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EMBRACED BY WORDS: Narratives and Metaphors of Illness in the Communication between People with Spinal Cord Injury, Caregivers and Health Professionals

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INTRODUCTION: WHEN A DISEASE ENTERS SOMEONE'S LIFE STORY

This paper will examine research on patients with Spinal Cord Injury (SCI), focusing on metaphorical language used in the communication between patients, caregivers and health professionals along the care pathway from the traumatic event, through diagnosis, hospitalization for rehabilitation and treatment, discharge and return to daily life.¹



To deal with a life-changing trauma, one needs kind words because they can bring hope and indicate a path to patients and caregivers, just as one mother said: "*I felt embraced by these words*", hence the title of this paper. Paying attention to the language used by patients and caregivers, and in particular to the metaphorical language, allows us to understand their world and have a wider understanding not only of the biological aspects (disease), but also the experiences (illness) and the social aspects (sickness) (Byron J. Good 1999). When patients, caregivers and professionals tell the stories of their experience and suffering, they assume an active role. As their narratives unfold, they gain a better understanding of their own situations, which become more comprehensible, more explainable and therefore more acceptable. "In medicine we think we live in a world of facts, something that simply happens, but the world of humans is actually a world of symbols. Care cannot be deprived of metaphor, image, symbol, meaning and interpretation. People experience meaning in their lives and illnesses; they (like all of us) experience themselves as characters in a life narrative; they seek patterns of meaning and symbols to make them complete." (Coulehan 1997).

¹ The metaphors have been grouped into tables, according to the main phases of the care pathway, and are partly supported by the narrative excerpts of the participants. To ensure anonymity the excerpts are identified by a code [number/role (patient-Pt, caregiver-C, professional-P)/ sex (m., f.)].

Can we discover meaningful metaphors? If so, can they help us to communicate the incommunicable? In a relationship, could they evolve to give shape and meaning to illness and encourage compliance? These are the questions that have guided our reflections and to which we have sought answers.

A FOCUS ON SPINAL CORD INJURY (SCI)

SCI is one of the most important causes of mortality and permanent disability in the world. It often affects young people with long life expectancies, so the associated health and social burdens are high. The most frequent causes of traumatic SCI are road accidents, falls, sports accidents and acts of violence; whereas, the main causes of non-traumatic SCI are cancers, infections, and degenerative spinal cord diseases.

SCIs have a significant impact on the quality of life and life expectancy of those who suffer from them. The outcomes affect routine aspects of everyday life, school and work activities and even the simplest physical and social activities. SCIs affect also the lives of caregivers.

Although SCI affects only 0.1% of the population worldwide – compared to 20% of the disabled population – this condition can be considered paradigmatic for two reasons: on one hand, it is often an unforeseen, sudden event that disrupts people's lives and forces them to reposition themselves in the community, with all of the associated trauma and difficulties; on the other hand, the condition is highly disabling, and represents a major risk factor for social exclusion, poverty and premature mortality.

THE RESEARCH: THE AUDACITY OF FRAGILITY: PATIENTS WITH SPINAL CORD INJURY CAREGIVERS AND PROFESSIONALS MEET EACH OTHER THROUGH NARRATIVE MEDICINE

The original research was conducted at the Montecatone Rehabilitation Institute in Imola, Italy, in 2017, with the aim of acquiring information on the path to discharge and on the strategies used by people with SCI to confront the challenges of their disability, both during the clinical phase and after they have returned to their family and social context for at least 2 years. The transition to home life is extremely delicate. For months, the patients have lived in a "protected" environment that provides a sense of safety regarding clinical-assistance, and where strong relationships have formed with the health professionals and patients who have shared this dramatic phase of their lives.

To address this, we conducted interviews and administered questionnaires to 28 patients with SCI and 25 caregivers between October 2016 and July 2017, representing perhaps the first time that such work was conducted in Italy. Both qualitative and quantitative methods were employed, responding to the need to integrate Evidence Based Medicine and Narrative Based Medicine. Instruments included semi-structured narrative interviews with patients and caregivers; the Carver's *Brief Cope Questionnaire* administered to patients at the end of the interview; the Health in Aging Foundation's *Caregiver self-assessment questionnaire* administered to caregivers at the end of the interview; and a focus group with 19 health professionals at the Montecatone Institute.

CRITICAL THINKING ABOUT METAPHORS IN LITERATURE

The first studies on metaphors can be traced back to Aristotle, who conceived the metaphor as a transfer, or literally a movement of meaning, saying one thing in place of another. Aristotle said that the metaphor is a transfer that is immediately evident, but unusual or unexpected, through which people see things while they are acting and are in progress (Paduano 1998). In a passage from the Rhetoric, Aristotle argues that in philosophical reasoning, the ability to grasp the analogy between very different things is a sign of intuition (Dorati 1996).

In the 1960s, interest in metaphors ceased to be only literary and became common to several disciplines, including medicine, although its importance in the scientific realm is debated. The French philosopher Paul Ricoeur takes up Aristotle's reflections and makes an epistemological distinction between "living metaphors" that produce something new to generate astonishment, and "dead metaphors" that are not able to generate new knowledge (Ricoeur 1978).

In *Metaphors We Live By*, the linguist George Lakoff and philosopher Mark Johnson define the nature of the metaphor as a way to highlight some essential aspects of a concept or object to help us explain something that is unfamiliar to our interlocutor, drawing on similarities with better known concepts (Lakoff & Johnson 1980).

According to Bateson, metaphors are expressed whenever we "experience a linguistic wall", when we try to translate a sensory experience into words, or to give meaning to events that we cannot explain otherwise (Bateson & Bateson 1989). The metaphor is not only a linguistic expression but also an essential way to symbolize our experiences, deeply anchored to our bodies (Edelman 2006).

In this regard Max Black points out that the recognition and interpretation of a metaphor requires attention to the particular circumstances in which it was expressed (Black 1983).

Psychotherapist Stephen Lankton says that metaphors work because "the mind is metaphorical". He explains that there is something particular in them, which has a profound effect on listeners, because they teach, inspire, guide, communicate, remind and are everywhere (Lankton 2002).

According to the American educator James Banks, "*the metaphor we are*" is structured in a dynamic that is lifelong (over the course of life), lifewide (in all formal, informal and non-formal contexts) and lifedeep (radically touching the system of values and beliefs) (Banks et al. 2007).

In the field of medicine the metaphor can also have a therapeutic function: A patient's word choices can provide insight into their self-image. This may allow the health professional to direct a patient towards a new self-image that the patient knows subconsciously.

However, Barker cautions against using metaphors that make patients uncomfortable and might compromise the relationship, and stresses respect for the patient's rhythms and times (Barker 1985). Susan Sontag, who has written widely about the importance of metaphors for describing pathologies such as cancer and AIDS, suggests that the excessive use of metaphors may confuse patients, especially those in delicate situations such as oncology (Sontag 1979; Sontag 1989).

METAPHORS IN THE NARRATIVES OF PATIENTS, CAREGIVERS AND PROFESSIONALS

Life changes in a flash: You are living your life when suddenly you find yourself in a hospital, catapulted from ER to OR, then ICU, and finally to the Spinal Injuries Unit, accompanied by strangers on a journey you did not plan. This is the SCI patients' path. The hospital becomes his or her new home, a place where time is suspended while the outside world continues its reassuring everyday life. Because of the abrupt change to body and soul, people often can't find the words to express themselves, except through metaphors.

We found that metaphorical language was present along this path above all in the illness-centered narrations that described personal, family, social and work experiences; it may have allowed people to better explain their emotions. Illness-centered language was used by 32% of patients and 29% of caregivers; whereas health professionals used mainly disease-centered language, shifting to illness-centered language when explaining the motivation for their career choices. Female patients and caregivers used more metaphorical language and expressed "living metaphors" (Ricoeur 1978), which generate new knowledge.

Accepting the narratives and grasping the meta-message within a relationship is a listening skill; however, one can only tune in to the feelings of a particular patient by knowing their story, learned over time. This requires the health professional to have reflective skills that allow them to learn by *reflecting on the action while it is taking place* (Schön 1993).

In the following section, we will look at the use of metaphorical language in different stages, from diagnosis to hospitalization and treatment to the return home and visions of the future.

Diagnosis: Encountering the disease. Metaphors in patients' narratives fully express SCI: They feel they are *a broken vase, a broken pencil, a broken branch, a halved body*. This experience causes also a "*biographical disruption*" (Bury 1982), a point of fracture in the existential plot that leads people to rethink their biography and self-concept, and mobilize resources to deal with the situation that has been altered by the disease.

Both patients with traumatic lesions (79%) and non-traumatic lesions (21%), as well as their caregivers described having a vivid memory of when the diagnosis was communicated. At such times people fail to master the meaning of words, which is perceived as a linguistic barrier.

According to Rita Charon, our world is transformed when we receive a diagnosis of serious illness, because "*it changes everyday life - with new pains, with pills, with falls, sometimes with a wheelchair - but also in the deepest dimensions of meaning: in the limits, in the denials, in the separations, in the desires*" (Charon 2006).

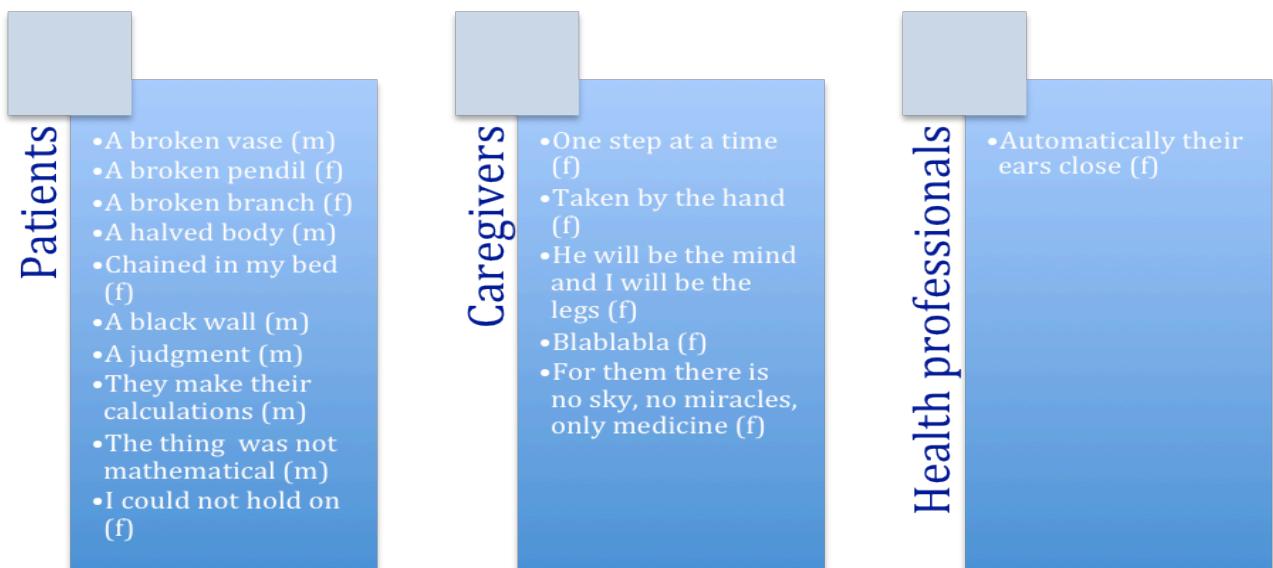


Fig. 1 Metaphorical language in the diagnosis phase

Patients live the communication of their diagnosis as a sentence:

- “...a very frightful meeting, a fearful exam. You know how they make their calculations.” (18Pt, f.).
- “So many people to say there's no hope. It was like a sentence (4Pt m.).

In this case, metaphors adopt words from legal and mathematical language. What do they want to tell us? That a court has issued a sentence? Or underline that the judgment defines the borderline between life before and life after? Or that the sentence cannot be appealed and therefore there is no escape? Or that a sentence can be opposed when it is considered wrong; "to err is human". And finally the outcome could be a defeat, a victory or a draw.

A very painful image is that of a person who cannot *hold on*. Perhaps they do not have points of reference. Are their surrounds collapsing around them? Disappearing? Are they disoriented because they are in a new place? Perhaps they don't find support in relationships that should provide security and, above all, hope. Has the only life they know ended? Replaced by a completely new one, in which they cannot move as they want, chained in a wheelchair by the pain of living?

Metaphors, if we explore them in depth, allow us to open new scenarios and learn to move beyond labels. As for the patients, the moment of the diagnosis is crucial also for caregivers, and their metaphors express relationships and feelings. A caregiver tells how the diagnosis was communicated:

- “*For them [Doctors] there is no sky, there are no miracles, only medicine*” (11C, f.).
- Does it mean that the professionals do not take feelings into account, or in medical practice there are variables that we cannot manage? Is medicine just certainty? Or is there something bigger than us that can help us? Medicine is not just certainty?

The mother of a young patient recounts the moment in which she was welcomed by the professional:

- “*At first the only memory I have is of the woman who welcomed us...she was explaining, but I heard only "blablabla", I only remember the mouth that was speaking. My head was somewhere else*” (17C, f.).

Even an onomatopoeic word like "blablabla" provides us with valid elements to understand difficulties in communication. Were the words of the professional received as unintelligible sounds? In a dramatic moment, are words not heard because the mind of the patient or caregiver is racing ahead, extrapolating worse case scenarios... somewhere else?

Also the metaphors used by the health professionals express difficulties in communicating the diagnosis:

- “*They [patients] listen up to a certain point, then automatically their ears close*” (12Pr, f.).
- The diagnosis and awareness of the new condition generates multiple reactions in both patients and caregivers: despair, fear, confusion, guilt, denial, worry, fatalism, resignation but also hope and fighting spirit. Listening and speaking accompany this moment:
- “*Words have an immense power: they are able to help, to indicate a path, to bring hope, or despair... it is necessary to choose words that can be immediately understood, and that do not hurt. This is the task, not easy but necessary, of those who care*” (Borgna 2014).

It is very important that people are not left to assimilate this new situation alone, but are accompanied and supported in this critical phase, to ensure that complex and painful feelings are accepted and shared.

In hospital: care and rehabilitation. During this long phase, the metaphors of patients and caregivers are mainly centered around their relationships with health professionals, other patients and other caregivers.

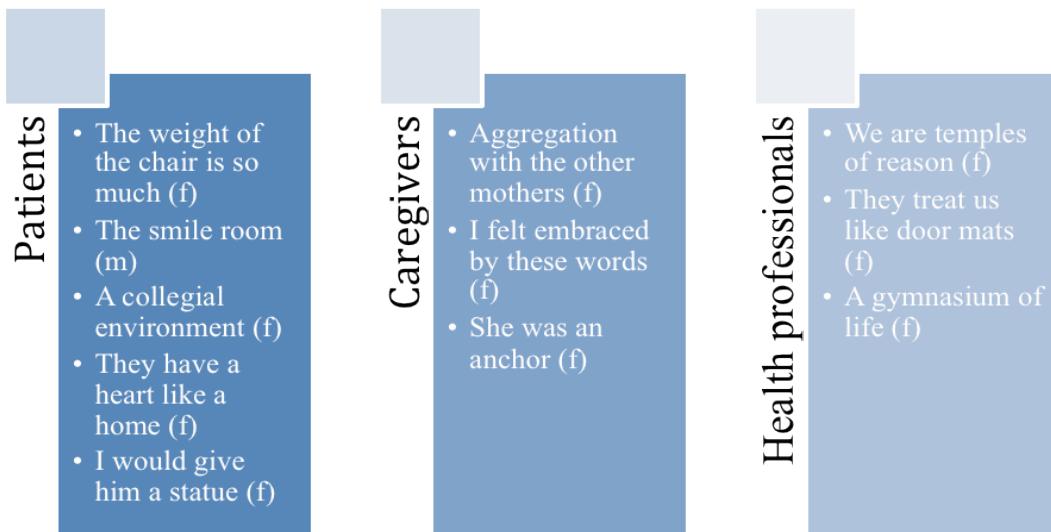


Fig. 2 Metaphorical language during hospitalization

The relationships between patients and their health professionals, peers and family members, create a particular context often described as a "big family." However, as in all families, relationships are not always easy and often generate misunderstandings on the one hand and

dependence on the other. The solidarity that develops among patients and caregivers over time at the Montecatone Institute is essential. It forms an unofficial network, parallel to the official one, where questions not addressed to professionals because of embarrassment find answers from people who share similar experiences.

- *"At anytime I asked more of friends who were in my conditions, than I did of my mother and father. You can explain it, but they can't understand our suffering. We have a hard task: give strength to others as well as to ourselves. The weight of the chair is so much!"* (17Pt, f.).

In the hospital everyday life is also colored by pleasant moments such as sharing food, music, walks, drinking a coffee, having long conversations:

- *"My room is the smile room: all kinds of people come to have a lot of fun until late at night"* (5Pt, m.).
- *"Montecatone is a collegial environment and you feel part of a community. When you go back home, you lose this supportive community"* (18Pt, f.).

Positive relationships can even overcome feelings of discomfort:

- *"The first time they washed me I felt ashamed and embarrassed. I didn't want a man to do this to me. I soiled myself on a field trip once and could not do the catheterization; a male nurse had to help. I don't want to name names, but I'd give him a statue. I started crying in front of him. Looking at me, he asked "is it just because I'm a man?" I cried and laughed. It solved all my problems in a minute, I had no more barriers"* (1Pt, f.).

Making a statue is an act of appreciation. Statues are commissioned for important, significant people: it is an acknowledgement of something important that has been received.

Significant relationships are recognized: *"There are 2 or 3 nurses here who have a heart like a home"* (7Pt, f.). In this case we have two metaphors associated, two images that represent intimate and deep places for the person. For Bachelard, the house represents the space of daily life, a place of serenity and peace, intimacy and security (Bachelard 1975). Here, the image of the heart, the seat of feelings, emotions and affection, is associated with that of the home, telling us that there was a real interest in helping people in need, in providing support, indicating a path, giving hope.

These words of thanks are important for the health professionals as recognition of their work.

During hospitalization, emotional support from members of other families is important for caregivers:

- *"I was comforted by the aggregation with the other mothers"* (17C, f.).
- *"G, 87 years old, has been my anchor, she called me her baby and I felt embraced by these words. She was the right person at the right time"* (22C, f.).
- Sometimes health professionals express disappointment at the lack of professional recognition. *"They treat us like door mats"* (10Pr, f.).
- *"We must not be friends with the children and we must not be friends with patients. We are temples of reason and bureaucracy."* (4Pr, f.).

Despite the difficulties, the strength that sustains professionals often comes from their career choice: *"This is the most gratifying place: I fell in love with this place because of the satisfaction I got from the patients. The satisfaction of seeing a quadriplegic patient eating alone. This is a gymnasium of life for me"* (13Pr, f.).

Returning home after discharge to daily life. Even though they prepare for this towards the end of their hospital stay, patients and caregivers find this moment particularly critical.

Whereas, 36% of patients report feeling reassured and ready to face the return home, 28% express worry and 36% express feelings of fear and loss at this critical juncture.

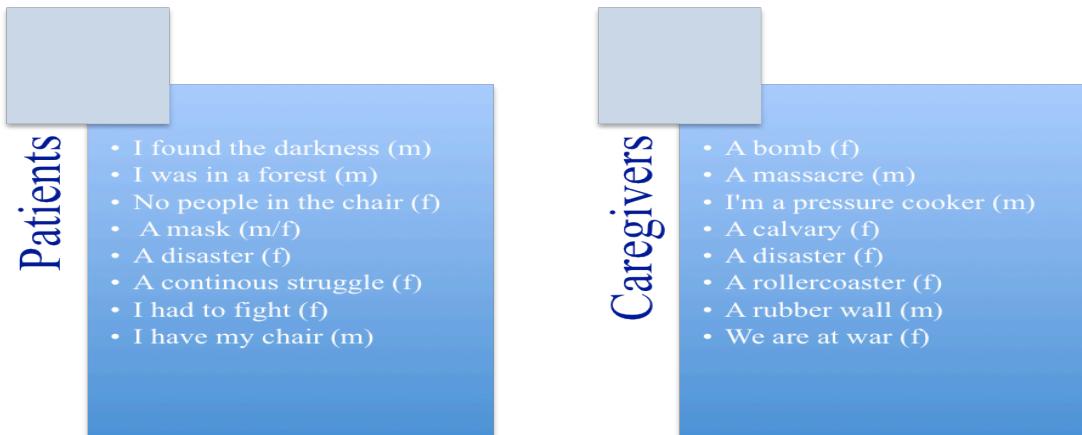


Fig. 3 Metaphorical language in daily life

The changes in the body, mind and heart put a strain on the person who has to deal with an environment (family, social, work) that has become foreign to them. They feel left on their own: the people who took care of them are no longer there; the network of supportive friends is gone. The metaphors communicate a sense of bewilderment, fear and loneliness:

- “*When I went back home I found darkness*” (25Pt, m.).
- “*I had come out of a protective environment; it was like I was in a forest*” (10Pt, m.).
- “*At home I kept my relationships, but not with everyone. I preferred not to spend time with people like me, but wanted to be with normal people. Other people are only comfortable with people in the chair [wheelchair – ed]*” (17Pt, f.).

To survive and inhabit the world some people need a stage and a mask to wear: “*When you have people in front of you, pretend to smile because if you're serious they say you're always serious. Laugh, wear a mask and laugh. In fact, it's no accident that my poems are called masks*” (16Pcs, m.).

In the patients' narratives one metaphor emerges as the synthesis of their new condition: *the chair*.² The chair represents both the outcome of the pathology but also the new identity. We think that this image forms first during the course of care, and then in the formal and informal contexts frequented by patients with SCI after returning home. It touches deeply their personal system of values and beliefs. In this case we must highlight some risks associated with metaphors. As Sontag found in her studies, metaphors may have negative consequences: fear, stigma, and instilling some therapies with mythical qualities. Their use is deeply rooted in social language (Sontag 1979; Sontag 1989). The chair, in this case, is a support that facilitates daily life. The person is not an object; the person is not the outcome of a disease.

Among the metaphors used by caregivers and also some patients, we found a coherent metaphorical paradigm of everyday life as war. Different linguistic expressions have at their roots a specific way of experiencing events (e.g., everyday life) by analogy with other events

² People with SCI often use the word “chair” instead of “wheelchair”

(e.g., war). It is the metaphor that builds the analogy on the basis of a perceived similarity between a war and everyday domains. This confirms Lakoff's thesis that the metaphor is a "figure of thought" (Lakoff & Johnson 1980).

The following expressions are all realizations of the same metaphor that identifies everyday life with armed conflicts:

- "*With regard to care, the return home has been a real disaster. I can't understand why paralysis is unknown: It's a continuous struggle*" (17Pt, f.).
- "*At the end a new physiatrist prescribed me another wheelchair. But I had to fight to get the right one*" (25Pt, m.).
- "*Nobody knows our daily life. Daily life is a massacre*" (4C, m.).
- "*It's a bomb that exploded and the shrapnel sticks in everyone's heart*" (1C, f.).
- "*Home care has been a disaster. My daughter had problems with her bowels and we didn't know who to contact. General practitioners don't know spinal cord injury*" (17C, f.).
- "*We are at war with social services*" (25C, f.).

Metaphors of war (*massacre, war, fight, disaster, struggle*) that we find in the literature refer to the fight against the disease that patients and their caregivers engage in. In the case of people with SCI, metaphors of war are used to describe the many battles they and their caregivers face in their daily lives, such as the fragmentation and slowness of the social and health systems, bureaucracy, and physical and cultural barriers.

Stress accompanies the daily lives of caregivers. In the transition to home, they move from a supporting role, while the hospital staff are the protagonists of care, to a situation in which they have to reconcile the needs of the patient with the needs of other family members and in many cases with their jobs. They also need to maintain social networks and avoid isolation, to overcome physical, cultural and bureaucratic barriers.

The metaphor of the *roller coaster* was used very effectively to describe everyday life full of hard climbs, free falls, suspensions, turns that could lead to derailing if not managed well. For this reason, caregivers need to have a pause now and then, as one of them says: "*I need a relief valve, I'm a pressure cooker. I ride my bike three hours, I go swimming, running. Why do I run? Running is the force from which I draw energy*" (4C, m.). We can assume that the pressure cooker is the container of emotions, responsibilities, feelings of guilt, fatigues and the valve is the voice that materializes the search for help, for solutions. In this case the caregiver found a positive strategy in sports that reduces daily pressures and renews positive energy.

Space for the future. How much space is devoted to the future in the narratives? Patients are more afraid of aging and further loss of autonomy; but in their narratives we also find planning and openness to hope. The reorganization of one's life can also allow them to transform a painful event into a process of learning and growth. Through metaphors, we can observe some of these changes that look positively at tomorrow, like *overcoming the wall* or like *the phoenix* that can rise from the ashes. The disease perceived as an opportunity to *open the drawers of memory, a limit but also a perspective, a path of training and learning*.

On the other hand, the caring and emotional burden of caregivers can be so heavy that, for many of them, the future is annihilated by the present: "*I don't want to think about tomorrow. My mantra is here and now*" (9C, f.).

SOME CONCLUDING CONSIDERATIONS: DO METAPHORS HEAL?

When a treatment process cannot lead to healing, as is the case for many people with SCI, the only viable solution is to provide the best possible care. This consists of a high level of professionalism, advanced technology, a friendly environment where trusting relationships can thrive, kind respectful words that provide care, support and hope. The patient's story is an element to evaluate when making treatment decisions: The way patients with SCI integrate the narratives of health professionals into their life stories can also play an important role in the therapeutic path to be undertaken.

During the entire care pathway, health professionals, patients with SCI and their caregivers communicate on a daily basis. Metaphors come and go from their narratives, expressing elusive concepts of difficult delimitation, as well as feelings and emotions. We could say that it is important to search for the metaphors used by patients and caregivers in every phase of the care process, to share the meaning of these metaphors and help them evolve into soothing images that provide useful information and practices and do not leave them alone.

Diagnosis and discharge are two extremely critical moments, when particular attention is warranted. The clinical workup and diagnosis of SCI takes a long time and patients need to be accompanied and supported; at discharge, it is essential that a support network be in place to deal with the many problems that arise in everyday life: often the bureaucratic reality does not match the expectations and needs of daily life.

To better accompany and support patients and caregivers when they confront important changes and find their new place in the world, health professionals can pay attention to the metaphors that enter into the stories, and use them as a narrative register to give rise to the fragmentary story of those who need points of reference and words of hope.

Do metaphors heal? If by heal we mean getting in touch with the inner world of patients and caregivers, and improving communication, we can say that they do. The strengths of metaphors include giving a sense to difficult events and overcoming the linguistic wall to give voice to fears, fatigue and emotions. With an image, people give us information about what they are experiencing and give meaning to their experience, which might otherwise remain unexpressed.

Metaphorical language is a resource that professionals can integrate with their technical skills; it should always be used with caution so as not to stigmatize the disease. Besides increasing the understanding of patients needs, it improves communication skills. We hope that the use of narration and metaphors can provide a paradigm shift in healthcare, from a biomedical to a bio-psycho-social-medical paradigm.

In fact illness narratives can be *a creative bridge* able to connect scientific understanding about the patient's illnesses with the feelings that they experience (Kleinman 1998).

Questioning metaphors, which should always be used with caution, underlines the fact that we are open to uncertainty. It means "*conversing with the situation*" (Schön 1993, 2006), which is to say, putting one's self into the problematic situation and remaining open to the "*impertinent answer*". We think that exploring these issues further can help to clarify the curative capacity of narratives by putting the experience of the patient at the center of care.

Metaphors provide access to an inaccessible world, often anguished, but also creative and vital, that health professionals must pay attention to and value in communication.

Attentive health professionals who have deep knowledge of their patients' stories have the task

of reworking and evolving something unrepresentable into information, and reconnecting life, illness and health. Charon says that we must *honor the stories of sick people* (Charon 2006); this means paying tribute to the experience of teaching patients by being attentive and providing the appropriate space and time for listening and reflection. This kind of relationship creates the conditions needed for the "human things" and the "medical things" to meet in a narrative in which the protagonists are those who provide care and those who receive care.

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