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‘I’m Cured But....’
Perceptions of Illness Following Treatment

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Abstract
The current qualitative research studied representations of illness post-treatment from a heart transplant group, a panic disorder group, and a tic disorder group. All three groups were preoccupied with perceptions about the impact of the illness, perception of self and the perception of how others view the ill person. The heart transplant group seem to adopt an active style of coping compared to the panic disorder group who presented a more passive, anticipatory mode of coping, and the tic group who were preoccupied with control over the perceptions of others. This qualitative information could help optimize adaptation strategies.

Keywords
- heart transplant
- panic
- tic disorder
- illness representation
- qualitative methods
Introduction

RECENT research suggests that patients’ beliefs about their disease are of fundamental importance in their adaptation to their condition. Scharloo et al. (2000) reported that illness perception and coping contributed to the prediction of mental health, health perceptions and social and global functioning at one year follow-up in participants suffering from chronic obstructive pulmonary disease. In a population of chronic fatigue syndrome participants Moss-Morris, Petrie and Weinman (1996) found illness perception explained 37 percent of the variance in dysfunction and 30 percent of the variance of psychological adjustment. In particular, illness perceptions are linked to decisions about adherence in different areas such as rehabilitation (Petrie, Weinman, Sharpe, & Buckley, 1996) and medication adherence (Meyer, Leventhal, & Gutmann, 1985).

The health psychology literature suggests that the way in which individuals interpret their illness or the representations they form of their illness are associated with the adoption of behaviors aimed at adapting to their health problem. Representations have been defined in the anthropological literature as a complex and organized entity that includes information, thoughts and attributions on a particular subject (Abric, 2003). In health psychology, this concept explicitly addresses how people actively represent the illness to themselves. The main advantage of understanding illness representation is that it can explain what seem to be irrational health behaviors for health professionals, but make sense in the understanding of the patient (Coutu, Dupuis, Marchand, O’Connor, & Trudel, 2000).

The importance of understanding illness representations has been supported by several studies in various health conditions (Buick, 1997; Haidet, Kroll, & Sharf, 2006; Heijmans, 1999; Moss-Morris et al., 1996; Petrie et al., 1996; Whitmarsh, Koutantji, & Sidell, 2003; Wyer, Earll, Joseph, & Harrison, 2001). Illness representations have been mostly studied in physical disease. In fact, to our knowledge, only one study has addressed a psychological disorder. Illness representation of depression was assessed in order to predict medication compliance and coping behaviors, such as active coping, and passive coping (Brown & Dunbar, 2001). Also, there have been no studies comparing health perception across physical and mental illnesses. Furthermore, existing quantitative measures tend to be formulaic and standardized and may lack subtlety in recording idiosyncratic information on perception (French, Marteau, Senior, & Weinman, 2005). Qualitative approaches have been increasingly the methodology of choice for exploring subjective representations and discourse in health psychology and seem essential to accurately reflect patient experiences.

Aim

The aim of this study was to improve knowledge concerning representations of illness in three types of problems, one physical, one psychological and the third psychophysiological. The three types of problems, respectively: heart transplant; panic with agoraphobia; and Gilles de la Tourette and tic disorder, allowed a transdiagnostic assessment of people with both physical and mental problems, in order to assess the role of illness representation across illness domains. The research questions concerned the similarities and differences between patient groups in illness representation, both within each illness domain and across diagnostic categories, and transdiagnostic links that could clarify our understanding of the role of illness representations and clinical utility of this qualitative information.

Choice of qualitative approach

All qualitative methods share the aim of describing the richness of personal testimony with as little imposition of outside explanatory theory. Experience and the context of psychological experience is well captured by phenomenological approaches. Giorgi (1985) has developed a phenomenological method involving reduction of personal narrative to key meaningful contents and was preferred over other interpretative phenomenological techniques because description is narrow and accords more directly with the verbatim. In addition, of interest in the current study was moving from personal themes to cognitive constructs since it was cognitive representations, particularly of how the person was actively positioned regarding their health issue, which were hypothesized to function as guides for health decisions.

Kelly’s (1955) personal construct theory offers a way of capturing cognitive constructs in a qualitative manner by use of his repertory grid technique. Here significant elements of a person’s world are compared by a process of triadic sorting to elicit both implicit and explicit poles that structure perception of the world. Implicit constructs represent the polar opposite of the constructs explicitly elicited in the sense that, for example, the explicit construing of an element as ‘good’ implies an implicit opposing construct of what
is ‘not good’. The extent to which each construct pole applies to each significant element is then assessed, so yielding a personal idiosyncratic picture of how personal constructs apply to elements in a person’s world.

Personal construct psychology can be used in combination with the phenomenological reduction in that events, preoccupations, people arising naturally within the person’s narrative can form significant elements of the person’s life which are relevant to the construal of their illness (Blowers & O’Connor, 1996). These first order constructs can also be grouped into super-ordinate constructs depending on their shared content. The personal construct dimension gives additional information of how significant elements in the person’s life are construed (or not) in terms of the themes relating to illness representations.

**Method**

The population was composed of five people who had received a heart transplant, five people who had received a cognitive-behavioral treatment for panic disorder with agoraphobia and three people treated by a behavioral-physiological program for managing tic disorder. All participants were aged between 18–65 years. At the time of interview all people had already followed a recommended evidence-based treatment protocol, which minimized differences in preoccupations between patients due to treatment expectation.

The population with panic disorder was recruited from the outpatient department at a hospital clinic setting in Montreal (Québec, Canada), specializing in the treatment of anxiety disorders. The participants experiencing Gilles de la Tourette syndrome or chronic tic disorder were recruited from a behavioral-psychophysiological treatment protocol at a specialized research center in Montreal (Québec, Canada). The heart transplant population was recruited from a hospital specialising in cardiac care. All participants had received a transplant during the last three months and had not been previously diagnosed with a psychiatric disorder (according to their medical notes).

The same recruitment procedure applied to all participants. A health provider attached to each of the three respective clinics established an initial contact where the project was outlined. The project description emphasized the importance attached to personal discourse and the key contribution of the person’s experience and their personal testimony to understanding health perception. If the person showed further interest, a research assistant attached to the project re-contacted the person. An individualized one-on-one meeting with the participant permitted explanation of the aim, format and duration of the project.

The person then signed a consent form that had been approved by three local ethics committees (University, Institute and Hospital committees), which fully explained their right to withdraw from the study at any moment without prejudice. Participants also completed a battery of quantitative measures and a further arm of the study looked at the qualitative evolution of the health representation through telephone follow-up over an eight-month period. The present report concerns the initial baseline interviews conducted with each participant.

**Interview procedure**

Three doctoral students (CJ, CK, MJL) formed in qualitative methods and analysis techniques, undertook the interviews. All students received two months’ training in qualitative methods and personal construct psychology given by Dr Geoffrey Blowers and Dr Kieron O’Connor and attended workshops given by Professor Amadeo Giorgi in phenomenological methods. Finally, pilot cases served to train the group in consensus criteria. Each student had specialized in one of the three health areas. The interviews took place either in the respective clinic setting or at the participant’s home. At the time of interview, all tic disorder and panic disorder groups had completed a course of cognitive behavior therapy, while the transplant group had returned home following successful transplant. All patients were adhering to a post-treatment therapeutic schedule.

The interviews followed the phenomenological reduction approach developed by Giorgi (1985) and emerging themes were structured to elicit personal constructs using personal construct psychology methods (Blowers & O’Connor, 1996; Kelly, 1955). In this phenomenological approach, the entire description rests with the actual words and phrases of the person.

The domain boundaries and horizons of the conversational event space were defined by elements relevant to the health and illness representation of the person, namely: events surrounding the health problem; implication of significant others; significant or unusual events associated with the problem; interactions and interpersonal relations with friends, family and colleagues, and also with health professionals;
the person’s models and understanding of the problem and its future management; the vision of the person regarding quality of life; future control of actions and management of the problem. Each interview lasted between one to two hours and was audio-recorded for later transcription.

**Phenomenological reduction**

The phenomenological reduction was carried out through group consensus. The consensus group was composed of the three students plus a fourth independent graduate student in psychology (AR). The four members of the team extracted from the verbal transcript groups of ideas which repeated themselves, or which seemed to appear regularly in different forms. Points of contradiction and transition were also targeted with the idea of focusing on key ideas and themes of the person as they appeared in the text. The decision on the first descriptive reduction grouping together key themes was made by consensus following the discussion of each participant. Themes were retained or modified depending on the degree of consensus. As a check on validity, the final reduced themes were traced directly back to the original verbatim (see Table 1).

**Themes to constructs**

The themes were subsequently used to elicit implicit and explicit constructs. Explicit constructs were determined by members of the team and were derived to represent one or several similar themes, if several themes seemed to share common ideas. The team member who had conducted the initial interview returned to re-interview the participant. The participants were presented with the themes derived by the team and asked to confirm or disconfirm their significance. The construct was then derived from the themes and the person asked to provide an opposite (implicit pole) construct. The implicit pole is not the logical but the personal opposite of the explicit pole. So for example the idea of ‘directly addressing problems’ may be opposite not to ‘not addressing problems’ but rather to ‘thinking, living with keeping problems and staying with them’. At the same time, a modified form of Kelly’s construct grid was completed whereby significant elements (e.g. events, people, goals) in the person’s life were ranked according to the relevance of the construct evaluation (implicit or explicit pole) to each significant element emerging from the person’s discourse (e.g. people, events, situations, problems).

Key criteria for validity of the qualitative approach (Elliott, Fisher & Rennie, 1999) were met, namely: internal consistency; test–retest reliability; external validity or generalizability; inter-rater reliability. Additionally the sensitivity and specificity of themes was assured through element-construct matching within Kelly’s grid, according to personal relevance.

**Super-ordinate constructs**

A final reduction of the constructs themselves helped determine the ‘super-ordinate constructs’. The consensus group distinguished similar and discordant constructs, so permitting a reduction in the number of applicable constructs to each participant. The pathway from transcript to super-ordinate construct was traceable at each stage to the specific wording of the participant (see Table 1). The series of super-ordinate constructs for each participant are reported in Table 2.

**Results**

**Super-ordinate constructs within each group**

*Participants with a heart transplant*  A construct shared by all in this group related to their attitude and style of coping. In general their style was to face a problem head on, not give up, go forward with the struggle. Some rely on themselves as the key resource, some withdraw and search for a solution and for others it was a question of waiting apprehensively and prudently.

There was also a tendency for this group to see themselves as no longer ill following transplant and that the transplant marked a transition point between illness and normality. Although they considered themselves cured they realized they had limits to functioning, required further care and had to be prudent in their new well-life: ‘Well, yes, I’m cured but … there are difficulties and I need to be careful’ (Mr E).

Another theme consistently emerging was the idea of hope, faith and spirituality. Although only one patient alluded to miracles, it was clear that the recipients considered themselves blessed in the hands of faith. Several participants were also concerned to give back to others some of what they had received, almost as a duty. Here the explicit construct was defined variously in terms of exchange: to give, to help, to show concern for others versus being ungrateful.

*Participants with agoraphobia and panic disorder*  A dominant theme to emerge in this group was their ambivalent relations with others. On the one hand they needed others, but on the other hand they
<table>
<thead>
<tr>
<th>Themes</th>
<th>Explicit Constructs</th>
<th>Implicit Constructs</th>
<th>Super-ordinate construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of illness: Mr. C reports no difference between first and second transplant, but was more afraid of dying after the second transplant particularly. He notes he fears dying and not seeing his children again and not enjoying life at all. He specified that his first heart was for his children and the second for himself. Before the transplant he saw only darkness since there was no dreams or goals in life. It was punishing but worth it. He sees the transplant as a gift of life which permitted him to survive and imagine all that is possible.</td>
<td>I move on to other things. I spend my time attending to others.</td>
<td>I do not progress. I prefer to decide for myself.</td>
<td>I move on and I decide, otherwise I stay in the same place.</td>
</tr>
<tr>
<td>Coping with the problem: Mr. C says generally he has a solution to problems, if affairs don’t go well, he recovers quickly and maybe a bit impulsively. He notes when he makes mistakes, he learns to live with them. He can put aside problems, not be too preoccupied, or stress himself, but gives himself time and the problem solves itself. He always finds a satisfactorily solution to solve the problem.</td>
<td></td>
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<tr>
<td>The future: He future is his dreams and they are being fulfilled. They are simple dreams concerning walking, being with friends and pursuing a long held dream of buying a lot to build a chalet. His second heart is for him. He intends to do things his way. He will decide for himself and not spend his life listening to others and be influenced by others as he had previously. This new attitude is part of his dream and for him confirms that the future will be more relaxed and he will spend less time counting minutes and use the time more profitably.</td>
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Table 2. Super-ordinate constructs of each participant

<table>
<thead>
<tr>
<th>A) Heart transplant group</th>
<th>B) Panic and agoraphobic group</th>
<th>C) Gilles de la Tourette/chronic tic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr. A: 65 years old, married, working part-time</td>
<td>Mr. F: 50 years old, in a relationship, working full-time</td>
<td>Mrs. K: 26 years old, in a relationship, working part-time</td>
</tr>
<tr>
<td>Mr. B: 59 years old, married, working part-time</td>
<td>Mrs. G: 29 years old, in a relationship, working full-time</td>
<td>Mr. L: 55 years old, married, working full-time</td>
</tr>
<tr>
<td>Mr. C: 50 years old, married, working full-time</td>
<td>Mrs. H: 31 years old, single, working full-time</td>
<td>Mr. M: 29 years old, in a relationship, working full-time</td>
</tr>
<tr>
<td>Mr. D: 50 years old, divorced, invalid</td>
<td>Mrs. I: 44 years old, in a relationship, working part-time</td>
<td>Mrs. J: 39 years old, married, working full-time</td>
</tr>
</tbody>
</table>

**Address solutions and don’t just shrug shoulders**

- Mr. A: 22 years old, Mr. A: 65 years old, married, Mr. B: 59 years old, married, Mr. C: 50 years old, married, Mr. D: 50 years old, single, working part-time
- Mr. E: 22 years old, single, working and studying part-time

- It’s me who knows what is best for me, otherwise others will decide all the time
- I finish upright to the end, otherwise I accept what happens and I’m cured but… (being cured means lots of restrictions)
- I’m cured but… (being cured means lots of restrictions)

**I will give back to others or will seem like I am indifferent to other people**

- I will give back to others or will seem like I am indifferent to other people
- To fight, struggle and live to the full or I’ll be giving in
- I like to be helpful, otherwise it seems like I’m not interested in others

**I’ll be calm, peaceful, content, or I’ll be a bundle of nerves**

- I will give back to others or will seem like I am indifferent to other people
- To fight, struggle and live to the full or I’ll be giving in
- I like to be helpful, otherwise it seems like I’m not interested in others

**B) Panic and agoraphobic group**

- I must deal with problems and work them out myself, otherwise it’s like I’m shrugging my shoulders
- When I’m not able to control myself, then I’m in a panic and it frustrates me
- I need to know myself and my needs or else I’m ignorant
- I need others but I feel they judge me
- I need others around me or I’m not secure

**I need to know myself and my needs or else I’m ignorant**

- I must deal with problems and work them out myself, otherwise it’s like I’m shrugging my shoulders
- When I’m not able to control myself, then I’m in a panic and it frustrates me
- I need to know myself and my needs or else I’m ignorant
- I need others but I feel they judge me
- I need others around me or I’m not secure

**C) Gilles de la Tourette/chronic tic group**

- If I can’t control my tics, then I’m out of control and the tics will get worse
- I fear upsetting others but I’m not upset, so why should other’s be upset
- I can’t control my tics but I want to be taken as I am for myself
- Everything in life is important but if you relativize, you could miss important things
- It’s a constant battle to relax, otherwise you stay tense all the time
- If you’re not like everybody else, you’ll be excluded
preferred to cope with their problem on their own and desired autonomy. Also, there was a theme of fear of being abandoned and rejected; the fear of the judgment of others was expressed frequently in their discourse. The fear of being judged badly if they spoke of their difficulties or if others saw their difficulties was also an important preoccupation. Interestingly they were often very severe and judgmental about themselves. Implicit–explicit constructs reflected representations of dealing with problems but depending on others: ‘I need the presence of others continually. I’m unable to stay alone in the house. I’m scared of everything. Yes if I was on my own I wouldn’t be here. I’d be in the wood. Alone in the wood’ (Mrs I).

Participants with Tourette/tic disorder A constant concern in this group was the impact of their tics on others around them. There was the hope that others would see them as who they were despite the tics, but some feared that the tics disturbed and annoyed others. Most had developed strategies to foresee the reaction of others and to insist that they were just like other people, and that nobody is perfect. The construct representations viewed the disorder in terms of normality and control: over tics, over self, acceptances by others.

Similar to the participants with panic disorder, their attitude toward others showed ambivalence; on the one hand, they seemed to present an attitude of ‘take it or leave it’ toward the viewpoint of others (‘if they don’t like me, it’s their problem, they should take me as I am, their opinion doesn’t affect me’ [Mr L]). But on the other hand, they were clearly preoccupied about what others thought, and the expectancies and interpretations others formed on the basis of their reactions to the tics. Nonetheless participants wished to be like everybody else.

Transdiagnostic links

Attitude to the problem In those with heart transplants, attitude seemed to take a front seat in coping; they spoke of the importance of being proactive, struggling to the bitter end and not giving up. The approach was positive and optimistic with respect to future obstacles and they were insistent that they not get discouraged or passively resigned to fate: ‘You must remain positive, because if you give up it’s deadly. You need to be positive. You need to believe you will get where you went’ (Mr A).

This fighting stance was in contrast to the panic group who also spoke of their coping difficulties but verbalized these more as anxieties, fears, doubts which they anticipated as surpassing their capacities. Their coping style was hence more one of contemplation and rumination about their difficulties rather than acting on them: ‘I need to anticipate all the time. Any day, I’m always thinking ahead to tomorrow. I need to do this and that and the other’ (Mr M).

As with panic and agoraphobia, for people with tics, the condition was perceived as chronic, with the emphasis on better control not on cure. Also the distinction of the problem from the person was less evident as expressed, for example, in the phrase: ‘It’s part of my personality’ (Mrs I).

In both tics and panic there was a sense that ‘vigilance’ or prudence needed to be maintained, but in the transplant case such prudence was of a different nature post-operation, whereas for both the panic group and the tic group there was a feeling of a continuity of the problem and the need for vigilance pre- and post-treatment.

Interpersonal relations The transplant group saw themselves as able to cope by themselves and hence enter into relations with others as an equal exchange. An exchange one could accept or refuse. There was no need to listen to others to decide on what was good for them, but even if the best course was self-protection and not letting others interfere, it was noble to help, it was noble to help others to give back attention and concern:

You know, letting yourself be helped when you are used to fixing everything yourself, and now you need help, that’s what I found the hardest. (Mr D)

And when I say I’m realizing my dreams, no one is going to change my opinion. I’ve spent my life listening to others: ‘You must do it like this . . . ’ OK. For once in my life it’s me who decides. (Mr C)

In the panic group the impression was one of ambivalence toward the other. On the one hand they require others to feel safe, but they also desire to be alone and autonomous: ‘I shut myself off for a period of time because I didn’t wish to see anyone’ (Mr F).

For the tic group, the relationship with others turned largely around their fear of upsetting others with their tics, of being judged prematurely and badly and not being accepted for who they really are. The fear of judgment of others is also reported in the discourses of those with panic but absent
completely in the transplant group. However, in the tic group, the fear of judgment seems related directly with being accepted by others as normal.

Personally I’m not disturbed in any way whether people see my tics or not. The only issue is, let’s say, I’m sitting in the metro and there is someone beside me. People think I cough. Sometimes they cough themselves. They don’t know I have tics. (Mrs K)

Discussion

The aim of the study was to obtain qualitative information on illness representation in three patient groups, one having undergone a heart transplant, a second suffering from a psychiatric disorder of panic with agoraphobia and a third diagnosed with Tourette syndrome/tic disorder which could be considered a neuropsychiatric or psychophysiological disorder.

After phenomenological reduction, themes were grouped into explicit and implicit personal constructs as they applied to significant elements surrounding the illness. Transforming the themes into personal (super-ordinate) constructs allowed us to see more clearly the way the illness representations affected significant elements in the person’s life, and how perception of the illness formed part of a wider construction of social reality relevant to functioning. The constructs revealed distinct positions toward illness, treatment, recovery and others and in particular a dynamic representation characterized by a concern about interaction with others. The discourses revealed how the importance of interactions with others, impact on interpersonal relations, work, profession, quality of life, and how the reactions and behavior of others impacted on their sense of self and independence and how this influenced coping, thoughts of the future and adaptation in life.

In a dynamic model the relationship between the representation of the self as ill, representation of the impact of the illness on relations and life and the representation of how others perceive the self as ill, may combine synergistically to dictate successful adaptation strategies. All three groups were concerned with how illness touched their self and coping, how it impacted on others and how others viewed them and their illness. But the three groups were preoccupied in different ways (see Fig. 1).

For the transplant group the preferred self-view was of autonomy and independence, with a feeling of...
equality and equal exchange toward others. Too much interfering from others would likely negatively impact on treatment adherence. For example, intensive monitoring of diet regime by others could frustrate the goal and lead away from adherence. Here empowering the patient with shared decision making perhaps involving the whole family moving to a healthier diet would be more likely to boost adherence.

In the case of the group with panic and agoraphobia, the support of others also played a crucial role in rehabilitation. Whereas the family, friends and partners may be aware they are the first line of security for the person, they may also feel trapped in the role of the protector helper, not realizing that their compassion and role may be exacerbating the problem. Also the sufferers themselves are ambivalent about this dependence and in fact desire more autonomy, but without anxiety.

The transplant group tended to prefer to attack problems head on, not to wait on others or circumstances but to advance to the goal of meeting the challenge. The panic group tended to invest a great deal in anticipation and rumination, which generated doubt and anxiety in their coping abilities. For people with tics, clearly adopting strategies to relax and be themselves with others may be most likely to boost adherence, as opposed to being too directive and rigid, so perceiving the supportive others as also favoring more independence in accordance with the abilities of the person to overcome anxiety, might improve adherence to treatment, reduce resentment and also allay fears of abandon and rejection. In the transplant group the health professional could adapt his/her attitude to be collaborative, open and flexible as opposed to being too directive and rigid, so permitting the patient a feeling of active participation in the treatment. The tic group were concerned largely from the first author on request.

The information derived from this phenomenological approach provides an important addition to educating helpers in managing adaptation. Such studies necessarily move beyond standard questionnaire information to look in depth at the daily lived-in reality of illness and recovery. In particular the qualitative approach reveals the nuances in different attitudes toward the same illness domain and how recognizing these nuances may favor an improved therapeutic alliance and adaptation. Future studies seem necessary to clarify the influence of subjective perceptions on management and treatment of illness, in particular to aid education of helpers and professionals participating in readaptation.

Note
A full account of themes, explicit and implicit constructs elicited for each participant are available from the first author on request.

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