

Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control

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Abstract

Studies that focus on patient empowerment tend to address more specifically two issues of patients' experience of illness: managing regimens and relating to health-care providers. Other aspects of illness experience, such as coming to terms with disrupted identities, tend to be overlooked. The outcome of empowerment is therefore usually referred to as achieving self-efficacy, mastery and control. We conducted an inductive exploratory study, based on individual in-depth interviews with 40 chronically ill patients in Belgium and Italy, in order to understand the process of empowerment as it may occur in patients whose experience of illness has at some point induced a feeling of powerlessness, which we conceptualised as a threat to their senses of security and identity. Our findings show that empowerment and control are not one and the same thing. We describe patient empowerment as a process of personal transformation which occurs through a double process of (i) "holding on" to previous self-representations and roles and learning to control the disease and treatment, so as to differentiate one's self from illness on the one hand, and on the other hand (ii) "letting go", by accepting to relinquish control, so as to integrate illness and illness-driven boundaries as being part of a reconciled self. Whereas the process of separating identities ("holding on") was indeed found to be linked to efforts aimed at taking control and maintaining or regaining a sense of mastery, the process of reconciling identities ("letting go") was found to be linked to a need for coherence, which included a search for meaning and the acceptance that not everything is controllable. We argue that the process of relinquishing control is as central to empowerment as is the process of gaining control. As a "successful" process of empowerment occurs when patients come to terms with their threatened security and identity, not only with their treatment, it may be facilitated by health-care providers through the use of narratives.

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Introduction

In the field of health-care, empowerment has been acknowledged as an alternative to compliance in order to guide the provider-patient relationship. Whereas in the compliance-oriented approach to health-care patients

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are seen as the recipients of medical decisions and prescriptions, the empowerment-oriented approach views patients as being responsible for their choices and the consequences of their choices.

As a recent literature review has shown (Aujoulat, D'Hoore, & Deccache, 2007), studies that focus on patient empowerment tend to address more specifically two issues of patients' experience of illness: managing regimens and relating to health-care providers. Other aspects of the illness experience, such as coming to terms with disrupted identities, which are central in the sociological approach to chronic illness (for a review, see Bury, 1991; Conrad, 1990) tend to be overlooked, in as far as their implications to the process of patient empowerment is concerned. Indeed, the outcomes most frequently associated with the process of empowerment in the literature are self-efficacy regarding disease and treatment-related behaviours, and effective self-management of disease and treatment (e.g. Anderson, Funnel, Fitzgerald, & Marrero, 2000; Keers et al., 2006; Lorig et al., 1996).

Patient empowerment is therefore most often defined as a process of behaviour change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment. In this definition, empowerment is viewed as a process of "activating" patients, who as a result of "*rejecting the passivity of sick role behaviour and assuming responsibility for their care (...) are more knowledgeable about, satisfied with, and committed to their treatment regimens*" (Steele, Blackwell, Gutman, & Jackson, 1987).

In accordance with Salmon and Hall (2003, 2004), we believe that such a definition of empowerment is a professional construction, which may not be relevant to all chronically ill people. As it is built on the assumption that patients most value being in control of medical decisions and management of treatment, it ignores some underlying factors of the decision-making capacity, which are linked to important dimensions of the patients' illness experience, such as their need for security, self-determination, and a continuous sense of self. Such a model of empowerment implicitly acknowledges the loss of bodily control and the lack of medical knowledge and skill to deal with it, as the main factor of powerlessness in patients with chronic conditions. However, in our previous work we have shown that the situations and feelings of powerlessness, from which a process of empowerment may evolve, extend well beyond strictly medical and treatment-related issues, as the participants in our study ($n = 40$) all expressed or demonstrated to have at some point or another experienced a distressing feeling of insecurity and a threat to their social and

personal identities (Aujoulat, Luminet, & Deccache, 2007). Building on our findings regarding situations and feelings of powerlessness experienced by chronically ill patients, we argue that a "successful" process of empowerment occurs when patients come to terms with their threatened security and identity, not only with their treatment.

Only a few authors (e.g. Paterson, Thorne, Crawford, & Tarko, 1999) suggest that empowerment may be related to a process of personal transformation, thus pointing to identity issues which are currently insufficiently addressed in theories of empowerment. Yet, there is some evidence that identity issues have an impact on patients' self-care behaviours and self-management capacity. A case study by Tilden, Charman, Sharples, and Fosbury (2005) showed how a young woman with diabetes became motivated to manage her diabetes once her identity was confirmed as being separate from her diabetes. Moreover, in a study with 30 adult asthma sufferers, Adams, Pill, and Jones (1997), found that those people who had accepted asthma as part of their identity, and therefore viewed their illness as being an integral part of themselves, demonstrated a better self-management capacity.

How one's sense of self and identity may be affected by the experience of illness has been well documented, in particular from the symbolic interactionist perspective (Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1987). Following the pioneering work of these authors, the need for reconstructing one's identity or redefining one's self in the process of adjusting to chronic illness has been acknowledged in relation with various chronic conditions, such as asthma (e.g. Adams et al., 1997), cancer (e.g. Heidrich & Ward, 1992; Mathieson & Stam, 1995; Shapiro, Angus, & Davis, 1997), chronic fatigue syndrome (e.g. Clarke & James, 2003), diabetes (e.g. Paterson et al., 1999; Tilden et al., 2005), physical disability (e.g. Galvin, 2005; Morse & O'Brien, 1995; Yoshida, 1993), traumatic brain injury (e.g. Nochi, 2000), etc. In other words, it has been well acknowledged that the experience of chronic illness, by disrupting a person's life in many ways, has a general and profound impact on a person's identity, i.e. a person's sense of self-worth and continuity, in relation with previous representations of self and social roles (personal and social identities).

However, there is no clear evidence from this body of literature of how the very process of restructuring oneself in response to chronic illness occurs. This process is described in different ways, as for instance a process of differentiating self from illness (Tilden et al., 2005), a process of reintegrating the social identity of ill person with other social identities (Adams et al., 1997), a process

of adjusting through the lowering of self-expectations (Heidrich & Ward, 1992), or a process of meaning-making mediated by the revision of one's self-narrative (Mathieson & Stam, 1995; Nochi, 2000; Shapiro et al., 1997). As pointed out by Paterson et al. (1999), the transformative process inherent to having to live with a chronic illness is usually described with a focus on restructuring either one's self or the illness experience.

In this paper, which seeks to clarify the meaning of empowerment in relation to the process of reconciling one's identity as an ill person with other personal and social identities, we will describe how the processes of restructuring the illness experience and restructuring the self are two inter-related processes, which can be best described as a double process of "Holding on" and "Letting go", occurring through strategies of taking control and attitudes of relinquishing control.

Methods

Our intention was to allow for the emergence of the meaning of empowerment, as it may be experienced by participants with various chronic conditions. We therefore opted for an inductive qualitative approach, and conducted an exploratory study based on individual in-depth interviews. We referred to phenomenology for methods of data collection and descriptive analysis, and to Grounded Theory for methods of interpretation and theorisation, as these methods offer a flexible set of inductive strategies for building theories from within the participants' own frames of reference (Charmaz, 2003), which are often different from the researcher's frame of reference.

Our study was examined and approved by the ethics committee of the St-Luc University hospital in Bruxelles (Belgium).

Sampling and data collection

We conducted 40 in-depth interviews of patients. The participants in our sample were interviewed in two different settings (Belgium and Italy), and presented the following characteristics:

- type of chronic disease: lupus erythematosus (9 participants), asthma (7), heart disease (4), multiple sclerosis (3), diabetes (3), chronic pain (3), sclerodermia (2), psoriasis (2), multiple myeloma (2), Job syndrome (1), cystic fibrosis (1), polycythemia vera (1), AIDS (1), poliomyelitis (1);
- duration of disease: 21 participants had had the disease for over 10 years; 16 participants for 1–10 years; 3 participants for less than a year;

- age: the age varied from 23 to 75 years, with a mean age of 51.85 years, and a median age of 55 years;
- marital status : married or living in couple (30), living with another family member (3), widow (3), single (3), divorced (1);
- gender: female (30), male (10).

According to their preferences, the participants were interviewed either at hospital, at their general practitioner's, or at home. The interviews lasted up to 3 hours, with an average duration of an hour and three quarters.

Interview guide

Our work was initially based on an interpretation of the outcome of empowerment as the capacity to eventually act on a situation that had previously been experienced as overwhelming or impossible to cope with. The research interviews were guided by two categories of open-ended questions. The first aimed at identifying situations and feelings of powerlessness, and therefore inquired about the difficulties the participants had met or were still meeting in their everyday-life due to their disease. The second category aimed at identifying possible processes and outcomes of empowerment, and therefore inquired about the attitudes or strategies, and inner or external resources that had helped the participants to overcome their difficulties. As recommended in the tradition of phenomenological methodology (Ashworth, 1996; Giorgi & Giorgi, 2003; Moustakas, 1994), the interview guide contained no question at all referring to any known definition of empowerment.

Data analysis

All our interviews were tape-recorded with the consent of the participants, and transcribed verbatim.

In order to validate our understanding of the participants' experience, we wrote up individual syntheses which were presented or sent to the participants for their approval and further comments. The writing up of the individual syntheses was done using emerging categories from the transcripts, and coincided with the first step of our analysis, which was descriptive of the participants' experience.

In a second stage, in order to look for the commonalities in the specific experiences of feeling powerless or empowered in relation with the general experience of being ill, across the different thematic categories, which had emerged in the process of writing up the syntheses, some conceptual categories were allowed to emerge. By

conceptual categories, we mean categories that go beyond the mere description of the phenomenon that is being studied, to start assigning an interpretative meaning to the descriptions that emerge from the interview transcripts (Paillé & Mucchielli, 2003). In order to refine and articulate our initial emerging categories, as recommended by researchers using the Grounded Theory methods (Chamberlain, 1999; Charmaz, 1990), we compared the emerging categories to other findings in the literature, and tested their relevance by confronting them to the experience and knowledge of other patients and various health-care professionals. Our refined categories were then checked against the original interview transcripts again, and we eventually conceptualised the state of powerlessness from which a process of empowerment may evolve as “A loss of one’s senses of security and identity”, and the very process of empowerment as “A process of reconciling identities, based on a dialectics between holding on and letting go”.

As already mentioned, the findings relating to the first objective of our study, i.e. the situations and feelings of powerlessness from which a process of empowerment may evolve, have been reported elsewhere (Aujoulat, Luminet et al., 2007). This article presents our findings regarding the second part of our study, i.e. the description and meaning of empowerment as it may be experienced by people with a chronic illness, who have experienced illness as a threat to their senses of security and identity. The results are presented hereafter according to the two above-mentioned subcategories, namely “Holding on” and “Letting go”. Moreover, in both sections, the meanings of “Holding on” and “Letting go” are examined in relation with one’s identity as an ill person on the one hand, and in relation with one’s other social identities and representations of self on the other hand. In the process of analysing the data, we specifically and systematically checked if our emerging categories could be associated with factors such as age, or the type and duration of disease. No such evidence was found.

Findings

Five participants in our sample explicitly conveyed that they enjoyed a sense of a reconciled identity, which they expressed in terms of being aware that the disease was part of them, and yet distinct from their selves:

“I am not a diseased person... I am a person with a disease, and I feel that this is very different. I have my heart and I have my mind, and it does mean a lot, doesn’t it?” (Marie-Catherine, 62, diagnosed with multiple sclerosis at the age of 32).

“My illness is part of our life (...) to have this illness is like having a third person at home” (Julie, 37, diagnosed with cystic fibrosis at the age of 12).

These participants were also found to enjoy a greater sense of control and agency (in that they reported to be able to act and take decisions within the boundaries imposed upon them by their illness), as well as a greater sense of coherence, which they expressed in terms of perceiving that their illness experience had a meaning which was fitting well within their general life-world: *“My illness has not been an obstacle to my life. I have always considered it as something that has pushed me to change my own existence”* (Blanche, 60, diagnosed with scleroderma at the age of 47).

Participants who were able to distinguish themselves from their illness, demonstrated that they were also able to consent to sometimes important life-changes. As a very disabled participant put it: *“My world has shrunk. But I want the best for me out of this little world that is now mine”* (Marie-Catherine, 62, diagnosed with multiple sclerosis at the age of 32).

By contrast, three participants in our study constantly expressed a sense of lack of control over issues that mattered to them, such as their work, family life, self-image, etc. Their experience of powerlessness was very close to what has been termed “learned helplessness” (Miller & Seligman, 1975; Seligman, 1972), “amotivation” (Deci, 1975), or “resignation”. (Lacroix & Assal, 2003) by other authors: individuals behave as if there were no resources within themselves to act on their environment and to pursue goals within a self-determined desirable direction. All three of these participants struck us as feeling uncomfortable in dealing with the emotional impact of their illness on their lives, even if they were specially asked about it:

R: Have you ever tried to explain to your friends how you feel about having this disease?

P: Never. I must admit that I never talk directly about things... I’d rather make a joke so as to try and convey things in an indirect manner... Yeah... I prefer jokes to long talks, actually!

R: Are you scared that they would not be able to take it if you were more direct?

P: May be... (silence) however, what frightens me most is to expose myself to their judgment... (silence)

R: Have you ever tried to talk to them in a more direct fashion, just as we are trying to do it right now?

P: (abruptly) I do not like to talk about myself in a direct manner. I know I am not able to do it and I do not even want to think about it (Fabrice, 25, diagnosed with asthma since childhood).

Another participant, Jacques, 73 years old, who was diagnosed with diabetes at the age of 17, demonstrated that he felt very insecure by the time of the interview, with the overwhelming feeling that he could rely only on himself to try and control the disease. This participant stated an obsession with controlling things, and yet he admitted to not feeling in control at all. It was perceptible from his account that he had long ago withdrawn from social activities and professional relationships that were perceived to be a threat to his identity. Indeed, as his identity as a chronically ill person was overshadowing other aspects of his identity, his professional choices had always been limited to subordinate paramedical functions, as only those who had some kind of acquaintance with illness would be able, he thought, to accept a chronically ill person among them.

“I think I was lucky enough to be able to work all my life with a doctor. Because my boss was a doctor, he could understand (that I was a diabetic). (...) So I used to work for a doctor... who was a dentist... but being a dentist, he was a doctor, wasn't he? He had studied medicine, so... well... he therefore knew what I had... (...) Later, I worked for another dent... humm, I mean another doctor. So, you see, I was lucky (...) I don't know if I had to do it, but with my type of personality, I have always preferred to keep my illness a secret”.

As far as his social activities were concerned, his account revealed that whereas he had very much enjoyed company in the past, his illness had allowed him to develop only solitary activities. The analysis of this account suggests that insecurity can lead a person to develop a restrictive life, so as to avoid taking risks: not only the risk of developing complications of the disease, but also the risk of appearing as a sick person, or simply perceiving oneself as a sick person in the eyes of others. As Bury (1991) and Van Manen (1998) have explained, loss of confidence in the body leads to embarrassment and loss of confidence in social interaction.

Between these two extremes, namely empowerment associated with a sense of reconciled identity, agency and coherence, and disempowerment associated with a sense of helplessness, amotivation and resignation, most participants were found to be struggling between two dimensions of identity work, namely the process of separating their identity as an ill person from previous

or “preferred identities” (Charmaz, 1987), by “*Holding on*” to previous social roles and self-images and trying to take control over the diseased body, and the process of integrating their identity as an ill person into a coherent whole by “*Letting go*”, and thereby learning to identify and accept both the boundaries and possibilities linked to their being ill.

“Holding on”

As patients experience a “biographical disruption” (Bury, 1982) as a result of having to learn to live with a chronic illness, formerly taken for granted activities, roles and values are questioned. Strategies of holding on or taking control were reported by most participants as a way to cope with the feeling of insecurity linked to the occurrence of their chronic illness. This way of coping was found to relate to an intrinsic need for mastery, and was described by one of the participants as a struggle aimed at maintaining a sense of control:

“To be in control means to struggle so as to not be defeated by the disease. I try hard to maintain the idea that I am still the same person, although I have this illness... I try hard to keep believing that I am stronger than the fear of the disease that is inside me” (Daphné, 63, diagnosed with sclerodermia at the age of 57).

“Holding on” in relation to one's identity as an ill person

A sense of security provides the basis of self and self-growth. The loss of control over the body or the inability to link new bodily sensations to previous experiences and knowledge, as it is the case when chronic illness occurs, creates a strong feeling of insecurity (Toombs, 1993). In an attempt to fight their sense of feeling insecure, most participants reported to having engaged in cognitive coping strategies, so as to take control over the diseased body by increasing their knowledge and sense of self-efficacy in relation to their disease and treatment. To take control over the disease and treatment has been described as a way of separating one's identity as an ill person from other personal and social identities, so as to maintain a sense of normality (e.g. Charmaz, 1987).

Accurate and sufficient medical information was found to be an important factor of being able to keep the disease at distance, as an object distinct from one's self, which could be explained to self and others. The perception of having accurate and sufficient knowledge was associated with the feeling that the disease was

manageable to some extent, whereas the feeling of not being knowledgeable enough often lead to a feeling of helplessness. Access to knowledge is an important aspect of empowerment, not merely because it might ultimately lead to a better self-management of the disease and treatment, but for the sake that it offers an opportunity to conceptualise the disease as separate from the individual's self (Bury, 1982; Van Manen, 1998).

However, knowledge over illness is not created only through the assimilation of medical information, but also through the acknowledgment and interpretation of bodily sensations and emotional states linked to the very experience of being ill. As a result of enhanced self-awareness, many patients with different conditions said that they had learned to experience the manifestations of their illness as being linked to their own emotional state and ability to cope with stress and emotions. Factors such as emotions that were thought to be internal were usually dealt with better than external factors, as the latter were considered to be less controllable.

"I think my illness depends a little on my emotional well-being (Researcher: Did your doctor tell you so?). No, my doctor never told me so. But I know I am right" (Valérie, 42, diagnosed with lupus erythematosus at the age of 29).

"Unfortunately, I tend to keep things to myself. However, if I don't confess I am unhappy, I end up unable to walk, with my knees all blocked" (Jean, 35, diagnosed with lupus erythematosus at the age of 28).

"Holding on" in relation to other personal and social identities

Most participants spontaneously acknowledged having engaged, on several occasions, in huge efforts to continue functioning in various former social roles, pretending for as long as possible that the disease was not there to stop them. This attitude often entailed a denial of physical and emotional needs and boundaries, such as tiredness, need for intimacy with self, etc.

Finding one's own and true boundaries was described as a major challenge by several participants. To "hold on" to previous social roles and self-representations was described as a way of experiencing how far one could go. One participant explained how difficult it had been at the beginning of her illness to know what consequences her illness might have on her health. She therefore continued to work as hard as before and to do sports, refusing to acknowledge any boundaries, until she had to be recovered because of a serious seizure. She described the process of getting to know her

boundaries as a matter of experience rather than knowledge:

"I remember feeling a little frustrated when I got around 16 or 17. My friends would go out, and my mum and dad would tell me that I had to stay at home and that I needed to be more aware of my limits. I remember them telling me all the time: "You have your own limits". As far as I am concerned, my limits are not mental but physical. However, it took me some time to get to know them. With time, I have learned to know them better. I have come to know that further than a certain point I cannot go" (Victoire, 26, diagnosed with lupus erythematosus at the age of 14).

One participant expressed a very personal attitude toward experiencing and testing her limits. Although she was well aware of some of her boundaries because her illness had constrained her years ago to give up work and a great deal of activities, she felt the need for constantly overtaking her limits:

"It's all about limits... Being ill confronts you with your limits. They (doctors) keep telling you: "don't do this, don't do that" ... When you manage somehow to do this or that (which is contrary to what you were prescribed), only then may you realise that you don't belong to the Dead as they had already categorised you, but that you are still alive instead!"

Later in the interview, she mentioned:

"I feel a need inside me to always go over my limits. To disobey is a source of energy for me. It makes me feel better" (Monique, 45, diagnosed with Job syndrome at the age of 38).

Another participant, who acknowledged that she had probably pushed herself too far and that her condition might have worsened as a consequence of her not taking enough rest, questioned herself: *"Looking back, I ask myself if I have not exaggerated? With respect to my condition, the answer is: yes, certainly ... I should have taken more care of myself. However, with respect to what had to be done in my life, the answer is: no, I could not have acted any differently!"* (Nicole, 53, diagnosed with lupus erythematosus at the age of 29).

These quotations provide an illustration of the tension felt by many participants between sometimes conflicting priorities: on the one hand, the need to conform to medical advice in order to possibly protect their physical health; on the other hand, the need to pursue self-determined life-goals, which they felt were

meaningful for their mental, social and spiritual health. As scientific knowledge was balanced against individual priorities and values, some participants preferred to neglect their medical care.

Self-control strategies were found to relate not only to social roles, but to self-images as well. Some participants admitted to having conflicting representations of self, particularly with regard to interiorised or exteriorised self-images:

“Everything looks nice externally, but inside me it’s all rotten. Yet, there is no need for people to know what is going on inside me (...). When my son comes, I prepare a good meal for him, and I open a good bottle of wine. He says: ‘you look good’ ... (...) He only sees the image I let him see of me. And I am happy that way. (...) I feel, it’s important to control the image of myself I allow others to see” (Claire, 53, diagnosed with multiple sclerosis at the age of 31).

Moreover, quite a few participants acknowledged spontaneously, or upon being asked about their inner resources to cope with their illness, that they felt they were “strong” and “independent” people. One may wonder if this particular aspect of their personality might have been emphasized in an unconscious attempt to make up for the loss of some aspect of bodily control, in order to maintain a greater sense of self-worth:

“I have always been a strong person. It’s probably a family trait. (...) My mother has always taught me to be strong. And that’s probably why I developed this type of personality. It surely helped me. Had I not been so strong, I don’t know how I would have coped... or... may be I don’t know... may be I would have asked for help?” (Caroline, 32, diagnosed with asthma since childhood).

“Letting go”

To be able to precisely “ask for help” was associated in our study with the acknowledgment that not everything could be managed by the patient alone, and thus the acceptance that not everything could be controlled. This attitude of “Letting go” was found to be helpful, as it was part of a broader process of meaning-making and developing a sense of coherence.

“Letting go” in relation to one’s identity as an ill person

To express awareness and acknowledgment of one’s boundaries was found to be an important step of

empowerment. Some participants expressed relief about acknowledging that some things were out of control:

“During the two first years, I had to fight against myself. But as soon as I accepted I had to take insulin, as soon as I surrendered... because for me, it was like accepting to surrender... I had to admit to myself that I was not able to control my illness!.. as soon as I surrendered, I could also disclose my illness” (Laure, 60, diagnosed with diabetes at the age of 35).

The attitude of “letting go” in relation to one’s identity as an ill person was linked to a search for meaning, as most patients demonstrated that they were not only trying to medically explain their disease, but also trying to get a sense of being situated as an ill person within their own personal and family history. Thus, within their accounts of illness, their becoming ill was often related to past events in their own life or the history of their families. When a genetic predisposition for a particular illness was acknowledged, people tended to look for a precipitating factor which would make sense for them. All the participants recalled having explored the origin or cause of their disease. Whereas some participants associated their disease with a “family inheritance”, others referred to personal events, such as a stressful experience, or the death of a loved one. These participants believed their illness to be a consequence of their former inability to cope with stress, and therefore the manifestation of a depression that had remained unacknowledged so far. The ability to identify a cause or factor which would make sense helped quite a few participants accept the lack of control over their illness.

Some participants associated their need for meaning with a symbolic function to the experience of illness. The participants who were able to identify such a symbolic function stated that it helped them to accept and make sense of their experience of illness. Louise, 47 years old, diagnosed with lupus erythematosus at the age of 31, mentioned that her daughter had been suffering a serious and disabling illness ever since she was born. She was experiencing her own illness as making her feel like her daughter, which somehow contributed to alleviate her sense of pain and guilt toward her daughter’s condition.

We would like to stress here that, in the context of a medical encounter, to assign a function to illness may be considered relevant only if this meaning or function is identified by the patient himself or herself, as meanings suggested by the practitioner but not appropriated by the patient may be perceived as very

disempowering. Moreover, whereas the medical explanation of illness may be corrected or validated by health-care professionals, the meaning attached to the illness experience should be acknowledged as a personal representation, and should therefore not be corrected. However, health-care professionals may act as facilitators to help their patients become more aware of their beliefs and expectations.

Another aspect of the patients' meaning-making process was found to be linked to the identification of a purpose in life. Indeed, a few participants acknowledged their illness as adding sense to their lives because they had committed themselves to activities aimed at helping other patients. To look at others, and to feel like "*a link in the chain*", in order to alleviate present or future suffering for others, was a way to put things into perspective and to feel truly human, with a sense of purpose:

"I believe my suffering will make sense in the end, if my experience of today is a step toward helping out other patients in the future" (Lucie, 56, diagnosed with multiple sclerosis at the age of 49).

Eventually, a few participants explicitly acknowledged their illness experience as having allowed them to explore the spiritual dimension of their lives, which would otherwise have remained unknown to them, or simply disregarded. Richard, 51 years old, who had had a heart attack 5 years before the interview, said that he had always had a sense of transcendence but that he could give it more space now, as his illness had allowed him to be more aware of his true values and priorities, and to consequently consent to some important life-changes: "*I go for a walk in the mountain, and looking at the flowers and the birds, and all the beauty, I feel connected. I do not need to go to church to find God in my life*".

Spirituality is increasingly being acknowledged as an important dimension of people's quality of life and well-being (WHOQOL SRPB Group, 2006). Spirituality may be defined as a "*personal search for meaning and purpose in life, which may or may not be related to religion. It entails connection to self-chosen and/or religious beliefs, values and practices that give meaning to life, thereby inspiring and motivating individuals to achieve their optimal being. This connection brings faith, hope, peace, and empowerment*" (Tanyi, 2002). A good balance between body, mind and spirit has been described by Albrecht and Devlieger (1999) as the cornerstone of a strong sense of coherence in life. Such a sense of coherence, which Antonovsky (1983) conceptualised as a three-dimensional construct (*manageability, comprehensibility, and meaningfulness*), is

usually associated to the experience of feeling healthy, and enjoying a good quality of life despite adverse events. In our findings, the attitude of "letting go", which was part of the participants' meaning-making process, aimed precisely at gaining a stronger sense of coherence in order to perceive the illness experience as acceptable and making sense.

"Letting go" in relation to other social identities and self-images

A great feeling of relief regarding self-presentation and social interactions was conveyed by a participant as she reported how she had finally managed to explain to the students attending her course that she had a chronic illness, which she was not able to manage all by herself. The following quotation illustrates the tension experienced by many participants between a certain wish to protect their image by appearing as a "normal" person who is in control, and yet the desire to feel fully integrated, rather than split into different persons or self-images:

"I really feel that I have grown from the very moment I was able to tell my students that I too had a chronic illness. I remember going to hospital one day and telling my friend who was replacing me for the day: "don't tell them... just say that I am not there, and that's all for today!" However, when I went back to my class, I faced my students and explained that I had a chronic illness which I was not able to control all by myself, and that I needed the help of medicine. That's why, every month I needed to go to the hospital... pffff... what a relief... I felt so much better afterward. At least now I am really the person they see!" (Blanche, 60, diagnosed with sclerodermia at the age of 47).

The attitude of "letting go" was also well illustrated during the very interview process by Daphné, 63 years old, who was diagnosed with sclerodermia at the age of 57, as she suddenly started to question her major coping strategy which had thus far consisted in minimising the emotional impact of illness on her life:

Participant: The things I had to give up are not so important. For instance, I would very much like to go for a walk up in the mountain. I'd like to go high, but I can't... but this is not important, is it?

Researcher: this is not important...?

Participant: Well... (silence). Yes, it is. But I believe one can live without it... (silence). I realise I always

tend to minimise... I minimise the problems by trying to convince myself that things will be better tomorrow... but I realise now that it's not that true, it's not that true at all....

The dialectic between “Holding on” and “Letting go”, in other words taking or relinquishing control, was found to be an ongoing rather than a linear process, linked to the perception the persons had of their limits and resources on the one hand, and to the perception of conflicting priorities on the other hand. The attitude of “Letting go” was found to be an important step in the process of restructuring the self and the illness experience. In accordance with Fischer and Tarquinio (2002), we believe that the expression of changes in values and priorities could be considered a useful indicator of a person’s capacity to find meaning in the process of adjusting to illness.

Discussion

In conceptualising patient empowerment as evolving from a threat to one’s senses of security and identity, we found that empowerment was about integrating different and sometimes conflicting aspects of one’s self in order to develop a renewed and valuable sense of self, by differentiating one’s self from illness on the one hand, and by integrating illness and illness-driven boundaries as being part of a reconciled self on the other hand. Bensaïd (1978) called this a process of “*Becoming a same, yet different person*” (“*Devenir autrement le même!*”), stressing that a person needs to establish a continuous sense of self if the changes inherent to having to live with a chronic illness are to be integrated in a renewed sense of equilibrium and identity. Bensaïd (1978) took this to be the very essence of healing, provided the focus of healing is not only on the diseased body, but on the mind as well.

Whereas the process of separating identities was linked in our study to efforts aimed at taking control and maintaining or regaining a sense of mastery, the process of reconciling identities was linked to a search for coherence, which included the acceptance that not everything is controllable.

The tendency to separate one’s identity as an ill person from other personal and social identities has been convincingly described as a coping strategy aimed at maintaining a sense of normality (e.g. Charmaz, 1987; Finlay, 2003). The differentiation between self and body, which occurs when ill persons try to explain their illness and take control of it, is a very important step toward empowerment because it enables the person to

“perceive the self as the subject and no longer the object of the disease” (Paterson et al., 1999). However, it has been demonstrated that separating identities alone is not sufficient and may be ultimately disempowering (Adams et al., 1997; Zoffmann & Kirkevold, 2005).

The extent to which one is able to take control is linked to individual coping capacity and preferences, and could be described as the behavioural dimension of empowerment. In an article which describes the positive and negative consequences of seeking and gaining control, Shapiro, Schwartz, and Astin (1996) have made clear that “*when events are beyond an individual’s personal control, problems may be exacerbated by persistent efforts at control, a strong sense of self-efficacy, or a high desire for control*”. In relation to empowerment, control may be helpfully defined as a two-process construct, with a process of primary control in which people attempt to bring the environment into line with their wishes, and a process of secondary control, in which people attempt to bring themselves into line with environmental forces (Rothbaum, Weisz, & Snyder, 1982). If empowerment is conceived as an attempt to help people gain only a sense of “*primary control*”, such an approach may be ultimately disempowering as it tends to disregard the uncontrollability of some of the situations experienced by patients with a chronic illness. As the integration of boundaries, which we have described as a dialectics between “holding on” and “letting go” (alternatively: “taking control” and “relinquishing control”), was found to be a central theme in the participants’ experience of illness, our findings are congruent with Morell’s (2003) model of “*embodied empowerment*”, in which power and powerlessness are “*understood as co-existent and interpenetrating, rather than as polar opposites that exist in hierarchical relation*”.

Whereas adjusting to illness is sometimes presented as occurring through a lowering of self-expectations (e.g. Charmaz, 1987; Heidrich & Ward, 1992), our findings support the idea that accepting the loss of control is not necessarily an end-point leading to a devalued sense of self, but may be part of a personal transformational process, in which people do not become adjusted to their illness, but in which the illness becomes an element of a person’s personal and social identities, thereby allowing the person to develop a new sense of coherence in life.

Other than control, an important dimension of empowerment was found in our study to relate to meaning, as most participants expressed the need to not only become knowledgeable about their disease and treatment, but also to assign a meaning to their illness experience, so as to perceive their lives as meaningful, coherent and

worth living. According to Fife (1995): “*Meaning sustains a sense of personal vitality, competence and power. An important aspect of the coping process is to maintain a sense of meaning that is not devastating to the self, and which allows the individual to maintain a sense of wholeness and personal integrity*”. The ultimate aim of what we have called a process of reconciling conflicting identities is precisely to maintain such a sense of wholeness and personal integrity.

In our work, as most participants spontaneously started the interview with a detailed account of their illness experience, we were able to evidence how a narrative, i.e. a story about one’s experience, may be a means of conveying to oneself, not only to the listener, what the meaning of a particular experience is, and how it fits within one’s more general life-world. Through narratives, people may be able to place the medical explanation of the condition within a more meaningful biographical context (Williams, 1984), and thus to articulate the illness experience and establish coherence (Hydén, 1997). We therefore support the idea that in order to be truly empowering, health-care professionals should not only provide for information and opportunities of negotiation and choice regarding treatment-related issues, but should invite their patients to tell the history of their illness, in order to assist them “*to come to terms with — that is accept, master or change — those personal significances that can be shown to be operating in their lives and in their care*” (Kleinman, 1988). This process of meaning-making is at the very heart of an empowering education, as described by Freire who has conceptualised the process of education not as a “*transference of knowledge*”, but as a process of “*communication and dialog*”, in which knowledge is co-created through the search for significance (Freire, 2005, first published 1974). Under such circumstances, treatments are understood as being “*a continuation within the framework of the patient’s illness narrative*”, rather than “*something that the doctor brings in from outside*” (Hydén, 1997). Hence, the patients’ motivation for self-care may be enhanced.

Conclusion

Building on our findings, we argue that empowerment and control are not the same things. Indeed, the expression of a strong sense of mastery or feeling of control should not be mistaken with the experience of being empowered as, in some cases, it may be an indicator that the patient is avoiding awareness of the impact of illness on his/her life. An individual’s expressed sense of mastery or control may therefore be considered as

a valid indicator of empowerment, only if at the same time the individual is able to express some changes in values and priorities, along with some present or past distress in relation to the fact of being aware of some physical boundaries or life-limitations due to the chronic illness. Moreover, there should be some evidence of a general sense of coherence and the perception that the illness experience is meaningful. The empowerment process in patients with chronic conditions may be facilitated by health-care providers through the use of narratives, as those change the perspective from disease management to illness experience, and therefore from cure and compliance to care and empowerment.

Limits and perspectives

Although our aim was to understand better what the process of empowerment may mean and how it evolves in the context of chronic illness, our study design did not allow us for a “follow up” of the participants over time. Therefore, we could not witness the process of empowerment (or disempowerment) as such. Our representation of the process is therefore a theoretical reconstruction, based on the articulation of different pieces of information regarding different moments of living with a chronic illness. Moreover, we are aware that our findings, which were shaped by our inductive methods of analysis and involved constant comparison within the transcripts, between the transcripts, and across the literature, are reflective not only of the participants’ experience, but also of our interactions with the participants, and our own understanding of the conceptual categories as they emerged during the process of analysis. Despite these limitations, we feel rather confident about the consistency of our findings. Indeed, the characteristics of our sample and interview technique gave us access to a huge amount of information regarding what it is like to live with a chronic illness according to different periods of life and different durations of disease, and we feel confident that our findings represent some commonalities of patients’ experience, independently of the type and duration of disease. However, we think that the dialectic between “*Holding on*” and “*Letting go*” deserves further research, so as to examine further the validity of our hypothesis that accepting to relinquish control to some extent is an important dimension of empowerment.

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