Empowerment of patients and families: a multifaceted challenge!

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Marianne

- 38 years old
- Was diagnosed with cystic fibrosis at the age of 12
- Married, no children
- Met for a research interview* during a week of hospitalisation
- Coordinating nurse present during interview

* research interview on patients’ perspectives regarding their own empowerment
Issues tackled during interview

- Difficulties encountered during childhood
  - In relation with family:
    - Dysfunctioning aspects were revealed and amplified with announcement of diagnosis and management of treatment
    - Ambiguity in confront to her sister
  - In relation with condition:
    - Functional limitations (impact on social network)
    - Frequent hospitalisations, including non-planned emergency hospitalisations

- Mixed feelings about treatment
  - Depends on it in order to survive, and is grateful for it
  - Yet in the same time, hates treatment because of side-effect
    - self-determined and planned « drug holidays »

- Conscious risk-taking behaviours
  - Participation in outdoors events, in cold and rainy season
  - Refusal to eat
    - AFTER EVALUATION OF PROS AND CONS
Issues tackled during interview (2)

- Personal involvement in patient association
  - Recalls her best friend who has passed away... Her fight is also in memoriam of her

- Considers herself at risk of dying anytime
  - Has not made up her mind about the possibility of a transplantation

- Is well educated, but chose not to work
  - 100% invalidity pension

- Personal resources:
  - Tends to experience difficulties as positive challenges
  - Has real and own hobbies and pleasures
  - Is active and creative

- Illness representation:
  - « there are three of us at home that need to be taken care of: myself, my husband and my illness »
Following interview (in the elevator)

**The researcher:**
- Feels well and lighthearted
- Full of energy from the « diseased person » encountered

**The nurse:**
- Silent
- Pale
- Looks at her shoes
- Not at ease in relation to what has happened during the interview?
Leaving the elevator…

I have known this patient for years… I didn’t think she was like that…

What do you mean?

The invalidity pension for instance... well, not all patients stop working. Most continue to work actually. I used to think that she could make an effort... like the others... that she could have more willpower. However, I realise that I was completely wrong: In fact, she knows what is good for her, and she does what needs to be done in order to manage well her condition and her life!
Successfull process of empowerment

She knows what is good for her, and she does what needs to be done in order to manage well her condition and her life! »...

Outcome includes: autonomous decision making, self-management capacity, self-esteem, pursuit of meaningful life-goals, etc.

Concept of « healthy ill people » (Milz, 1972)
Broad definitions to set the scene

- **Empowerment**: A social process of recognizing, promoting and enhancing people’s abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their lives (Gibson, 1999)

- **Powerlessness (feeling disempowered)**: Occurs when an individual assumes the role of an object acted upon by the environment, rather than a subject acting in and on the environment (Freire, 1973)
  
  An individual’s belief that he cannot reach his goals through his own actions » (Seligman, 1972)

→ **Powerlessness significantly associated with poorer learning of health-relevant information, and with greater morbidity!** (Seeman & Lewis, 1995)
The risk of powerlessness is inherent to living with a chronic disease

- Chronic illness is a TOTAL EXPERIENCE, with consequences in all dimensions of patients’ (and their families) lives: physical, mental, social and spiritual dimensions!
  - Not all consequences are negative, but all are challenging!

- Every illness experience is NOVEL, UNIQUE and UNFORSEEABLE!
  - Former attitudes, norms and values may not be adapted anymore; new coping mechanisms need to be invented...

- Patients (and families) do much more than « adjusting to illness »... their process of empowerment leads to self-TRANSFORMATION!
A disrupted sense of security
- Changes in bodily perceptions
- Functional limitations
- Loss of control over daily life-situations that are generally taken for granted
- Etc.

A disrupted sense of identity
- Conflicting self-images
- Changes in social roles
- Loss of meaningfulness
- Etc.

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

Aujoulat et al., Q Health Res, 2007
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 regimes 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.

Keywords: Belgium; Italy; Chronic illness; Patient Education; Powerlessness; Empowerment; Self; Identity


The essence of the process of empowerment

Need for Security
GETTING CONNECTED

Need for Control
TAKING ACTION

Need for Coherence
MEANING MAKING
& LETTING GO
The essence of the process of empowerment

Need for Security
GETTING CONNECTED

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Need for Coherence
MEANING MAKING & LETTING GO

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Abstract

Studies that focus on patient empowerment tend to address more specifically two issues of patients’ experience of illness: managing regimes and relating to healthcare 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 48 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 was conceptualised as a threat to their sense 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) “building up” 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 (ii) “letting go”, by accepting relinquishing control, so as to integrate illness and illness-driven boundaries as being part of a reconstructed self. Whereas the process of separating identities (“building up”) was found to be linked to efforts centred at taking control and maintaining or regaining a sense of mastery, the process of reconstituting 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 healthcare providers through the use of narratives.

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Common challenges

- **Illness work:**
  - managing symptoms, understanding physiopathology, preventing and managing crises, etc.

- **Everyday work:**
  - « unescapable » routine tasks: housechores, children, profession, eating, bodycare, etc.

- **Biographical work:**
  - reconstruction of one’s identity
    (Strauss & Corbin, 1985)

All three are equally important in a successful process of empowerment!
Need for control

Taking action
Need for control

- Attitudes of forcing oneself to go beyond limitations to maintain former social roles and self-images
- Active search for information regarding disease and treatment
  → expert patients...

Relevance of patient education to address this need and support self-management capacity!
Need for control

I have never indulged myself to miss a single day of work. Had I done so... I would have felt more ugly than a maggot!

I gathered the necessary information and discussed it with my doctor (...). I made the necessary photocopies for my colleagues to know how to react in the event of a crisis.
Features of empowerment supporting patient education interventions

Promotes and respects the patients’ responsibility and right to self-determination

Is patient-centred (acknowledges patients’ needs, priorities, values, possibilities...)

Is based on experiential learning and shared decision-making

Facilitates the development of transversal as well as specific skills (life skills as well as specific disease-management skills)

Adjusts to the patients’ time...

Acknowledges uncertainty... that of the patients and that of the healthcare providers!

Aujoulat et al., Pat Educ Couns, 2007

GENERAL PRINCIPLES... DOES NOT TELL US HOW IT WORKS FOR PATIENTS AND PROVIDERS

Aujoulat - Bruxelles 24 MAY 2012
Interventions that support patient empowerment

- **Are necessarily complex and adaptative** (Greenhalgh, 2009)
  - Healthcare providers do not empower patients…
    - they need to find ways to support/facilitate their patients’ own process of self-empowerment!

- **Double bind**:
  - Therapeutic patient education interventions need to be STRUCTURED and PLANNED, and yet be flexible enough to respond to the patients’ and their carers’ (families and healthcare providers) UNIQUE NEEDS in unforeseen situations
To become knowledgeable about one’s condition and treatment, ie. expert patient

An essential aspect of patient empowerment:

- Increases self-efficacy (precursor of capacity to take action) (Bandura, 1977)
- Enables to develop knowledge and skills involved in self-management
- Enables to define and master relevant objectives for the safety of the patient (Gagnayre & d’Ivernois, 2001)
- Enables to conceptualise disease as an object that is separate from self (Bury, 1991; Paterson et al., 1999)
- Contributes to maintaining a sense of normality (Charmaz, 1987; Finlay, 2003)
To become knowledgeable about one’s condition and treatment, i.e. expert patient

An essential aspect of patient empowerment:

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- Increases self-efficacy (precursor of capacity to act) (Bandura, 1977)
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- Enable to define and master security objectives (Gagnayre & d’Ivernois, 2001)
- Contributes to maintaining a sense of normalcy (Charmaz, 1987; Finlay, 2003)

...is it sufficient?
Louise, 47 years

Looking back,
I ask myself whether 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!
Monique, 45 years

“It’s all about limits...
To be ill confronts you with your limits.

They (doctors) keep telling you:
“don’t do this, don’t do that”,
and there you are made still.

When you manage somehow to do this or that
(which is contrary to what you were prescribed),

then only may you realise that
you don’t belong to the Dead
as they had already categorised you,

but that you are still alive instead!”
Need for sense and coherence

Meaning making & Letting go
Need for sense and coherence

Therapeutic objectives and life priorities need to be congruent, and meaningful

- **MEANING-MAKING** = process of reconciling conflicting identities
  - One’s identity as an ill person may be appropriated as part of self
  - Disease may be perceived as making sense, life as worth living
- **Attitudes of LETTING GO**
  - Acknowledgement and acceptance of what is not controllable

To let go does no mean that one is passive, but that one is active in a different way: in order to live with a chronic condition, one must take action without wanting to control (…) The ability to tell what may be controlled from what may not be controlled, results from action. It does not precede action » (Mol, in: Lefève, 2011)
Need for sense and coherence

Therapeutic objectives need to be congruent with life priorities and meaningful
Search for MEANING = process of reconciling conflicting identities
Disease may be perceived as making sense, Life as worth living
The identity as an ill person may be appropriated as part of self, without threatening
Attitudes of LETTING GO
Acknowledgement and acceptance of what is not controllable
emergence of new values and priorities; creative involvement in modified projects
To let go does not mean that one is passive, but that one is active in another way: in order to live with a chronic condition or to care
for others or oneself, one must act without wanting to control (...)
The ability to tell what may be controlled from what may not be controlled, results from action. It does not precede action »
(Mol, in: Lefèvè, 2011)

During the two first years, I had to fight against myself. But as soon as I accepted 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 the disease! (...) Then I was able to manage it.

When I went to hospital, I asked my colleague to replace me. I asked her to not tell my pupils about my illness. However, when I came back, the first thing I told them was: « you know, I have this disease which I am not able to control »... Now I know that they see me the way I am...
The worse about all of this, is that terrible feeling of POWERLESSNESS: one feels as if one’s life was completely out of control!

I CONTROL myself, and struggle so as to not be defeated by the disease. I force myself to keep feeling that I am stronger than the fear of the disease that is inside me

I am not a diseased person… I am a person with a disease, and that’s much different!
Empowerment of patients and families

- A PROCESS that is always in progress!
  - shaped by the patients’ and their families’:
    - Own activities and experience, self-reflection, learning, self-determination, creativity, etc.
    - Interactions with others (including experiences of dependence!), that support needs for security, control and coherence

- Why is it important?
  - Better self-management of condition
    - Impact on physical health and emotional well-being
  - Better integration of illness representation and self-concept
    - Impact on mental and social health
  - Access to better care
    - Reciprocal relationship between patient empowerment and patient-provider interaction: Less clinical inertia toward empowered patients!
  - .... Better HEALTH and better LIFE!

Thank you for your attention