint map. It consists of a horizontal axis related to feeling good or bad (self-concept, ease/dis-ease in salutogenesis, self-regard, pain) and a vertical axis about locus of control. The quadrants are psychological spaces created by the intersection of self-regard and locus of control.

The process of using this simple grid as a self-assessment tool had a profound impact on my career. In my former work, I had developed a number of standardized tests and surveys, in particular the adaptive functioning index (AFI) (Marlett, 1973) training and assessment tool. It led to trainees assessing themselves according to a standardized instrument that they had been part of creating.

CAIL presented an even more disturbing challenge for me: the role of the test designer and assessor was removed completely.

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