ORIGINAL ARTICLE

The process of acceptance among rheumatoid arthritis patients in Switzerland: A qualitative study

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BACKGROUND: Rheumatoid arthritis (RA) is a chronic, painful disease with many injurious psychological effects. Acceptance is an important component of pain management and is associated with improved quality of life, and lower levels of pain and depression. While studies have begun to identify the stages of acceptance, little is known about factors influencing the ease and speed with which patients pass through these stages.
OBJECTIVE: To explore the main stages through which RA patients pass and the strategies they adopt to learn to live with the pain, and to identify factors shaping patients' capacities to achieve acceptance.
METHODS: A qualitative study involving 20 semistructured interviews with RA patients in the Italian-speaking region of Switzerland was conducted. Analysis of the data followed the precepts of grounded theory.
RESULTS: Although the present study revealed that acceptance is not a smooth or linear process, five main stages in patients' struggles to accommodate the newly imposed limitations were, nonetheless, identified: naming the illness; realizing the illness; resisting the illness; 'hitting the bottom'; and integrating the illness. Diagnosis proved to be an especially tortuous stage in the case of RA, and the effects of delayed diagnosis continued to be felt during the subsequent stages. Patients' understanding of the notion of acceptance and the strategies that they used to achieve it were also explored.
CONCLUSIONS: Diagnosis of RA is notoriously difficult. Beyond the clinical difficulties, structural reasons for late diagnosis (symptoms being neglected by patients and medical professionals) were identifed. Delayed diagnosis hindered the acceptance process throughout, and led to more resistant behaviour and to a struggle to achieve the optimal formula for acceptance – accepting the losses of prepain life while still pursuing personal goals.

Key Words: *Acceptance process; Diagnosis; Integration strategies; Patients' view of acceptance; Rheumatoid arthritis*

Le processus d'acceptation chez les patients atteints de polyarthrite rhumatoïde en Suisse : une étude qualitative

HISTORIQUE : La polyarthrite rhumatoïde (PR) est une maladie chronique douloureuse aux nombreux effets psychologiques délétères. Son acceptation est un élément important de la prise en charge de la douleur et s'associe à une meilleure qualité de vie et à une douleur et une dépression moins intenses. Les études commencent à déterminer les phases d'acceptation, mais on ne sait pas grand-chose des facteurs influant sur l'aisance et la vitesse avec lesquelles les patients traversent ces phases.
OBJECTIF : Explorer les principales phases par lesquelles passent les patients atteints de PR et les stratégies qu'ils adoptent pour apprendre à vivre avec la douleur, et déterminer les facteurs qui façonnent les capacités des patients à parvenir à l'acceptation.
MÉTHODOLOGIE : Étude qualitative de 20 entrevues semi-structurées de patients atteints de PR de la région de la Suisse italienne. Analyse des données selon les principes de la théorie de terrain.
RÉSULTATS : La présente étude a révélé que l'acceptation n'est pas un processus harmonieux ou linéaire, mais que le combat des patients pour s'adapter à leurs nouvelles limites se déclinait tout de même en cinq grandes phases : nommer la maladie, se rendre compte de la maladie, résister à la maladie, « toucher le fond » et intégrer la maladie. Le diagnostic était une phase particulièrement tortueuse de la PR, et les effets d'un diagnostic tardif continuent d'être ressentis pendant les phases subséquentes. Les auteurs ont également exploré comment les patients percevaient la notion d'acceptation et les stratégies qu'ils utilisaient pour parvenir à cette acceptation.
CONCLUSIONS : La difficulté de diagnostiquer la PR est notoire. Au-delà des problèmes cliniques, les raisons structurelles d'un diagnostic tardif (symptômes négligés par les patients et les professionnels de la santé) ont été déterminées. Le diagnostic tardif nuisait à tout le processus d'acceptation et suscitait une plus grande résistance et une difficulté à parvenir à la bonne formule d'acceptation, c'est-à-dire s'adapter aux pertes liées à la vie avant la douleur tout en continuant à chercher à réaliser leurs objectifs personnels.

Rheumatoid arthritis (RA) is a chronic, disabling disease characterized by progressive joint destruction and persistent pain. RA affects individuals during the most active period of their lives (30 to 50 years of age), and its unpredictable and painful course often involves serious secondary consequences such as depression, reduction of social activities, job loss and financial decline (1,2). In particular, RA may have a powerful psychological impact, evoking a variety of negative thoughts and emotions. The different ways in which patients respond to these feelings give rise to different behaviour patterns (3). Patients unwilling to accept pain are prone to resistance behaviours that reduce their quality of life (4-6). On the other hand, patients may focus on finding a way to live with pain that enables them to pursue their values and maintain the activities that matter to them. This distinction, and the acceptance required to achieve the latter outcome, were the basis of the present study. In addition to building on previous studies that have begun to elaborate on the process of achieving acceptance, in the present study we highlight the key role played by diagnosis – itself a particular problem in the context of RA – in helping or hindering patients during that process.

In a qualitative study by LaChapelle et al (7) involving 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" (also see McCracken [8]). We can, thus, consider acceptance to be 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 (7). Dissecting those stages is key to understanding how patients succeed in dealing with the implications of a disease such as RA.

Acceptance is typically considered to be one of a broader cluster of concepts such as adjustment, adaptation to or negotiation with chronic pain (9-16). From this extensive literature, several common and recurring themes or stages can be identified: becoming aware of the problem and receiving a diagnosis; acknowledging the chronicity of the pain and the resulting losses; and establishing a new way of living. Several studies show that acceptance plays a positive role in patients' physical, social and emotional functioning (17-21). Individuals who come to terms with pain report more positive clinical

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outcomes, greater confidence in their coping ability, higher daily uptime, less depression and less pain (22,23).

These studies highlight key themes and demonstrate the importance of acceptance for improved health outcomes. However, they place more emphasis on the nature and consequences of acceptance than about how patients actually achieve it. There remains only limited information regarding the strategies that patients adopt to accommodate diseases, to face the changes imposed by the illness and, thus, to find a way to live with it. We also know little about how patients understand and react to the notion of acceptance itself. Third, and critical in the context of RA (in which correct and swift diagnosis is notoriously difficult [24]), there is little research investigating the role of diagnosis, not only in giving patients awareness of their condition but influencing the ease with which they pass through the entire acceptance process. A fourth reason for further research is the well-established point that sociocultural context shapes the way in which patients comprehend and adapt to illness (25-27). Because the existing literature comprises only Anglo-Saxon studies, it is useful to broaden the evidence base. Performing studies in Switzerland, a smaller country in continental Europe, also enables us to assess whether and how a system of private health provision shapes the way doctors and patients deal with the disease. It is also a country in which RA is a serious problem, affecting approximately 1% of the adult Swiss population (28). More generally, approximately 1.5 million individuals in Switzerland have some type of rheumatic disease, and 300,000 have a severe chronic form of arthritis requiring constant care. RA has generated increasing costs for the Swiss health care system, and one in four disability pensions is paid for a rheumatic pathology.

In the present study, therefore, we aimed to expand the field of RA-acceptance research to a new setting, addressing three core questions: What are the main phases patients pass through in learning how to live with their disease? What is the specific importance of the diagnosis of RA in shaping patients' capacity for acceptance? Which strategies do patients adopt to accommodate the disease in their selves and lives?

METHODS

Participants

A qualitative study based on 20 semistructured interviews with RA patients (Table 1) was conducted. Approval was obtained from the Ethics Committee of Canton Ticino (the Italian-speaking region of Switzerland) and informed consent was obtained from each participant before their interview. During the transcription process, personal data were removed and fictitious names were attributed. The interviews were conducted in the Italian-speaking part of Switzerland by one of the authors (ZK). Apart from the Swiss patients, there were five Italian participants and one Dutch participant.

The substantive selection criteria were: having had an RA diagnosis for at least three years (allowing enough time for patients to undergo a process of acceptance); age >35 years (for the same reason, given that RA may occur as early as 30 years of age); and the absence of any other chronic diseases. To maximize the variability of respondents' experience, patients of different sex, age, level of education and socioeconomic status were selected. The sample was composed of 13 women and seven men (the disease has a fourfold higher prevalence among women compared with men), with ages ranging from 35 to 69 years.

The medical definition of an early diagnosis of RA is within six months of presentation (29). According to this definition, only seven of the participants had an early diagnosis; the majority of the rest waited years before obtaining the correct diagnosis. The mean time to diagnosis was approximately two years (range three months to 10 years) and the average length of time since diagnosis was nine years (range three to 14 years).

Recruitment and data collection

Recruitment occurred in collaboration with the Swiss Association of Rheumatology. Three rheumatologists were asked to nominate patients that they recognized as being successful in having learned to deal with the implications of the disease, enabling the observation of the entire process. These patients were first contacted and asked to participate by their rheumatologist; those who agreed were then contacted by the authors. Interviews, which lasted between 60 min and 90 min, were conducted in medical offices in the rheumatology clinics. After having introduced the aim and the modalities of the research, the authors 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, the impact of the disease on the main domains of life, such as family, work and social life, was explored; the conditions under which patients moved through the process of acceptance were identified; and participants' views of the concept were explored.

Data analysis

A grounded theory approach was used, with data collection and analysis performed in cycles. To assist this iterative exchange, the interviews were conducted during two periods: January to March 2012 and December 2012 to January 2013. The constant comparative method (25) was used to code interviews, link and group the identified codes into larger categories, and define more abstract concepts. These operations enabled the reduction and interpretation of large amounts of data, and continued until data saturation was achieved. The literature was used throughout the research to support the process of questioning and interpreting the data. The results discussed in the present article are the outcome of this continual to-and-fro movement between empirical data and developing theory, the aim being to present findings that constitute a reasonable representation of the phenomenon studied (30).

RESULTS

Five main stages through which patients passed in reaching the point of learning to live with the disease were identified: 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 enabled the definition of common patterns. For example, while only one patient used the term 'hitting the bottom', when questioning others' narratives, similar experiences were not only found but were the culmination of resistant reactions and often the trigger for a process of integration.

Before discussing each stage in detail, the authors acknowledge that any such model or structure is inevitably a simplification of complexity, a smoothing of 'rough edges' in the data. In this case, two complexities should be noted at the outset and will recur in subsequent discussion. First, while the model captures the broad chronology, the process of acceptance is not straightforwardly sequential or linear. Patients are prone to get 'stuck' at a particular stage and to regress to earlier stages. In addition, the stages are not distinct but may overlap; eg, patients engaged in integrating the illness may also encounter feelings of resistance. There is also the fact that the nature of RA, with symptoms liable to recur at any time, means that patients never reach an 'end point' at which they are safe from the pain and, hence, the psychological challenges that it poses. Thus, acceptance always remains a process rather than an outcome. Second, there are pronounced differences among patients in the way that they experience the five stages. A given stage may be very intense or difficult for some patients but so easy for others that they may almost be said to have skipped it altogether. One major source of these differences was the timing of diagnosis. This was, therefore, more than simply the first stage of the process: it also considerably affected the subsequent stages. Patients obtaining an early (and correct) diagnosis arrived at the final stage of integrating the illness much more rapidly, and suffered little during – or even avoided altogether – the stages of realizing, resistance and hitting the bottom.

Given the importance of diagnosis, patients' evidence of the causes – which went beyond the typical medical difficulties – were

TABLE 1
Characteristics of the participants

Sex	Age, years	Nationality	Years since diagnosis	Time between first symptoms and diagnosis	Marital status	Education
Female	35	Dutch	7	5 months	Single	High school
Male	37	Swiss	3	6 months	In a relationship	University degree
Female	49	Italian	5	2 years	Married	Middle school
Male	49	Swiss	11	2 years	Married	High school
Male	50	Swiss	10	1.5 years	Married	University degree
Female	52	Italian	14	2 months	Married	High school
Male	52	Italian	8	3 years	Married	Middle school
Female	54	Swiss	13	5 years	Married	Middle school
Female	55	Swiss	6	2 years	Married	High school
Female	58	Swiss	10	10 years	Widow	University degree
Female	67	Swiss	14	4 years	Married	High school
Female	69	Swiss	8	6 months	Married	High school
Female	69	Swiss	9	2 years	Widow	Middle school
Male	38	Swiss	3	3 months	Single	University degree
Male	42	Swiss	4	1.5 years	Married	High school
Male	53	Italian	5	6 months	Married	Middle school
Female	41	Swiss	3	2 years	Married	University degree
Female	40	Swiss	4	3 months	Married	University degree
Female	58	Swiss	8	1.5 years	Married	High school
Female	61	Italian	9	1.5 years	Married	High school

All patients had a diagnosis of rheumatoid arthritis

also considered in the discussion of late diagnosis. Several specific strategies that patients adopted to accommodate the disease and the new restrictions that it placed on them were also identified. Finally, by confronting patients directly with the idea of acceptance, their understanding of and reactions to that notion were examined.

Naming the illness

The acceptance process was initiated by patients' discovery of the cause of their pain. This was rarely straightforward. While several interviewees obtained a correct diagnosis within the six months typically specified for 'early diagnosis', most waited substantially longer. Clearly, one major reason for late diagnosis is the medical difficulty of RA diagnosis per se. However, there was also evidence of the neglect of symptoms by both patients and doctors. 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. When patients did recognize and take symptoms seriously, they complained that general physicians did not do the same, but rather tended to downplay patients' suffering. Most patients felt accused of exaggerating their symptoms: they felt 'ridiculed', disrespected and that their credibility had been questioned. That period of fighting for credibility without knowing the cause of pain invoked angry reactions and obviously ruled out acceptance – how could patients be expected to accept something of which they remained unaware?

In a vivid example of neglect, one male Italian patient complained that his doctor simply attributed the reported suffering to cultural background:

> Many years passed before my diagnosis…because he [the doctor] didn't believe me (…) He told me that I was exaggerating, that I was suffering from the "illness of the Italians". So what does that mean: if you are Italian, you are not allowed to feel pain? (...) I felt belittled, I felt he was making fun of me (...) So I spent many years like that without knowing what I have. (Gianni, 49 years of age, male)

This case illustrates two key points: first, the doctor's skepticism made the patient feel distrusted and ignored; second, late diagnosis left patients in a state of such uncertainty that acceptance is very hard to attain.

Most of the patients blamed their general practitioners (GPs) for not having done enough to discover the illness more promptly, and some attributed this to the Swiss private health system. Indeed, the country's health care system is private, and participants believed GPs feel conditioned and restricted by the health companies. In particular, they believed that there may be a tendency to diagnose more common conditions rather than to undertake the additional examinations that are expensive but necessary to identify RA. For one patient, the internalized anger at late diagnosis was still impeding acceptance four years later:

> She [his GP] destroyed my life (…) When I was first feeling pain, I went to the doctor, they did the blood test and she said that I don't have anything (...) Then I went to the other one, he didn't even do any exams, just took my hands, looked at them, and again nothing (...) So now, when I think about 'acceptance' I still cannot accept the initial errors of the doctors…all my anger is about the beginning, because I am sure that if they got it since the beginning, I would not be like that now. (Eric, 42 years of age, male)

Another patient blamed the health system for her going 10 years without a correct diagnosis:

> I think family doctors feel too limited by the health assurance companies to do a lot of exams. Doctors say: let's not exaggerate – before making lots of expensive exams, let's do everything possible we can do, and without a lot of costs. And they are not giving you all the exams, and so you are going on with painkillers or anti-inflammatory pills, and you get worse and worse…In Switzerland they talk a lot about prevention. But prevention without many costs. (Rosa, 58 years of age, female)

The meaning of the diagnosis stage itself depended to some extent on the length of time that it took to obtain diagnosis, and also on their age. The longer that patients waited – indeed, often fighted – for a diagnosis, the more they perceived it as a relief because it gave them certainty about their condition, legitimizing their complaints and reasserting their credibility.

> I had a moment of relief after the doctor told me: you have rheumatoid arthritis. Maybe it was a psychological matter, or maybe because the other doctor didn't believe me, [but] at least I thought, ok: I have something. Because at one point it makes you doubt yourself when you are living in uncertainty for such a long time. (Gianni, 49 years of age, male)

Conversely, patients who were younger and who had spent relatively little time awaiting a diagnosis reacted to it initially with shock because it was a source rather than a resolution of uncertainty:

> It's a very difficult illness; it wasn't easy when they told me I had RA…My fears were: so, what does that mean? Does it mean that after five years I will be in a wheelchair? Or that maybe after 20 years I will die because of the medications' side effects? You know, for the elderly people I think, I hope, it's easier...because at least you expect it…when you are young, at least in my case, the diagnosis was shocking. (Billi, 35 years of age, female)

This period of shock notwithstanding, early diagnosis was ultimately very beneficial for patients. This is true in obvious physical terms because swift diagnosis saves at least some patients from severe joint deterioration. However, diagnosing the disease early also had beneficial psychological effects, greatly easing the return to normal life and, thus, the process of acceptance. Following from the previous quote:

> …but I was quickly back to the normal life, at least they discovered it quite soon so the whole damage to mind and body is less… (Billi, 35 years of age, female)

Another patient who had been diagnosed early confirmed that the resolution of uncertainty was fundamental for acceptance:

> The fact that you know pretty soon the name of your pain is a big step to accept it. (Josephine, 40 years of age, female)

In contrast, the negative psychological effects of late diagnosis have already been highlighted in some of the earlier quotations. Protracted uncertainty not only delayed the initiation of the acceptance process but proved to be a barrier at each subsequent stage. The longer that patients waited for a diagnosis, the more severe their negative reactions: not simply anger at not being trusted by the medical profession but also broader uncertainty and self-isolation.

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, partners or workers – all domains central to individuals' 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. One female patient illustrated this very clearly, emphasizing that her entire identity as a woman was threatened by the constraints on her capacity to fulfill key life roles:

> What I miss more is my independence. I've always been a free and independent person, I was doing everything alone. And now you don't feel free – I can't do what I want, even in grocery shopping I feel limited (...) Everything changed: at home, as a mother, as a wife, at work. Your sexuality also changes with your husband. And it wasn't easy, it was awful to go through all that. It puts in doubt your being a woman, you don't feel nice. (Liria, 49 years of age, female)

This 'realizing' stage can be considered in terms of patients developing different representations of their illness. The way patients perceived their disease in the postdiagnosis stage was founded on two interpretations of the illness: as an unjust punishment and as a stigma. It is difficult to accept something that is not one's own fault and the lack of any logical explanation of the causes of the disease made it an injustice in patients' eyes – a cruel joke of destiny:

> I found a lot of anger inside of me. You think: why did this happen to me? It's very significant as a disease; it's not like catching a cold or something like that. If you have it already in your family, you can say, ok, it happened to me because my family has it. But when you are the first one, you say: great, so I won this in the lottery – but I'd have preferred to win €1 million! (Marita, 41 years of age, female)

Patients also experienced their disability as an abnormality. They were ashamed and embarrassed of being perceived by others as different. One male patient tried to hide his disease, citing his fear of being stigmatized by others. Patients often felt uncomfortable at the prospect of being judged as different by others, especially in the immediate postdiagnosis period:

> At the beginning the thing is that you are not saying what you've got, because you don't know how others will react (…) I was trying to hide it [arthritis]…because you are in that stage when you feel weak, right at the beginning…(Mario, 37 years of age, male)

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 impeded the acceptance process.

As a post-traumatic reaction after diagnosis, some patients had denied its unpleasant truth:

> During the first months, after my doctor told me I had RA, I was thinking "this guy [the rheumatologist] is crazy, I don't have anything!" I was saying to myself that I wasn't sick. I didn't want to accept my disease. (…) My life was changing so much and I was not feeling ready, it was not only the pain, but all my habits had to change, my emotional life. I was feeling so fragile. (Roberta, 54 years of age, female)

Feeling imprisoned by the new restrictions and not being ready for such significant changes, patients were fighting to retain their life roles from the prepain days. It was difficult to accept the severe constraints on their activities in key arenas, such as work and family, and patients struggled to maintain their previous way of life. One female patient described trying to sustain her previous work duties – and her lack of success in those attempts:

> I was fighting the acute episodes of pain, filling myself with painkillers, and I was going to work. I did not want to stop working, I thought I could manage it. And I acted like this for a couple of years and then I thought, no, it doesn't work, this is not the right system for me: better stay home. (Rosa, 58 years of age, female)

Denial was sometimes encouraged by the ephemeral character of RA symptoms, but hopes became exposed as unrealistic once the symptoms returned:

> At that time, it was one year [after] I started the medication treatment, it seemed like it [RA] was finished, it seemed to disappear! But then the doctor told me: "Listen, now it seems like the arthritis has gone, but it's under the surface and at any moment can come back." But I wanted to interrupt my medications and to try some alternative medicine. But then at one point I couldn't move any more because I felt an unbearable pain in my hands and legs….so I went back to the medications. (Giulia, 58 years of age, female)

Some of the patients faced the imposed losses with reactions of self-isolation and episodes of depression. This only reinforced their feelings of uselessness and did not help them to face the truth. This was clear from the account of a male patient who described his moments of depression after having to leave work, which, for male patients, emerged as their main focus of self-identification:

> I lived through two episodes of major depression...I wanted to jump off my balcony. I had to leave work, and in that period of time I felt myself like a nobody (...) Before I was more likely to call friends, then I didn't feel like calling anybody, because you see that nobody is calling you and at some point you think: I don't interest anyone. (Alessandro, 50 years of age, male)

All of the foregoing quotations are from patients who waited longer than 18 months for diagnosis (Table 1). Those obtaining early diagnosis related much less dramatic stories about their coming to terms with the disease, and none spoke of anything approaching depression or significant psychological harm. This is not to say that their physical symptoms were minor or easily manageable; rather, it appears that the long wait for diagnosis makes it more difficult for patients subsequently to cope with that news.

Hitting the bottom

Consistent with the argument that swift diagnosis spares patients the worst psychological effects of RA, there is little to relate here about those who obtained early confirmation of their disease. For most of the 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 fight was not only unwinnable but was also endangering their valued roles and activities served as a major trigger for patients to change strategy in dealing with the illness. One patient graphically described this moment when, having conceded to the pain, she was so passive that she was unable even to fulfil her role as a mother. She also illustrates how this moment provided the motivation to change:

> It was the worst period of my life, I just gave up...I couldn't even go to the bathroom on my own – my husband would carry me, put me in the bath and wash me. I felt like I was 80 years old. During that time I had my little baby and the first six months I hit the bottom, I couldn't even hold him…I was so demoralized, everything made me angry and I didn't want to do anything about it. When you hit the bottom, when I really hit the bottom, I said to myself: I cannot let this illness beat me, I have to fight it! At one point I said: now stop! I will beat this illness! It's like when you touch the bottom of a swimming pool – you touch the bottom, then instantly give a push and you go up. (Liria, 49 years of age, female)

The realization that there is no other alternative, that one cannot fight the illness but accept it as part of oneself, was an important condition of acceptance. As one patient starkly stated:

> Either you commit suicide, or you accept it and wait to die without doing it yourself. (Viara, 69 years of age, female)

Although few early diagnosis patients could really be said to have 'hit the bottom', they nonetheless also experienced trigger factors that made them aware of the irreversibility of the situation and pushed them to change. For one patient, that moment of change was the realization that changes in her body were threatening her personally valued sporting activities:

> I was watching myself getting bigger and bigger. I was not doing my sports in the first two years, because of the pain. I feel the pain anyway when I am doing sports now, but at one point you say: ok, if I always did sports and if I miss doing it, even if now I have this illness, I want to start again! At one point I said: enough already! I am not going to put on weight anymore. And it was the same for everything else… (Billi, 35 years of age, female)

Integrating the illness

'Hitting the bottom', and the realization there is no alternative to living with the disease, was the turning point for the patients to change their behaviour. They then began to develop personal strategies that enabled them to manage the implications of the disease and to integrate it in their lives. For some early diagnosis patients, this process was often so straightforward as to be hardly conscious. One interviewee, probed for information about how RA affected his daily life, eventually said simply:

> To be honest, I never really think about it. I suppose there were a few changes early on but they're not something that I pay much attention to. (Luigi, 38 years of age, male)

However, most of the other patients, especially those who had struggled to obtain and come to terms with their diagnosis, needed to be much more consciously reflective about its impact. 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. Three types of integration strategies were identified: practical, identity-based and affective.

The practical strategies related to the need to change everyday habits and routines to respect new limitations. One patient provided several examples and, in the process, highlighted the importance of willpower in finding and sticking to these strategies:

> You have to teach yourself some small tricks...for example, for my personal hygiene, I am using a long towel so I can reach across my back. You should manage things somehow. Or, in the morning, my body is very rigid, so I do some small gymnastics before I get out of bed. You should adopt some tricks and learn how to live with it. (Zara, 55 years of age, female)

The second type of integration strategy was related to identity. Patients attributed a personal value to the illness, making it part of a reconstructed personal narrative. Some of the patients asserted that they grew personally because of the disease, turning to their advantage their past experiences and ongoing struggle. This accommodation of RA in their life stories was a fundamental precondition of acceptance. The disease had challenged the integrity and stability of patients' lives and personalities; recognizing not only this but also their positive responses to these challenges helped patients to maintain an unbroken life story and to adjust to a new normality. Most patients stated that the illness had taught them to fight and confirmed their powers of will in ways that had beneficial applications elsewhere in life:

> The illness taught me to fight, and not to get down. I can even say that, till now, it's actually helped me. Or maybe I've learned through all this trouble to deal better with the pain. I've learned to tolerate the pain. And that also helped me in other things in my life. (Antonio, 52 years of age, male)

A parallel argument to that involving personal growth can also be made about recognition and redefinition of values. RA means that patients live with constant pain and face numerous unpleasant consequences. However, patients also find that the resulting suffering enables them to appreciate their lives more, reasserting the values and activities that are most important to them. In that sense, it can be said that having known the pain caused patients to re-evaluate their life and to consider it from another perspective:

> I've learned to look at things with different eyes, to give importance to other things. Sometimes you can't even handle a pen; but then you just say, ok, there are more important things that have more value, like my family, my children. I've learned to live like that. (Antonio, 52 years of age, male)

> In certain ways my illness became a strong point. It made me a better person. I became more tolerant of things. In a sense, before I was more dogmatic as a person: I saw everything as black or white. Now, the illness has taught me to be much more flexible. Now I appreciate things more. (Lucrezia, 61 years of age, female)

Another set of strategies to integrate the disease was affective. Some patients started to perceive the disease in a positive way, either by humanizing and considering it as a 'friend', or giving it a name, or treating it as a 'beauty spot'. Thus, realizing that the disease is something that cannot be changed, patients accommodate it as part of themselves:

> It's an aggressive illness, but it depends how you see it. You should see it as a friend. Seems absurd, but if you have this

> power to see a negative thing as a positive one, you are ahead. Now, after eleven years, it is part of my life. It's like when you have a beauty spot: you always have seen it there, and you don't pay attention any more. After eleven years, I have learned to live with that illness. (Josephine, 40 years of age, female)

Another patient faced the pain by ironizing the situation and humanizing his arthritis:

> At night you go to bed and you go crazy, you can't ever find the best position, because she is like that – I am calling her "my young lady". She is making fun of you, and then, when she finishes doing as she pleases, you start breathing a bit. (Gianni, 49 years of age, male)

Most patients acknowledged that the best way to live with the disease is to face the pain and accompanying challenges in a positive spirit:

> For me, every single day is different. Today maybe everything is black, but tomorrow might become red. My positive way of being, my own will power, helped me a lot. (Anna, 67 years of age, female)

Another way of seeing the positive side of the condition was the recognition that things could be always worse. Making comparisons with worse situations helped patients to be thankful of having 'only' this:

> Actually, my motto is: better this than cancer. Outside there are so many young people dying from worse illnesses. So at one point you say: I prefer this. (Ilenia, 69 years of age, female)

As would be expected, these affective strategies were most useful to those who had endured more with the disease, whether because they had experienced RA for longer or because they had waited longer for diagnosis. In either case, it was the psychological problems that were in need of psychological solutions. Even when probed, the early diagnosis patients reported using practical rather than identity or affective-based strategies. Because they had seldom experienced significant emotional upheaval, they tended to find the integration process a considerably more practical and straightforward matter.

Patients' views of acceptance

It follows from the abovementioned statements that patients diagnosed early, and those experiencing milder forms of the disease, were less likely to reflect on the acceptance process. However, other patients gave quite detailed narratives about what acceptance signified for them.

Two main points became clear considering patients' views of the optimal 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 long-standing 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 prepain way of living but, at the same time, they had to preserve their identity, finding new ways of managing their important activities. For that reason, the word 'acceptance' was unwelcome to many patients. It appears to indicate passivity in facing the illness – in effect, implying that the illness has won. They asserted that they would never accept the disease but "learn how to live with it".

Two examples of "learning to live with" RA highlight the importance ascribed by patients to confronting the challenges of the disease by continuing to pursue personally valued activities. For one patient:

> The most important thing is not just to accept things but to meet the challenge. Life should be faced. If I am able to do something, then I have to do it. (…) Every Saturday I needed to go and see my father [in a nursing home], I never missed a day! Even if my wrist was hurting me, doesn't matter, I drove the car to get there! (…) In life it's necessary to try all possible roads; never stop! This is the biggest lesson from my illness. (Antonio, 52 years of age, male)

Another emphasized that, while bodily changes are inevitable in RA and should be accepted, she would not accept that these precluded the pursuit of important life activities such as sports:

> I don't think I will ever accept it in the sense of saying ok, I have it and that's it. But I've learned how to live with it…I've accepted what I had no choice but to accept – that my body had changed and that it will be never as before.. But anyway I started again doing my sport, something I was always doing before. You know, a lot of steps make up your path. (Billi, 35 years of age, female)

The final sentence in the quotation above illustrates that patient's grasp of a point made earlier, namely that acceptance is not an outcome but a process of continuous adaptation to the imposed limitations, composed of successive compromises between what must be accepted and what cannot be accepted if core values are to be maintained. Another reason why integration and acceptance are constantly 'under review' lies in the nature of RA. Because the evolution of the disease is so unpredictable, patients are perpetually unsure about when acute episodes of pain may recur:

> I cannot rely on myself anymore. I never know when I will remain blocked because of the pain, so I cannot make plans anymore with the others. Today you don't feel pain, but tomorrow you don't know (…) you cannot control when the pain will be back, so you are never safe…and it's not easy to accept something like that. (Viara, 69 years of age, female)

Understanding the ephemeral character of RA symptoms was, for some patients, an important part of the acceptance process itself:

> My motto now is: today I am able to do things and I am doing them, tomorrow I might feel pain, so I will not do anything. I am living like that, depending on what the illness allows me to do. This is my theory (…) I understood that I have my limits and I do not go beyond them. (Maria, 52 years of age, female)

DISCUSSION

The present study provides a deeper understanding of the phases that RA patients must pass through to accept and accommodate the illness in their selves and their lives, placing emphasis on diagnosis as a factor shaping the acceptance process. Studies of life-adjustment processes in chronic pain patients have established that providing an understandable diagnosis is a necessary step for patients to begin their cognitive reconstruction (7). Without being aware of the problem, patients cannot initiate the process of learning to live with it (11,12). However, 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. While we have emphasised that the process of acceptance is in any event less smooth and linear than may be suggested by our five-stage model, that process was most uneven and most prone to interruption among patients who waited longest for diagnosis.

In particular, later-diagnosed patients were more likely to experience a dramatic turning point that we refer to as 'hitting the bottom', a concept already identified in the field of recovery from drug addiction (31,32). According to the literature in this field, various types of dramatic events could be the reason for 'hitting the bottom' and the definition of 'bottom' varies from one person to another: what encourages individuals to change is hitting their 'personal bottom' (33). Turning points were also present in the narrative of early diagnosed patients, but they were not described as such dramatic events, consistent with our argument that these patients are spared not only the worst physical effects of RA but also the anger, frustration and uncertainty that were the psychological consequences of a long wait for diagnosis. It could almost be said that these patients shifted directly from diagnosis to the stage of integration, swiftly finding and adopting practical strategies to live with the disease. That reinforces the point that the acceptance process is not only more uneven but also more heterogeneous among patients than the five-stage sequence could imply.

The powerful impact of the timing of diagnosis is all the more important given that, for most patients in our study, diagnosis came after a long and frustrating process. This is common with RA for obvious medical reasons. However, there are other, more avoidable reasons. One relates to the private health care system in Switzerland. Virtually none of the patients reported being immediately referred by their GPs to a specialist. Most had to wait for more detailed examinations and, in some cases, years passed between the first symptoms and the diagnosis. According to some of the patients, this could be attributed, at least in part, to the features of the Swiss health care system. In their opinion, GPs feel restricted by the private health care companies and, hence, attempt to keep patients' costs down. This delays diagnosis and, in turn, increases both the severity of the illness and the uncertainty facing patients. Indeed, some patients felt – and still feel – considerable anger toward health professionals, whether for failing to spot the disease or for giving priority to the financial considerations imposed by the health system, and these emotional reactions continue to inhibit acceptance. In summary, late diagnosis is unsatisfactory not merely because of the extra pain that it causes; it also takes a psychological toll on patients that hinders acceptance and recovery.

Of course, there are many other factors that may influence the acceptance process. Probably the most obvious is the severity of the illness, but factors such as the length of time since diagnosis, and the patient's age and personality type also play key roles. Most of these, however, are out of the control of health professionals. The timing of diagnosis is also difficult to control given the nature and symptoms of RA. However, there is potential for health policy and health professionals to reduce the long waits for diagnosis highlighted in our interviews. It is also clear that early diagnosis plays a major role in encouraging a much less disruptive route to integration of the disease.

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 on patients' capacity to cope with the disease (34,35). In particular, we observed representations changing as patients passed – albeit slowly and often unsteadily – through the acceptance process. During the early postdiagnosis period, patients were more likely to perceive the illness in a negative way as a 'stigma', 'punishment' or 'abnormality'. This also echoes results from other studies. Holloway et al (36) labelled chronic back pain patients' feeling of weakness as 'moral stigma', citing patients' perception of being stigmatized by health professionals, family members and significant others, and that had a profound effect on their self esteem and behaviours. Other studies have shown that patients with chronic pain perceive their illness as a moral event and experience feelings of shame as a result (37-39).

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 (40).

The notion of personal growth illustrates a broader point. Patients were able not only to identify positive side effects of the painful illness but also to weave these into their life stories. This supports previous studies showing narratives to be another integrative strategy whereby RA patients can rebuild their biographies (41,42). Bury (43) argued that chronic illness is a 'biographical disruption', interrupting the basic structures of patients' everyday life, their biography and their self-concept. Williams (41) expanded on this point by suggesting that patients try to 'repair' their lives by finding a meaningful place for illness in their lives, in an attempt to create a sense of coherence and stability. From this point of view, 'hitting the bottom' – beside being a real stage in the patients' illness history – may also be seen as a culturally available narrative by which they could explain and make sense of their personal trajectory. Through this process of narrative reconstruction, patients manage their biographical disruption by keeping the continuity in their diversity. This is why we described acceptance as being built on two pillars: grieving for losses from the past and, at the same time, retaining a connection with that past. Patients need to adjust their expectations of what is realistic and achievable, while at the same time retaining their identity and personal values. Achieving this combination is the crucial step for acceptance. As other studies have suggested, it is a process of redefinition that establishes a new attitude toward life, adapting patients' beliefs and patterns of behaviour to the new normality (7,12,44).

The need to maintain continuity is also why the term 'acceptance' was often rejected by patients, who saw it as a synonym of passiveness. While prepared to acknowledge the losses of the prepain life, patients were not willing to accept disengagement from their valued goals and activities. This echoes findings from other studies in which the word 'acceptance' elicited frustration among fibromyalgia and arthritis patients, who typically understand it as 'giving up' or 'giving in' and prefer expressions such as 'dealing with' or 'coming to terms with' their pain (7). These findings are important because, if the goal is to help patients along the path toward acceptance, it is useful to understand how and why they may resist the notion.

Practical implications and limitations of the study

There are important clinical implications in understanding how RA patients come to accept and deal with their pain and its consequences. The present study provides health professionals with insights into the type of support needed to help patients down the difficult path toward 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 provides insights for the implementation of new communication strategies for health professionals.

The main limitations to our study concern the limited scope for exploring diversity in patients' experience of the acceptance process. This diversity appears to be correlated with various individual-level factors. For instance, we have emphasized the importance of prompt diagnosis. However, these data allow us only limited scope to observe the effects of late diagnosis. Future qualitative research could compare early- and late-diagnosis patients in more depth with regard to how late diagnosis affects each stage of the acceptance process, and the manner in which it shapes different representations of the illness at those different stages. Taking a more quantitative approach, we could examine the functional form of the relationship – which is unlikely to be simple or linear – between the length of time spent waiting for diagnosis and the psychological consequences of this wait. Another feature of our sample is that it included only patients who had achieved at least some success in integrating and managing their disease. It would be instructive to interview those 'stuck' at intermediate stages of the process and, thus, with more immediate negative experiences to report. Finally, we also observed that patients' social contexts were a fundamental factor shaping their pattern of behaviour in the face of this disease. Again, further study is needed to explore the main sources and types of social support that may foster patients' acceptance behaviour. More broadly, it would be useful to perform more focused research comprising purposively selected samples, focusing on other key differences – eg, age, sex, personality type, etc.

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