Murmurations:
Journal of
Transformative
Systemic
Practice

Relating to illness in therapy: A pilgrimage through uncertain terrain

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Volume 1

Issue 2

Autumn 2018

Keywords:

counselling, illness, recovery, meaning-making, response-based practice, metaphor, indigenous people, systemic therapy

Citation Link

Abstract

In this article, I author explore the subject of supporting clients living with illness in the context of my counselling practice. I weave this approach to clinical practice, informed by response-based practice and the use of metaphor, together with my personal story of illness and recovery. I contextualise my own history as a Metis woman and therapist into the life of my family, living in Canada's north. There, my maternal family lived in the midst of uranium extraction, a form of mining that resourced the Cold War and fueled the atomic bombs dropped on Hiroshima and Nagasaki. Canada's implication in militarism had devastating effects on Indigenous community members. I explore the use of metaphor as a form of co-constructed meaning in therapy. I present my own symbolic journey through cancer and treatment as a sacred pilgrimage in Spain. The various key points in treatment parallel significant stops along the Camino de Santiago de Compostela. As well, I explore how clients negotiate medical systems, impositions and negative social responses, as well as how they resource love, strength and care from family and friends. I apply a framework of response-based practice, seeking to understand the ways in which people preserve dignity and try to maximize safety and well-being. This includes the ways in which patients manage unsolicited advice and undesirable procedures with courage and grace.

Abstract (French)

Dans cet article, j'explore le sujet de l'accompagnement des clients vivant avec des maladies dans le context d'intervention. Mon approche est teinteé par la pratique axée sur les réponses/la résistance et avec de l'utilisation de métaphores. Cette raconte est liée avec mon vecu personel avec le cancer et ma guerisson. Je contextualise mon vécu en tant que femme est psychotherapeute Métisse avec la vie de ma famille maternalle dans le nord du Canada. Cette histoire de ma famille maternelle a affaire avec le minage de l'uranium pendant les années de la guerre froide et les bombes atomiques lances sur Hiroshima et Nagasaki. Cette histoire nucléaire avait les effects terribles pour les personnes autochtones dans le nord du Canada. J'explorerai l'usage des metaphores présentant mon chemin symbolique en tant que pélinerage en Espagne sur le chemin de Santiago de Compostela. Dans un deuxiéme temps, j"explorerai comment les clients interagissent avec les systems médicaux, les impositions et les réponses sociales negatives bien que le soin et l'amour des autres. Je mobiliserai le modèle de la pratique basée sur les réponses, permettant de témoigner la façon que les personnes préservent leur dignité malgré les conseils non-voulus et les processus médicaux diffiçiles avec le courage et la grâce.

Life work/Context

I am a professor in the School of Social Work at the University of Montreal and a therapist in private practice. I work a lot with the Indigenous community addressing issues of historical violence as well as responses and resistance to oppression. I am a Metis woman with Cree, Gwichin and Dene ancestry, as well as a cancer survivor. I am a co-founder of the Centre for Response-Based Practice.

As a therapist, I have worked with many people, often women, who suffer from illness involving physical and emotional pain. Body pain and the accompanying feelings can sometimes manifest in ways that are non-detectable by others outside of that body. Often, invisible disabilities receive little empathy, particularly in societies where individual strength, stiff upper lip and the denial of personal suffering are valued. Reports of suffering are sometimes viewed unsympathetically, as if they are inventions. Almost everyone knows the word hypochondriac or hysterical! Sometimes, clients must work hard to forge their own path of dignity, care and resistance to the off-track view of others.

In this article, I explore some my experiences working with illness as a psychotherapist, particularly in the present context of exploring illness within my own body. I am interested in illness as a social issue and how the illness experience is affected by social positionality including privilege, race and gender. This privilege includes the degree to which one is “familied”, or has family and friends as part of a caring system of support. I am interested in the kinds of social responses received by women and other marginalised groups in their treatment. I am also interested in how the person “frames” and conceptualises illness/disability and how they speak about this. Is illness something that happens to us? Is it something we go through? Are we hapless victims, punished for an unhealthy lifestyle or are we transversing a field, an abyss, a valley? For myself, the metaphor of a pilgrimage seemed pertinent. I had been to Spain recently and was excited by the marked entries into the ancient and sacred trails of the Camina Santiago de Compostela, a path understood as the resting spot of Jesus’ apostle St. James. Though there are numerous points of departure, many pilgrims start in St. Jean France and walk to the Santiago de Compostela in the province of Galicia. For many years I have felt a strong desire to undertake this walk but my hips and legs would not permit it. Even before experiencing cancer, I have had three hip operations to maintain my ability to walk. I have spent time in a wheelchair as well as body casts when I was little.

As a Metis woman in Canada with Cree, Dene and Gwichin ancestry, I am intrinsically linked to connections between well-being, environment and the degree to which societies care for Earth, and care for women. Through my ancestry, I am connected to global events such as the uranium mining in the north which fuelled the atomic industry, the Cold War, and the death of untold millions on the planet. Mamatowisowin is a Cree word denoting the interconnection of all things and all forms of life (Ermine, 2000). I believe in this.

My mom lived in Uranium City with her family, in contact with a radioactive presence on a daily basis. Environmental researcher, Jim Harding (2007) discusses how Canadian mining companies worked with the US government to provide one third of the world’s uranium for bombs, including those dropped on Hiroshima and Nagasaki (see Canada’s Deadly Secret). The connections between well-being and environment are blatant. After living in Uranium City, Saskatchewan, Canada my grandmother lost her hair by age 40. My mother and her sisters suffered numerous food and metal related allergies; all the girl babies in my generation were born with dislocated hips and other joint-related diseases. My grandfather kept uranium ore in their basement and my grandmother lined her garden with radioactive rocks. The Canadian National Film Board film “Village of Widows”, by Peter Blow, shares the history of Deline, where all the Indigenous men in a Sahtu Dene community died due to their work in the uranium industry. A number of mining companies operated out of Uranium City including Eldorado Mining and Refining, Nesbitt Lebine, Laredo, Cayznor, Gunner 1955-1963. In such cases, the potency of the toxin/carcinogen tend to overpower the skill of the medical field. Still, living with illness can result in stigma for the individual who is trying to preserve their dignity across various contexts and often without adequate resources.

Stigma... “What is wrong with you?”

In North America, people who protest mining and pipelines are stigmatised and arrested, seen as national traitors. This is apparent when studying the events at Standing Rock in South Dakota (Dhillon 2017). Erving Goffman (1961, 2009) wrote about spoiled identities and the (small p political) resistance of patients in asylums and institutions in ways that can be applied also to pro-environmental protesters. He notes that humans try to preserve their dignity in the face of every slight, command, and act of humiliation. One way that persons living with illness, adversity and various forms of violence experience social support, or its absence, is through the interaction known as the “social response” to the person. Illness and disability, particularly non-visible conditions such as those of the auto-immune system, are made even more uncomfortable when the person has to deal with the negative social responses of others. The notion that positive social responses are central to well-being and recovery, after disclosure of violence or adversity, has been elaborated in the social science literature over the past four decades. Typically, women and members of minority groups are more likely to receive negative social responses than are European men (Andrews, Brewin & Rose 2003; Andrews & Brewin 1990; Fromuth 1986; Goffman 2009, 1961; Wade 1997).

One example relates to the diagnosis of PTSD. In cases of violence or life-threatening diagnoses, people are often referred to as being *traumatised* (Carr 2008). Originally used in the context of head injuries, car accidents and natural disasters, this terminology has now entered counselling through the door of neurology. As a construct, or metaphor, *trauma* is worthy of closer analysis for a number of reasons, one being that it does not consider the quality of the social responses received by the person, a highly influential factor. Again, when people receive positive social responses, from family, friends and professionals, they are likely to recover quickly, experience fewer symptoms of ongoing suffering, mental illness or feelings of suicide (ibid., Richardson & Wade 1997). In a paper with Allan Wade (2008), we discuss how women and members of socially marginalised groups are more likely to receive negative social responses. These individuals are also more likely to blame themselves, sometimes as pre-emptive protection against the (social) blame they receive from others. Similar to victims of violence, people living with adversity and illness also fare better when they are listened to, believed, supported and treated with compassion. Talking about trauma can also be problematic when it transfers the problem from being an event in the social world to a condition of someone’s brain.

Trauma talk conceals violence, the presence of a perpetrator and collapses events such as an earthquake and rape into the same reality when they are categorically different. The notion of trauma does not offer a challenge to the status quo by invisibilising both the violence and the resistance to it, or the absence of social justice which created the conditions for the violation. The contaminated bodies of people living in radioactive and environmentally toxic mining communities were contaminated through a very dangerous and profit-generating activity linked to war and domination. The Sahtu Dene men who died in the Northwest Territory due to work in the uranium industry did not die from trauma. They died from exploitation and deliberate exposure to dangerous materials and activity at work. How we choose to talk about these events can make a difference for how we responsibilise human beings and hold perpetrators accountable for violence. I have the sense that, in the middle ages, illness and disability would have resulted in social stigma but being seen as a pilgrim would have brought one great esteem.

A Study of Dignified Resistance to (Various Forms of) Violence and Negative Social Responses

Family, friends and professionals can help to reduce or prolong certain forms of suffering based on the quality of support they offer, which is often related to upholding dignity. Dignity preservation is linked to being validated for one’s intelligence, decisions, knowledge and thus protected from unsolicited advice and criticism. For example, a cancer diagnosis can kick open a number of doors, including a myriad of advice from well-intentioned individuals. Unsolicited advice can be contradictory and confusing for the patient who is trying to use their own intuition and body wisdom to negotiate their situation. For example, resisting the hegemony of the medical system at the same time managing the perspective of others can take a lot of energy that might be better used for rest and healing. People with long histories of institutional mistreatment may react strongly to medical professionals who they do not deem as respectful. Women have over time been accused of being hypochondriacs and “hysterical”, a diagnosis developed by psychotherapy’s grandfather Sigmund Freud (O’Sullivan, 2015).

In terms of offering counselling support for people living with illness, there are various ways to go. As a response-based therapist, I listen to accounts of social interaction, accounts of suffering and situational analysis. I consider these accounts within the larger context of the society (e.g. who has the most power, is most enabled by structural violence and who is most blamed in the society). This conceptual analysis has been outlined in an article called “Creating safety and social justice for women in the Yukon” by Richardson, Maje-Raider, McInerney & Carrier (2017). I ask questions which elicit both the events of a particular situation and then about the kinds of social responses received in relation to that event. I understand the actions of the person as serving their personal dignity (or that of others) and trying to maximise their sense of safety in settings which sometimes are psychologically or culturally unsafe (Blanchet-Cohen & Richardson 2017). Through this way of talking, I can get a stronger sense of whether the client possesses the personal networks, relationships and bonds which translate into emotional and practice care. People in the north need resources to travel to hospitals in the south for illness. While the state may pay for the patient, it does not cover costs for family and friends. This means the person travels alone; the mother must leave her children behind; her partner cannot be by her side during and after surgery. In Montreal, family members may make their way from Nunavut (in northern Quebec) and find the street community near Cabot Square for fellowship, even if street life is risky and dangerous. Their relative lack of intersectional privilege means they have fewer options that families with means or families who can access traditional organisational supports. Many Indigenous families, including the Inuit, are large and stay together. Their collectivist ways of being mean that they do not fit into the culture of a shelter or an organisation geared toward the individual or the nuclear family.

Throughout my illness, I was offered great care from my friends and family. I literally had the benefits of medical care offered through my employer’s insurance plan. My mother, sister and dear friend flew out from the west to take care of me. At the same time, my academic life informed me theoretically, and through clients’ experience, that people do not always receive the support they need. Indeed, being born into a kind, caring family is a form of privilege and where there is goodness, there can be safety in numbers. One Inuit boy was once asked if he would rather have money or a big family. He replied “a big family because if you have family you always have someone to feed you!” It is interesting to me that many times I have been offered a “mirror” of my experience through my counselling clients.

Throughout this past year, I did not have clients who suffered personally from cancer. I worked with a number of people who were in the process of losing, and then subsequently lost, a family member due to cancer. I was given many opportunities to discuss the meaning of life, death and how this transition can be painful for remaining family members. Exploring how the client makes meaning, and responds to the situation remained a primary focus of the therapeutic conversation. Even though I was living through a similar experience, I remained careful to not project my own experience onto clients but rather let my knowledge inform my questioning and "intervention", I would also explore these parallels in supervision or my own therapy. Due to the fact that I offer counselling in a closely-knit community, some of my clients knew that I had recently had chemotherapy and radiation, others did not. I have a reputation in the community of being helpful to Indigenous people. Sometimes I would make it clear that I work in a response-based practice-informed way and sometimes we do not talk about it. Some clients are not so concerned with the mechanistics of counselling, but I do feel they notice my attention to their responses (acts of resistance), to using language accurately (fitting words to deeds), to look at how they see themselves in the world and how they are supported by others (social responses) (Coates & Wade 2015). When abuses and power violations are made clear, often through exploring the person's responses to them, we avoid blaming the victim and can clarify responsibility. One might ask whose role it is to hold perpetrators accountable, whether for large scale acts of violence through industrial activity, through attacks on women or in the context of professionals humiliating or mistreating clients. Through helping clients to distance themselves from undeserved guilt or shame, and through clarifying responsibility for actions, they can then make decisions around creating a way forward for themselves… where to go next on their own journey. Some clients want support to launch a complaint process or to confront a family member or a doctor who did not listen to their need or preference.

As a therapist, I can advocate for a client, support them in their own action as well as act on a social and transpersonal level. For example, I can fight to preserve socialised medicine and speak out against privatisation through political action. I can lobby organisations to take on certain issues. I often write letters for insurance companies on behalf of my clients. And, on a conversational level, I can help the person orient towards the metaphor and/or descriptions of their experience that are the most empowering for them. Typically, I assist them in mapping out their relationships, their sources of support and identify the situations that are not working well for them, strategising for change. It is clear to me that negotiating difficult health contexts can drain one's energy away from recovery. Not everyone has a peaceful place to rest and heal and this can be a source of tension, one which each person manages in their own way.

Cancer patients often have to navigate the views of others. One hears that cancer is manifested by our thoughts, our mental attitudes, our diet, our lack of exercise, our lack of forgiveness, towards self or others. Cervical cancer is now articulated as a virus, like a STD. Too much sex? There are major contradictions in how illness is explained. On one hand, there are various individual-blaming perspectives which exist to explain why, in a highly toxic and polluted world, some people get cancer and others do not. And, in a more medicalised view, you are seen as unlucky to get cancer, but told that today, about one in four people will become afflicted by this condition: the fact that you are sick is due both to mathematics and bad luck.

Finding meaning on the path

Is cancer a hell or another opportunity to learn about life, love and making-meaning? Can an experience be qualified or evaluated retrospectively through the collateral blessings that come after? Spiritual teachers tell us that these states of heaven and hell are a mind-set and not a geographical location (Huxley 1954). I, similar to my clients, have a lot of experience managing health care professionals. At the age of one year, after being born with hip dysplasia on both sides, I was subjected to many painful and confusing procedures: I know I must have had my own way of managing them. With much help from my mother and my grandmother, I would be animated by songs and stories, by sweet distractions, jello, toys, hugs and responding positively to the kindness of good-hearted health professionals. I know this because, today, I often look forward to going to the hospital, until its reality sets in a few days later and I am ready to leave again, until the glory of the care and attention has worn off.

Structurally, there is a belief-system at work in the medical realm based on science. Medical wisdom puts little focus on healthy nutrition, pesticide-free food grown in rich, uncontaminated. Donations to cancer research are not given to Greenpeace. In Canadian hospitals, most patients are served food and drink in disposable, styrofoam cups, meals reheated in microwaves, non-live foods packaged in a factory several months back. The contradictions, and even spiritual pain, associated with these incongruencies make it difficult to live in integrity while trying to recover, or stay alive. Yet, clients face the risk of inciting anger and scepticism if they complain; if I speak up will it jeopardise my good care? As a therapist, this is where I benefit from asking response-based therapeutic questions, to learn how my clients try to preserve their values, their safety and their dignity in times of an affront, a humiliation or a risky situation. Their response typically involves an analysis of the power in the room and the social context. In a social setting where there is recourse for abusive behaviour, such as a complaint process, and where human rights are respected can serve to influence whether a person will challenge a medical professional.

Working with context and metaphor

I call up a support centre for cancer patients because I would like to access their free yoga and tai chi classes. A well-meaning volunteer answers the call and asks me if I am a cancer survivor. I tell her that I hope I will survive but I am not there yet. She says that everyone who has lived long enough to receive a diagnosis is a survivor.

For me, the story of cancer is the story is the drama of being an Indigenous woman whose mother lived in an environmentally polluted and radioactive community. In the aftermath of a family history linked to uranium mining and the ongoing toxification of many Canadian communities, the treatment, ironically, is nuclear medicine and having cys-platinum placed in my body to kill cells. They are called good cells and bad cells and they will all be killed. During the process, I hear certain metaphors used to represent the cancer and the treatment process. I wonder what implications exist for the way we see and represent the illness in our body and the way we are interacting with it.

Cancer in the body is often referred to as “a fight” … “You can fight this!” “You can beat this!” It is not always clear what one is fighting… one’s own body, the system, the mining industry? Fiona, a cancer survivor, writes on her blog:

> People say women with breast cancer are so strong. You can beat this,
> Everyone cheers, like sisters of cancer are warrior Amazons, set to battle
> The Mygdonians. Well, shit. What else can we do? Like a drowning man,
> We are going to kick and thrash and push to reach the surface.
> (Mooney 2015)

Tumours are also described with metaphors of colonisation… I have a visitor in my body. An uninvited "drop-in", an occupier. If I do not fight this visitor, see to its departure, it will invade and take over. I will be ushered out of my own home. More than temporary co-existence is not possible. We could co-exist if you do not spread. Again, this metaphor is ironic for an Indigenous person… we know these things often end badly.

There is a kind of externalising that happens with the use of metaphor for cancer. The focus shifts from the person as resistance fighter to the medical machinery as resistance fighter. I have been told to exercise, to strengthen my body, as one way of becoming victorious in this onslaught. This can be difficult when the treatment makes you feel sick and compromised.

There are fewer metaphors about making peace with the illness, with the tumour. "You can stay… as long as you do not deplete my life energy. We can co-exist." Cancer survivor and blogger Fiona Mooney elicits a partnership metaphor in relation to her chemotherapy drugs. Fiona Mooney made a mindful decision to "partner" with her powerful chemotherapy drugs rather than fear them as poisonous. In naming them, and having weekly dates with them, an unexpected relationship develops. She consciously refers to the drugs as the ultimate cleansing.

Are there benefits to co-creating metaphors that do not involve a fight? The way is unique for each person. Each person can be engaged conversationally or therapeutically and discover their own descriptions and metaphors that characterise the process more precisely, for them.

The Way

I have decided to be with the metaphor of the pilgrim and the pilgrimage. In the summer of 2017, I visited the Spanish Pyrenees and walked a few small stretches of the St. James trail, el Camino de Santiago de Compostela. At that time, I knew something was wrong but I did not know that my cancer had returned. I loved the land and felt a rich energy that I would describe as spiritual. The mountains and trees were magnificent, the water seemed clear and clean, and the sun was radiant. It turns out that my own treatments will take approximately the same length of time as the journey across the Camino. This path has been characterised as being filled with personal spiritual quest, wild dogs, disrupted sleep, time to reflect on one's life. It is a time to take water, eat what the body will allow, and try not to get burned skin, as from the radiation treatments. Mostly, the pilgrim is asked to keep placing one foot in front of the other and to be open to whatever appears along the way.

During one of the most difficult times in my hospital stay, a few days after surgery when I had to have a tube down my throat, I was most despondent. I got help from a friend, Natasha, to decorate my hospital room. Her mother had travelled in Tibet, Bangladesh and Central America. Natasha brought various beautiful and brightly-covered scarfs, shawls and rugs and hung them on the walls around my bed. I felt like I was staying in a beautiful pension or a luxurious castle with magnificent healing powers. One of the nurses came in, looked around and said "Well, this is nice… almost too nice!"

Clients respond in a number of ways to affronts in the medical system and supportive networks. Some debrief the actions of family members they deemed less-than-supportive and discuss how they can provide feedback and invite people into their own version of what is needed. A number of clients spoke of their exhaustion, having to balance work life and then extended visits with their ailing loved one, meaning they had little or no time for self or collective care, spending much time in the car and eating out of food machines. In these situations, we would explore ways they could bring some grace and care into their life, and mutual-aid between family members. In cases where the client was a member of a blended family or a “step family”, painful family dynamics sometimes arose in relation to how the afflicted person should be treated during the illness and at the time of the funeral. At these points, I would draw from my systemic, family therapy background to map out some of the dynamics, alliances, tensions to explore where movement and increased openness might be possible. The conversations would often move into the realm of “complicated grief” when the client was dealing with the primary loss as well as unsupportive acts or transgressions from within the family. Sometimes, problematic dynamics existed before the illness are enhanced. Here, I can explore possibilities of “coming together” for collective grieving or finding what Vikki Reynolds would call “groups of solidarity” for support, discussions of values, ethics and preferences, as well as honouring ways to remember the loved one (Reynolds 2013, 2011).

One of the approaches I have borrowed from Vikki Reynolds is “people-ing the room”. I used it myself before two different surgeries and put it in place with others. Together with another, I ask them to describe how they imagine the operating room will look like in terms of layout. Then, we do a meditative activity where they fill the room with all the people, pets and loveable presences they would like to have with them during the surgery. We might do a smudge ceremony, including the doctors and the nurses. This is an Indigenous cleansing ritual where a medicine such as sage or sweetgrass is burned. The smoke is passed over the person’s body with an eagle feather and prayers are said for cleansing and to release negativity. The person then imagines the positioning of each of their loved ones, perhaps with someone holding each of their hands, their feet and someone standing behind their head doing the laying on of hands. Some people imagine their pets being present; others fill the room with beautiful flowers, angels or spirit guides. In addition to the presence of loved ones, we discuss and plan for how the room should feel, look, and smell. In this way, the person is maximising their sense of control and empowerment over procedures that can often feel objectifying rather than interactive. Through exploring what is most important and how to enhance the grace and beauty, experience more dignity and presence, and transform the quality of a very difficult situation.

Fluctuating Identity

Cancer has brought me new opportunities. In exchange for becoming a part-time medical service-user, I have gained various freedoms. I have some time off work for reflection, care and rest. And, it is not just self-care… it is about having friends and family who step forward to cook, entertain and laugh with me. I have promised myself I will read more. Most of the time I do not think about being sick; I think about being alive, my loved ones and places I want to travel. I think, for me, the best metaphor is to think of myself as an adventurer… This is one more thing I am experiencing because it will expand my knowledge, my spirit and perhaps temper my impulse to live a sometimes unreflective and fast-moving life.

Kris Carr, Crazy Sexy Cancer Survivor, writes:

> A survivor is a triumphant person who lives with, after, or in spite of a diagnosis or traumatic event. Survivors refuse to assume the identity of their adversity. They are not imprisoned by the constructs of a label. Instead, survivors use their brush with mortality as a catalyst for creating a better self. We transform our experience in order to further evolve spiritually, emotionally, physically and mentally. Our reality challenges us to go deeper.

There are writers available to us who have been helpful in developing analysis around cancer in women. Audre Lorde (1980) wrote “The Cancer Journals” offering a feminist analysis of her experience through the lens of gender and race. Eve Ensler, author of The Vagina Monologues (1996), is a cancer survivor who has worked with women in the Congo to develop a safe village, free of violence and rape as a terrorising practice linked to war. She shares a few points which are relevant to this conversation. The Congo is filled with mining companies, many of them Canadian. There is an industry of security which hires guards to keep locals away from the mines, unless they are of course working there. Ensler reports that more women are raped closer to the mines, as rape is a form of terror used to undermine resistance and protest. Secondly, she speculates that there are links between sexualised violence against women and uterine/ovarian/cervical cancer, cancers in a women’s reproductive area. Although not a highly studied topic in the medical field, there is a somewhat “common sense connection” here for many women. She, along with writers such as Andrea Smith (2005), draws a parallel between violence against women and violence against Earth. Gloria Steinem has made the point that societies where there is more violence against women are more likely to go to war. Invading the earth for particular substances (minerals, uranium, oil, gold, etc) is linked to the war industry, both from a supply and demand perspective (e.g. we go to war to gain access to these parts of the Earth in order to use them to build machines of war). They are parts of Earth’s body.

To me, it is important that we reconceptualise processes, sometimes referred to as “Earth rape” by activists to depict the damage they actually do. Through human activity, and man-made climate change, parts of Earth are becoming uninhabitable. Counselling and therapeutic conversations can help both at a micro or individual level and at a broader social level. Firstly, individuals can benefit from help in exploring their feelings about their illness, with invitations to cry, grieve and express their fears. Much is at stake, including potential loss of family, friends and life itself. At a philosophical level, it is difficult to envision the end of everything we know. More and more, discussion and spiritual groups are emerging to help people explore and process the end of life. Although life on Earth is time limited for each and every one of us, western culture has not done a good job at helping people embrace this transition as natural and sometimes gentle. Patriarchal religion has not moved much beyond after life experiences based on rewards, punishments and threats. Even more open-ended offerings of an afterlife or reincarnation do not offer too much comfort when facing end-of-life possibilities. My point is there is no real road map for how to think about this journey before-the-fact.

Counselling practices

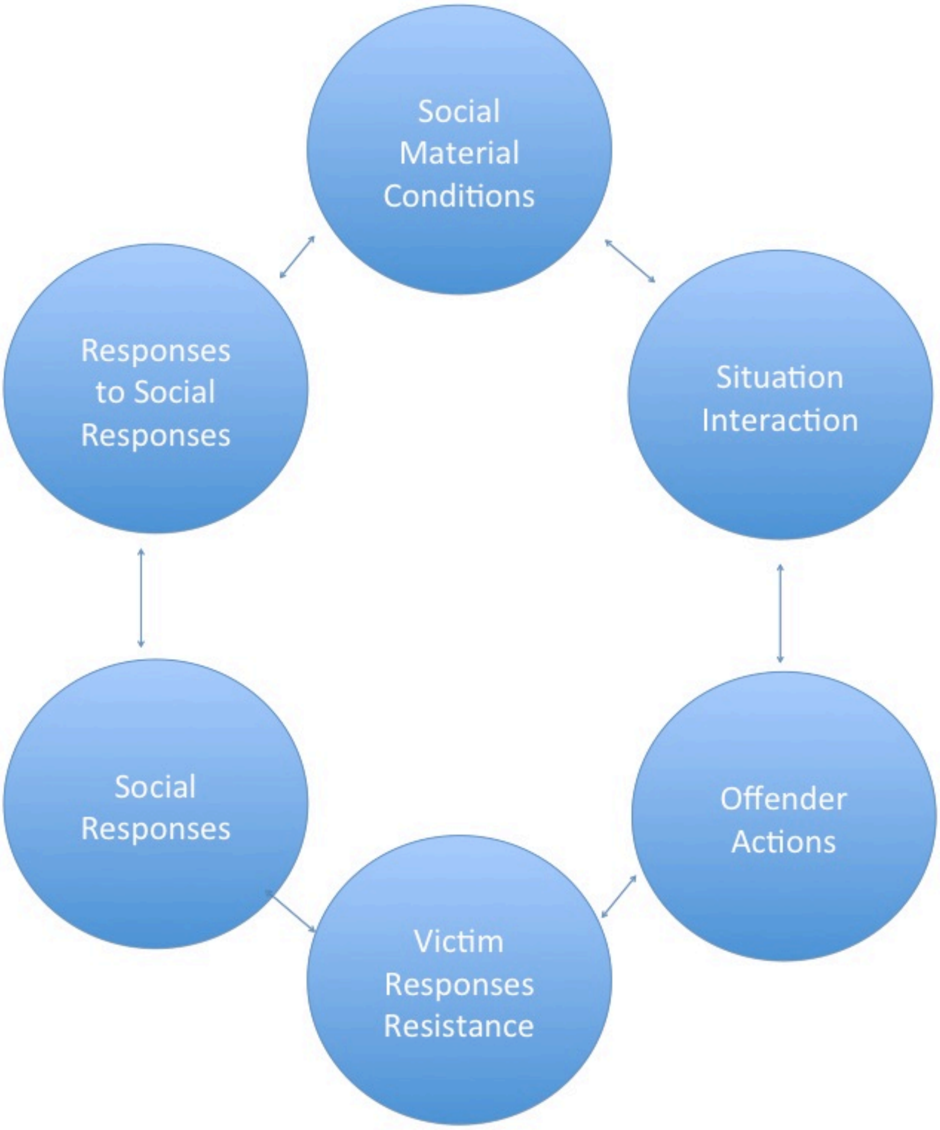
When working with clients, context is important. This means learning about the client’s life, family, social engagement, values and hopes. I will often use response-based practice (see www.responsebasedpractice.com) to see how the person has responded to or resisted the various intrusions and demands of the medical system, trying to preserve their dignity. I rely on the response-based conceptual model designed by Allan Wade (2012), to clarify the context and the interaction within that context, as shown in the diagram at the top of the next page.

Aspects of narrative co-creation can be helpful to more fully explore rich identities (beyond that of “patient” or “sick person” and how a person views themself within the context of their life story. Some of the practices documented in Michael White’s “saying hullo again” (1988) can be used in a session while the person is living… How does this person want to be remembered? What do they want to leave behind for others? Where are the places they might come and meet with loved ones, in a loving embrace of spirit? These things can be discussed in advanced, not only imaged after the parting.

Response-Based Contextual Analysis

Assessment Tool, Documentation Instrument & Response-Based Interview Guide

Wade, A. (2012)



After having lived various hospital and medical experiences, one's identity has often been totalised as a cancer patient. This is not helpful for the person who wants to keep a foot in the real world, a world not necessarily dominated by illness.

Working with couples and families

Some people do get well. Upon recovery, it can be like a plunge into upbeat existentialist questioning… "Yay, I am not going today, well at least not today!" This can offer the person a chance to "reboot" and examine changed priorities. If there is a lesson in illness, what is it? How might one live differently after serious illness or injury? A study out of the University of Southampton shows that people with depression take longer to get their life back "on track" after cancer (Foster, Haviland & Winter). Perhaps this study asks the wrong questions. Do people who receive positive social responses and appropriate support prior to cancer, and during cancer treatment, tend to get depression? What proportion of women experiencing violence get cancer? How do we take into account the “Louise Hay-like” ideas that state that our bodies respond to our mental states in some way? Counselling can help clients find their way, through difficult and unknown terrain with the understanding that we become who we are along the way.

When working with families, I elicit accounts and stories of survival, mutual aid, beautiful moments, small blessings. I look into my therapist back-pack for Milan circular questions, questions that join, connectivity and transfer-of-knowledge questions. I ask families about their resources, “Before you set about to solving problems, what kinds of resources (skills, experiences, beliefs, values, etc.) do you have at hand to help you solve problems?” “In the past, have you faced tough issues together as a family? How did that go?” I may ask a miracle question if I anticipate some positive visioning. If we are deep in grief work, I want to know where their strength comes from, how they hold themselves together in the hardest moments (if they do) and who helps them to do that. Ultimately, much of the work is about love, exploring loving connections, and the small acts of living (gestures of *spirit* and hope), particularly in times of deep sadness.

Next steps

In two days, I have an appointment for a scan. They will tell me if my tumour is gone or if it still inhabits my body. I am scared. For the past months, I have felt great. I have reclaimed a new joy at being alive and have identified many special things I want to do, places I want to see. I feel fine.

My stomach is no longer engorged where the tumour last sat. My stomach has gone back to its normal roundish self, after four pregnancies and years of enjoying food. Life is really good now. I am seeing new possibilities. There are some openings that I have been waiting for, glimpses of a new me.

I am sitting with the tension.

I am missing my dad.

My dad passed away from bladder cancer being in remission for 2-3 years. I watched him deteriorate and sat at his bedside with my family. It was a sad time but very authentic; I felt I was connecting with a deep moment of living. For me, I am not ready to make that transition because I have three beautiful children who still need me, we still need each other. I am afraid for them because I have seen people in their position, people who don’t know how they can live without their mother (their father, their sister, their brother, their grandma…) and yet they are asked to do that. I still have my mother.

I feel fine. I will sit with the tension. I may cry.

There is nothing stronger than a broken woman who has put herself back together![1]

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[1] This is a closing line in “Nanette”, by Australian comedian Hannah Gadsby. I have been using this line and find a lot of truth in it.

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Citation

Richardson, Cathy (2018). Relating to illness in therapy: A pilgrimage through uncertain terrain. *Murmurations: Journal of Transformative Systemic Practice, 1, 2, 14-26.* https://doi.org/10.28963/1.2.3