Improvisation: 5 Capacities for Coping With Trauma and Loss in Chronic Illness

Patricia Fennell, John Esposito, Anne Fantauzzi

Abstract
To live fully in spite of the changes and losses that chronic illnesses bring, we must learn to accept our new circumstances and find meaning in our experience. The arts, whether through music, humor, movement, writing, painting, or other means, help people with chronic illnesses develop acceptance and meaning.

Improvisation, the skill of top artists, can offer new ways to respond better to change. In improvisation, we use our existing knowledge and skills to create something new in an unplanned, innovative way.

Validated, evidence-based research has established that people experience Four Phases in the process of adapting to live with chronic illness. These phases -- 1. Crisis, 2. Stabilization, 3. Resolution and 4. Integration -- describe a predictable passage that patients navigate on their way to defining a new self and a new life after the onset of chronic illness.

It is in the third phase, Resolution, where individuals recognize deeply that their old life will not return. They begin to find meaning in their experience, establish an authentic new self and develop a supportive, meaningful philosophy. The tools of improvisation offer a pathway toward establishing meaning in the chronic illness experience.

There are five capacities of improvisation that are explored through the arts and that people with chronic illnesses need to acquire to establish acceptance and meaning in their changed circumstances. These capacities are 1) Tolerate ambiguity, 2) Take risks, 3) Become curious, 4) Take action, and 5) Innovate. The five capacities offer tools to help clinicians and their clients cull prior experiences for better assessment of present circumstances and create innovative ways to respond to change.

Key Words: Chronic illness, art, innovation, Fennell Four Phase Model, innovation, coping, resolution, trauma, improvisation.

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1. A Paradigm Shift

Over the past several decades, medicine has undergone a paradigm shift from an acute to a chronic model of illness. This transformation is due to several factors,

including advances in medicine that have transformed once fatal illnesses into long-term chronic conditions, and has resulted in an aging, and increasingly ill, population. Many people are now living for decades with chronic illnesses that would have been fatal to previous generations.

This is not a short-term trend. The World Health Organization reported in June 2011 that between 15.6% and 19.4% of people worldwide have a disability; between 2.2% and 3.8% have disabilities considered "severe."[1] These numbers have increased since the 1970s, when 10% of the world's population had a disability, and are expected to continue rising due to factors including:

-- the aging of the world's population (as living into old age increases the likelihood of having a chronic illness),

-- public health advances, such as availability of cleaner water and maternal/pediatric health care that have decreased childhood mortality,

-- changes in diet and lifestyle that have increased the prevalence of obesity-associated conditions such as diabetes and cardiovascular disease, and

-- improvements in medical care that have transformed previously fatal illnesses, such as cancer, stroke, and HIV/AIDS, into chronic conditions.

More than acute illnesses, chronic conditions require coordination of care among a multidisciplinary, interdisciplinary team of professionals, laypeople, and community members. As a result, health care systems are struggling to develop chronic comprehensive case management methods to supplant the acute clinical treatment models that have worked for many generations, but largely fail today's long-term illness patients.

2. Chronic Illness & Trauma

The experience of living with a chronic illness, often defined by symptoms over signs, individual perception rather than laboratory tests, can be highly traumatic to the patient, as well as to his or her family and loved ones. Patients may suffer from social stigma, economic losses, and lack of knowledge and understanding about their condition. In addition, the unpredictability and chronicity of waxing and waning symptoms, the patterns of relapse and remission can be extremely frustrating to all parties.

Chronic illness-associated trauma can stem from several sources:

-- **Disease/Syndrome Trauma:** Realization that something is profoundly wrong and that what was once considered 'normal' is no longer so. Lifestyle, livelihood, function, and predictability are some of the losses that can result in trauma.

-- **Iatrogenic Trauma:** Health care providers who question the veracity or severity of a person's symptoms, or suggest that the person is morally or mentally weak, or somehow responsible for their illness (or inability to recover) can precipitate trauma in patients.

-- Cultural Trauma: Bias against the chronically ill is common in our culture and may be fostered by sensational media accounts of unexpected recovery, preliminary research findings, or 'against the odds' performance by athletes or other luminaries. Friends, family members, colleagues, and general society can show fear, misunderstanding, or bias toward the chronically ill and their disabilities. As a result of these attitudes, many people find themselves without jobs, housing, friends, or other support.

-- Vicarious Trauma: People who live with and care for the chronically ill can also suffer trauma. Stigmas conveyed by health care providers, the media, and general society against the chronically ill can result in traumas in family members and friends who support them. The need to take time from work to accompany their loved one to medical appointments can result in job loss or career stagnation.

-- Pre-Morbid / Co-Morbid Trauma: Serious trauma may exacerbate illness symptoms. These might include a death in the family or natural disaster. In addition, pre-morbid trauma, such as an auto accident, may decrease resilience and therefore may make it more difficult to cope with additional traumas.

3. Four Phases of Chronic Illness

Validated, evidence-based research has established that people experience Four Phases in the process of adapting to chronic illness. These phases describe a predictable passage that patients navigate on their way to defining a new self and a new life after the onset of chronic illness. Within each Phase, the Fennell Four-Phase Model (FFPM) addresses three domains: the physical/behavioral, the psychological, and the social/interactive.[2,3,4,5,6]

In **Phase 1, Crisis**, the individual moves from onset of illness, which may be specifically detectable or may happen gradually, to an emergency period when the patient knows that something is seriously wrong. The task of the individual, caregivers, and clinicians during this Phase is to cope with and contain urgency and trauma.

In **Phase 2, Stabilization**, the individual discovers that he or she fails, sometimes repeatedly, to return to normal regardless of interventions or behavior. The task in this Phase is to initiate stabilization and life restructuring.

In **Phase 3, Resolution**, the individual recognizes deeply that his or her old life will never return. Early in this Phase, many experience significant grief and loss. The task of this Phase is to begin establishing an authentic new self and start developing a supportive, meaningful philosophy.

In **Phase 4, Integration**, the individual defines a new self in which illness may be an important factor, but it is not the only or even the primary one in his or her life. Integration of the illness into a meaningful life is the goal the individual seeks.

4. Finding Meaning in Suffering

It is in the third phase, Resolution, where individuals recognize deeply that their old life will not return. They begin to find meaning in their experience,

establish an authentic new self and develop a supportive, meaningful philosophy. The tools of improvisation offer a pathway toward establishing meaning in the chronic illness experience.

To live fully in spite of the changes and losses that chronic illnesses bring, individuals must learn to accept their new circumstances and find meaning in their experience. The arts, whether through music, humor, movement, writing, painting, or other methods, help people with chronic illnesses develop acceptance and meaning.

Improvisation, the skill of top artists, can offer new ways to respond better to change. In improvisation, we use our existing knowledge and skills to create something new in an unplanned, innovative way. Authenticity is the bedrock, the guiding principle of finding meaning. While authenticity can be very difficult to define, it is instantly recognizable as honest, truthful, and genuine.

5. Improvisation, Creation, and Innovation

The 'Five Capacities of Improvisation' model states that Improvisation leads to Creation, and Creation leads to Innovation. It recognizes that change can be either good or bad and also that it is inevitable. It also presupposes that improvisation, creation, and innovation help us respond more effectively to that inevitable change.

Creation requires active reflection, action, and authenticity and, therefore, it, in itself, is a powerful stance against the helplessness which results from trauma, illness, and ambiguity.

6. Five Capacities of Improvisation

We have identified five capacities of improvisation that are explored through the arts and which help people with chronic illnesses establish acceptance and meaning in their changed circumstances.[7,8]

A. Tolerate Ambiguity: This capacity recognizes that ambiguity is unavoidable and it's possible to survive in spite of not knowing what lies ahead. Here, people take the time and allow themselves to feel uncomfortable in order to get where they need to be. They find the patience to wait for the right answer, rather than the quick answer, even if it is difficult. People learn how to do the 'emotional heavy lifting' that leads to the wisdom of appreciating the value of the unknown and the understanding that something good can come of even the worst of circumstances.

B. Become Curious: This capacity understands that change is an opportunity and that curiosity leads to innovation and change. Unfortunately, our culture sometimes squelches children's curiosity, wonder, and risk-taking, often pushing people into conformity. A culture's toleration of questioning common knowledge, customs, and expectations is influenced by gender, race and social class. For

example, someone from the upper, educated and/or wealthy class might be praised for ingenuity in asking why something is done a certain way, while someone from the lower, uneducated, poorer class might be accused of insubordination. Curiosity may have positive ('childlike wonder'), negative (nosy, 'killed the cat'), and ambiguous (questioning authority) connotations; context and culture are determining factors on how curiosity is perceived.

C. Take risks: Risk taking can be very difficult for many people. The very act of 'sticking your neck out,' intentionally engaging in activities without a certain outcome, is uncomfortable. But without risk, there is no reward. To be successful, risk taking should be conscious or planned, versus unconscious or impulsive. Calculated risk taking is informed by a person's understanding of his or her physical, mental, financial, etc. limits and abilities. It also is engaged in a manner that minimizes shame, embarrassment, or fear of failure, and has a pre-planned 'exit strategy' in case things don't go as planned. An important consideration in the evaluation of what risk to take is a thorough evaluation of the traditional forms, interventions, or strategies that would be, or already have been, typically utilized. Can they be utilized or referenced in your current situation? Can options/possibilities be reengineered within the traditional frameworks and approaches? Or is it time to stretch these forms/constructs to the point of innovation?

D. Take action: To improvise -- to respond in the moment to present circumstances -- requires making a choice to take action. This statement or choice results in an action. This action then produces a reaction, to which you must then react, and the cycle continues. The painter chooses to pick up a paintbrush. Then he decides what color to use. Some people wait for that 'light bulb,' the 'a-ha moment' before making a choice to act; waiting for certainty may mean missed opportunities and stagnation.

E. Innovate: Once a person been curious, taken risks, made choices, and taken action, innovation is the result. It's important to recognize that the result – an idea, a paragraph, a picture, a song – whether small or large, is a victory. People should consider tapping into their community to get outside help, such as training, instruction, or assistance, to further or improve their creative expression. In all cases, the chronically ill need to accommodate their limits and abilities throughout the capacities.

6. Using The Five Capacities To Respond To Change

Using the five capacities to respond to uncertainty, crisis, or change requires first defining the present situation, problem, or crisis. By understanding which capacities are strengths, and which are weaknesses, you can ask for help where

needed. Through artistic expression -- music, visual art, writing, drama, etc. -- you can apply the capacities to the crisis or trauma you are experiencing.

An attitude of persistence and fortitude is a key element of the five capacities. This willingness to fail is crucial in developing the self-reliance and resilience in the face of change, trauma, and crisis that are integral with the chronic illness experience. The five capacities also recognize the importance of community, and the ability to borrow from the strength of others when you don't feel you can persevere.

Notes

[1] World Health Organization, and World Bank Group, 'World Report on Disability 2011' (Geneva: World Health Organization), Viewed 17 July 2011, <http://www.who.int/disabilities/world_report/ 2011/report/en/index.html>.

[2] Patricia A. Fennell and Lucinda Bateman, 'Matching Best Medical Practices to Phases of Illness,' Lecture: IACFS Conference, Salt Lake City, Utah, October 9, 2004.

[3] Patricia A. Fennell, Leonard A. Jason, and Susan Klein, 'Measuring Phases of Recovery in Patients with CFS,' *Journal of Chronic Fatigue Syndrome*, 5 (1999): 88-89.

[4] Leonard A. Jason, Guy Fricano, Renee R., Taylor, Jane Halpert, and Patricia A. Fennell, 'Chronic Fatigue Syndrome: An Examination of the Phases,' *Journal of Clinical Psychology* 56 (2000): 1497-1508.

[5] Leonard A. Jason, Patricia A. Fennell, Renee R. Taylor, Guy Fricano, and Jane Halpert, 'An Empirical Verification of the Fennell Phases of the CFS Illness,' *Journal of Chronic Fatigue Syndrome* 6 (2000): 47-56.

[6] Leonard A. Jason, Patricia A. Fennell, Susan Klein, Guy Fricano, and Jane Halpert, 'An Investigation of the Different Phases of the CFS Illness,' *Journal of Chronic Fatigue Syndrome* 5 (1999): 35-54.

[7] Patricia A. Fennell, 'When Illness Tears Your Soul, Art Gives It Back: Finding Meaning in Illness Through Artistic Expression,' Lecture, DePaul School of New Learning Chronic Illness Initiative Symposium: Chronic Illness & the Arts, Chicago, IL, May 12, 2010.

[8] Patricia A. Fennell and Lynn Royster, 'Working the Third Phase: Meaning, Community and the Arts,' Lecture, DePaul School of New Learning Chronic Illness Initiative Symposium: Chronic Illness & the Arts, Chicago, IL, May 12, 2010.

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Author Biographies

Patricia A. Fennell is a researcher, clinician and author specializing in chronic illness, trauma, forensics, hospice, global health care concerns, and the validated Fennell Four Phase Treatment model. President and CEO of Albany Health Management Associates, she is regularly invited to lecture to, advise, and consult with government, professional, medical, academic, management, and patient organizations in North America, Europe, and Africa. Her books include *Managing Chronic Illness: The Four Phase Treatment Approach* and *The Chronic Illness Workbook*. Patricia works as a professional jazz singer and in 2009 she recorded her first CD, *Frim Fram Sauce*.

Ann Fantauzzi is has worked in the field of education for 34 years. She has taught upper elementary grades, as well as administered and taught the gifted and talented program in her district. She is a published children's author, an innovator in classroom teaching methods and a teacher mentor. For the past three years, she has trained student teachers in Namibia.

John Esposito has been active as a jazz pianist and composer for 40 years. He has performed and recorded with jazz masters including Nick Brignola, J.R. Monterose, Dave Holland, John Stubblefield, Carter Jefferson, Sam Rivers, Joe Lovano, Arthur Rhames, and Pharoah Sanders. John is the founder and executive producer of the independent record label Sunjump Records. He has been a professor of music since 2000 at Bard College in New York, where he teaches theory, history, composition, piano, drums, and performance ensembles. He is currently producing music for a documentary on guitarist/painter/poet Sangeeta Michael Berardi, "Playing With Parkinson's" with filmmaker Burrill Crohn. He has also just recorded a new trio CD of his own compositions and is preparing several archival projects for release. He resides in New York's Hudson Valley.