The Perspective of Patients on Their Experience of Powerlessness

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Although self-determination is a key issue in empowerment, the perspective of patients on their experience of empowerment has been poorly investigated. The authors have attempted to understand better what the process of empowerment means to patients by investigating the situations and feelings of powerlessness from which a process of empowerment might evolve. They conducted 40 interviews of patients with various chronic conditions and looked for the commonalities in their experiences of powerlessness. Their findings show that powerlessness extends well beyond strictly medical and treatment-related issues, as the study participants 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. The authors therefore suggest that an empowering provider-patient interaction should address these issues by providing for reassurance and opportunities for self-exploration as a prerequisite to participation and self-determination in treatment-related decisions.

Keywords: chronic illness; patient education; powerlessness; empowerment; insecurity; identity

Patient empowerment is often referred to as being an alternative to compliance in guiding the provider-patient interaction in the context of chronic illness. A recent literature review has confirmed the importance of the concept for the field of patient education (Aujoulat, D’Hoore, & Deccache, 2006). The ultimate outcome of empowerment is often implicitly or explicitly referred to as being self-management of disease and treatment through the reinforcement of self-efficacy and control over one’s health-related behaviors. For the professionals, putting empowerment into practice usually means allowing patients to enter a negotiation process and to participate in their health care decisions. Yet, a few studies have shown that not all patients wish to participate in their health care decisions (e.g., Loft, McWilliam, & Ward-Griffin, 2001; Wong et al., 2000), thus suggesting that empowerment might not always be considered a desirable process or outcome on the part of the patients. However, it has been argued that the key issues of empowerment are self-awareness and self-determination, and that the notion of empowerment should therefore extend to decisions such as the decision to hand over one’s responsibility for disease and treatment, provided the decision is sufficiently informed and self-determined (Anderson, Funnel, Bazrr, Dedrick, & Davies, 1991). In brief, the meaning of patient empowerment is considered to be the adoption of self-determined, not necessarily healthy, behaviors. Self-determination is here defined merely as the ability to make choices and accept the responsibility for one’s choices, and does not refer to a particular theory (e.g., theory of self-determination, Ryan & Deci, 2002).

The key features of an empowering provider-patient relationship, as reported by several authors (e.g., Chang, Li, & Liu, 2004; McWilliam et al., 1997; Paterson, 2001) include continuity, patient-centeredness, mutual acknowledgement, and relatedness. According to McWilliam et al. (1997), the empowerment process

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occurs while the patient tells his or her story, and the health care provider facilitates the understanding they both gain of the patient’s situation and situativeness, thus adding or creating meaning to the patient’s experience. On the other hand, discounting experiential knowledge and providing inadequate resources, particularly in terms of time and continuity, were found to be the main features of a disempowering relationship (Paterson, 2001).

The notion of empowerment was initially imported into the field of public health from the community psychology, with the rationale that a situation of powerlessness is a source of alienation and therefore a factor in ill health. Powerlessness was defined by Freire (1973, as cited in Kieffer, 1984) as occurring when an individual assumes the role of an object acted on by the environment rather than a subject acting in and on the environment. As there is a multiplicity of situations and contexts of powerlessness from which a process of empowerment can evolve (or not), Rappaport (1984) has considered that one should accept the idea that the form, meaning, and outcomes of empowerment are varied and cannot be standardized into a unique and consensual definition:

Empowerment is easy to define in its absence: powerlessness, real or imagined; learned helplessness; alienation; loss of a sense of control over one’s own life. It is more difficult to define positively only because it takes on a different form in different people and contexts. . . . Understanding that H₂O can be in liquid, gas or solid form and still be H₂O is like the realization that empowerment for a poor, uneducated black woman can look very different than for a middle class college student or a thirty-nine-year-old business man, a white urban housewife or a single elderly person resisting placement in a nursing home. (p. 3)

As far as patient empowerment is concerned, although empowerment is said to relate to self-awareness and self-determination, the perspective of patients on their process of empowerment, as well as their perspective on situations or feelings of powerlessness, have been poorly investigated so far (Aujoulat et al., 2006). We conducted a qualitative study to gain a better understanding of the experience of both powerlessness and possible empowerment in patients with different chronic conditions. In our study, empowerment was broadly defined as an experience that can evolve from situations or feelings of powerlessness. To issue recommendations for the facilitation of patient empowerment in patient education activities, we found it useful to gain better insight into the situations that can lead to feelings of powerlessness before tackling the meaning of empowerment. In this article, we present the findings of the first part of our study, that is, the situations and feelings of powerlessness as they were experienced by the patients in our sample.

**Method**

Our intention was to allow for the emergence of the meaning of empowerment as it might be experienced by patients with various chronic conditions. We therefore opted for qualitative methods and conducted a descriptive and exploratory study based on individual in-depth interviews. As is recommended in grounded theory (Chamberlain, 1999), as well as in interpretative phenomenological analysis (Smith, Jarman, & Osborn, 1999), we postponed a thorough literature review on patient empowerment so as to not let us be influenced by some existing theory while collecting or analyzing the participants’ narratives on their experience. As far as possible, we “bracketed” (i.e., temporarily suspended) our prior knowledge and understanding of powerlessness and empowerment to be fully curious and receptive of the experience reported by the participants, and to be able to perceive more clearly its intrinsic meaning and reflect on it (LeVasseur, 2003). However, as our work was done in French and Italian, and there are no satisfying translations for the term empowerment in either language, our work was 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. In our interpretation, people might therefore experience powerlessness when they are facing a situation with which they have not yet learned to cope and if they feel that this situation is beyond their control.

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

**Sampling and Data Collection**

To look for commonalities in the specific experiences of feeling powerless or empowered in relation to the general experience of being ill, we conducted 40 in-depth interviews of patients with various chronic conditions. The patients in our sample were interviewed in two different settings (Belgium and Italy). Types of chronic disease included lupus erythematosus...
(9 patients), asthma (7), heart disease (4), multiple sclerosis (3), diabetes (3), chronic pain (3), scleroderma (2), psoriasis (2), multiple myeloma (2), Job syndrome (1), cystic fibrosis (1), polycythemia vera (1), AIDS (1), and polyomyelitis (1). Twenty-one patients had had the disease for more than 10 years, 16 patients for 1 to 10 years and 3 patients for less than a year. Ages of participants varied from 23 to 75 years, with a mean age of 52 and a median age of 55. Thirty patients were married or living as a couple; 3 were living with another family member (2 with their parents and 1 with her sister); 3 were widowed; 3 were single; and 1 was divorced. Thirty were female, and 10 were male.

Because of practical constraints, our sample was a convenience sample, with patients recruited consecutively within a time period (April-June 2003). The participants were selected on a voluntary basis and were referred to us by their physician according to both the patients’ and the physicians’ convenience and possibilities. This is why two types of disease, lupus erythematosus (9 patients) and asthma (7 patients), account for more than a third of our sample. The persons who participated in the study had first been approached by their physician, who had explained the general scope of the study using a letter signed by the researcher and first author of this article. When the patients presented to the researcher, they were first asked about what they had understood about the study and what had motivated them to participate. After the scope of the study had been explained again by the researcher and the desire to participate was confirmed, a signed informed consent was obtained from each participant.

All interviews were conducted by one researcher (the first author). Whenever possible, an observer was present. In total, 4 different observers attended 26 interviews. The observer had to be a member of the medical or paramedical staff, and his or her role was to allow the patient to get some therapeutic follow-up in the form of psychological counseling after the interview if needed. According to their preferences, the patients were interviewed at the hospital, at their general practitioner’s office, or at their home. The interviews lasted between 20 minutes to 3 hours, with an average duration of 1 ¾ hours. (The 20-minute interview represents the extreme case of a lady who had accepted to participate in the interview but in the same time was denying that she had a disease). All interviews were tape-recorded with the consent of the participants.

### Interview Guide

The research interviews were guided by two categories of open-ended questions. In the first, we inquired about the situations that could lead to a feeling of powerlessness by asking the patients about the difficulties they had met or were still meeting in their everyday life due to their disease (an alternative question was about the changes that had occurred in their lives since they had had the disease). In the second category, we inquired about the attitudes or strategies, and inner or external resources that had helped them to overcome the difficulties they had met. The interview guide contained no question referring to any known definition of empowerment. As recommended in the tradition of phenomenological methodology (Ashworth, 1996; Giorgi, 1997; Moustakas, 1994), the researcher set aside all prior assumptions about what the experience of empowerment might mean to the patient.

To encourage the participants to focus not only on the disease itself but on other dimensions of their lives that might have been altered by the disease, our interview guide was adapted from an existing instrument, the Sei-QoL (Hickey, O’Boyle, McGee, & Joyce, 1999; O’Boyle, McGee, Hickey, & Joyce, 1992), which aims to evaluate the individual quality of life by asking patients to list the five most important dimensions of their quality of life and then to rate them by level of satisfaction and order of priority. Although the aim of our study was not to evaluate the patient’s quality of life, the tools provided by the Sei-QoL were chosen to help the participants to put their responses concretely within the specific contexts of their lives, according to the dimensions of their lives that mattered the most to them at the time of the interview and that they had freely chosen to discuss. In practice, the Sei-QoL was used in most cases only to close the interview, as a way of reformulating and synthesizing the main issues that had been raised during the interview. Indeed, most participants started the interview with a spontaneous and detailed account of the history of their illness, and the interview was consequently allowed to evolve freely, with the researcher building her questions on the participants’ stories and responses. However, in a few instances, the Sei-QoL proved useful either to start the interview with some people who had difficulties in starting to talk about themselves and their lives or during the interview to help some participants make their responses more concrete by putting them into the specific context of their lives.
All of our interviews were tape-recorded and transcribed verbatim. Because of logistical and financial constraints, we were not able to analyze the data thoroughly while we were still in the process of collecting it. We therefore decided on a formal two-step analysis, in which the theorization of empowerment emerged not only directly from the primary material (i.e., the transcripts of the interviews) but also from secondary sources, which consisted of (a) the thematic analyses and syntheses of the patients’ narratives, (b) the researcher’s memos at all steps of the research process, and (c) a number of publications (literature review on the various categories of analysis as they emerged from the transcripts), as well as (d) formal and informal discussions about our emerging results either with health care professionals or with patients. How we moved from a descriptive level of analysis to an interpretive level of analysis is subsumed in the following descriptions (Figure 1).

**Descriptive Analysis**

To validate our understanding of the participants’ experience while we were still in the process of collecting data, we felt the need for a tool that would help us to present the participants with a written synthesis of their narrative account quickly.

At this stage of the research process, as recommended by Miles and Huberman (1985), we opted for a mixed method of categorization by predefining the main thematic categories according to the objectives of our research and subsequently allowing subcategories to emerge from the interview transcripts. Our predefined thematic categories concerned (a) the problematic and potentially disempowering situations the patients had experienced or were still experiencing in their everyday life as a consequence of living with a chronic illness and (b) their ways of reacting to the different situations (in an attempt to feel more powerful), with a focus on:

- the attitudes and strategies they had developed or were still developing as a response to the difficulties,
- the type of external support they (had) needed to overcome the difficulties, and
- the inner resources they could identify as helpful, whether these resources were perceived as being indeed present, or lacking.
A somewhat overlapping category was added to keep track of all pieces of information where the participants had explicitly used words such as (lack of) “power,” “control,” or “mastery” when referring to a particular experience or feeling.

This initial matrix of categorization enabled us to make a “quick” classification of the data contained in the transcripts and provide the participants with a written synthesis of their interview. Ten participants received their synthesis while we were still in the process of collecting the data. The remaining patients received their synthesis later by post. The length of the syntheses varied from 5 to 13 pages, with an average of 9 pages. Each participant received three copies of his or her synthesis: one to keep, one to send back to the researcher with corrections or additional remarks, and one (optional) to share with the physician who had referred the patient to the researcher. The comments made by the participants validated our understanding of their experience.

After the analysis of the first 10 interviews was completed, the definition and content of the various common thematic categories and subcategories were checked by two independent reviewers, who made us aware of some possible overlaps and helped us to refine the definition of some of our categories. Each definition was supported by a quotation from one of the 40 interview transcripts. Each time a new theme emerged in an interview, it was tested against earlier transcripts. The general matrix of thematic categorization was thus allowed to evolve until the end of the process of analysis.

**Interpretative Analysis**

The process of writing individual syntheses coincided with the first coding of the material, as the individual syntheses contained different thematic subcategories that had emerged from within the transcripts. As the aim of our study was to identify shared experiences across a relatively large number of participants, the lists of subthemes contained in the different individual syntheses were compared to facilitate the identification of shared themes, as recommended by Smith et al. (1999). We used the software Microsoft Excel to organize and articulate the different subthemes into our matrix of categorization, which we used to keep track of relevant citations from the transcripts for every participant and by subcategory of analysis.

Across the different thematic categories, 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 thematic descriptions that have emerged from the interview transcripts (Paillé & Mucchielli, 2003). For instance, three of the thematic subcategories that had emerged within the predetermined category, Problematic Situations, were deconstructed and allowed to merge into two conceptual categories, which we provisionally named Changing Roles and Modified Self-Image. Along with another emerging category, which was named Need for Coherence, the categories Changing Roles and Modified Self-Image suggested that our core category would relate to Self and Identity. We provisionally named it Difficulty to Think of Oneself as the Same.

At this stage, we felt the need to leave our original material for a while and to move formally to the literature, to help us refine and articulate our emerging conceptual categories. Just to name a few, Bury’s (1982) Biographical Disruption and Charmaz’s (1983) Loss of Self provided a confirmation of the relevance of our abovementioned category. To elaborate on our final conceptual categories, we then went back to the initial interview transcripts, searching for a final confirmation of the conceptual categories that had emerged so far. In particular, the data were specifically and systematically examined for evidence of relationships with factors such as age or the type and duration of disease. No such evidence was found.

Our core category was eventually named A Same, Yet Different, Person! This category was found to encompass well our findings on both the situations and feelings of powerlessness, and the process of empowerment. The conceptual categories that were retained to describe the experience of being or feeling powerless are the Loss of One’s Sense of Internalized Security on the one hand, and the Loss of Social and Personal Identities, on the other. Our findings on powerlessness are presented hereafter according to these two categories of analysis.

**Findings**

Above all, there is an overwhelming feeling of powerlessness... the feeling that you are not in control of your own life anymore, of your existence, of your future. Everything in front of you is black. (Participant)

**Loss of One’s Sense of Internalized Security**

As they were facing multiple and distressing losses, the participants reported that their lives and...
worlds had become unpredictable, leading them to feel insecure and out of control.

**Loss of Control Over One’s Body**

When asked about what it was like for them to live with a chronic illness, most patients started the interview with a history of their disease, recalling the first symptoms or when they were first told about the disease. Many patients recalled how distressing it had been to feel that they were no longer in control of their body:

I had a crisis... it was the first time... and I got terribly frightened because it would not stop... and I got so terribly frightened. I lost my sensitivity, my fingers hurt... it was horrible. And I did not know it was the disease, I did not understand what the problem was.

Fear and horror are experienced when one first faces unexpectedly the manifestations of an incapacitating chronic disease. Not knowing what was going on was associated with major distress. Some patients reported how distressing it had been to remain undiagnosed, sometimes for years, and yet be aware that something was going wrong with their body. Finally having a diagnosis to explain symptoms was a relief to many participants.

The participants in our study reported increased awareness of their bodily sensations after the diagnosis of their particular disease. One difficulty the participants experienced while they were learning to live with their disease, and sometimes still years after their diagnosis, was to distinguish “normal sensations” from sensations that are induced by the disease. One question often raised was “How do I know if what I feel is normal or serious? When do I know I need to visit my doctor?” In particular, tiredness and stiffness were often associated with such questioning. A young woman who had been diagnosed with lupus 3 years earlier questioned herself:

When I go home after a day of work and it’s hot like today and I feel tired... how do I know whether my tiredness is normal and everybody would be tired under the same conditions, or whether my tiredness is due to my illness?

As they learned to know better the symptoms of their disease, most patients tried to understand more fully the extent to which their symptoms were predictable so as to adopt prevention strategies if possible.

Unpredictability of symptoms was found to be associated with major distress. One participant compared her disease to “a dog that would sometimes bite you and sometimes not, and never bark before,” suggesting that in her particular case the symptoms were unpredictable and inescapable. Some participants found their symptoms to be predictable if they were linked to their emotional state or to some known external factor. However, factors that were thought to be internal were usually dealt with better than external factors, as the latter were considered to be less controllable. To regulate their emotions, for instance, which were defined as a factor of illness by a few participants, one participant said that she had undertaken psychotherapy, whereas another was practicing yoga. These two participants were quite confident in their capacity to prevent some outbursts of their disease by controlling their emotions. On the other hand, great distress was observed in participants who considered only external factors, such as environmental factors, to be at the origin of the manifestations of their disease, because these factors are by nature uncontrollable.

**Loss of Control Over One’s Emotions**

Not always were negative emotions considered to be controllable. Strong feelings of distress and anxiety were reported at some point by most participants in our study. Some felt that they were at risk of becoming overwhelmed by their emotions. Difficulty in controlling emotions was obvious in a few participants during the interview: Two patients cried while talking about their life limitations, and one had to take an anxiety relief medication while recalling difficult events.

Anxiety and distress were presented by some patients as resulting from their being ill. In some persons, be they aware of it or not, anxiety and distress had preexisted but had been reinforced and given more visibility by the disease. One patient, who demonstrated a high level of distress and anxiety during the interview, complained about not being the same person as before, as she never “used to be like that before.” However, later in the interview, she admitted that she had previously been accustomed to seizures of panicking, with the general practitioner having to visit her at home to inject her with Valium. Another participant demonstrated greater self-awareness, admitting, “There has always been a general sense of anxiety in me. Before it used to give me headaches. If it were not for the disease, my anxiety would find other ways of manifesting itself.”
Although it is difficult in some cases to know from a single interview whether the difficulties faced by some participants are, indeed, inherent to their disease or whether the disease is used as an excuse for justifying one’s difficulties, some specific situation-related fears were reported as well, such as the fear of leaving home to go somewhere:

I am terrified that something could happen. I might consider leaving my home for the day. But more than that is impossible for me... it’s like jumping in the dark... I do not control things and do not know what to expect.

In any case, the disease was often felt as having rendered preexisting feelings of distress and anxiety more present or obvious, either because such feelings could no longer be ignored or because they could no longer be kept under control. To ruminate over difficult events was presented by some patients as an undesired but uncontrollable coping mechanism.

Loss of Control in the Context of Transgenerational Transmissions

The fear of transmitting their disease and, to a lesser extent, the fear of transmitting their fears to their descendants was present in many participants. In their search for meaning, most patients demonstrated that they were trying to get a sense of being situated within their personal and familial history. Thus, within their accounts of illness, their becoming ill was related to past events in their lives or the histories of their families. In particular, past illnesses in other members of the family were recalled, which sometimes situated their present illness within an inescapable chain of transmission.

Contrasting with these results, some patients reported that their illness seemed to have appeared from nowhere, as it could not be related to any personal life event. The feeling of uncontrollability was stronger for those patients who could not make any sense of their illness, no matter how hard they tried:

Before I got ill, my life used to be quite pleasant. It’s true that my sons had gone abroad, but I felt happy for them. My husband died years ago, and I have come to terms with it. So, my life was all right then. I still do not understand why... why... for what reason this disease... I am not obsessed by it, but I must admit that I keep asking myself why. All the sick people I have met had a very clear understanding of why they had developed a particular illness.

For instance, one person said “I lost a son, and then my illness started”; another one said she had had three children one after the other.

Whether the origin of the disease could be explained or remained unexplained, a sense of uncontrollability was expressed by some participants regarding the risk of transmitting their disease to their descendants. One female participant, who had decided not to have children because of the risk of genetic transmission, reported how anxious she had been during her sister’s pregnancy because of the risk of transmission to her nephew. In the case of communicable diseases, such as AIDS, the risk of transmission appeared to be less frightening because it is more controllable.

Although not the majority, some participants reported feelings of fear and of uncontrollability regarding the unconscious transmission of their fears and negative feelings associated with their disease:

Although it is not what I wanted, I could not control my fears during the first years of my daughter’s life, and I passed my fears on to her. I was so much after her that she did not allow herself to walk until she was over 15 months old... Today, I realize with great satisfaction that my daughter is a pragmatic and confident young lady. Knowing how much children are able to understand and absorb from their parents’ feelings, although I tried to keep my fears to myself, her development could have been affected by my fears.

Loss of Control Over Time

The experience of time was reported to have fundamentally changed since the participants had to learn to live with a chronic illness. The time one could devote to oneself and one’s priorities was defined as being limited to the time remaining after the disease has taken all the time it needs:

It’s hard to get dressed in the morning, to attach my necklace, to put my earrings on, to comb my hair... everything is hard... Simply attaching hair clippers has become a whole story... In the morning, I need to be cautious not to hurry myself or push myself around because I cannot bend down. My stomach won’t take it! Therefore I need to take an awful long time to get ready in the morning. If I have an appointment at 9 o’clock, I need to get up at 7. I have breakfast and then I have to stand for a while. Only then can I start doing my other things. If I hurry I get stomachache.

Not only the experience of present time but the perception of the time that remains to live was modified, as
well as the representation of what might be done or achieved during this time. For instance, 2 female participants in their 60s, as well as a participant in her 30s, all married and with children, reported that they had long thought they would never be able to marry because of their disease. A young man in his 20s, talking about future career options, reported being unable to make choices and set goals for and by himself, as he felt that his life was controlled by the perceived uncertain course of illness.

The perceived uncertainty linked either to some episodes or the future course of a disease, made it difficult for many patients to plan even short-term projects:

My hobbies mean a lot to me but I’d like you to know that it has become very difficult to plan anything now. It’s hard to decide let’s do this or that next week-end because who knows if I’m not going to be stuck and unable to move. It has happened before and we had to cancel our plans. Of course, the children complain.

There is no future. There was a time when I did not even know what I would do the following day. It was impossible to make any holiday plan. Life had changed to the extent that it was impossible to talk with my husband about anything but my illness.

Intense suffering was associated with having to renounce some long-term projects that used to be linked to essential aspirations of the person, such as the project to have a child. One participant’s reported lack of motivation to study while she was an adolescent can be explained by the perceived uncertainty regarding the future course of her disease. She felt a pragmatic urge to enter an active professional life rather than to study for a hypothetical better future. However, at the time she was a student, she was aware only of her difficulty in concentrating.

Several patients pointed out that to feel serene, they had been forced to learn to live for very short periods at a time, carefully avoiding making plans: “In order to feel well, I concentrate on living one day, one hour, sometimes even one minute at a time.”

Loss of Control Over One’s Environment

Many participants in our study explained how their disease had made them more dependent on some aspects of their environment. Especially when the disease is disabling, any physical environment other than home becomes threatening, because it is not adapted to the person’s needs:

Even in hospital, you know... I was in hospital and during two days, I did nothing but cry. I was out of my home... I felt like a fish taken out of the water and left on the floor to... you don’t know who you are anymore. Even in a hospital... don’t you think it’s different! Even there... you’re so dependant on others.

For another participant, losing control over the environment meant that she could not travel as much as she did before. Therefore, she felt that the world for her had shrunk to her immediate surroundings, with consequences on her social network as well. Two participants mentioned that the fact that they were now unable to drive had made them dependent on another person’s goodwill to have access to some facilities and activities that had been at hand before. A few participants reported that their environment and possibilities had shrunk to a great extent, not so much as the result of their own physical limitations but more as the result of the cost of their disease, including treatment, home facilities, caregivers’ salaries, and so on.

Some participants explained that they had become the prisoners of an undesired situation as a result of their inability to act by themselves on their environment; in particular, 2 participants felt that their disease had made them dependent on a spouse whom they would probably have otherwise divorced.

Becoming dependent on some aspects of their environment or on another person resulted for some participants in the feeling that they had lost their inner sense of control and confidence as well. Several female participants in their 30s expressed an increased need to be in the presence of their mother, even in the absence of a physical disability:

Every afternoon, I visit my mum. . . I take the dog out and we walk to my mum’s. We leave at 3:30 pm and arrive there at 4:00 pm. My mum makes a cup of tea, we chat a bit. Usually, my nephews are there as well. At 5:45 pm, it’s time to go home. At 6:15, I am back home and start preparing the meal for me and my husband. . . Sometimes, I also go shopping in the morning with my mum. We ask my dad to take care of the little ones and here we are, my mum and myself, out for shopping and a cup of coffee. I feel I have managed to organize my life quite well that way!

Loss of One’s Social and Personal Identities

The loss of identity as a consequence of being ill appeared in our study to be the most distressing
situation of powerlessness. People who had previously enjoyed being in control of things and who described themselves as having a managerial type of personality appeared in our study to be at greater risk of experiencing a feeling of loss of their sense of identity:

Before, I was in my role... even when I was a little girl, I always used to... and everybody used to say to me that I should have a job where I would be supervising others... Well, I had my job and I was the boss, wasn’t I?... So when you fall and you can’t get up again, you wonder “what happens to me?” and you start putting yourself down and you don’t know who you are anymore.

The findings presented hereafter emphasize two dimensions of a person’s identity that might come to be threatened or challenged by chronic illness: (a) the social dimension of identity, that is, how the person perceives him- or herself as functioning in different social roles; and (b) the personal dimension of identity, that is, the person’s self-image or self-representation.

The Social Dimension of Identity

Being unable to maintain social roles or functions, or fearing that some social roles might be impossible to maintain in the future has been experienced by many participants as a threat to those stable dimensions or features that are constitutive of a person’s sense of identity.

Many participants in our study acknowledged some dimension of their lives where they could not function anymore as they previously did, and reported feeling changed and appearing as changed to others. One domain often cited was work. Being able to work appeared to be an important dimension of a person’s social identity, although different participants had different reasons for the importance to them of being able to work. For some participants, work was presented as being part of their system of values, which was deeply rooted within the family history. A participant who explained that she had never relinquished work, often disregarding physical symptoms such as pain or tiredness, remarked, “I would have felt like a worm if I had indulged myself not to go to work.”

For other people, provided colleagues knew about their disease, work was considered a source of social consideration that added to their self-esteem. However, only those who had already accepted their “being ill” as a part of their identity considered work as a source of social consideration and self-esteem.

For those who had not yet accepted it and were still refusing to talk about it, work was still considered as an important dimension of the social identity, but in the sense that as long as they were able to work and conceal their illness from colleagues, their sense of being a normal person was maintained.

Eventually, work was considered a source of financial autonomy and an opportunity to meet other people. One person, who had been homebound several years, happily stated that she had just started working again as an employee. This person had sufficiently accepted her identity as an ill person to not complain about the loss of her former job, where she had been more independent and made more money. On the contrary, although she did not have any physical disability that would have impeded her from working, one young woman explained that she had made the choice to stay at home rather than to continue working because she felt she was not the same person any more and could not bear the idea of presenting herself in a different way to her colleagues; “I feel I cannot be 100% myself with my colleagues... in such conditions I refuse to show up.”

For many participants, the difficulty or inability to function “normally” led to some changes in hobbies and leisure as well. As it was the case with work, some patients decided to give up an activity or a social network they had enjoyed before, not always because they were strictly prevented from doing it because of some physical or medical limitation. The feeling that one was not the same any more was sometimes sufficient for a person to take the decision to stop an activity. There were three possible explanations for the feeling of isolation experienced by some participants, possibly reflecting a more or less internalized locus of control. Some participants considered the disease itself as a source of isolation, insofar as they had physical impediments to participating in activities. Depending on the level of acceptance of the disease, this situation was either accepted or considered revolting. Other participants considered that it was other people’s fault if they were alone. They said that people had gone off them and expressed a sense of stigmatization and injustice. Eventually, some participants were aware of their own inability or refusal to participate in the same activities as before because they felt they had changed too much.

Role changes as a result of the person’s illness occurred frequently in the family life as well.

As stressed before, some patients became more dependent on a reassuring person, such as a spouse or parent:
I could go anywhere, provided my husband is with me. Without my husband, just by myself, I am not able to go anywhere . . . It’s very important for me to have my husband by my side. I tried . . . I went to the sea once. After 3 days, my husband had to go back to work and left me. The day he was going to go, I started to feel bad, having nausea and vomiting . . . I guess you could call it a psychosomatic disorder. It was due to my fear of being left by myself.

Although some participants enjoyed feeling close to someone who was taking care of their well-being, others, who were aware of role changes in their families, complained about feeling overprotected or being put at the wrong place:

It’s a bit hard with my husband sometimes. I know it’s for my own good but I must admit that the concern he shows for me, telling me to eat this, reminding me that I should eat more of that . . . well, I must admit that these sorts of reminders get on my nerves sometimes. He knows well that I do things right most of the time; so I think it’s a bit exaggerated . . . he tends to be overprotective sometimes, and I don’t like it much.

I got in trouble with my daughter at the beginning of my illness. She stopped studying for a while and came to live with me when I was homebound. She was frightened that I might die, and at the same time she was frightened that I might pass the disease on to her. She did not understand anything about the disease. It was too much for her . . . the problems came from both sides. Let’s put it that way: whereas we used to have a normal parent-to-child relationship before, the disease changed it all . . . it was as if she had become the parent and me the child. And that, I couldn’t accept . . . She always wanted to decide things for me and I kept telling myself, what is going on here? We had many disputes, we broke off many times.

Great suffering was associated with the awareness of not being able to fulfill completely a family role, such as the role of mother or grandmother. One participant explained that she had not been able to be fully a grandmother because of her fear that she might drop her grandchildren while trying to hold them in her arms when they were babies. Another one stressed that she had come to dislike family meetings because of others’ making her feel as if she was not normal because she did not have children although she had been married for a few years. One male participant felt particularly distressed, as he felt he could be neither a proper spouse nor a proper father, and maybe not even a proper man:

My wife does a lot at home. I do my best to do the most I can. However, she often does the hardest jobs now. She’s the one to mow the grass now sometimes. I wish I could help more.

Some participants stressed that the family roles had not necessarily changed as a result of the family’s adjusting to the illness of one of its members. Their disease, however, had made them aware of preexisting dysfunctional behaviors within the family. One participant, who was diagnosed at the age of 12, described her disease as having revealed or uncovered her father’s lack of involvement and responsibility for family matters. Another participant realized how little help she had always gotten from her husband in running the house and how big the burden of her responsibility had always been there without her being aware of it before.

The Personal Dimension of Identity

The social dimension of identity is not the only thing that changes as a result of having a chronic illness. Perhaps more difficult to deal with is one’s changing self-representation or self-image. A latent question most patients reported as having had on their mind at one time or another was, “Am I still a normal person despite my disease?” Some patients reported having conflicting self-representations, in particular when the image reflected by others did not correspond to their inner self-image.

Without being aware of it, one participant explained that he had always restricted his life to places and people where he felt his self-image would not be threatened. His career had been limited to secondary positions, his priority being not to do something he liked but to work with medical or paramedical staff, as only persons with medical knowledge, he thought, would accept working with a sick person and not make him feel that he was abnormal. In other words, this participant had engaged in a process of self-stigmatization that had made him dependent on his environment’s reactions to feel normal or abnormal. In other participants, the internalization of a representation of abnormality was found to be linked to avoidance behaviors, including avoidance of seeking timely medical help.

On the other hand, some participants were very assertive about their being normal beings despite...
other people’s stigmatizing representation of them. One participant, whom we visited at home, was very angry by the time we arrived because she had just been sold rotten vegetables from the shop downstairs:

People who see you are ill try to take advantage of you and cheat you. They never realize that before being ill you used to be a normal person, just like anybody else. . . . For these people, your disability is not only physical. They consider that you also have a mental disability. And that’s the problem. And that’s why I am so angry. . . . People should be aware of our disease but always bear in mind that they are talking to normal people not to stupid sick idiots. . . . It is true that we are sick and that our capacities are therefore somewhat different, but I am fully able to talk and to think in a coherent manner . . . I am still the same. I have not changed. My problem is that I cannot allow myself to be as assertive as I used to be because people will think badly of me, and pretend that I am pretentious and authoritative. Because I am dependent on other people to have the necessary time for me, I cannot behave anymore as I used to. I have to change my way of being. But looking deep into myself, I am still the same.

Independent of other people’s reaction, some patients reported to have had at some point a feeling of abnormality due to their physical changes, which they found hard to accept. As one participant put it, “The disease makes your body change and you start to not like yourself anymore.” Not only did the participants complain about changes in physical attributes, some also complained about changes in character that made them appear as strangers to themselves and tended to lower their self-esteem. For instance, one participant considered that she had acquired a tendency to be lazy, whereas she had enjoyed being more active; other participants complained about mood swings or being visibly too emotional.

Some feelings, such as guilt, shame, or jealousy, which are generally associated with low self-esteem, were described by some participants as being new and unpleasant to them. “One feels so guilty for being sick. I think I am over it now but I used to feel so guilty at the beginning because everything was upside-down because of me.”

Different self-images might exist within the same person, sometimes leading to a conflicting sense of identity. In our study, some participants were found to hang onto their former self-image, which tended to form an ideal representation of self against which the present self and future possibilities were difficult to define and to judge acceptable. Implicit or explicit conflicts were found to exist as well between internalized and externalized self-images. One participant stated:

When I do not feel well, I am very talkative within myself. Everything looks nice externally, but inside 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 and open a good bottle of wine. He says: “you look good” . . . He doesn’t see me that often. He only sees the image I let him see of me. And I am happy that way. . . . I want him to leave without being worried about me. If he’s like me, he may ruminate it all in his head and I don’t want that to happen. For me, it’s important to control the image of myself I allow others to see.

Although admitting to directing most of her mental efforts toward controlling her image so as to maintain the appearance of a person who was in control, this participant also admitted to feeling “like a turtle on her back” when she was in an environment other than her known environment. The struggle to maintain one’s appearance might appear to be a response to a desperate need to feel in control, but in some cases it might endanger the person, who becomes at risk of developing a split personality. As a participant said, “It’s like leading two lives in parallel. It creates a contradiction within your existence, your personality.”

Discussion and Conclusion

The ultimate aim of our study was to understand better the meaning of the experience of empowerment as it can evolve from a situation or feeling of powerlessness in patients with various chronic conditions. In an attempt to better understand and describe the general feeling of powerlessness from which a process of empowerment may evolve, we looked for the commonalities in different individuals’ experiences of illness. Although every situation, every life-world, was unique, our analysis, which consisted of a slow progression from thematic categories of analysis within individual interview transcripts to conceptual categories that emerged across the reconstituted narratives and were examined in relation to findings from the literature, allowed us to identify Insecurity and a Disrupted Identity as two major factors of powerlessness that were common to the experience of all the participants in our study. Building on these findings about the experience of feeling powerless, we argue that a “successful” process of empowerment
might occur when patients come to terms with their threatened senses of security and identity, not only with the management of their treatment. One of the primary aims of an empowering relationship might therefore be to not provide immediately choice and opportunities for participation and self-determination but to provide reassurance and opportunities for self-exploration instead.

The Loss of One’s Internalized Sense of Security was one of the two conceptual categories that emerged from our transcripts, as we were looking for the commonalities in the problematic situations that were described by the participants as potentially or effectively leading to a feeling of powerlessness. A sense of security provides the basis of world exploration and self-growth, and develops very early in childhood, as infants experience constancy in bodily perceptions and responses of their environment (i.e., their caregivers) to their actions. As Kelly and Field (1996) put it

A central prerequisite for the development of the human (i.e., social) being is the control of the physical body and its capacities. Such control and the knowledge it brings provide a sense of constancy of the embodied self and the ability to plan and predict future actions. (p. 244)

Hence, 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, might create a feeling of insecurity that can inhibit one’s ability to explore and learn.

As in other studies about the experience of chronic illness (Adams, Pill, & Jones, 1997; Bury, 1982; Charmaz, 1983; Mathieson & Stam, 1995; Nochi, 1998), the second important category that emerged from the analysis of our transcripts was related to the sense of disrupted identity, which we have named the Loss of One’s Personal and Social Identities. This category is very similar to what Charmaz (1983) has termed the Loss of Self. However, we opted in the presentation of our findings for the term identities rather than self. What we have named a Loss of Personal and Social Identities could be usefully interpreted as a loss of the sense of Sameness, which Ricoeur (1990, 1991) has identified as one use of the concept of Identity, distinct from another possible use: Identity as Selfhood. In our current understanding, it is not so much the sense of Selfhood (the very sense of being an individual, the author of one’s actions and feelings) as the sense of Sameness (the sense of uniqueness, continuity, and permanence) that is at stake when chronically ill patients struggle to maintain a sense of Identity. Moreover, the self might also be defined as the very regulatory and integrative process by which one’s sense of identity is being constructed (Horrocks & Jackson, 1972; Ryan & Deci, 2002). Although the issue of a disrupted identity is a central theme in the sociological approach to the experience of chronic illness (for a review, see Bury, 1991, and Conrad, 1990), and the importance of identity work (Adams et al., 1997) or identity formation (Tilden, Charman, Sharples, & Fosbury, 2005) for the successful management of a chronic condition has been well demonstrated, the literature on therapeutic patient education and empowerment (for a review, see Aujoulat et al., 2006) has failed so far to address this issue explicitly.

One reason might be that part of the process of developing and maintaining either a sense of security or a sense of identity occurs at the prereflective level of the lived body (Stelter, 2000; Toombs, 1993). As prereflective knowledge is difficult to put into words, these issues are difficult to tackle directly in the patient-provider relationship. In our work however, we have found that issues of feeling insecure and changed can be tackled indirectly by inviting people to talk about the concrete situations and difficulties they meet in their everyday lives as a result of having to live with a chronic illness. While recalling particular situations, some participants made use of metaphors, which were found to be a powerful way of expressing true feelings and representations while allowing both the researcher and the participant to keep a certain distance from the emotional impact of the situation or feeling revealed in the metaphor

When it is time for me to die, I am sure I will be given only little wings to leave Earth. That way, I will stick to the ground again, instead of being able to fly high up in the air.

**Limitation and Perspectives**

Congruent with the characteristics of our sample and our methods of data collection (one single exploratory interview), our findings are limited to a description of the commonalities in situations that might lead to a feeling of powerlessness. Specific aspects, such as the duration, intensity, and interaction of the two dimensions of powerlessness (i.e., insecurity and loss of identity), were not examined but deserve further investigation, as they might have an impact on
the general process of adjusting to illness and learning to manage treatment. As our aim was to look for the commonalities in the different experiences of powerlessness, we systematically checked the data for evidence of relationships with specific factors. We found that our findings could not be related to some “objective” characteristics of the participants, such as their age and sex, or the type or duration of their disease. For instance, at the time of the interview, a young participant with asthma and an older participant who had had diabetes for nearly 60 years were found to be using the same strategies to conceal from themselves how insecure they were feeling about having to manage different and conflicting self-images. Both reported meeting difficulties in managing treatment, and feeling that the disease was out of control. On the other hand, although she was quadriplegic and very dependent on sometimes very careless caregivers, one participant with multiple sclerosis demonstrated a high sense of personal worth and a great capacity for self-determination. This was not the case of a young participant with lupus, who admitted to feeling at ease only when confined at home, although her disease had not yet made her a visibly different person.

Using these few examples, we wish to stress that the feeling of powerlessness, from which a process of empowerment might evolve, does not seem to characterize a particular level of invalidity or a particular period, such as the onset of disease. Our findings are illustrative of an experience that the participants reported having undergone at some point since their illness had been diagnosed. For some participants, the problem of insecurity and difficulty in constructing a valuable sense of self through the consolidation of their identity was still an issue, years after the onset of their illness. To respond to the patients’ need for security and reconciled identity is a real challenge for health promotion and patient education activities.

References


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