

The acceptance process and the ephemeral character of Rheumatoid Arthritis

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Background

Rheumatoid Arthritis (RA) is a chronic, disabling disease characterized by progressive joint destruction and persistent pain. Approximately 1.5m people in Switzerland suffer from some type of rheumatic disease and 300,000 suffer from a severe chronic form of arthritis, needing constant care. RA affects people during the most active period of their lives (30-50 years), and its unpredictable and painful course often involves serious secondary consequences such as depression, reduction of social activities, job loss, and financial decline (Verbrugge & Juarez, 2008). In particular, the invisible and unpredictable course of RA is likely to have powerful psychological impact, evoking a variety of negative thoughts and emotions (McCracken, 2005). Patients with RA are negotiating life in a state of uncertainty, dealing with variable and unpredictable symptoms of pain and discomfort that may suddenly appear exacerbate or lower during remission. This variable course of disease experience can negatively affect the way patients *accept* the disease. Disease acceptance is associated with improved quality of life and lower levels of pain and depression. This qualitative study conducted at the University of Lugano in the Italian speaking part of Switzerland sought out to explore how patients with RA achieve acceptance and the likely impact of disease course onto patients' experience.

In the qualitative study of LaChapelle, Lavoie and Bourdreau (2008) among women with fibromyalgia and arthritis, acceptance was defined as "an overall attitude toward the pain experience involving acknowledgement of the chronicity of the condition

and a willingness to engage in valued activities despite pain" (p. 14). We can thus consider acceptance as a process whereby patients begin to make choices that maximize their quality of life. It has been shown that acceptance is not a single decision, event or belief but a process with distinct stages, each involving different realizations (McCracken, 1998). Dissecting those stages is key to understanding how patients succeed in dealing with the implications of a disease like RA. There are many studies highlighting key themes and demonstrating the importance of acceptance for health outcomes (Gullacksen & Lidbeck, 2004; Schaul, 1995). Yet they say more about the nature and consequences of acceptance than about how patients actually achieve it. There remains only limited information about the factors that impact the acceptance process, such as the ephemeral nature of the disease and the difficult diagnosis for example.

The unpredictable and invisible character of the pain typical for RA makes the achievement of acceptance a difficult process. Patients are living in a state of uncertainty, without knowing the short and the long term progression of the disease, dealing with the fear and the frustration of the unknown future. Moreover, the kind of chronic pain patients suffer is invisible and this can make it very difficult for the significant others around them to understand patients experience. In a previous study on the role of the social support over the acceptance process it has been shown that RA patients often complain about the lack of understanding from their social environment due to the fact that pain is socially invisible and difficult to be comprehended by those who are not affected (Kostova, Caiata-Zufferey, & Schulz, 2014). As a consequence, chronic pain

patients feel misunderstood and sometimes even accused of using the illness as an alibi to escape from work and other responsibilities. This lack of comprehension due to the variable character of RA is a factor hindering acceptance, making the fight against pain even more difficult.

In this study, then, we expand the field of *RA-acceptance* research providing evidence on (i) the main stages RA patients pass through in learning how to live with their disease, and (ii) the strategies they adopt to accommodate the disease into their lives, considering the overall impact of the co morbid symptoms of RA.

Methods

We conducted a qualitative study based on 20 semi-structured interviews with RA patients from the Italian speaking part of Switzerland. After having introduced the aim and the modalities of the research, we asked a general question: "Would you please describe for me your experience with arthritis, starting from the first symptoms?" Using follow-up questions and probes, we explored the impact of the disease on the main domains of life such as family, work, and social life, identifying the conditions under which patients moved through the process of acceptance, and then exploring their view of that concept. Our substantive selection criteria were: i) having had an RA diagnosis for at least three years (allowing enough time for patients to undergo a process of acceptance); ii) age over 35 (for the same reason, given that RA may hit as early as age 30; and iii) the absence of any other chronic diseases.

A grounded theory approach was used, with data collection and analysis carried out in cycles. The constant comparative method (Strauss & Corbin, 1990) was used to code interviews, link and group the identified codes into larger categories, and define more abstract concepts.

Results

We distinguished five main stages through which patients passed in reaching the point of learning how to live with the disease: *naming the illness; realizing the illness; resisting the illness; 'hitting the bottom'; and integrating the illness*. These passages emerged inductively in that, while the patients did not necessarily report their experiences in chronological order, the similarity of experiences across interviews allowed us to define common patterns. Before discussing each stage, we should acknowledge that any such model or structure is inevitably a simplification of complexity, a smoothing of rough edges in the data. The unpredictable character of the pain and the nature of RA, with symptoms liable to recur at any point, means that patients never reach an 'end point' at which they are safe from the pain and hence the psychological challenges that it poses. As such, acceptance always remains a process rather than an outcome.

I. *Naming the illness*

The acceptance process was initiated by patients' discovery of the cause of their pain. This was rarely straightforward. While a few interviewees obtained a correct diagnosis within the six months usually specified for 'early diagnosis', most waited substantially longer. A major reason of the late diagnosis was not only medical, but also due to the unclear and unstable symptoms. That brought to the neglect of symptoms by both patients and doctors again due to the unstable and varying episodes of pain. Patients ignored their initial symptoms, attributing them to external factors such as "age", "humidity", or their "work", and thus delaying the start of any acceptance process. Where patients did recognize and take symptoms seriously, they complained that GPs did not do the same but instead tended to downplay patients' sufferings. Most patients felt accused of exaggerating their symptoms:

they felt “ridiculed”, disrespected, and that their credibility had been questioned.

The meaning of the diagnosis stage itself depended to some extent on the length of time that it took to obtain diagnosis: The longer that patients spent waiting – indeed, often fighting – for a diagnosis, the more they perceived it as a relief; those who had spent relatively little time awaiting a diagnosis reacted to it initially with shock, as it was a source rather than a resolution of *uncertainty*.

II. *Realizing the illness*

The second important phase of acceptance was patients’ realization that their condition is chronic and – especially for those with a more severe grade of disability – places tight constraints on their freedom in managing their lives. Patients faced the potential erosion of their roles as mothers, or partners, or as workers – all domains central to people’s identities and in which they express their most basic values. The result was a major rupture in patients’ previous *normality*, depriving them of freedom and independence. This ‘realizing’ stage can be seen in terms of patients developing different representations of their illness. The way sufferers perceived their disease in the post-diagnosis stage was founded on two interpretations of the illness: as an unjust punishment and as a stigma.

III. *Resisting the illness*

Facing the losses and realizing that life is not as before, some patients – especially those with a more severe grade of disability but also those who had waited longest for diagnosis – were resistant to accept the imposed limitations, and some even held out hopes that the illness may disappear. Common resistance reactions were denial, self-isolation, and struggles (usually futile) to live as before. All of these reactions were sometimes encouraged by the ephemeral character of RA symptoms, but hopes

became exposed as unrealistic once the symptoms returned. Attempts to fight or repress uncontrollable and unchangeable events such as pain reinforced patients’ feelings of uselessness and were impeding the whole acceptance process.

IV. *Hitting the bottom*

For most of our patients, however, there was a climactic moment when they realized that previous resistance reactions were unworkable. Reaching back for their previous life rather than accepting the reality of their illness made patients into victims of the disease, which in turn induced reactions of resignation, passiveness, self-pity and anger. These feelings tended to culminate in a moment of *hitting the bottom* which was an important turning point in the acceptance process. Realizing that their fights were not only unwinnable but were also endangering their valued roles and activities served as a major trigger for patients to change strategy in dealing with the illness, moving to the final stage of integration.

V. *Integrating the illness*

“Hitting the bottom”, and the realization there is no alternative to living with the disease, was often a turning point for the patients to review and change their behaviour. They then started to develop personal strategies, which allowed them to manage the implications of the disease and to integrate it in their lives. At length, they understood that they should find a way to live with the disease, making it part of themselves and establishing a new concept of self and life. We identified three types of integration strategies: practical, identity-based, and affective. The *practical* strategies were about the need to change everyday habits and routines in order to respect new limits. Examples are doing some stretching in the morning, using some tools at home as ergo-tools for cleaning, driving and cooking. Identity strategies consisted in attributing a personal

value to the illness, making it part of a reconstructed personal narrative. The affective ones were related in perceiving the disease in a *positive way*, either by humanizing it and considering it as a “friend”, or giving it a name.

Thanks to patients’ accounts we also evidenced the way they perceived the word *acceptance*. Two main points became clear considering patients’ view of the right acceptance strategy. On one hand, patients were supposed to *grieve for the past* that had been destroyed by the condition. On the other hand, they had to *keep a connection* with that past if they wanted to continue to pursue their longstanding goals and cherished values. In that sense, there were two potentially conflicting types of acceptance: accepting losses and limitations, but not accepting to be a passive victim of those limitations. Patients had to realize that they had lost their pre-pain way of living, but at the same time they had to preserve their identity, finding new ways of managing their important activities.

Discussion

This paper provides a deeper understanding of the phases that RA patients have to go through in order to accept and accommodate their illness in their selves and their lives, placing emphasis on the invisible and ephemeral character of the disease that often can be a barrier for the acceptance process. We placed importance also on the diagnosis as a factor shaping acceptance and our findings go beyond the existing literature by showing that the timing of diagnosis not only affects *when* the acceptance process begins; it also affects whether, how, and how easily acceptance proceeds. The timing of diagnosis is also difficult to control given the nature and symptoms of RA. Yet there is scope for health policy and health professionals to reduce waiting period for diagnosis highlighted in our study. We also examined patients’ representations of the illness and of its acceptance. As in previous studies, we found these

representations to be multifaceted and to have considerable impact over patients’ capacity to cope with the disease (Heijmans, 1999; Heijmans & Ridder, 1998). In particular, we observed representations changing as patients passed – albeit slowly and often unsteadily – through the acceptance process. During the early post-diagnosis period, patients were more likely to perceive the illness in a negative way as a “stigma”, “punishment” or “abnormality”. In contrast, by the stage of integrating the illness, patients found more positive representations of the illness: as a “friend”, a “strong point” and, in particular, as a source of personal growth. The literature documents similar change among patients after trauma and adversity as in chronic diseases. Post-traumatic growth is positively correlated with acceptance and negatively correlated with subsequent distress (Linley & Joseph, 2004).

There are important clinical implications in understanding how RA patients come to accept and deal with their pain and its consequences. It provides health professionals with insights into the kind of support needed to help sufferers down the difficult path towards acceptance. Understanding the losses and difficulties that patients face in establishing a new way to live within the restrictions of the disease is an important part of the treatment process and of the doctor-patient relationship. Furthermore, a deeper understanding of the meaning that patients ascribe to acceptance gives insights for the implementation of new communication strategies for health professionals.

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