

Case Report

Adapting to Multiple Sclerosis: An Ongoing Balancing Act

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Abstract

This case report illustrates the continuous process by which a person with moderate to severe multiple sclerosis adapts while maintaining her sense of identity in continuity with her personal history and in coherence with her values. The Seek-balance is a graphical representation of such a process that can serve as a clinical dialogue tool to facilitate the necessary choices and fluidity for recurrent adaptation. The experience of living with a chronic health condition requires reconciling different needs, sometimes in tension with each other. A number of coping strategies help to attain a certain balance between them.

Keywords: Multiple sclerosis; Adaptation; Sense-making

Case Presentation

Since being diagnosed with multiple sclerosis (MS) more than 20 years ago, Marie, now 48 years old, has seen her disabilities slowly progress. She stopped working in 2008, and she now uses a motorized wheelchair. Her torso and legs are so weak that she falls when making transfers or when leaning forward. Her left hand is less and less functional. Marie lives in a partially adapted house that she owns with her spouse, who does most of the domestic chores. Over the years, Marie has tried various forms of non-pharmacological treatments: acupuncture, osteopathy, naturopathy, anti-exercise [1], ECHO healing [2], musical improvisation, and psychotherapy.

The seek-balance tool

The analysis of Marie's narrative account, and that of seven other people with moderate to severe MS, led to the conclusion that life retains its value as long as these people can say, "It's still me"; if they can recognize themselves with, despite, or thanks to MS [3]. The narratives of their experience showed that adaptation occurs through daily renewed choices. These findings have led to the new Seek-balance adaptation model. The Seek-balance (Figure 1) illustrates this complex process of sense-making when one has to adapt to a chronic health condition. It is not a series of steps but a variety of possible coping strategies to choose from. The appropriate choice will depend on a set of contextual factors [4].

The Seek-balance consists of five concentric circles, each representing a dynamic component of the real-world that influences which adaptation strategy is chosen. In the background, the cultural environment highlights the values, practices, and ambient discourse that can influence behavior. The second circle consists of the social environment, which is one's network of close relationships, including loved ones (family and friends) and also those with whom one interacts in the community (representatives of the various services available, coworkers). Next is the health condition, which refers to one's physiological condition, and the ability to respond to a desire for action. In MS, this most often refers to fluctuating states of relapse and remission, more or less rapid changes of functional limitations, and especially fatigue. The last two circles, creative tensions and strategies to reconcile them, will be described in more detail.

Creative tensions

While talking about her experience of living with moderate to severe MS, Marie emphasizes her active search for a dynamic balance between contrary needs or attitudes. The main needs that Marie identified herself with are grouped in seemingly opposing thematic pairs.

A major source of ambivalence arises between tenacity and letting go. The challenge is to muster the necessary determination to deal with the disease and its consequences, and yet also to let go, such as the renunciations to which the disease often leads. Determination fuels the desire to act, while the need for rest encourages letting go. A second fundamental tension is between the desire to enjoy the present moment, when appropriate, and the need to plan, which requires energy that is in limited supply. A third creative tension is between giving and receiving. Marie expresses a fundamental need to feel useful and maintain reciprocal relationships, while being aware of needing care and being grateful to receive help. In the background, looms her concern not to become a burden for her loved ones: "I know my partner is tired and I don't want to ask more of him."

Marie describes herself most readily as determined, acting spontaneously, and self-sacrificing, compared to the opposite characteristics. The tension arises from the challenge of meeting two equally basic needs, even though at first they seem irreconcilable. Creative adjustment is the result of this search for a compromise: a new arrangement that unifies these opposing forces along the same axis.

Identifying creative tensions gives Marie the impression of finding a way out of a dead end, and the despair/panic to which it leads. She avoids extremes by making adjustments toward a middle ground between the opposing needs, such that she can best meet all her needs using one of the following five strategies.

Five balancing strategies to reconcile creative tensions

To find a balance between the polarities observed within the creative tensions, five strategies were identified that could allow Marie to give meaning to her experience, consistent with her values and identity.

"Do as if" means "do as usual" or "do as before". This strategy

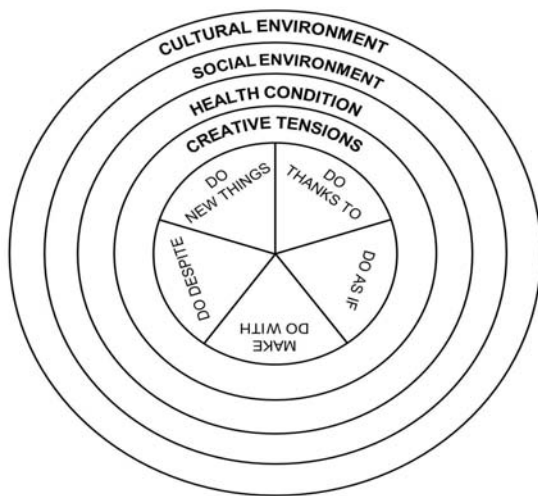


Figure 1: Seek-balance (customizable version).

allows the disease and its restrictions to be disregarded. It encourages adopting the most spontaneous behavior, which is often related to a dominant personal quality, strength, or resource in the creative tension. By recognizing “do as if” as a consciously chosen strategy, as opposed to denial, Marie validates her preferred strategies and thus maintains her resources. For Marie, her automatic reflex is to put the needs of others first: “Sometimes I wonder if it’s that serious, and if it’s worth it to put so much money into a house renovation project. I’m still able to manage with the bathroom I have.”

“Make do with” is dealing with limitations, choosing actions according to one’s disabilities. Marie finally applied for a grant to make her bathroom accessible to a motorized wheelchair after remaining, for several hours, on the floor after a fall.

Managing to “do despite the illness” is to put energy into rediscovering, maintaining or reintroducing meaningful activities. It is an active strategy to solve technical problems by finding practical solutions to compensate for limitations. Marie makes constant efforts to minimize the disease’s impact on her quality of life: “I can’t do musical improvisation anymore, so I offered to be a facilitator for the mindfulness workshop.

“Doing something new” is to discover new activities or new aspects of oneself to explore in terms of resources or attitudes. This strategy involves considering the advantages of a situation and seeing the desirable side effects of a condition, which, for that matter, is neither desired nor desirable. One of the advantages highlighted by Marie is having more time to be attentive to herself and to others. “I’m also more available to others, compassionate. Before, I could be impatient (laughs); things had to happen quickly...”

“Doing thanks to” is to consider the illness an opportunity to live one’s life according to one’s vision of human development. In Marie’s words, “to heal her life”: “Fatigue helps me. (...) it cools my jets. (...) The disease, through all that it’s made me go through, became my ally. It helps me anchor myself in my body, to cure my anxiety.”

Whichever strategy is used from one moment to another, every successful adaptation, from Marie’s perspective, is the one that allows

her to say “that’s me, too,” by being coherent with what she is and in line with what she has always been.

Discussion/Conclusion

From a phenomenological perspective, Toombs [5], having MS herself, considers sense-making as necessary to preserve one’s identity in this paradoxical experience of a body that both intrudes by its dysfunction and also undermines the ability to act. Research conducted with large samples has also identified factors related to better adaptation to MS, such as considering advantages, sense-making, acceptance, quality of relationships and commitment to action [6-9]. These quality of life components agree with the daily adaptation process described by Marie.

The Seek-balance emphasizes the optimal harmony sought between the various levels of an ever-changing world, given a situation at a given time. Rehabilitation workers could use the Seek-balance as a dialogue tool with people with MS and their loved ones. It can be customized based on their specific context, using their words, and identifying their own strategies. For Marie, the Seek-balance exercise allows taking a step back, which promotes awareness. She insists that the central point of the Seek-balance, the key element in this approach, remains the person. Thus, for her and for others, sense-making is consistent with their identity and values, in line with their personal history, and extends to the activities and relationships that people with MS have with their entourage.

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