

# Hope and Loss

## Multiple Realities when Bodies Are Injured

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### Abstract

In this article the authors discuss the development of counselling practices at the Auckland Spinal Rehabilitation Unit in New Zealand. These developments arose from a study that invited former patients of the Spinal Unit to reflect on their experiences of counselling (or lack thereof) when they were newly injured. Centring patients' experiences opened space for illness and disability narratives to be storied. The repertoire of narratives includes hopes and losses that result from their spinal cord injury. This article also pays close attention to the practices of power in a medical setting such as a spinal unit, and the importance of making space for patients' local and cultural knowledges to be heard alongside specialised medical knowledges.

This article is a story about how Susan's research shaped her practice through listening closely to patients' feedback. Susan invited former patients to comment on their experiences of counselling (or lack thereof) during the time they stayed in the Auckland Spinal Rehabilitation Unit, where she is the counsellor (Sliedrecht, 2007). The focus of the research resonates with Manthei's (2006) sentiment that there is a need for more research that investigates local issues, situated in local settings with local participants. The importance of clients' perspectives on counselling is supported by research done by Gaddis (2004) and Singer (2005). For Susan, the research journey included experiences of struggle, inadequacy, competency, doubt and being moved by the research. Along the way, Elmarie was privileged to join the process through the supervision of Susan's practicum and her research. We tell the story in Susan's voice.

### Background

Prior to working at the Spinal Unit, I had worked in a unit for adolescents who had

been sexually abused, and in a Burns and Plastics ward at a tertiary hospital in New Zealand. With this background experience in trauma-related work, I expected that at the Spinal Unit I would mostly be relating to patients' experiences of emotional turmoil, confusion, hopelessness, worry about the future, and lack of purpose in life. This expectation was based on the severity and permanency of physical injury (not being able to walk, lack of bowel and bladder control, compromised hand functioning, compromised sexual functioning) for most of the patients at the Spinal Unit. What I more often heard, however, were patients making adjustments to their lives, in particular, adjustments to not being able to walk again. I frequently heard patients talk about the gains they had made with their physical rehabilitation, how supportive their families were, and how grateful they were that the situation was not worse. I did not often witness hopelessness, despair and disinterest.

I also, however, met patients whose injuries had occurred some time ago. Two of them, in particular, informed me that they were dissatisfied with their lives. They attributed this to their spinal cord injury. Storylines of 'deficit and disability' were available and expressed more frequently than storylines of competency, skill and ability. They reported that drugs and alcohol had become a very central part of their lives, relationships had broken down, and their identity claims focused more on deficit, pain, and disability. Storylines of competency and agency seemed inaccessible and hard to find as they re-established their lives within the community.

The ready availability of differing storylines between patients who were newly injured and those who had lived in the community for a number of years invited me to question my own counselling practices. I wondered what counselling practices would support the development of a repertoire of storylines of agency that could sustain patients once they were discharged from the Spinal Unit and re-integrating back into community life. I suspected that the counselling conversations I was having with patients touched mostly on what was "easy and acceptable to say" within the available rehabilitation discourses. However, I was reaching for counselling conversations that would open space for the less frequently voiced, marginalised, harder-to-talk-about storylines within rehabilitation discourses.

When reflecting on this gap between the kind of conversations I was having and the kinds of conversations I was reaching for, frustration was often close at hand. Space to speak multiple realities seemed to be restricted. I was unsure how to make these pathways of conversation available for consideration. During my first meeting with Elmarie she noticed my frustration and introduced me to the work of Frank (1995) and illness narratives. This book had immediate applicability to my dilemma.

The work of Frank (1995) in relation to illness narratives guided me into reflecting on my own illness and disability narrative preferences, and how these preferences were limiting the space for the speaking of multiple realities by the patients.

### **Illness narratives: What are my own illness narrative preferences?**

Frank (1991) suggests that narratives are used as listening devices to filter in, or filter out, available information. Through the use of narratives we make sense of what is happening to us. Frank (1995) invites health practitioners and counsellors to investigate how these narratives shape their listening to clients' narratives. Frank mentions that, as a patient, he wanted to ask health professionals important questions about his life. However, his experience was that certain questions were not allowed; they were not speakable, nor even thinkable: "... the gap between what I feel and what I feel allowed to say widens and deepens and swallows my voice" (Frank, 1991, p. 13). He continues by saying that:

*... one of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy.*

(Frank, 1991, p. 25)

I put questions to myself, informed by Frank's reflections on his own experiences. What was I filtering in or filtering out in my counselling conversations with patients? To what extent, when counselling patients who were newly injured, was I filtering out struggle, difficulty, confusion? Was this a reason why they appeared to be managing well, because all else was filtered out?

I realised that I had a strong preference for what Frank (1995) calls the restitution narrative, as this was supported by the rehabilitation discourse being fore-grounded in the Spinal Unit. This narrative filters in "gains made" and filters out "loss of function."

Through deconstructing my own narrative preferences I now notice that, in the initial stages of living life with a spinal cord injury, hesitant, faltering speech and muddled messages are commonplace—provided space is made for their expression. These are the marginalised, less easy to talk about stories, within rehabilitation discourse. Frank cautions health practitioners to make space for these voices and not edit them or filter them out.

In tandem with my reflecting, Elmarie wanted to open space for me to witness

myself (Weingarten, 2003) as I worked toward developing my counselling practice. In supervision she asked questions that invited me to share the multiple storylines of my professional practice—the storylines of competence and skill, storylines of the affect that the counselling was inviting, storylines of exasperation and struggle, and the many challenges and opportunities I experienced in this work.

Elmarie asked me questions in supervision that helped me to (initially, tentatively) talk about the less frequently voiced, marginalised, harder to talk about storylines of my counselling practice. For example, I remember sharing with her one day about how many young men (aged 16–22) were on the wards and how these young men were touching my life on many different levels: the randomness of accidents; how one of these young men could so easily have been my son; the hopes and aspirations of parents for their children and how these can be dashed in a matter of seconds. Some of these young men had represented New Zealand in sporting activities. One young man was looking through his photo album at all the events he had won, and he shared with me that the memories of these was helping him through the hard times. It was all just sad, really sad.

Elmarie offered a space in which I wanted to—as opposed to felt I should—discuss and share with her these profoundly touching experiences. Voicing the personal within the professional made a significant difference to how I positioned myself as a counsellor. This supervision gave me the opportunity to give myself permission to acknowledge how the work affected me, and to review my preferred illness and disability narratives. The supervision supported my witnessing my own compassion. This witnessing self (Weingarten, 2003) enabled me to be more attuned to the multiple storylines of patients. I took seriously the following:

*We cannot afford for people to believe that they must blunt their feelings to stay “sane”. We need those who serve us to be in touch with their emotions as they perform their duties, for it’s this comfort that allows them to express care and concern for others as they do their jobs. We want to preserve not crush this ability.*

(Weingarten, 2003, p. 115)

Through attending to this self-witnessing, I wove my practice between what Bird (2000, p. 93) calls “connection” and “detachment”. Connection is described as the ability to really listen and move in step with a patient. Detachment is seen as not being over-involved in a way that makes it difficult to decide what will be useful and what is not useful in the counselling relationship. Connection assists me to listen for intonation, emotions, body sensations, visions, dreams, and for what is partially said.

Detachment assists me to stand back from the experience and decide whether the knowledge I hold belongs to the therapeutic relationship or to my life experiences. Detachment helps me to decide if, how, and when to use this knowledge as a partial knowing, a possibility (Bird, 2000, p. 93).

### **Loss, grief, and hope**

The next section of this article looks more closely at the spectrum of losses and grief as a result of a spinal cord injury, as well as how patients and families “do hope” (Weingarten, 2000, p. 399) in the face of these losses. The centralising of the magnitude of loss through death overshadows, and sometimes obscures, other losses which may result from disability and spinal cord injury. Participants in this research were very explicit about the significance and variety of losses they experienced, and identified loss as part of the journey of living life with a spinal cord injury. These losses included the spectrum from losing a loved one in a car accident to what may seem to other people to be mundane.

Highlighted below are examples of the more insidious, unspoken, everyday experiences of loss as a result of a spinal cord injury, as told by the research participants. My hope is that having these experiences witnessed and acknowledged helps make more visible the significance of these losses.

*About a month after I was discharged I thought, I am going to do my own washing... I went into the laundry and I had a hell of a job because the wheelchair did not fit in, I had no end of problems to get in [to the laundry] but ... when I went back to get the washing I had to lean forward and I fell out of my chair. I was lying there, trying to get up, it took me about an hour and a half just trying to get up, I tried to climb up into [the chair] and I damaged my backside. I was exhausted, I hurt all my ribs because I tried to pull myself on the tub, and then I slipped. It was a terrible experience. It is a big adjustment, big adjustment, a lot of learning about how to do things. If you were not confident you would find it really hard. Like when I fell out of my wheelchair, that really buggers your confidence. You think: can I really keep going like this, am I going to have to go to a rest home. How the hell am I going to cope with all this? I think for me it would have been mainly the grieving of it all...*

(David)

*You don't really have the support that you want, bar your family. I have also returned to normal family chores, washing and cooking.... I learned all that at*

*the spinal unit but when I came home it was a different story because I was unable to get into areas like the kitchen and the bathroom, so for a while [one year] I couldn't do any of those things. I didn't care as much as I wanted to for the kids... I couldn't.*

(Avril)

*There are some nights that I sit down and have a bit of a cry, nothing too much, just sometimes I will sit down for no reason and just cry to get it out... It would have been helpful to have someone to talk to ... not so much straight afterwards [discharge] but a month afterwards that's when it sort of sets in. You've got around and you start to meet a lot of people that you haven't seen for a while and that's when you start to realise who your bloody friends are... When I came out of hospital all I had was the clothes I had with me in my bag... Everything I owned was stolen, they even stole my dog and my home brew. I had nothing.*

(Paul)

*I have always worked outside. Landscape gardening, driving trains, some carpentry work, always been things with my hands and legs moving around. And then of course the minute this happened—bang, I cannot do that for a living anymore... What are you going to do with your time? Am I going to do what I did today for the rest of my life? It sounds pretty boring.*

(Paul)

The participants in this research have assisted me to be more aware of the insidious, unobserved losses associated with spinal cord injury. In my counselling practice I am reaching for counselling conversations, with patients, that open space for the storying of the spectrum of losses associated with a spinal cord injury.

### **Acceptance of losses: Is this a destination to be reaching for?**

On a number of occasions patients have told me that they never really grieved properly for the losses brought on by spinal cord injury. To understand this comment better I have invited these patients to tell me more about their understanding of “grieving properly.” One patient said: “Well, I never really got angry and so I do not think that I went through all the stages properly.” Another patient told me that he had been crying a lot so he did not think that he had really accepted his injury. These comments about grieving loss invited me to reflect further.

Many of the more readily available medical and psychological accounts of grief centralise a linear or cyclical process—denial, anger, bargaining, depression, with

acceptance as a successful result or desired destination (Kübler-Ross, 1970). This then becomes storied as a “right way to grieve.” In a rehabilitation environment acceptance is also centralised as a desired destination, for example the “Acceptance of Disability Scale” (Groomes & Linkowski, 2007; Linkowski, 1971). A research participant, Lequecher, suggested that striving for acceptance may not always be important. At the time of her injury, Lequecher was a solo mother with young children. As a result of her injury she had very limited arm and hand functioning. This meant that she was unable to care physically for her children. She shared in the research interview how she hates her caregivers, and at the same time, loves them. She hates them because her children would run to them for hugs and cuddles, but she loves them because they care for her children: “I know I must accept my injury but I can’t accept my injury. I was too much of a sporty person and the loss of my motherhood has had a very traumatic impact on me.”

Ideas about acceptance as a desired destination for managing grief position Lequecher as reaching for a destination that for her is not possible (or preferable). Her dilemma is: Why should I accept that my identity as a mother is no longer possible because I cannot give hugs and cuddles? These challenges about acceptance resonated with the work of the peer counsellors of the Irish Wheelchair Association and the National Council of the Blind of Ireland (Boyle et al., 2003). Their work mentions how the concept of acceptance can be used to disqualify and categorise people with disabilities. They further say that, as peer counsellors, they prefer to ask questions like: What sort of life is it that you want to lead? What does acceptance mean to you? What parts (if any) of this notion of acceptance are useful to you? One of the writers of that article says, “personally accepting my disability is not something I’m interested in doing. Sure I need to adapt to my disability. But welcome it? Accept it? That’s not for me” (Boyle et al., 2003, p. 15).

These questions about the place of acceptance brought to my attention the multiple possibilities I wanted to provide for patients to story their preferences regarding “adapting” to spinal cord injury and/or the destinations they are reaching for. I became interested in the kinds of questions that made it possible for patients to explore a range of meanings of their experience and their preferences for future directions. These possibilities seem to sit more comfortably with patients, as they provide more options. For example, one woman told me that the relationship with disability she is reaching for is that “disability should be like a distant cousin.” Another man described the destination he is reaching for as follows: “I know I am disabled but I want to get to a place where I do not feel disabled, I just feel normal.”

Again, I notice the importance of going beyond single explanations and accounts of loss, grief and “accepting reality.” In the next section we will look at how holding hope and experiencing loss can co-exist alongside each other.

### **Holding hope for a different outcome**

Dominant medical rehabilitation discourses suggest that “acceptance of reality” (reality being the medical version of events) is an important milestone for a person in rehabilitation (Attawong & Kovindha, 2005). Although participants talked about loss, for some of them hope was a very central part of their experiences of spinal injury. From this research I learned that there are many different versions of events. I am striving for my counselling conversations to hold and respect a person’s hopes, beliefs, and dreams for their lives (which frequently do not include wheelchairs, catheters and caregivers), and also to talk about a life that may be dependent on some of these. The research participants have assisted me in seeing that it can be helpful to hold multiple, seemingly inconsistent, and contradictory stories about experiences related to spinal cord injury.

Sitting alongside the stories of loss, participants also related stories of triumph, stories of determination, of finding a way. I think of these as stories of agency, where the speakers are selecting actions and accounts in and for their lives. Below are some of those stories:

*One day I said to her [the physio], “do you think I would ever be able to walk?” And she said: “I don’t think so.” Then one day I asked the physio, “could I please have a go on that walking thing [walking frame] because I had seen another lady do it”... and I could, I made myself and she could not believe it ... then she let me go on the parallel bars, and at first I could hardly do it, but after two or three days I was getting better and better at it.*

(David)

*If no-one is going to help me, to hell with that, I will do it on my own. I have always been that way... I am lucky because I have got an attitude, what the hell, I will find another way of doing something. A lot of people are not like that.*

(Paul)

Boyle et al. (2003) mention how “non-disabled” people may attend only to the story of sorrow, misery and hopelessness of the person living with a spinal cord injury. Through listening to patients’ voices, I learned to open space for the multiple stories



of disability, of hope, of success, of positive thinking, of fear, and of facing loss on many levels. Their reflections guide my intentions to listen and to make meaning *with* them of their life and illness experiences. From the participants' sharing of hope and loss, I have learned about hope amidst loss and the importance of hope being storied. Here are some of the participants' ideas about hope:

*There is a part of me that hopes every day that something is going to click or snap in a good way and that I will have 100% back. But I have realistically been told on a number of occasions that pretty much after two years what you have got is what you have got. I am grateful that I am still walking and that I live in a two storey house and that is fantastic etc. etc. But there is a very strong part of me that is upset; not having 100%, I am not able to run and sprint and I do not have that much feeling in my hands...*

(Brett)

*From the time I was injured, there was a part of me considering being injured and being back to full health.... My wife said that people told her that they would be surprised if I ever walked properly again.... I am an optimistic person, most people do not have the self belief like I do. I think for myself. I was only on that continuum to be completely well again.*

(Matthew)

I wanted to find ways to work alongside patients, respecting the multiplicity of versions of events, and not to regard the dominant medical discourse as the only version of the "truth". If as a counsellor I filter out other versions of events and thus insist on a single version, I potentially can increase the person's experience of loss by expecting them to loosen their relationship with their own hopes and dreams.

In order to respect this multiplicity of versions of events my ear needs to be closely attuned to the patients' knowledges that they bring to the counselling conversation. These knowledges may initially be offered in a whisper, or expressed as a faint hope, or as a not-yet-formed idea which can easily be drowned out and silenced by the barrage of medical information a person receives when they are newly injured.

### **Medical knowledge and power relations**

Medical settings centre medical knowledges. This body of medical knowledge can quickly disqualify other local and indigenous knowledges, leaving the holder of these indigenous knowledges in a less power/knowledge relation (Foucault, 1980). In

particular, in a setting such as a rehabilitation centre for spinal injuries, where I work, health practitioners hold a sophisticated body of medical knowledge about spinal injuries and rehabilitation which can easily subjugate other personal and cultural knowledges.

Raheim et al. (2006) suggest that relations and practices of power which influence our lives are often invisible to us. If we do not proactively look at how relations of power operate to create advantages for some and deny these advantages to others, our work as counsellors and health practitioners may be limited, and may produce negative effects that are outside our understanding. These ideas reminded me that if I am not very conscious of this power/knowledge, my practice may have the effect of objectifying patients and unwittingly enact privilege. I may privilege the knowledge professionals hold as more important and more relevant than the patients' knowledges. This enacting of privilege may be supported by discourses of race, class, gender, education, and physical ability, for example. Drewery and Winslade (1997, p. 35) suggest that if we acknowledge that there are many valid ways of seeing the world, we need to be vigilant about which accounts dominate and which are less often heard.

Raheim et al. (2006) suggest that therapists develop knowledges and skills related to noticing when they are enacting privilege, offering some reflexive questions to surface these practices of enacting privilege: When am I most likely to enact privilege? In what sort of circumstances will I most likely enact privilege? How can I tell when I am enacting privilege?

These questions seem to be very relevant reflections for me in my counselling practice. As a result of this research, I have become more finely attuned to how easily (and unwittingly) health practitioners can silence the voices of those they seek to help. For example, at the Spinal Unit, goal-setting meetings are held on a fortnightly basis. These meetings are facilitated by various members of the multidisciplinary team. The purpose of the meetings is to promote collaboration between the staff and the patient and their families (whanau) in the setting of goals. However, despite the structure of these meetings and the intention to promote collaboration, the meetings can potentially silence the patient further and centralise medical ways of doing things if they are not facilitated in a way that makes space for the patients' perspectives to be heard and respected. In this past year, I have been involved in re-developing the way these meetings are facilitated so that space is made for the voices of patients and their families. For example, a small (but very significant) change is that patients are asked first what they would like to discuss in the meeting, rather than the earlier practice in

which the medical team would give their feedback first and then ask the patients if there were any questions. This service initiative also demonstrates how counsellors can address organisational issues and not be restricted to one-on-one counselling.

How counselling services are accessed and made available is another area within a medical setting that demonstrates power/knowledge relations. For example, is a patient referred to the counsellor or do patients make selections about how they would like to access counselling? The next section of this article discusses research participants' ideas about how counselling should be offered in a setting such as a spinal unit.

### **Offering counselling services: Agentic positioning**

Without exception, all participants of the research project indicated that they preferred the counsellor to take the initiative to meet and introduce herself to the patient, rather than waiting for the patient to ask to see a counsellor. They wanted the counsellor to reach out and initiate a relationship, rather than relying on a practice of formalised appointments in the counsellor's office.

*... the counsellor never saw me when I was in my room ... never really made herself known, she was either in her office or not around ... the first time I talked to her, it was in her office, but it would have been easier if she had introduced herself from the start and then every now and again ... maybe once a week just pop in and just to say that you are making sure that you don't need anything, as opposed to waiting for us to approach...*

(Larry)

*... just someone to talk to, you see, like me, I did not have anyone to talk to, apart from the other patients, I had nobody around me. Just basically to know that there was someone there to talk to or, better still, have a counsellor that walks around, around the wards, just talking to people, just pop in and out like a friend does. It's a helluva lot more friendly. Like if you go to an office and you sit on one side of the table and the other person on the other side—you just sit there and you do not know what it is all about ... just come around it is more relaxed. It would have been good to have someone to talk to at the time...*

(Paul)

*... make informal communication and then across time you have your chances to talk about the bigger issues. Counselling should be like a systemic drug, a little bit all the time, not like a band-aid trying to seal over a wound.*

(Matthew)

Participants' preferences for being introduced to counselling services helped me develop a practice where I now introduce myself to all patients on admission, and maintain contact with most patients and their families throughout their stay at the Spinal Unit. This ongoing relationship with a patient in the unit and after discharge means that I get to know patients on a personal level and develop a relational history with them, which includes care and concern about their wellbeing.

### **Counselling and care**

Elmarie noticed the ongoing relationship that I had with patients and their families (whanau) and witnessed what Weingarten (2003, p. 106) refers to as the “dilemma of empathy.” Weingarten mentions that health professionals are shaped by a wider culture that acknowledges the expression of emotion as being healthy. Professional ideas, however, position health professionals to evaluate themselves as less than adequate, or not managing, if they show “too much” emotionality on the job. This is what she refers to as the “dilemma of empathy.”

To assist me with this dilemma, Elmarie introduced me to the writing of Weingarten, who centralises care as an important ingredient in counselling practice. Weingarten states, “if there is one thing I have learned from an adult life lived inside an unreliable body, it is that care not cure will keep us floating in the ocean” (Weingarten, 2001, p. 11). Weingarten's writings have invited me to centralise care as an integral and cherished part of my counselling.

In my practice I often see patients at their most vulnerable moments. Patients and their families share with me some of the most intimate and personal details of their lives. Based on what patients have told me and my own personal experiences of family illness, this kind of personal sharing and connection is best encouraged in a caring environment. A caring environment opens up multiple possibilities for a patient to make themselves known. Caring supports an environment where patients can story their experiences, even when words are not readily available. The story may be hesitant, jumbled, and chaotic, but it is the beginnings of meaning-making about what has happened. This story may be what Frank (1991) calls the chaos narrative.

I have no words to describe the poignant relationship I am at times invited into with some patients as they share with me their fears, sorrows, hopes and dreams for their lives. An intangible bond of caring emerges when, for example, a patient has tears rolling down their cheeks and I as the counsellor carefully, very carefully (with permission) wipe them away because they do not have the hand capacity to do it. There

is a bond of caring solidarity when one joins with a patient and literally moves or sways in step with where they want to take a counselling conversation. It is these practices of care that this research project has helped me to value.

In terms of care, Cheek (2000, p. 50) talks about the “nursing gaze” which designates the patient as an object on which technicalised and medicalised knowledge is applied. Standing against the “nursing gaze” is what Cheek calls the “nursing look”, which is a more empathic look and pays attention to the whole person. My intention in counselling is to value and centralise this “look” so that I can attend to the unique experiences of each person and “freshly” hear each person’s story. This nursing look is developed by a willingness to see things from a care perspective, a willingness to challenge the distinction between “caregivers” and “care receivers,” and to step into a “caring solidarity” (Sevenhuijsen, 1998, p. 137) because every person in different ways, to different degrees, will need care at some point in their lives.

Cheek (2000) also cautions that this “look” can often be marginalised in health-care settings as the “gaze” is favoured to produce evaluation, correction, and restoration to “normality” knowledge.

## **Conclusion**

My intention when I embarked on this research journey was to develop and refine my counselling practice. The purpose of this article is to share some of the learnings that have been gifted to me by the research participants, patients and their families.

I have learnt to notice the possible filtering out of stories of struggle and difficulty, both at the level of my own listening to patients, and in rehabilitation settings such as the Spinal Unit where the focus of the services offered is on improvement. I have learnt about the importance of voicing the personal within the professional, and how this supports me to move appropriately within spaces between connection and detachment. Patients showed me how loss takes many forms, and in particular this article exposed the significance of everyday experiences of loss.

I learned that ideas about acceptance as a destination to attain shaped the experiences of some patients. The effect of this was that they saw themselves as falling short and interpreted this as a deficit. I learnt the importance of talking with patients about the destination they are reaching for. I thus learnt from patients of the complexity of their experiences, and I now work on being open to hear multiple and at times competing stories of disability—stories of hope, distress, success, frustration, loss and determination. I learned that my work as a counsellor is much wider than in

the counselling room. I have contributed to changing the power-relations in the multidisciplinary meetings to give the first speaking position to patients; and patients have invited me to take the initiative to meet them in the context of their own rooms to form relationships of care. I acknowledge their very significant contribution to my ongoing practice.

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