

**Social Support and Acceptance among Rheumatoid Arthritis patients: “learning how to live with chronic pain”**

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## SUMMARY

Chronic pain sufferers with diseases such as Rheumatoid Arthritis (RA) are a category of patients that feels stigmatized, lacking understanding and support from the surrounding social environment (Davison et al., 2000). The invisible and unpredictable character of RA makes it very difficult to be recognized and understood by family, friends, colleagues, and so on, and patients often complain of being treated with scepticism and distrust.

In the last 25 years, the concept of social support and its relation to health has been studied by a burgeoning literature (see, *inter alia*, Krokavkova et al., 2008; Helgeson, 2003; Lee et al., 2004). There is strong empirical evidence that the support that chronic patients receive from their environment is fundamental for the way they cope with physical and psychological suffering. Nevertheless, in the case of RA, providing the right social support is still a challenge and such support proved to be often elusive and unreliable in helping patients to manage the disease (Kostova et al., 2014).

Acceptance is an important component of pain management, being associated with improved quality of life and lower levels of pain and depression. According to McCracken (2005), acceptance is not a single belief but a psychological process, driven by the willingness to experience pain without trying to control and avoid it. Patients able to pursue their life goals and the activities that matter to them, regardless of the pain, have better quality of life and better physical, social and emotional functioning (Geiser, 1992; McCracken and Eccleston, 2005; Viane et al., 2003).

There is therefore ample reason to suppose that, in facing and accepting the implications of a disease like RA, patients need access to a satisfying social context on which they can rely for both emotional and practical support (McCracken, 2005; Revenson, 1993). However, specific evidence on the link between social support and

acceptance, especially in a context like RA where that social support is harder to realize, is as yet missing. There are some quantitative survey studies demonstrating a correlation between social support and acceptance (Affleck, Pfeifer, Tennen, and Field, 1988; Gil et al., 1987; [Osborne](#), Jensen, Ehde, Hanley, and Kraft, 2007). However, these correlations between overall measures obscure the multidimensionality of both concepts, and the quantitative approach cannot trace the casual mechanisms along which the two are linked.

This dissertation is a collection of three papers that aim to overcome the aforementioned challenges, giving both breadth and depth to explanations of the relationship between social support and acceptance among RA patients. With the first paper, we defined a ‘key moments’ model of acceptance, exploring five moments or phases that RA patients experience in order to accept and accommodate the pain in their selves and lives. We identified the diagnosis, the first phase, as a particularly difficult step among RA patients that shapes the whole process of acceptance. The second paper is focused on the concept of social support, comprehending its multifaceted character. We identified the main social support sources from patients’ point of view and the circumstances under which the reactions from these sources may hinder rather than help acceptance. While we were able to link each source of support to particular phases of acceptance, identifying in which key moments the different sources do most to foster acceptance, the results were more holistic than that: the most effective sources can be helpful throughout the process. In the third paper, building on the insights of the first two, we describe and evaluate an online tool designed to be an alternative way of providing social support to chronic pain patients. Identifying both where this tool was and was not effective, we pinpoint the factors – at the level of design and at the level of the individual patients – that moderate the efficiency of online social support.

This dissertation provides theoretical and clinical advances to research on the concepts of acceptance and social support and the link between the two. A qualitative

approach allows us not only to consider the richness and variety of patients' perspectives but also to do justice to the multidimensionality of both concepts. The findings of the dissertation have practical implications, providing health professionals with insights into the kind of support needed to help sufferers down the difficult path towards acceptance. From a theoretical point of view, the dissertation contributes to the field of health communication in two ways. First, via a grounded theory approach we build on existing understandings of the multi-phasic and complex process of acceptances. Second, we ground the concept of social support in the model of Health Empowerment (Schulz & Nakamoto, 2005), identifying it as a fundamental factor that affects patients' self-management behaviour.

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## **CHAPTER I**

### **GENERAL INTRODUCTION**

## Introduction

*“All your life changes: at home, as a mother, at work. It is difficult, because you are suffering from a disease that is not visible, in the sense that when someone meets you they say: you don’t have anything, you look fine! But sometimes it is so difficult even to hold a glass! People outside, even your closest ones – they cannot understand you (...) I don’t think I will ever accept it [RA], I just learnt how to live with it.”*

The quotation above, from a Rheumatoid Arthritis (RA) sufferer, clearly illustrates the two main themes in this dissertation: the powerful impact that chronic pain has over patients’ lives; and the difficulty in obtaining the right form of support during the long process of learning to live with the pain and to accept the changes it enforces.

The impact of chronic pain diseases is not limited to pain and physical disability. There are many injurious psychological implications, causing significant losses in patients’ lives. Bury (1982) argues that chronic illness is a “biographical disruption”: living with chronic pain interrupts the basic structures of patients’ everyday life, their biography and their self-concept. The imposed limitations of chronic pain impede patients’ autonomy and independence in fulfilling their roles in important life domains, such as work, family and social life. The way that patients face those losses may differ: on the one hand, they may give way to resisting behaviours, becoming victims of unwinnable fights to recover their pre-pain life; on the other hand, they may become able to accept their condition as it is, trying to establish a new way of living and pursuing their personal goals, regardless of the pain (Hayes, Strosahl, and Wilson, 1999; McCracken, 2006; McCracken, Carson, Eccleston, and Keefe, 2004; McCracken, 1999). This latter approach has been termed ‘acceptance’ and is shown in numerous studies to deliver various positive outcomes.

Acceptance is the core dependent variable for this dissertation. The core independent variable is social support. Previous research indicates that the way in which patients

deal with chronic pain, and the ease with which they accept the new limitations it imposes, is strongly influenced by the support they receive from their environment (McCracken, 2005). In this dissertation, therefore, I focus on the relationship between these two concepts and variables, identifying a model of acceptance and exploring how social support – both in real life and in a purpose-built online environment – shapes the way in which patients learn to manage the disease.

The purpose of this introductory chapter is to set the scene for the detailed studies that follow, outlining the research context and the recurring theoretical themes. After some details about the case of RA, I review research about the relationship between social support and health, paying particular attention to the health empowerment model of Schulz and Nakamoto (2005) which provides a framework for understanding how social support has its positive effects. Then, to provide a backdrop to the practical component of the dissertation, I provide an initial assessment of the capacity of online social support to deliver those positive effects.

### **Rheumatoid Arthritis**

Among chronic pain conditions, Rheumatoid Arthritis (RA) is one of the most common with an estimated prevalence of 1% in the world population (Wood and Bradley, 1986), although it is four times more frequent among women than among men. Its onset comes during a highly active period of people's lives, between the ages of 30 and 50 (Hannan, 1996; Gordon and Hastings, 1997). The disease is characterized by progressive joint destruction and persistent, often severe pain. Its etiology is unknown and there is no cure (Gordon and Hastings, 1997). The painful nature of the disease implies serious secondary consequences such as depression, reduction of social activities, job loss, and financial decline (Verbrugge and Juarez, 2008; Pleis and Lethbridge-Cejku, 2006). The "Arthritis Hurts" survey in the UK reported that people with arthritis experience greater psychological distress than those with other

chronic diseases – 68% of them reported feeling depressed, fatigued and helpless (Simmons et al., 2002).

RA is an invisible and unpredictable disease: there are no clear visible signs of the symptoms and the acute episodes of pain are variable, appearing and disappearing over time. These characteristics mean that the disease is not readily recognized and grasped by others, and so patients often feel misunderstood by those in their surrounding social context, being treated in some cases with scepticism and distrust (Kostova et al, 2014). In that sense, giving adequate social support to RA patients is a difficult task, and often that support proves elusive or unreliable (Werner and Malterud, 2003).

### **Social support, health and acceptance**

The umbrella concept of social support takes in a range of aspects and dimensions. Some studies focus on the size and density of a patient's social network, others elicit the patient's subjective perception of social support, and still others explore the individual characteristics and cultural factors that shape willingness to give and receive social support (Strating et al., 2006; Park et al., 2013). Considering the various conceptualizations of social support, Suurmeijer et al. (2005) pointed out that is important to make a distinction between the actual occurrence of social transactions and the satisfaction of those involved with these transactions. Supportive transactions are the objective exchange of resources, but a patient's satisfaction with these exchanges depends on his or her needs and expectations according to the specific situation. The definition of Thoits (1982) is in line with this idea and emphasizes the importance of an individual's own perception and evaluation of support. He considers social support in terms of "the degree to which person's needs are gratified through interactions with others". More or less explicit in that definition is the notion that social support itself may not always be satisfying for patients, and in turn that it is im-



portant to understand sufferers' specific needs and difficulties with their disease in order to provide them with the appropriate type and amount of support. This is the reason why, in this research project, we first considered patients' point of view, exploring the main difficulties they faced during the internalization of the disease in their lives and selves. We gave substantial importance to what it means to live with RA from patients' perspectives and how they perceive the support from the external context, pinpointing what they miss as well as what helps them to face the pain.

Definitional detail aside, there is strong empirical evidence that receiving social support may have both direct and moderating effects on health, increasing patients' empowerment and self-management skills, and buffering also the negative impact of low literacy on health (Johnson et al., 2010; Antonucci et al., 2003; Lee et al., 2006; Strating et al., 2006; Courneya et al., 2000). According to the "strain hypothesis", social support can act as a "direct agent" leading people to know that they are valued and loved, strengthening their self-esteem and, in turn, their health and well-being (Vilhjalmsson, 1993; Thoits, 1995; Eckersley, 2000). The moderating (indirect) effect of social support instead entails buffering the effects of stress on health. In other words, social support could act as a coping strategy that helps people deal with stress and other threats to their psychological well-being.

However, while it is clear that social support can have a powerful effect on outcomes, the existing literature leaves some questions unaddressed. First, while quantitative studies have established a correlation between measures of social support and acceptance (Affleck, Pfeifer, Tennen, and Fifield, 1988; Gil et al., 1987; Osborne, Jensen, Ehde, Hanley, and Kraft, 2007), these have usually been moderate correlations (in the 0.15-0.30 range) that suggest some contingency and conditionality in the relationship between the two. One reason is that summary indices tend to combine the multiple dimensions (in terms of sources and types) of social support. It may be that some of these are more effective than others – or more effective for different pa-

tients in different phases – and this kind of detail may be more easily accessed by in-depth qualitative investigation of particular patients.

Qualitative study can also strengthen the causal inferences possible from correlational results. For example, while there has been extensive research focusing on spousal reactions and their effect on patients' acceptance behavior (Flor et al., 1987; Lousberg, Schmidt, and Groenman, 1992; McCracken, 2004; Romano et al., 2005; Williamson et al., 1997), other studies indicate that that correlation could be inflated by reverse causality, whereby patients' pain behavior (e.g. catastrophizing) influences perceived partner responses (Boothby, Thornb, Overduina, and Wardc, 2004; Cano, 2004; Keefe et al., 2003; Williamson et al., 1997). In any case, spouses are just one aspect or source of social support. To date there is no similarly extensive in-depth research considering the multiple aspects of social support, and how this support may impact the process of adaptation and acceptance of the disease over the time. In sum, then, quantitative studies have effectively established that there is a relationship between social support and acceptance; the comparative advantage of qualitative research is in its capacity to trace the causal paths along which that relationship operates – and sometimes malfunctions (McCracken, 2005, López-Martínez, Esteve-Zarazaga, and Ramírez-Maestre, 2006).

Meanwhile, turning to the qualitative literature (e.g. Affleck et al., 1988; Helgeson and Cohen, 1996; Strating, van Schuur, and Suurmeijer, 2006; Penninx et al., 1998; Primomo, Yates, and Woods, 1990; White, Richter, and Fry, 1992), this has focused primarily on the effect of social support on outcomes such as adjustment, adaptation, and self-management. There has been much less attention paid to acceptance per se, a significant omission because of acceptance's role as a mediator: it is the process by which patients achieve those "ultimate" outcomes. Even where acceptance is mentioned, it is folded into other concepts like accommodation or adjustment, or considered as a trait or state rather than a process. For example, Jefferey et al. (2011) interpret acceptance as a set of individual beliefs and perceptions regarding pain. Afrell

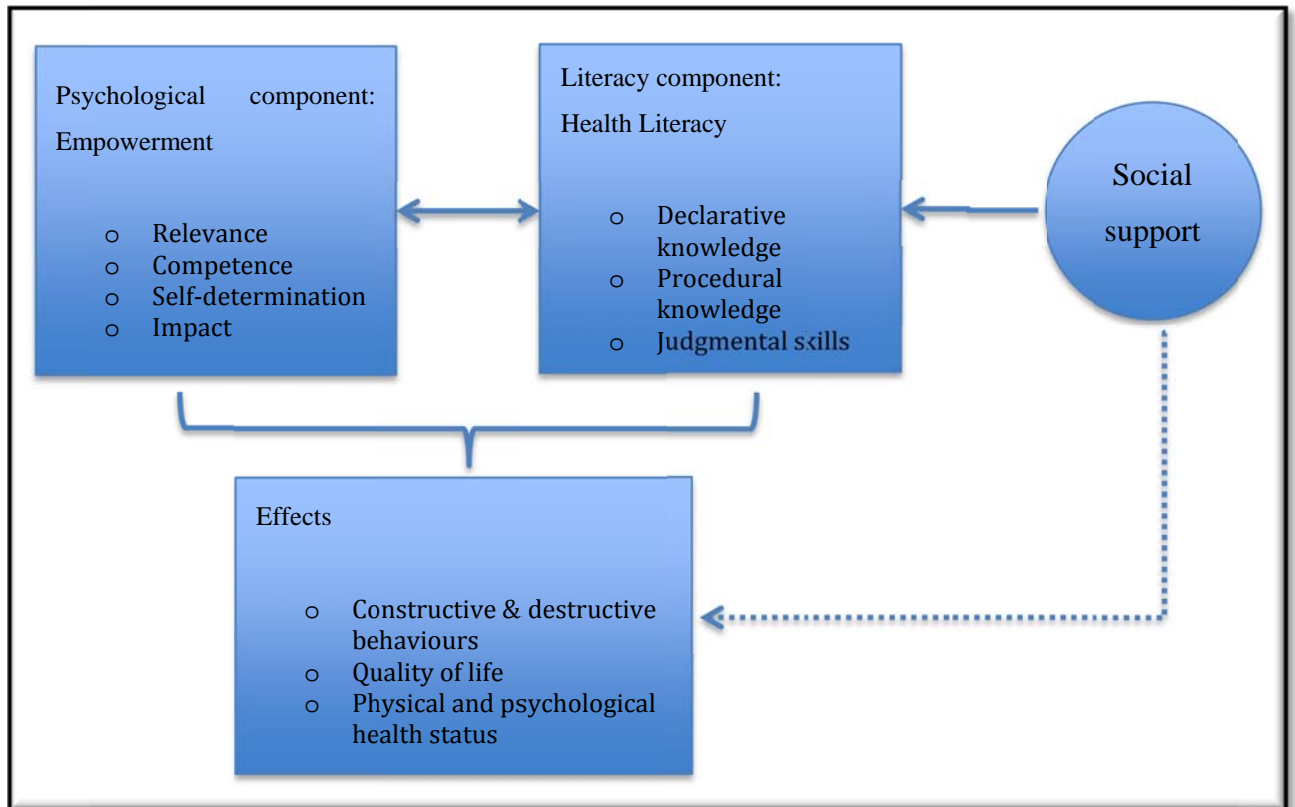
et al. (2007) see acceptance as a state that patients enter and exit during their long experience of “living with pain” – they fluctuate between accepting and rejecting the aching body. Their definition of acceptance, as an indicator of how pain influence patients’ self-perception and actions, is useful but they do not trace a path of acceptance from a biographical perspective. Gullacksen and Lidbeck (2004) come closer to recognizing a process, describing past, present and future as three progressive moments in the quest to “establish the new course of life”(p.149). Perhaps the most thorough treatment of acceptance in this context is in the study of LaChapelle et al (2008), which considers social support as a facilitator of acceptance. We build on their research by exploring the dimensionality – again, in terms of sources and types – of social support and the diverse effects of these dimensions in shaping the acceptance process.

In summary, the existing literature allows us to pinpoint some crucial themes that are common during patients’ experiences of coming to terms with the pain. Nevertheless, less attention has been given on how patients actually achieve acceptance and on how social support – in all its complexity – can affect this process, positively but sometimes not so positively. In this dissertation, then, we use qualitative interviews to investigate the concept of social support and its impact on acceptance behaviour from the sufferers’ point of view, considering the multidimensionality of both concepts. We identify the main difficulties that patients face in accepting the disease and the main sources and types of support that play a crucial role in patients’ adjustment to the pain. These findings guided an attempt to operationalize social support in practice. We created a website that meets and responds to patients’ needs as identified in the qualitative interviews, assessing to what extent online support can offer an alternative source of social support and identifying the factors and circumstances that determine the efficacy of such an approach.

### **The Health Empowerment Model**

The theoretical framework on which I based my dissertation is the model of Health Empowerment developed by Schulz and Nakamoto (2005). It considers social support as a fundamental factor that can impact on psychological empowerment and health literacy – crucial elements for the way in which patients with chronic illness manage their disease (Figure 1). According to the model, the information and the support that chronic patients receive from their social sources (such as friends, relatives, mass media and physicians) will determine their knowledge about how to deal with the disease, making them more autonomous and responsible in managing the illness. Of course, the type of support that chronic pain patients receive can also have a deleterious impact, contributing to destructive and inefficient behaviors (Schulz and Nakamoto, 2013). Thus, in my dissertation I grounded the concept of social support in the model of health empowerment, with a particular focus on its psychological component. The aim is to assess the impact of the support received by chronic patients from their significant others on the process of acceptance of the pain.

Figure 1: Health Empowerment Model and its effects (Schulz&amp;Nakamoto, 2005)



As we can clearly see the model of health empowerment emphasizes two main aspects – the informational (literacy) and the psychological effect of the social environment on the way patients deal with the disease. The main focus of this dissertation, as discussed in more detail below, is on the psychological component. However, since social support also has the capacity to improve the informational component, it is worth briefly elaborating on the concept of health literacy in Schulz and Nakamoto's model (2005). Importantly, this goes beyond simply the ability to understand health information; it refers more to the ability to critically judge that information in order to make decisions according to the specific situation of the disease. The authors expanded the concept, distinguishing three components of health literacy: declarative knowledge (the factual knowledge that people can acquire via

different information sources); procedural knowledge (the “knowing how” that guides the proper course of action); and judgmental skills (the ability to critically judge the health information in relation to one's own condition).

Turning to the concept of psychological empowerment, this entails the individual taking increased responsibility for, and playing a more active role in, decision making regarding his or her health. Spreitzer (1995), in her measure of empowerment, identifies four main constructs: (1) meaningfulness – “I feel that doing this is relevant for me”; (2) self-efficacy – “I am able to do this”; (3) self-determination – “I can choose between different ways”; and (4) impact – “I can make the difference”. These four propositions reflect patients’ motivation and willingness to be autonomous and responsible actors for their own health. According to the model, together the four powerfully influence the way that patients face the disease on an everyday basis.

Acceptance centres on patients’ willingness to pursue their own goals and values regardless of the pain, and the concept of empowerment is also related on the perceived ability to be able to deal with and manage the disease. We can thus see some similarity in the two concepts, as they are both related on volitional components regarding the one’s ability to cope with the pain. Acceptance could be seen as one dimension of empowerment, or perhaps as one means by which it is achieved. The precise causal relations between them are hard to establish but this need not trouble us here. For present purposes, the key point is that acceptance belongs squarely within the psychological component of the health empowerment model. One important way in which social support can shape that psychological component is by helping sufferers to accept the disease and its implications.

### **The Internet as an alternative channel for social support**

As mentioned above, the nature of RA means that social support often proves to be unreliable and elusive, patients often feeling that others do not sufficiently understand their suffering (Werner and Malterud, 2003). RA patients feel stigmatized and accused of using their illness as an alibi to avoid responsibilities, due to the lack of visible external signs of pain. Often even family members and close friends fail to recognize patients' internal suffering (Holloway et al., 2007; Eccleston et al., 1997).

The importance of social support for RA patients' health outcomes, coupled with the fact that patients often feel a deficiency in that regard, has moved health policymakers to seek ways in which such support can be boosted. However, the most intensive forms of social support are hard to provide for reasons of cost. Attention has therefore more recently turned to using interactive Internet tools as a source of support. There is a burgeoning literature that praises the internet as a tool of support for patients with chronic conditions (Fox, 2009; Kirsch & Lewis, 2004; Payne & Kiel, 2005; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). Support groups have formed on the web, thereby overcoming some of the barriers to face-to-face interaction, such as geographical and time distances, costs and anonymity. It has been shown that patient online support groups may improve psychological, social and health outcomes providing a virtual network and health information (Eysenbach, 2004; 2006; Murray, Burns, See, Lai, & Nazareth, 2005; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan, et al., 2008; Winkelman & Chun Wei, 2003). Participating online empowers patients, and therefore van Uden-Kraan, et al. (2008) in their study with patients with arthritis, fibromyalgia and cancer found improvements in a variety of outcomes, including being better informed, feeling more confident and self-esteemed and accepting the disease. Interacting online has a positive impact on the adjustment to the illness, helping sufferers to re-frame their own illness, to develop argumentative abilities and to improve self-confidence (Ziebland and Wyke, 2012; Brashers et al., 2002; Hesse, 2005; Caiata-

Zufferey and Schulz, 2010). In sum, online support has the potential to act on both the informational and the psychological components of the model set out in Figure 1.

Given this evidence that the Internet offers a potential tool of support, and having identified patients' specific needs, we developed an interactive online tool. This took the form of a website called Oneself. Reflecting the two major components of Schulz and Nakamoto's (2005) model, this tool provided patients with both informational support and the opportunity to be part of a virtual community sharing their problems and concerns with experts and other patients online. We used the insights that we gained from our studies on acceptance and social support to create tailored informational materials about the management of the disease, incorporating information about managing both the psychological and physical consequences of RA. The availability of health professionals online and the interactive features of the site (chat room, forum) were intended to operationalize of the emotional and practical support these patients needed.

### **Aims and outline of the dissertation**

The main objective of this dissertation is to deepen our understanding of the relationship between social support and the way in which RA patients accept their illness and manage the limitations that it imposes upon them. This in itself can generate insights for both academic researchers and medical professionals. However, we also aim to provide specific guidance for practitioners about whether and how social support and interaction can be delivered online to RA patients in a way that boosts health outcomes. To these ends, we conducted two qualitative studies and one experimental study exploring:



- The main stages through which RA patients pass and the strategies they adopt to learn to live with the pain; and the factors shaping patients' capacities to achieve acceptance.
- The key sources and types of social support that are relevant for rheumatoid arthritis patients; and when and how those sources are important across the different phases of the acceptance process.
- Whether and how social support can be operationalized online, highlighting the design factors that boost the efficacy of such support and the patients' characteristics that shape their engagement with online tools.

This list also summarises the structure of the dissertation. It consists of three papers that are the outcome of research conducted at the Institute of Communication and Health at the Università della Svizzera italiana, Lugano (Switzerland), between 2011 and 2014.

The first paper is therefore focused on the way in which RA patients achieve acceptance, exploring the main stages and key moments that shape this process. Acceptance is a process whereby patients begin to make choices that maximize their quality of life, being engaged in pursuing their life goals regardless of the pain (McCracken et al., 2004). Those patients who accept the chronicity of their condition without fighting against it are more willing to find alternative ways to manage the pain and to maintain the activities that matter to them. It has been shown that acceptance is an important component of pain management, being associated with improved quality of life and lower levels of pain and depression (McCracken & Vowles, 2006).

The paper is based on a qualitative study of in-depth interviews with 19 patients suffering from RA in the Italian speaking part of Switzerland. From patients' accounts we developed a model of acceptance, identifying five main stages – which we term

key moments – in sufferers’ struggles to come to terms with the disease and to accommodate the limitations: naming the illness; realizing the illness; resisting the illness; hitting the bottom; and integrating the illness. We identified some factors that have a particular impact over acceptance, in particular the difficulties in obtaining a prompt diagnosis that not only delayed the initiation of the acceptance process but created psychological barriers that impeded it throughout. We identified some structural reasons for late diagnosis, notably patients’ and doctors’ neglect of the initial symptoms together with the clinical difficulties in diagnosing RA. Moreover, we explored patients’ views of acceptance and of the illness and how these representations shape patients’ capacity to cope with the disease.

The second paper builds on the first and is based on the same set of qualitative interviews. It is focused on the relationship between social support and the process of acceptance. More specifically, we identify the key sources and types of social support that are important for RA patients in the way they face and come to terms with the disease, considering acceptance as a multistage process. The type of responses that chronic pain patients receive from their social environment (such as the family) may impact the way they face the everyday challenges of the disease (McCracken, 2005; Revenson, 1993). The surrounding environment plays a crucial role for sufferers’ willingness to hold on to their life roles and to accommodate the imposed changes. In this paper, we identified three main sources of support – family, doctors and significant others – and explored their impacts on the various key moments of the acceptance process, noting also the circumstances under which those sources serve to hinder rather than to help acceptance. In particular we observed that there is a pervasive risk either of underestimating patients’ suffering or of over-supporting, both of which prevent patients accepting the disease and developing a new ‘normal’ life. We sum these extremes up as skepticism and solicitousness and conclude that sources of social support need to find a middle way between these two extremes. Our findings about the limitations and conditionality of social support effects are useful in guiding

medical professionals – and those that they inform and advise – about how best to understand and to meet sufferers’ needs.

The third paper is based on an intervention in the form of an alternative on-line source of support, the aforementioned website Oneself. Using the insights gained from the previous two studies about patients’ support needs and their difficulties in accepting the disease, we answered those needs creating a website on which we provided tailored support. The site comprised both informational components – educational material based on what patients need to know in order to manage their disease on a daily basis –and a social support component with interactive features (chat room and forum) on which patients could receive emotional and practical support from experts and from fellow RA sufferers.

The paper is an evaluation of the Oneself tool. The aim is to understand how social support can be provided online and under which conditions such support can deliver positive outcomes for RA patients. The paper’s empirical starting-point is the insights gained from an experimental study that we first conducted with 154 RA patients in order to evaluate the impact of the website on different patients’ outcomes. This showed that Oneself generated improvements in health outcomes related to the daily and practical management of the disease (such as pain management and levels of health literacy) but was often unable to shift the deeper ‘mind-set’ variables, like acceptance, which are the main focus of the dissertation. In the third paper, then, particular attention is paid to the mixed results and the reasons for them. We conducted a follow-up qualitative study to clarify which are the factors that shape patients’ engagement and interaction online. In 20 semi-structured interviews with patients who participated to at least some extent in the online interactions, we asked about their experiences, impressions and perceptions of this participation, and about what made them more or less engaged in sharing their problems online.

The dissertation ends with a general conclusion that discusses the main contributions of the studies on social support and acceptance, some of the limitations of the indi-

vidual papers, and the generalizability of the findings to other chronic conditions and to other contexts.

## **CHAPTER II**

### **The process of acceptance among RA patients in Switzerland: a qualitative study**

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## **Abstract**

Rheumatoid Arthritis is a chronic, painful disease with many injurious psychological effects. Acceptance is an important component of pain management, being 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 those stages.

The goal of the study is to explore the main stages through which RA patients pass and the strategies they adopt to learn to live with the pain, identifying factors shaping patients' capacities to achieve acceptance.

We conducted a qualitative study involving 20 semi-structured interviews with RA patients in the Italian-speaking part of Switzerland. Analysis of the data followed the precepts of grounded theory.

While finding that acceptance is anything but a smooth or linear process, we were nonetheless able to identify five main stages in patients' struggles to accommodate the newly-imposed limitations: naming the illness; realizing the illness; resisting the illness; hitting the bottom; and integrating the illness. Diagnosis proves an especially tortuous stage in the case of RA, and the effects of delayed diagnosis continue to be felt during the subsequent stages. We also explored patients' understanding of the notion of acceptance, and the strategies that they used to achieve it.

Diagnosis of RA is notoriously difficult. Beyond the clinical difficulties, we identified structural reasons for late diagnosis, symptoms being neglected by patients and medical professionals. Delayed diagnosis hindered the acceptance process throughout, leading to more resistant behaviour and to a struggle to achieve the right formula for acceptance – accepting the losses of pre-pain life while still pursuing personal goals.

**Keywords:** Rheumatoid Arthritis, acceptance process, diagnosis, integration strategies, patients' view of acceptance



## Introduction

Rheumatoid Arthritis (RA) is a chronic, disabling disease characterized by progressive joint destruction and persistent pain. 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, 2008; Pleis and Lethbridge-Ceijku, 2000). In particular, RA is prone to 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 behavior patterns (McCracken, 1999). Patients unwilling to accept the pain are prone to resistance behaviors that reduce their quality of life (McCracken et al., 2004; Hayes, 1999; McCracken and Vowles, 2006). On the other hand, patients can focus on finding a way to live with the pain that allows them to pursue the values and maintain the activities that matter to them. This distinction, and the *acceptance* required to achieve the latter outcome, are at the heart of this article. In addition to building on previous studies that have begun to elaborate on the process of achieving acceptance, in this article 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 the qualitative study of LaChapelle et al (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; see also McCracken). 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 (LaChapelle et al, 2008). Dissecting those stages is key to



understanding how patients succeed in dealing with the implications of a disease like RA.

Acceptance is typically seen as one of a broader cluster of concepts like adjustment (McCracken, 1998; Li and Moore, 1998; Shaul), adaptation to or negotiation with chronic pain (Gullacksen and Lidbeck, 2004; Sofaer et al., 2005; Schaefer, 1995; Jeffery et al., 2011; Harding et al., 2005). From this extensive literature, we can pinpoint some common and recurring themes or stages: becoming aware of the problem and having 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 (McCracken, 1998; Geiser, 1992; McCracken et al., 2005; McCracken et al., 2005, McCracken and Eccleston, 2006; Viane et al., 2003). Those who come to terms with pain report more positive clinical outcomes, greater confidence in their coping ability, higher daily uptime, and less depression and less pain (Jacob et al., 1993; McCracken and Eccleston, 2003).

These studies highlight key themes and demonstrate the importance of acceptance for health outcomes. 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 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 where correct and swift diagnosis is notoriously difficult (Majithia e Geraci, 2007), there is little research into 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 (Green and Thorogood, 2004; Strauss and Corbin, 2004). Since the existing literature comprises only Anglo-Saxon studies, it is useful to broaden the evidence base. Switzerland, a smaller country in continental Europe,

also allows 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 about 1% of the adult Swiss population ([www.rheuma-schweiz.ch](http://www.rheuma-schweiz.ch)). More generally, 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 has generated spiraling costs for the Swiss health care system and one in four disability pensions are paid for a rheumatic pathology.

In this study, then, we expand the field of *RA-acceptance* research to a new setting, addressing in that three core questions: (1) What are the main phases patients pass through in learning how to live with their disease? (2) What is the specific importance of the diagnosis of RA in shaping patients' capacity for acceptance? (3) Which strategies do patients adopt to accommodate the disease in their selves and lives?

## **Methods**

### ***Participants***

We conducted a qualitative study based on 20 semi-structured interviews with RA patients (Table 1). Approval was obtained from the Ethical Committee of Canton Ticino (the Italian-speaking part of Switzerland) and informed consent was obtained from each participant prior to 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). Aside from the Swiss patients, there were five Italians and one Dutch participant.

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. In order to maximise the variability of respondents' experience, we selected patients of different sex, age, level of

education, and socioeconomic status. Our sample was composed of 13 women and 7 men (the disease has a four times higher prevalence among women than among men), with ages ranging from 35 to 69.

The medical definition of an early diagnosis of RA is within six months<sup>29</sup>. By that yardstick, only seven of our patients discovered the illness in time; most of the rest waited years before obtaining the correct diagnosis. The average waiting time before the diagnosis was around two years (ranging from 3 months to 10 years) and the average length of time *since* diagnosis was nine years (ranging from 3 to 14 years).

**TABLE 1.** CHARACTERISTICS OF THE PARTICIPANTS

DIAG NOSIS	S E X	A G E	NATION ALITY	TIME OF DIAGN OSIS	TIME BETWEEN FIRST SYMPTOMS AND DIAGNOSIS	FAMILY STATUS	EDUCATION
RA	F	35	DUTCH	7 YEARS	5 MONTHS	SINGLE	HIGH- SCHOOL
	M	37	SWISS	3 YEARS	6 MONTHS	IN A RELATIONSHIP	UNIVERSITY DEGREE
	F	49	ITALIAN	5 YEARS	2 YEARS	MARRIED	MIDDLE SCHOOL
	M	49	SWISS	11 YEARS	2 YEARS	MARRIED	HIGH- SCHOOL
	M	50	SWISS	10 YEARS	1,5 YEAR	MARRIED	UNIVERSITY DEGREE
	F	52	ITALIAN	14 YEARS	2 MONTHS	MARRIED	HIGH- SCHOOL
	M	52	ITALIAN	8 YEARS	3 YEARS	MARRIED	MIDDLE SCHOOL
	F	54	SWISS	13 YEARS	5 YEARS	MARRIED	MIDDLE SCHOOL
	F	55	SWISS	6 YEARS	2 YEARS	MARRIED	HIGH SCHOOL
	F	58	SWISS	10 YEARS	10 YEARS	WIDOW	UNIVERSITY DEGREE
	F	67	SWISS	14 YEARS	4 YEARS	MARRIED	HIGH SCHOOL
	F	69	SWISS	8 YEARS	6 MONTHS	MARRIED	HIGH SCHOOL
	F	69	SWISS	9 YEARS	2 YEARS	WIDOW	MIDDLE SCHOOL
	M	38	SWISS	3 YEARS	3 MONTHS	SINGLE	UNIVERSITY DEGREE
	M	42	SWISS	4 YEARS	1.5 YEAR	MARRIED	HIGH SCHOOL
	M	53	ITALIAN	5 YEARS	6 MONTHS	MARRIED	MIDDLE SCHOOL
	F	41	SWISS	3 YEARS	2 YEARS	MARRIED	UNIVERSITY DEGREE
	F	40	SWISS	4 YEARS	3 MONTHS	MARRIED	UNIVERSITY DEGREE
	F	58	SWISS	8 YEARS	1,5 YEAR	MARRIED	HIGH SCHOOL
	F	61	ITALIAN	9 YEARS	1,5 YEAR	MARRIED	HIGH SCHOOL

***Recruitment and data collection***

Recruitment was in collaboration with the Swiss Association of Rheumatology. Three rheumatologists were asked to nominate patients that they recognized as successful in having learnt how to deal with the implications of the disease, allowing us to observe 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 and 90 minutes each, were conducted in medical offices in the rheumatology clinics. 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.

***Data analysis***

A grounded theory approach was used, with data collection and analysis carried out in cycles. To assist this iterative exchange, we conducted the interviews during two periods of time: Jan-Mar 2012 and Dec 2012-Jan 2013. 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. These operations allowed for reduction and interpretation of large amounts of data, and continued until data saturation was achieved. Literature was used throughout the research to support the process of questioning and interpreting the data. The results discussed in this 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 studied phenomenon (Mays and Pope, 1995).

## 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. For example, while only one patient used the term “hitting the bottom”, when questioning others’ narratives we found not only a similar experience but that it was the culmination of resistant reactions and often the trigger for a process of integration.

Before discussing each stage in detail, we should 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 our 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: for example, patients engaged in integrating the illness may well also encounter feelings of resistance. There is also the fact that 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. Second, there are pronounced differences across patients in the way that they experience the five stages. A given stage might be very intense or difficult for some patients but so easy for others that they might almost be said to have skipped it altogether. One major source of those 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 were much speedier in arriving to the final stage of

integrating the illness, and suffered little during – or even avoided altogether – the stages of realizing, resistance and hitting the bottom.

Given the importance of diagnosis, in the discussion below we also consider patients' evidence of the causes – which went beyond the usual medical difficulties – of late diagnosis. We also identified some specific strategies that patients adopted to accommodate the disease and the new restrictions that it places upon them. Finally, confronting patients directly with the idea of acceptance, we examined their understanding of and reactions to that notion.

### *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 diagnoses, most waited substantially longer. Clearly, one major reason for late diagnosis is the medical difficulty of RA diagnosis *per se*. But 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. 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. 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, M)*

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 GPs for not having done enough to discover the illness more promptly and some attributed that to the Swiss private health system. Indeed, the country’s health care system is private, and participants thought GPs feel conditioned and restricted by the health companies. In particular, they felt there may be a tendency to diagnose more common conditions rather than to undertake the further examinations that are expensive but necessary to discover 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, M)*

Another patient blamed the health system for her going ten 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, F)*



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 spent waiting – indeed, often fighting – 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, M)

Conversely, patients who were younger and 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*:

*“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 5 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, F)

This period of shock notwithstanding, early diagnosis was ultimately very beneficial for patients. This is true in obvious physical terms, since swift diagnosis saves at least some patients from severe joint deterioration. However, catching 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...”*

Another early-diagnosed patient 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, F)

In contrast, the corrosive 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 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, 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. One female patient illustrated this very clearly, emphasizing that her whole 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, F)

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. It is difficult to accept something that is not your 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, F)*

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 post-diagnosis 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, M)*

### ***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 were denying 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, F)

Feeling imprisoned by the new restrictions and not being ready for such significant changes, patients were fighting to retain their life roles from the pre-pain 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, F)

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, F)

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, M)

All of the foregoing quotations are from patients who waited more than eighteen months for diagnosis (Table 1). Those obtaining early diagnosis told 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 seems that the long wait for diagnosis makes it more difficult for patients subsequently to cope with that news.

### ***Hitting the bottom***

Consistent with our argument that swift diagnosis spares patients the worst psychological effects of RA, there is little to say here about those who obtained early confirmation of their disease. 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. One patient graphically described this moment when, having given in 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, F)*

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 put it:

*“Either you commit suicide, or you accept it and wait to die without doing it yourself.” (Viara, 69, F)*

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, F)*

### ***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 started to develop personal strategies which allowed 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, M)

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. 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. One patient gave some examples and, in the process, highlighted the importance of will power 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, F)

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* thanks to the disease, turning to their advantage the 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, M)

A parallel argument to that about 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, we can say that having known the pain caused patients to *re-evaluate their life* and to look at 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, M)

*“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, F)

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, F)

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, M)

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, F)

Another way of seeing the positive side of the condition was the recognition that things could be always worse. Making win-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, F)

As would be expected, these affective strategies were most useful to those who had endured more with the disease, whether because they had suffered from 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, our early-diagnosis patients reported using practical rather than identity or affective-based strategies. Since they had seldom experienced significant emotional upheaval, they tended to find the integration process a much more practical and straightforward matter.

### *Patients' views of acceptance*

It follows from what we said just above that patients diagnosed early, and those suffering from 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' 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. 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, M)*

Another emphasised 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, F)*

The final sentence in the quotation above illustrates that patient’s grasp of a point we 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, F)*

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, F)*

## Discussion

This paper provides a deeper understanding of the phases that RA patients have to pass through in order 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 (LaChapelle et al., 2008). Without being aware of the problem, patients cannot initiate the process of *learning to live with it* (Gullacksen and Lidbeck, 2004; Shaul, 1995). 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 might 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 called ‘hitting the bottom’, a concept already identified in the field of recovery from drug addiction (Biernacki, 1986; Bess et al., 1972). 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 people to change is hitting *their* personal “bottom” (Caiata-Zufferey 2006). Turning points were present also in the narrative of early diagnosed patients, but they were not described as such dramatic, 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 some *practical* strategies to live with the disease. That reinforces the point that the acceptance

process is not only more uneven but also more heterogeneous across 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 mission. 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 try 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 – still feel – considerable anger towards 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 sum, 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. Yet there is scope for health policy and health professionals to reduce the long waits for diagnosis highlighted in our interviews. And it is 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 over patients' capacity to cope with the disease (Heijmans, 1999; Heijmans and de 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 likelier to perceive the illness in a negative way as a “stigma”, “punishment” or “abnormality”. This also echoes results from elsewhere. Holloway et al (2007) labeled 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 behaviors. Other studies have showed that chronic patients perceive their illness as a moral event, and suffer feelings of shame as a result (Åsbring, 2001; Charmaz, 1983; Eccleston, 1997; Lillrank, 2003). 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 and Joseph, 2004).

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 backs up previous studies showing narratives to be another integrative strategy whereby RA patients can rebuild their biographies (Williams, 1984; Bury, 2001). Bury (1982) argues that chronic illness is a “biographical disruption”, interrupting the basic structures of patients' everyday life, their biography and their self-concept. Williams (1984) expands 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” – besides 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 built on two pillars: grieving for those 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 behavior to the new *normality* (Gullacksen and Lidbeck, 2004; LaChapelle, 2008).

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 pre-pain 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 (LaChapelle et al, 2008). These findings are important because, if the goal is to help patients along the path towards acceptance, it is useful to understand how and why they might resist the notion.

### ***Limitations and practical implications of the study***

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.

The main limitations of our study concern the limited scope for exploring diversity in patients' experience of the acceptance process. This diversity looks to be correlated with various individual-level factors. For instance, we have stressed the importance of prompt diagnosis. However, these data allow us only limited scope to observe the effects of late effects of late diagnosis. Future qualitative research could compare early- and late-diagnosis patients in more depth in terms of the way that late diagnosis impinges on each stage of the acceptance process, and the way 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 do more focused research comprising purposively-selected samples, focusing on other key differences – by age, gender, personality types, and so on.



## **CHAPTER III**

### **The impact of the social support on the acceptance process among RA patients: a qualitative study**

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**Abstract**

Acceptance is an important component of pain management, being associated with improved quality of life and lower levels of pain and depression. In enabling patients with chronic diseases to accept unpleasant consequences and to establish a new way of living, the support they receive from their social environment may play a decisive role. In this article, we identify the key sources and types of social support that are relevant for rheumatoid arthritis (RA) patients, and explore when and how those sources are important across the different stages of the acceptance process. We conducted a qualitative study involving 20 semi-structured interviews with RA patients in Switzerland. Analysis of the data followed the precepts of grounded theory. We found that, amid the complexity and variety of patients' struggles for acceptance, there were some common experiences or 'key moments' in which social support played an important role. While three sources of support – *family*, *physicians*, and the *external social context* – are fundamental for RA patients, all three may inhibit as well as encourage acceptance, due to the invisible and unpredictable character of the disease. There is a pervasive risk either of underestimating patients' suffering or of over-supporting, both of which prevent patients accepting the disease and developing a new 'normal' life. We conclude that sources of social support need to find a middle way between skepticism and solicitousness.

**Keywords:** Rheumatoid Arthritis, social support, acceptance, scepticism, solicitousness, balance

## Introduction

Coping with Rheumatoid Arthritis (RA) involves a number of stresses and challenges (Revenson, 1993). In addition to the physical toll – pain, stiffness and restrictions on activities – patients must also confront numerous and often severe psychological consequences and come to terms with the implications of the illness for their lives. The way that patients face those challenges may differ: on one hand, they may give way to resisting behaviour, becoming victims of unwinnable fights to recover their pre-pain life; on the other hand, they may become able to accept their condition as it is, trying to establish a new way of living and pursuing their personal goals, regardless of the pain (Hayes, Strosahl, and Wilson, 1999; McCracken, 2006; McCracken, Carson, Eccleston, and Keefe, 2004; McCracken, 1999). This second approach has been termed ‘acceptance’ and is shown in numerous studies to have more positive outcomes. When patients accept their pain without fighting against it, they have better physical, social and emotional functioning (Geiser, 1992; McCracken and Eccleston, 2006; McCracken, Eccleston, and Bell, 2005; McCracken, Vowles, and Eccleston, 2005; McCracken, 1998; Viane et al, 2003).

Research attention has therefore turned to the conditions that foster this positive outcome of acceptance. In this article, we consider one of the most important such conditions: the *social support* available to patients during their struggles with the disease. Patients are social actors and much of the chronic pain behavior happens in social contexts which can influence that behavior and, in turn, the amount of suffering (McCracken, 2005). There is ample reason to suppose that, in facing and accepting the implications of the disease, patients need access to a satisfying *social context* on which they can rely for both emotional and practical support (McCracken, 2005; Revenson, 1993). However, existing research on the relationship between acceptance and social support has been limited in scope in two important respects.

First, the quantitative studies on social support and acceptance establish that there is a link between these two concepts but they are less suitable for tracing the numerous ways in which that relationship might operate (Affleck, Pfeifer, Tennen, and Fifield, 1988; Gil et al., 1987; Osborne, Jensen, Ehde, Hanley, and Kraft, 2007). Correlational results are inevitably a summary of complex and often contingent effects and it is difficult to capture through them the multidimensionality of the concepts of acceptance and social support (McCracken, 2005, López-Martínez, Esteve-Zarazaga, and Ramírez-Maestre, 2006).

One aspect of this multidimensionality is that acceptance is not a single event, decision or belief but a process that may comprise multiple experiences or phases. While the complexity of such transitions means that the acceptance process inevitably differs across individuals, studies have nonetheless picked out some common experiences and key moments. One example is the model of Kostova et al. (in press) that identifies five such moments: (i) naming the illness – obtaining a diagnosis that explains the reason for the pain; (ii) realizing the illness – realizing the constraints that the disease places on life roles; (iii) resisting the illness – a period of denial and often self-isolation, as patients struggle to recover their pre-pain life; (iv) hitting the bottom – a climactic moment at which patients realize that resistance is futile and that they need to change outlook and behavior; (v) integrating the illness – accepting the limits imposed by the illness and developing strategies to pursue key goals despite those constraints.

Models like this are, of course, inevitably simplifications. As Kostova et al. themselves acknowledge, there are pronounced differences across patients in the way that they go through these key experiences and a given key moment might be very intense or difficult for some patients but fairly easy for others. Moreover, the process of acceptance is not straightforwardly sequential or linear. Patients are prone to get stuck at a particular *key moment* or to regress to earlier points. And the key moments are not distinct but may overlap: for example, patients engaged in integrating the illness may well also encounter feelings of resistance. There is also the fact that the

nature of RA, with symptoms liable to recur at any point, means that patients never reach an ‘end point’ – in that sense, acceptance always remains a process rather than an outcome. Nonetheless, with these important limitations in mind, models like the one presented by Kostova et al. (2014) are useful in unpacking the relationship of interest to us here. Given the multiphasic character of acceptance, and likely variation in patients’ openness to social support during the process, it is instructive to examine whether and how the role of such support varies across those key moments. Like acceptance, the concept of social support is also multidimensional. It usually refers to three groups—family, friends and significant others (Clara, Cox, Enns, Murray, and Torgrudc, 2003; Zimet, Dahlem, Zimet, and Farley, 1988) – and can include three basic levels, (1) emotional, (2) instrumental and (3) informational (Helgeson and Cohen, 2003). Thus, again, correlations based on a general measure – such as the Arizona Social Support Satisfaction Scale – may conceal the fact that some dimensions are more important for acceptance than others. Another important consideration is that, as the evidence on spousal responses highlights (see also Gallant, Sptize and Prohaska, 2007; Helgeson and Cohen, 1996), some sources of support may actually hinder acceptance and thus dampen the overall positive correlation between the two. These points help to explain why, where the correlation between social support and acceptance – or related variables – has been measured, it has sometimes been relatively weak (in the order of 0.10-0.15), perhaps surprisingly so (e.g. Affleck et al, 1988; Gil et al., 1987; López-Martínez et al., 2006; McCracken, 2005, Osborne et al., 2007. For an unusually strong correlation between social support and acceptance, see McDonald, Wykle, Suwonnaroop, and Barrant, 2002).

In respect to the second main limitation, most of the qualitative studies highlighting a link between social support and health outcomes are focused on *outcomes* – adjustment, adaptation, self-management – rather than on the acceptance *process* crucial for achieving these outcomes (e.g. Affleck et al., 1988; Helgeson and Cohen, 1996; Strating, van Schuur, and Suurmeijer, 2006; Penninx et al., 1998; Primomo,

Yates, and Woods, 1990; White, Richter, and Fry, 1992;). The nature and contingency of the support-acceptance relationship has not yet been thoroughly explored. There has been extensive research focusing on spousal reactions and their effect on patients' acceptance behavior (Flor et al., 1987; Lousberg, Schmidt, and Groenman, 1992; McCracken, 2004; Romano et al., 2005; Williamson et al., 1997). Other studies have emphasized the reverse relationship between patients' pain behavior (e.g. catastrophizing) and perceived partner responses (Boothby, Thornb, Overduina, and Wardc, 2004; Cano, 2004; Keefe et al., 2003; Williamson et al., 1997). However, spouses are just one aspect or source of social support. There has not yet been similarly in-depth research considering the multiple phases of the acceptance process, and assessing how patients at the various key moments are helped or hindered by other forms of support.

One final point about previous research on social support and acceptance is that it comprises largely Anglo-Saxon studies. Since research has shown the importance of the specific sociocultural context in influencing the way that patients deal with chronic disease (Green and Thorogood, 2004; Strauss and Corbin, 2004), it is instructive to broaden the evidence base to other contexts. There are sociological and political reasons why a study in Switzerland usefully broadens the evidence base. First, the Italian-speaking part of the country, Ticino, contains large numbers of both native Swiss and immigrant Italians, and there are persistent tensions and cultural prejudices between the two ethnic groups. This has the potential to shape patients' relationships both with their doctors and with the wider social context. On the political side, Switzerland is a country in which the health care system is private. This is likely to influence the way in which doctors and patients deal with the disease, and in turn to shape the nature and extent of social support offered by medical professionals.

The central purpose of this article, then, is to extend and elaborate on previous studies by reporting on a detailed qualitative study of the complex relationship

between social support and acceptance. We pay particular attention to the multidimensionality inherent in both concepts and thus provide evidence bearing on three core questions: (1) which are the different sources and types of social support RA patients consider most relevant in order to achieve acceptance, comprehending their particular needs and expectations? (2) at which key moments in the acceptance process do the different sources have most potential to foster acceptance? (3) under what circumstances do the different sources serve to hinder rather than to help acceptance?

## **Methods**

### ***Participants***

We conducted a qualitative study based on 20 semi-structured interviews with RA patients in the Italian-speaking part of Switzerland. Approval was obtained from the Ethical Committee of Canton Ticino (the Italian-speaking part of Switzerland) and informed consent was obtained from each participant prior to interview. During the transcription process, personal data were removed and fictitious names were attributed.

Recruitment was in collaboration with the Swiss Association of Rheumatology. Three rheumatologists were asked to nominate patients that they recognized as successful in having learnt how to deal with the implications of the disease, having in that way a broader view of the acceptance process. These patients were first contacted and asked to participate by their rheumatologist; those who agreed were then contacted by the authors.

Our substantive selection criteria were: i) having had an RA diagnosis for at least three years (allowing time for patients to undergo a process of acceptance); ii) aged over 35 (for the same reason, since RA may hit as early as age 30); and iii) the absence of any other chronic diseases. In order to explore diverse experiences, we

selected patients of different sex, age, level of education, and socioeconomic status. Our sample was composed of 13 women and 7 men (the disease has a four times higher prevalence among women than among men), with ages ranging from 35 to 69. 15 of the patients were married, one in a relationship, 2 were single and 2 were widows. The median waiting time before diagnosis was 18 months (ranging from 3 months to 10 years) and the median length of time *since* diagnosis was 8 years (ranging from 3 to 14 years).

We conducted the interviews in two batches: between January and March 2012 and between December 2012 and January 2013. The break was designed so that, in line with our grounded theory approach to data analysis (see below), we could reorient our sampling in relation to the common themes and concepts from the first set of interviews. For example, the initial interviews highlighted the importance of obtaining a diagnosis, yet most of the patients interviewed during the first period had experienced that key moment some time ago. So for the second period we sought patients whose experiences with diagnosis were more recent, so as to have a clearer description of that phase.

### ***Data collection***

Interviews, which lasted between 60 and 90 minutes each, were conducted in medical offices in the rheumatology clinics. The interviews were conducted by one of the authors. After briefly introducing 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 were able to explore the sources from which patients drew support and to identify commonalities in the role and impact of these sources during the process of acceptance. The follow-up questions were deliberately open-ended – for example, “can you tell me a little more about what helped you during that period?” or “and can you say a bit more about why things were so difficult at that time?” In other words, we did not prompt



participants to talk about particular sources of social support. The sources that they mentioned arose spontaneously from their reflection on important moments in their experience with RA.

A similar clarification is in place concerning the five-stage model of Kostova et al. (2014). That model was actually developed – using a parallel inductive approach – from the same data collection used in this article. So we were not prompting participants to report their experiences of support at each of the key stages; rather, participants spontaneously reported the key moments and periods during their illness, and in so doing also reported their experiences with social support (and lack of support). More broadly, while our introductory question did prompt a loosely chronological narrative from patients, there was no attempt on our part to suggest any kind of sequential process of acceptance. And, while the data did suggest some ‘key moments’, our open-ended approach allowed patients to reveal the irregular, even erratic, nature of their progress in struggling towards acceptance.

### ***Data analysis***

Following the example of various studies in health psychology (e.g. Kearney, 1998; Gavois et al., 2006; Carr, 2001; Tse and Yeats, 2002) – including Jakobsson and colleagues’ (2005) study of acceptance among cancer patients – we used a grounded theory approach to analyzing our data. One aspect of this was the cyclical approach to data collection and analysis described above. Another was the use of the constant comparative method (Strauss and Corbin, 1990) to code interviews, to link and group the identified codes into larger categories, and to define more abstract concepts. These operations allowed for reduction and interpretation of large amounts of data, and were continued until common patterns were established and data saturation achieved. For example, one early interviewee emphasized the importance of the family in overcoming the crisis that she called “hitting the bottom”. In others’ narratives we found not only a similar experience but again that support from family

was often the trigger for a more successful period of integrating the illness. By what became the final interviews, we had reached data saturation in the sense that patients were tending to describe the same experiences of social support – even if in different ways and under different circumstances – rather than to highlight new or different key moments or sources of support. Cast in more general terms, data saturation was achieved at the point at which additional data seemed redundant in the light of the emergent model.

The literature cited earlier was used throughout the research to support the process of questioning and interpreting the data but, as described in the section above, existing theories and models did not drive our data collection. The results discussed in this article are thus the outcome of a continual to-and-fro movement between empirical data and developing theory, the aim being to present findings that constitute a reasonable representation of the studied phenomenon (Mays and Pope, 1995).

## **Results**

Three main categories of social support were identified as fundamental during the acceptance process: *family*, *physicians*, and the *external social context* (the latter comprising significant others). Here, taking each source in turn, we examine when and how they were relevant, identifying their roles at different key moments of the acceptance process and clarifying the conditions under which they might act as *facilitators* or as *barriers*. Our aim is not to produce a neat cross-classification of key moments and sources of support, suggesting that each source moves in and out of relevance as patients move smoothly through the process of acceptance – that would belie the complexity of the process and the diversity of experiences. Rather, we want to see whether there are commonalities in the sources and types of support that patients reached for and received at those key moments during their struggle to achieve acceptance.

### ***Family***

The main source of support during the entire acceptance process was the family, most notably spouses and children. Family itself, and especially the responsibility that patients felt towards their families, were already a strong motivation to avoid becoming a passive victim of the disease and to seek alternative ways of managing duties and re-establishing roles. For some patients, the family's existence as a unit was in itself reason enough to fight the disease. Family support played a crucial role throughout the acceptance process but was especially significant in taking patients from "hitting the bottom" to integrating the illness. One patient clearly described how she found reason in her family to "go ahead":

*"I went through some moments when I was crying during the night because of the pain and I was feeling wronged, helpless...I really hit the bottom then. My biggest thought that helped me was the love for my family; it helped me a lot to say to myself, come on, don't give up, don't get down, go ahead and you will succeed."* (Liria, 49)

Beyond this general role as an intrinsic motivator, family was also a vital source of emotional and practical support. Both types of support were important in showing patients that they were accepted and that their needs were recognised and anticipated. We distinguished various specific reactions from family members, and partners in particular, that shaped the acceptance process.

### ***Facilitators***

Unsurprisingly, patients were best able to achieve acceptance themselves when they felt *accepted* by their families. Being treated as a normal person was one of the strongest facilitators of acceptance, and a crucial part of this was being encouraged (or even pressed) by partners to live normally rather than avoiding certain activities. This made patient's feel trusted and empowered to move from the passive role of the "disabled" towards a more active engagement in valued pursuits:

*“I think the most important thing that helps you accept it (RA) is being accepted by your family...the feeling that you are anyway accepted as an equal and not considered as a burden (...) For example, recently I went to the North Pole – a place that someone with RA normally wouldn’t dare to think about going. On the contrary: my wife pushed me, saying “come on, you are not disabled, you just have one problem, but we can see how to solve it.” So, all these things together gave me the strength to go ahead and accept it.” (Antonio, 52)*

The most difficult loss for patients to accept was that of their *independence* in managing life roles as before. For example, some women felt the restriction on their management of the household as a restriction of their identity. Patients therefore needed practical support from their partner but without feeling invaded or replaced in their key domains and duties. A continued sense of usefulness and autonomy was essential for patients to maintain their self-identity. For that reason, family members needed to strike a *balance*: being present in cases of need, but at the same time allowing patients some space and independence in the territory that mattered to them:

*“My husband helped me a lot to find the balance with my disease; he was doing the things that were difficult for me, but always giving me the space to clean, to cook, to iron... He never took me away my role as a woman and for me that was important.”(Liria, 49)*

This is a clear statement of appreciation for exactly the balance described above.

### *Barriers*

Some reactions from family members appeared to inhibit rather than to encourage acceptance. Again, balance was crucial because the most unhelpful reactions were either the underestimation of or the over-reaction to patients’ suffering. The most important failures of family support from patients’ perspective were distrust and incomprehension regarding their disability. Due to the fact that RA is an *invisible illness*, without specific visible symptoms, some family members were unable to

understand or to believe how much patients were suffering. As a consequence, patients felt misunderstood and sometimes even accused of using the illness as an *alibi* to escape from work and other responsibilities.

*“Even the family sometimes cannot understand you. They say you are using it (RA) like an alibi, to not help your wife, to not work, to not garden...and that makes you feel bad” (Ivan, 53)*

In other cases, family members overreacted to the severe pain, exhibiting anxiety or panic. This tended to reinforce patients’ own disquiet causing irritation: the relative in question was perceived more as over-dramatizing the problem rather than offering real help. During acute episodes of pain, patients needed a partner to remain unafraid, calm and encouraging:

*“My husband tends to be anxious. When I feel strong pain, he calls the doctor without telling me anything! He is playing the tragic, complaining to the others when I feel bad. He is so worried and that makes me so angry! (...) He cannot understand that he is not helping me in that way. In that moments you just need somebody who is stronger and calm and who is doing something to help you. I don’t want to make a tragedy out of things.” (Zara, 55)*

Another delicate point regarding family support was *having to ask* for it. Explicit calls for help were perceived by patients as a sign of weakness and increased their feeling of powerlessness. Hence, assistance that was requested rather than offered was seen more as a lack of support than as real help. For patients, the real sign of family comprehension was an anticipation of their needs:

*“Do you know what? I’ve noticed that I expect people who are close to me to know already that I need help and offer it to me. I shouldn’t have to ask them for help. I am not going to ask somebody who knows that I have difficulties; I get upset, because I think: you do it just because I asked you. Instead, when are the others in the family that know when to help you, is different – you better deal with it and probably accept it easier” (Rosa, 58)*

### *Physicians*

Doctors were the second of the principal sources of social support. Their role extended well beyond that of provider of medication, doctors also offering emotional, practical and informational support – all crucial for the acceptance process. The key health professionals referred to in patients' accounts were, first, their GPs – who played an important role at the time of diagnosis – and, second, the rheumatologists who were the current reference point for all of the interviewed patients. Since most patients had been under the supervision of the same rheumatologist for several years, these physicians had been involved throughout the acceptance process. However, their reactions seemed to be particularly important not only during the struggle for diagnosis but also during the subsequent adjustment period. RA patients have to recognise that their normality has drastically changed, and to integrate these changes into a new way of living and physicians have the potential to expedite but also to delay that process of recognition.

### *Facilitators*

A key moment during which the supportive role of the physician was vital was during the immediate post-diagnosis period and the ensuing search for the appropriate medication. Not least because RA medication often has strong side effects, it was particularly important that physicians made patients feel considered and involved in decisions about their medication. This not only improved patients' awareness of the implications of the disease but also gave them a sense of playing an active part in its treatment – undoubtedly a help in dealing with the unpleasant consequences of the illness:

*“[After the diagnosis] my doctor explained to me a bit about what Rheumatoid Arthritis is, how it goes and what are the options for the treatment with the positive and the negative sides, but I was the one who had to take the decision...and it took*

*me a lot of time to study what this illness means and what are the side effects of the medications. It wasn't easy in that time, you feel left alone...but looking back, I think it's better...you become quickly more aware of your disease, of what you will have to put up with." (Billi, 35)*

This point about medication is a specific illustration of a general theme: the importance of keeping patients informed about the implications and development of the disease. While the evolution of RA is unpredictable, physicians can mitigate the psychological effects of this uncertainty by discussing in detail with patients the trajectory of their own case. This allows them both to understand what is happening in their bodies and to gain trust in their doctor. Having the clearest possible view of the development of RA, rather than being reassured unrealistically or being kept in the dark (see below), was a helpful way to realize and confront it. A male patient emphasized this point, appreciating in particular the way that his physician used visual tools helping him to “see” the invisible disease and to feel involved:

*“When my doctor does each X-ray and puts it together with the last one, showing me that the holes are getting closer which means that it (the RA) is getting better, I can see it, because it's there! And that, for example, makes me trust him a lot – at least I understand what is going on” (Antonio, 52)*

### *Barriers*

The most common problems patients encountered in their relationship with doctors were the distrust or disregard of their complaints. RA is a frustrating illness because, besides the invisibility of symptoms noted above, there is no real cure and so patients are persistently at risk of acute episodes of pain, with little prospect of finding lasting relief. This combination makes it crucial for physicians to be sensitive both towards patients' reports of physical pain and towards the psychological impact of RA. A lack of such sensitivity was perceived by all patients, either prior or subsequent to diagnosis (or both). The pre-diagnosis period was a particularly difficult time. While they acknowledged the medical difficulties in identifying RA, patients were

nonetheless convinced that GPs' neglect of initial symptoms contributed to the common and lengthy delays in diagnosis, and they often reported feeling disbelieved, ignored or even belittled by their doctors:

*"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 ridiculed, I felt he was making fun of me (...) So I spent many years like that without knowing what I have." (Gianni, 49)*

Another patient had a similar complaint, directing blame not only at GPs but also the broader private health care system in which they operate:

*"I think family doctors feel too limited by the health assurance companies to do a lot of exams, and you are going on with pain killers and you are getting worse without even know what you have to accept." (Anna, 67)*

The psychological impact of this perceived neglect can be considerable and long-lived, as illustrated by another patient's account:

*"All my anger is about the beginning. I just can't accept it because I am sure that, if they'd found it at the beginning, if they'd taken it more seriously, I wouldn't be like this now...So when I think about acceptance, my first thought goes there – to the initial error that I will never accept" (Alessandro, 50)*

A different problem was noticed by patients particularly at the post-diagnosis stage of *realizing* the implications of their illness. Some physicians sought to buffer the shock of diagnosis by over-reassuring. Since this gave patients unrealistic hopes that they might return to the pre-pain way of living, it tended to set back the acceptance process. As noted earlier, patients are best helped to face and accept their disease if they are made aware at the outset about the inevitable limitations that they will confront. One patient explained:



*“At the beginning you expect to be as before...and I think the doctors should be more direct, and not so reassuring. They should tell you the truth: “Listen, unfortunately you have this illness and you will never be the same as before.” When you’re told “don’t worry, everything will be back to normal”, you delude yourself and never face the truth... Only when you know your limits you can decide how to act with that disease and may be accept the change” (Lucrezia, 61)*

Here, then, as with the family, the right support for acceptance is a matter of balance. In this case, physicians need to strike a balance between neglecting patients’ concerns and giving unrealistic reassurances about those concerns. This balance is most likely to be met by involving and informing patients, giving them clear expectations about the likely consequences of their disease and making them feel comprehended and considered. In terms of types of support, it becomes clear that physicians are potentially a source of emotional as well as of information and practical help. Involving patients in the choice of their medication and informing them about the evolution of the disease are all means not only of boosting patients’ health literacy but also of making them feel considered and thus emotionally supported.

### ***The external social context: significant others***

A variety of features in the surrounding social context – notably friends, colleagues and disability institutions – can also foster the conditions in which patients can feel accepted and accommodate the constraints imposed by their RA. External social context can play an especially prominent role in helping patients to overcome the initial stigma, to realize the implications of the disease, and to integrate these restrictions into their selves and lives. The potential for the surrounding social environment to encourage acceptance is well illustrated by our results but in a negative sense: that is, we found that many patients were aware of a lack of such

support and hence found acceptance more difficult to achieve. For that reason we re-report mostly the negative experiences of the patients regarding these sources.

### *Significant others*

‘Significant others’ is a broad term, encompassing all those people of sufficient importance in an individual's life to affect their emotions, behavior, and sense of self (Mead, 2009). The lack of understanding that many patients felt from their family, due in particular to the invisible character of the disease, was reported to be a common reaction from these significant others. Again, this left patients feeling doubted, even attacked, rather than supported:

*“It’s difficult with other people because you suffer from a disease which is not visible, in the sense that when someone meets you they say: you don’t have anything, you are ok! But sometimes even to hold a glass is so difficult! And that happens in many other things. You know, people don’t believe that you are suffering so much, especially at work. Your friends, your boss, your colleagues, they say: how is it possible?! Because, you know, this is a disease that could last 3 hours, or 3 days. You can be sick and already after half a day you can feel much better...I know it’s incredible, but that’s how it works. (...) I feel myself not accepted, not understood, not believed..” (Josephine, 40)*

*“What bothers me a lot is that this illness is something you can’t see, so you can’t understand. People say: you’re doing very well, you look great! And then you get upset because it might seem fine on the outside but it isn’t on the inside.” (Viara, 69)*

This lack of understanding can lead to scepticism and thus to more explicitly negative reactions. For example, some patients felt accused of using the illness for obtaining economic benefits of some kind. Such accusations often reflected broader prejudices, and provoked considerable anger and frustration. As one Italian patient complained:

*“There is a lot of prejudice among people; some people say that you are stealing the Swiss money (from the Swiss health companies)! And for me this is stupidity: if somebody tells me something like that now, with the pain I feel, there’s a good chance that I’ll beat them up” (Gianni, 49)*

The impact of external social context was felt especially during the immediate post-diagnosis period when patients were still embarrassed and ashamed of being “abnormal” and “disabled”. At first, some were very fragile and vulnerable and hence very sensitive to the reactions of others. Indeed, this sensitivity can make patients so reticent about their illness that they do not give significant others the opportunity to offer support:

*“At the beginning you don’t accept it, you are not even saying what you’ve got, because you don’t know how others will react (...) I was trying to hide it [arthritis], I was saying my friends I got hit ...because you are in that stage when you feel weak, right at the beginning...”(Mario, 37)*

These extracts from the interviews illustrate the general negativity among most patients when considering their social context. Only a few mentioned feeling supported by their significant others. In these relatively unusual positive cases, the key support offered by others was to create conditions in which patients could establish a new way of living and to feel accepted in their disability. As one patient said about her employer:

*“I was very lucky with my employer because he was very understanding, he allowed me to go part-time, he even helped me in some things. For example, when I had my pain and stiffness, it was enormously difficult for me even to pick up and answer the phone. And he was doing all these things for me – he was even doing the photocopying – and that really helped me a lot in my job. I felt understood somehow and not treated as a burden.”(Maria, 52)*

Significant others can thus serve as an important source of both emotional and practical support – and the two types can often be mutually reinforcing. The first

reactions that patients confront in their social networks are an important influence on their capacity to withstand the emotional impact of feeling disabled and different. Meanwhile, by giving practical assistance, significant others help patients not only to manage their daily activities but also to accept their illness and establish a new way of life.

## **Discussion**

The first and most obvious point to make is that our study confirmed the crucial importance of social support in fostering acceptance among these RA patients. Of course the way that patients confronted the challenges of the disease is influenced by other factors, such as age and the longevity of the illness, but the social context certainly played an important role in patients' acceptance behavior. Chronic illness implies a disruption in the structures of patients' everyday life, biography and self-concept (Bury, 1982). The "repair" process of accommodating the illness in their selves and lives is strongly influenced by the surrounding social environment.

We observed some patterns in the ways that different sources and types of support helped patients during the acceptance process. However, any attempt to reduce or summarize these risks obscuring the difference and complexity that was the central feature of the interview data. For example, while it was naturally the case that information from physicians was particularly helpful as patients sought diagnosis, and emotional support from family was often critical as patients struggled to come to terms with the impact of the disease, we should also emphasize that each source and each type of support is potentially important throughout the process. One reason for this is that, as must be emphasized alongside a simplifying model like that of Kostova et al. (2014), the different stages or moments of the acceptance process are not distinct but often overlapping and concurrent. Finding new ways of living is a long and complex process involving medical support and advice as well as

understanding and acceptance from family and friends. A related point is that, although conceptually we can distinguish different types of support, empirically the distinction is often blurred. We saw this particularly with the role of medical professionals. By involving and informing their patients regarding the evolution and treatment of the disease, physicians are not only providing advice and guidance but also helping patients to grasp their new reality – a key precondition for acceptance.

Our findings tend both to reinforce but also to refine the conclusions of other studies. In general terms, we found with RA that, while social support had considerable potential to assist acceptance, the nature of the disease meant that this support often proved elusive or unreliable. For example, as in previous studies, we found that the most important source of support was the family – it played a central role throughout the path of acceptance. The family is a central aspect of the social environment and serves as a foundation for social support (Logan and Spitze, 1996). Family exerts a type of informal social pressure on patients (Castel and Coppel, 1991) and can orient their behavior in facing the illness in one or other direction. So the reactions of the family members were indeed fundamental in helping patients to not give up during the most difficult moments of the illness and to find the balance between their pre-pain life and their current, real possibilities. However, as we will discuss, family reactions – however well intentioned – could not be relied upon to generate the positive outcomes.

The key reason why the effects of social support are conditional and sometimes unreliable lies in the nature of RA symptoms. These are less predictable and visible than in the case of most other chronic conditions, and this shapes the reactions of those who might offer social support. We distinguish some main kinds of unhelpful reactions and then argue that acceptance is fostered by those who find a middle ground between them.

The first type of unhelpful reaction is *skepticism*. Patients felt accused by family members of using their illness as an alibi or excuse avoiding work or other daily

responsibilities, and the invisibility of RA symptoms meant that such accusations were hard to rebuff. The fact that symptoms were not obvious and socially visible also meant that family and friends were not so ready to predict the needs of patients, who in turn resented the fact that they had to ask for help. In general, these shortfalls in understanding were often a reason of anger and frustration. The denial of the seriousness of the illness from family and significant others is perceived as unsupportive behavior and can bring negative implications on adjustment (Clark and Nothwehr, 1997; El-Kebbi et al., 1996).

Chronic pain patients are often met with skepticism and distrust by health professionals, feeling ignored or accused of faking and exaggerating their pain (Werner and Malterud, 2003). Our interviews confirmed that this problem was also encountered in patients' dealings with their doctors, some feeling that their symptoms were disbelieved or ignored. Two key aspects of the Swiss context, highlighted earlier, contributed to these perceptions of skepticism. The first is patients' suspicions that doctors were influenced less by their sufferings and more by the cost-cutting incentives within the Swiss health system. Kostova et al. (2014) suggest that these incentives not only create an atmosphere of distrust in doctor-patient relationships but also lead to delays in diagnosis which prevent the initiation of the acceptance process. The second contextual source of skepticism is ethnic tensions. Conflict between the Swiss and the Italians is usually implicit and some of our Italian patients may simply have assumed that perceived skepticism was due to cultural prejudice. However, others complained that their GP explicitly attributed the reported suffering to the patient's Italian origin and, in turn, to a supposed tendency to exaggerate.

The second unhelpful reaction, erring in the other direction, occurred when sources of social support offered too much *reassurance* and assistance. Again, we saw evidence of this from both family and from medical professionals. Our evidence echoes previous findings that encouraging patients to rest and taking over their duties

hinders acceptance behavior and reinforces the passive role of the “disabled” (McCracken, 2004). This study instead shows that patients were determined (often to the point of obstinacy) to keep their independence and not being invaded in what they considered as their domains. That reinforces the argument of Kostova et al. (in press) that acceptance is a matter of accepting losses but without becoming a passive victim of those losses, patients instead preserving their own identities and roles. In the light of this, it is clearly possible for social support sources to ‘over-help’, suggesting a subtle rather than a straightforward positive association between social support and acceptance.

There was also evidence that doctors could be over-reassuring, concealing from patients the irreversible consequences of the disease. This fuelled unrealistic hopes of returning to health and the pre-pain life and hence deterred patients from taking the action necessary to face the disease and to establish a new way of living. Other studies indicate that the impact of reassurance, a common intervention of many practitioners, depends on patients’ experiences and emotions – notably their level of health anxiety – and that reassurance can have unintended adverse effects on acceptance (Lucock, Morely, White, and Peake, 1997; Linton, McCracken, and Vlaeyen, 2008). It is therefore essential that doctors do not foster unrealistic hopes but instead be candid in preparing patients for what lies ahead.

It is clear, then, that the presence and availability of the key sources of social support is not enough. In order to encourage acceptance, sources of social support need to find a middle way between skepticism and solicitousness and thus help patients to develop a new ‘normal’ life. Thus, even if family itself was the key source of social support, it was real support only when meeting the specific needs of the patients. Concerning spousal relations, it was being treated as a normal person, and pushed to manage rather than to avoid life activities, that encouraged and empowered patients.

Patients’ interactions with doctors also highlighted an example of this middle way. By involving patients in the decision-making process concerning their illness,

doctors were able to offer support while encouraging patients to be realistic about its implications. Participating in these decisions had a positive impact over acceptance, exactly because it accelerated patients' learning of the consequences of the chronic disease (see also Joosten et al., 2008).

Earlier, we stressed that the most significant sources of social support remained important throughout the acceptance process. A simple model, with doctors crucial at the diagnosis stage and family then taking over as patients come to terms with this diagnosis, is too simple. Hence, for example, family support was critical from the earliest symptoms because, even without a diagnosis, patients already feel shame and embarrassment at their disability. Many studies shows that chronic pain patients feel stigmatized by family and significant others and this has a profound effect on their self-esteem and behaviors (Holloway, Sofaer-Bennet, and Walker, 2007; Eccleston, Williams, and Rogers, 1997; Lillrank, 2003; Åsbring and Närvänen, 2002). Of course, such stigmatization is a risk for RA patients at any stage. In our study, some patients felt shame even after years of the disease, avoiding social activities and isolating themselves, and effective social support is essential for overcoming this barrier to acceptance.

As for doctors, we naturally found their role to be critical at the diagnosis stage, but that their potential for offering social support – productive or counter-productive – persisted thereafter. This is partly because, like any chronic disease, RA involves a great deal of doctor-patient communication. It is also because, with RA, there is an unusual amount of shared decision-making about medications. We mentioned earlier that such shared decisions can have a positive impact on acceptance but that positive effect may only materialize some time after diagnosis. Initially, patients may feel lost and abandoned at being held responsible for such important decisions as the choice of medication. This chimes with previous findings about individual-level variation in patients' preferences for participating in health decisions. There is a distinction between “the desire to receive information and the desire to take responsibility for



the treatment decision itself” (Robinson and Thomson, 2001, p.36). The former desire dominates at the time of diagnosis while the latter develops more slowly. This is why the doctor’s role remains important beyond diagnosis, helping patients when ready to take a more active part in decision-making and thus to become better informed and prepared. This illustrates a broader point. Doctors always have the potential to offer social as well as medical support and a common complaint is that doctors often play only the latter role, treating patients as objects. This is unhelpful in any case but, in RA, the social support role that doctors may play is especially important.

Taken together, the findings of our study add to the literatures on social support and acceptance by elaborating the relationship between the two. As mentioned earlier, this association has received some scholarly attention (Affleck et al, 1988; Gil et al., 1987; López-Martínez et al., 2008; McCracken, 2005; McDonald et al., 2002; Osborne et al., 2007) but largely through correlational studies that underplay the multidimensionality of both concepts and the conditionality of their relationship. A particular contribution of this study is in understanding that conditionality. We have shown the various ways in which social support is far from a universal panacea. The effects of such support depend on the moment in the acceptance process at which it is given (and the way in which patients are experiencing that moment), on the source or sources from which support is available, and on whether those sources give the right type and extent of support. This conditionality helps to explain why the quantitative studies often showed only fairly weak associations between support and acceptance. And, if our evidence about the detrimental effects of ‘over-supporting’ implies a non-linear relationship between social support and acceptance, then that too may help to account for the same attenuated correlations.

The point should not be overstated, however. Our findings emphasize that, under the right conditions, social support can do a great deal to foster acceptance. This locates acceptance as an important means whereby social support can engender

psychological empowerment and self-management of chronic disease (e.g. Schulz and Nakamoto, 2013). In that expanded model, a significant reason why social support generates these positive outcomes is because it helps patients to accept the losses inevitable in a disease like RA but also to pursue valued goals and activities nevertheless.

### ***Limitations of the Study and Research Implications***

One of the features of our sample is that all of the patients had achieved at least some success in integrating and managing their disease. We were therefore reliant on patients' recall of their struggles to achieve acceptance. While they are harder to access for a range of reasons, it would definitely be instructive to interview those 'stuck' during the process. Another facet of what might be called 'selection bias' in our sampling is that most of our patients were married or in a relationship, and as such had some kind of close support. Future research could explore the particular experiences of those who do not have a partner at hand, assessing what might rather different ways in which they confront or accept the challenges of the disease.

Our findings point down both quantitative and qualitative avenues for further research. Taking a quantitative approach, such research could profitably examine the functional form of the relationship – which is unlikely to be simple or linear – between the extent and sources of social support and patients' progress towards acceptance. Meanwhile, future qualitative research could profitably address the 'supply side' in terms of social support: that is, the perceptions and viewpoints of the sources of support. Parallel studies of patients and their families could elucidate where there are gaps in understanding between the two. Similarly, researchers could also consider physicians' perspectives. The difficulties involved in diagnosing and predicting the evolution of RA are at the heart of patients' struggles during the acceptance process, and it would be useful to hear from GPs and rheumatologists

both about the support that they are able to give and where they feel unable to meet patients' expectations.

### ***Practical Implications of the Study***

Understanding the sources of social support, and the limitations on or conditionality of their help, is important for exactly those groups that we have seen can offer such support. Clearly, it helps physicians to meet their patients' needs if they recognize the points we have highlighted here: that early diagnosis is critical to enable acceptance to begin; that it is important not to drift into skepticism about patients' condition, despite the ephemeral nature of RA symptoms; that over-reassurance is a hindrance rather than a help to the acceptance process; and that they should not only treat the physical symptoms of the disease but also recognize the psychological importance to patients of maintaining their personally valued activities. Conversely, patients are likely to be helped if they have a greater insight into when and why physicians might find it difficult – especially due to the invisible and unstable nature of RA – to offer the desired support.

Perhaps less obvious but nonetheless important practical implications of the study are their potential to improve family-patient relationships. The more that family members know about the conditions fostering acceptance, and in particular the need to strike a balance between skepticism and over-reassurance, the better able they will be to help that process. This raises the question of how such results are to be communicated to family members. Here, physicians and health care organizations probably occupy the key communicatory roles, needing to produce and disseminate information and guidance not just for RA patients but also their significant others about the problems that they are likely to encounter – and the solutions likeliest to work.

Finally, there may be some specific implications concerning the context in which our study was undertaken. It seems – at least, many patients were convinced – that the implicit incentives within the Swiss health care system exacerbated difficulties in pursuing acceptance. This is partly because cost pressures on physicians may delay the testing needed for prompt diagnosis, and partly because the ephemeral and sometimes invisible nature of RA symptoms make it difficult for patients to convince both public and private health insurance providers of their illness. Financial constraints on health provision are of course inevitable; however, given that swifter diagnosis is likely to reduce the eventual physical and psychological toll taken by RA and thus the eventual cost of the disease, policymakers could profit from considering how to reshape incentives to accelerate diagnosis and treatment.

## **CHAPTER IV**

### **Can social support work virtually? Evaluation of Rheumatoid Arthritis patients' experience with an interactive online tool**

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**Abstract**

In this article we explore whether and how social support for RA patients can be provided online, and assess the conditions in which such support is effective. As part of a wider study, we designed an online tool, which provided patients with both tailored information and various opportunities to interact online with health professionals and fellow sufferers. In this article, we report on qualitative interviews with 20 users of this tool. The general purpose was to identify where the support provided did – and did not – help patients, and to judge whether the determinants of success lay more within patients – their engagement and willingness to participate – or more within the design or orientation of the website itself. A more specific purpose was to elaborate qualitatively on the results from a quantitative survey of users, which indicated that the tool's positive impact was confined to practical matters of pain management rather than extending to more fundamental psychological outcomes like acceptance. Overall, we conclude that online learning and interaction can do much to help patients with the everyday stresses of their disease, but that its potential for a more durable positive impact depends on a host of individual characteristics such as personality traits, existing social networks, and the severity and longevity of the disease.

**Keywords:** online social support, rheumatoid arthritis, chronic pain management

## Introduction

Providing the right social support to people suffering from Rheumatoid Arthritis (RA) is a crucial factor for the way they face and accept the implications of the disease (McCracken, 2005; Revenson, 1993). RA is one of the most prevalent causes of disability (Pleis and Lethbridge-Ceijku, 2000; Verbrugge 2008) and is prone to have many injurious psychological effects. The persistent pain, fatigue and progressive joint destruction invokes many losses in patients' lives disrupting their previous normality. RA has a very *unpredictable* and *invisible* natural course: the pain is unpredictably appearing and disappearing and there are no clear visible signs of the symptoms. These peculiarities make it difficult to be understood by others and often RA patients complain the lack of support being treated with scepticism and distrust (Werner and Malterud, 2003; Kostova et al, 2014).

The importance of social support for RA patients' health outcomes, coupled with the fact that patients often feel a deficiency in that regard, means that health policymakers have sought ways to boost such support. However, the most intensive forms of social support are hard to provide for reasons of cost, and this is one reason – alongside the versatility of the Internet and the gradual breaking down of the 'digital divide' – why attention has more recently turned to using interactive online tools as a source of support for chronic pain patients. The questions of how to operationalize the concept of social support online, and of which factors determine the efficiency of such support, are at the heart of this article.

There is literature that praises the Internet as an alternative tool of support for patients with chronic conditions (Fox, 2009; Kirsch & Lewis, 2004; Payne & Kiel, 2005; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). The virtual environment has the potential to impact decision-making, one's sense of isolation or support and one's adjustment to the illness (Ziebland and Wyke, 2012; Brashers et al., 2002; Hesse, 2005). The so-called Interactive Health Communication

Applications (IHCA's) are a way to exchange information and may improve psycho-psychological, social and health outcomes (Eysenbach, 2004; 2006; Murray, Burns, See, Lai, & Nazareth, 2005; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan, et al., 2008; Winkelman & Chun Wei, 2003). It has been proved that online interventions can reduce bodily pain in adults with at least mild to moderate baseline pain (Hausmann et al, 2014).

According to the health empowerment model of Schulz and Nakamoto (2005), the Internet is a source of support that may impact patients' psychological empowerment and health literacy – two fundamental concepts for the self-management of chronic pain diseases. The relationship between online social support and self-management is not necessarily linear and smooth, and it depends on some moderating factors such as the reliability of the information online, patients' levels of self-awareness and self-management, type of illness, social and personal dimensions (Caiata-Zufferey and Schulz, 2009; Davison et al., 2000). Despite the many studies focusing on the effects of the virtual interaction on health outcomes, it is still not clear enough under which circumstances online support could be beneficial for people with chronic pain.

The insights in this paper help to clarify how far social support can be provided online and under which conditions such support can engage RA patients to interact and share their problems online.

This article is based on the evaluation of an interactive website for RA called Oneself ([www.oneself.ch](http://www.oneself.ch)) that we purposely designed for the study which is part of a project financed by the Swiss National Science Foundation. The website provides RA patients with personalized information and with the possibility to communicate online with health professionals and other patients. The empirical basis for this paper is a qualitative evaluation of Oneself based on in-depth interviews with 20 of its users. Our two core research questions are cumulative: i) which was the factors shaping patients' engagement with the site and their interactions with other users? ii) in turn, under which circumstances – and these may be aspects of the tool itself or characteristics of the individual user – is this type of support more successful in



helping patients and making them feel supported? Put in simple terms, we wanted to know what led people to use the tool, and what enabled them to profit from it. More broadly, we wanted to explore patients' views and experiences with online interaction, identifying the things that shape their engagement and willingness to be part of an online support group. For the latter question in particular, we are guided by the insights from a prior experimental study of Oneself users, indicating that the tool did more to help with everyday matters of pain management than to foster deeper psychological outcomes like acceptance. Together, the answers to our two research questions lead to clear advice for those designing future online tools, guiding them in how best to meet chronic pain patients' needs and to maximize the effectiveness of online social support.

## **Methods**

### ***Needs assessment and development of the website Oneself***

Since the aim of this article is to evaluate the Oneself website, it is first worth briefly outlining the basis for and structure of that site. Oneself is realized by the University of Lugano in collaboration with health professionals from the Swiss Rheumatology Association. The structure and the content of the tool are based on the results of two qualitative studies with a total of 39 RA patients that we conducted previously in order to understand (i) what are the main difficulties sufferers face in order to accept the consequences of the pain and (ii) what do they miss and need from their significant others to facilitate the daily management of the pain. The findings of the studies allowed us to have a better understanding on what patients need from informational, practical and emotional point of view, and to create different sections that can reflect and meet these needs.

We structured the website with two main features: the informational part (informational support) and the interactive one (online interaction support). From a theoretical point of view the structure of Oneself was inspired by the Health

Empowerment model of Schulz and Nakamoto<sup>33</sup>, incorporating components of health literacy (the factual and procedural knowledge about how to deal with the disease) and psychological empowerment (feeling able to deal with the disease) in the different sections.

In the informational part of the website we created various sections, being guided by some problematic issues that we evidenced with our interviews. For example, we identified the problem of the late diagnosis as a crucial factor in shaping the acceptance process. Many of the patients complained that they struggled for years to find the name of their pain, being treated with scepticism and distrust by GPs. As the late diagnosis has many physical and psychological effects, we created a section called *Library* where together with other educational material about the nature of the disease, its etiology, and the possible future evolution, we provided information stressing on the importance of the early diagnosis giving concrete information about the recognition of the first symptoms. Another example of providing tailored support regarded some post-diagnosis common reactions that were impeding acceptance such as denial, self-isolation, anger and depression. In the section *Living with arthritis* we embodied this information, making patients aware about the negative consequences of the above mentioned reactions, giving them insights about more appropriated strategies towards acceptance. We created a section for the *Family* of the patients, (as there were often some conflict dynamics due to the lack of communication) giving suggestions for the better understanding of what the affected person needs in terms of support. Other examples of the informational part are sections as *Arthritis can be cared*, *Living with Arthritis*, *How to deal with Arthritis*, providing texts and videos with practical information about the possible medical and alternative treatments, information about occupational therapy and physiotherapy, suggestions for the every day diet and physical activities and in general information to help people in the every day dealing with the disease.

With the interactive part of the website we aimed to transfer interactions with experts and other patients online, giving the possibility to receive the support that people

were missing in their real life. We were organizing weekly meetings in a *Chat room* between experts (rheumatologists, physiotherapists, occupational therapists, and psychologists) and patients discussing relevant for patients topics that were usually not discussed during the medical consultations. Our idea was to operationalize the idea of support, giving to patients the possibility to talk with doctors and to connect with other people who share similar problems. In order to incentive the creation of a support group only between patients and to give them the chance to establish new network we created a private *Chat* where each patient could contact others confidentially, outside of the official meetings. The *Forum* was addressed for asynchronous interactions, where users could post questions and comments and expect them to be answered by both doctors and other patients. Other examples of interactive support are *My contribution* (practical advice posted by users), *The specialist answers* (video interviews with health professionals on relevant for patients topics) and *Testimonials* (interviews of real stories of other patients with the aim to empower participants in their struggles with the acceptance of the pain).

Through the educational materials in the informational sections we wanted to provide patients with informational support, increasing their health knowledge and in turn their constructive self-management behaviour. The interactive part of the site aimed to empower patients and make them feel supported and heard by professionals who were available online and to be part of a virtual community with people dealing with the same physical and psychological pain.

Two previous versions of the website on fibromyalgia and low back pain were evaluated mostly for their performance in relating information, showing the efficiency of the site (Schulz, et al., 2007; Maria Caiata, 2009). The third version that we developed was completely new and dedicated to RA – a disease calling for social support and we improved the interactive side of the online tool. The main author (ZK) was the coordinator of the website and was constantly available online during the official chats, moderating the discussions and encouraging users to interact.

### ***Evaluation methods and sample***

We used a mixed approach method to evaluate quantitatively and qualitatively the effects of the website on patients' outcomes and their usage of the tool. On a first stage we conducted an experimental study with 154 RA patients whom we recruited through the health professionals involved in the project. Patients who agreed to participate signed a consensus form and sent it to the University. Eligible for this study were patients suffering from RA who had cognitive function sufficient to use the website effectively, who did not suffer from other major chronic illness (e.g., cancer, diabetes), and who agreed to 1-2 hours per week of log-on time over a total period of 8 weeks. Once we recruited patients we randomly divided them in two experimental groups with different access on the site (one group had access to both interactive and informational sections and the other group had access only to the informational part) and a control group that didn't have any access on the site. Patients were solicited every week by emails and text messages to access the site, and those with access to the interactive features were invited to participate in the official chats with the health professionals. The experiment lasted 2 months.

The aim of the quantitative study was to assess the effect of the website on patients' health outcomes such as: psychological empowerment, perceived social support, health literacy, acceptance of pain, quality of life, self-efficacy, health care utilization, medication misuse, physical activity (for more details, see Allam et al., 2014). Through an online questionnaire before and after two months of using the site, we collected data that gave us information about the general impact of the website and helped us to classify users in terms of frequency of usage and impact of the site.

As the results of the quantitative study showed some improvements on some variables, but less on others (see the result section), we decided to further evaluate the factors qualitatively. For the qualitative study we conducted 19 in-depth interviews with patients from the group who had access on the interactive part of the

website, so we could evidence patients' views on the virtual communication (Table 1). We recruited patients with different levels of participation (highly active and moderate active users); health outcome improvement after the 2 months of online interaction (low and high); age (35-72), sex (11 women, 9 men), length of suffering (5-40 years), level of education (middle school, high/professional school, university). We defined the categories of *active* and *moderate* levels of participation considering three criteria: the total number of pages accessed (10-840 accessed pages); frequency of participation during the online meetings (in total 10 meetings) and activity in the chat determined through a content analysis identifying more and less active users.

In order to comprehend patients' views about what engaged them to interact and use the site, we prepared a flexible interview guideline, starting from more general questions about their opinions of Oneself and then moving on a more specific topics about what motivated or impeded them to interact online and their experiences with the site. Interviews were conducted at the University of Lugano and lasted approximately 1 hour.

### ***Data analysis***

Data collection and analysis were conducted simultaneously and carried out in cycles. We used the constant comparative method (Strauss & Corbin, 1990) to code each interview, to link and group the identified codes into larger categories, and to define more abstract concepts around which to organize the various arguments. These operations allowed for reduction and interpretation of large amounts of data, and continued until data saturation was achieved. Each interview was examined and read many times by the authors, in order to find the link among the retrieved categories. That enabled us to identify possible conceptual themes that we discussed several times, solidifying in that way some common themes. The results discussed in this article are the outcome of this continual, cycle process and the present findings

constitute a reasonable representation of the studied phenomenon (Mays & Pope, 1994).

**Table 1** Characteristics of the participants

	N
Level of education	
High/professional schools	10
University degree	4
Middle school	5
Marital status	
Married	12
In a relationship	3
Widow	2
Divorced	2
Accessed webpages for 2 months (0-830)	
Frequent users (> 40 accessed pages)	10
Moderate users (< 40 accessed pages)	9
Participation during the 10 organised online chats	
Active users (6+ meetings)	11
Low/moderate users (0-5 meetings)	8
Impact of the website	
High impact	7
Low impact	12

## Results

### *Evaluation of the study*

Before examining the interview data in detail, it is useful to set the context for those follow-up interviews by briefly reporting the mixed quantitative results from the experiment (for a more detailed analysis, see Ahmad et al, 2014). The analysis showed that there was no appreciable improvement in several of the key variables (see Appendix Table 1). However, there are exceptions, and these can be seen as falling into a pattern. The significant improvements occurred on variables that are

more related on the practical management of the disease (health literacy and pain management), rather than on a more psychological ones (psychological empowerment and acceptance). So, for example, there was an improvement in health literacy -- measured by a quiz of knowledge of RA -- and there was a particularly clear reduction in patients' immediate concerns and distress about the future evolution of the disease. By contrast, there was no change in a more psychological variables like acceptance and empowerment. Put another way, the experiment was able to influence patients' everyday experience of the disease but was less successful in altering their mindset in respect to the disease. In the light of these mixed quantitative results, we can explore patients' experiences and motivations in using the site, seeking potential explanations for Oneself having an impact on some outcomes but not others.

In the theoretical section (see Introduction) we defined some factors that might moderate the effectiveness of the received social support: characteristics of the web source (e.g. credibility), patients' experiences with the disease, personality type, and so on. We organize this results section under those subheadings, identifying from patients' point of view the things that affected the way they interacted online – what triggered them to seek online support and to participate in the interactions.

### ***Web related characteristics***

Undoubtedly the way the site was made and what was offering was fundamental for patients' motivation to use it. More precisely the *double interaction* with doctors and patients; the *reliability* of the source; the *anonymity* and the presence of a *moderator* were all elements that patients mentioned as important for their online participation.

#### ➤ *The simultaneous interaction with experts and other patients*

All of the interviewed patients evidenced that the key motivational reason that incentive them to interact with the website were the official weekly meetings with the doctors and with the patients. This double interaction was seen as a “*golden chance*” to obtain an immediate professional advice and to have real examples of how other people deal with the disease. The online communication with both experts and patients helped sufferers to reduce and “*calm down*” the worries about the disease and to reframe the illness, which were all ways to better manage the stress of the disease. In that sense we can explain why actually one of the most positively affected variable from the quantitative study is the stress management.

Many patients asserted that the organized chats with the experts helped them to ease concerns related to the disease. This helps to explain why measures of stress improved following the intervention (see Table 2). The fusing of professional and ‘peer’ interactions was particularly appreciated, giving patients a chance not only to receive medical advice but also to hear the views and experiences of others. The resulting ‘exchange of ideas’ again helped patients to become more confident in understanding the disease:

*“A website like that is a real help, because it’s a way to exchange ideas thanks to the others’ experiences. Especially benefitting from the doctors and taking advantage of their experiences, calm down your concerns, your anxiety, you better understand your disease. For me it was a mixture of two things: the side that gives you the answer – the doctor, the professional experience; and on the other hand to see the experiences of who is suffering in first line. It’s a fusion of the two things – having an answer and understand the solution, and that helps you a lot to overcome your fears, your concerns..” (Riccardo, 45 years old)*

Putting in written words the own concerns was a way to reframe the disease and give it a form. As one patient pointed out the online chats couldn’t solve their problems, but helped them to “*visualize*” the pain and to “*discharge*” the concerns, which was enough helpful to deal with the physical and the psychological impact of the disease:



*“It is like talking with a friend: is not that they solve you the problem, but it helps you to discharge what you have in your head. And those chats helped me a lot in that – to reformulate my thoughts in sentences and to put them in order, to give them a form. These chats simply help you to redimension everything; you put it in a frame. So you start visualizing that pain finally..” (Angela, 55 years old)*

➤ *The reliability of the website*

The fact that the website was managed by the University and by recognized health professionals made it a credible and reliable source, something that increased patients’ trust and its usage. The online presence of the doctors was seen as a guarantee of the trustworthiness of the available material – thus avoiding the risk of erroneous information that other websites may invoke.

One patient, who already had some bad experience on Internet, trusted Oneself because *“There is less risk of errors. If I enter in a random RA site I cannot make questions to the doctors – I must be able to understand alone the information and I may make some error, as I did in the past. Instead here (on Oneself) you can interact and understand immediately what is right and what is wrong, asking the doctors” (Andrea, 43)*

The trustworthiness of the site given by the presence of health professionals was clearly an incentive to interact and it gave a “double value” of the tool:

*“I found it extraordinary that during those online exchanges there was also a specialist. As a consequence the value of the site is double: you have the exchange with the patients and then you have the specialist who answers you. (..) This is important to me, because in that way you instantly clarify the things with somebody who is an expert, it gives you more trust to interact. (Virginia, 72)*

The fact that the site was developed locally and featured nearby professionals brought it closer to patients’ reality, another factor that encouraged interaction:

*“You feel it [Oneself] more close to you, because it’s Swiss, I trust it more...when you read the names of the doctors and if you have some question, you just know that they are here and you can contact them.” (Livia)*

➤ *The anonymous interaction*

In our study the anonymity of the virtual interaction had an ambivalent affect in respect to the different stages and levels of communication. On a more *technical* level during the official chats with the doctors, not *showing up* physically facilitated patients to interact as they felt more free of any responsibility and rules that the real interactions request. The privacy of the online chats buffered the “*direct confront*” and that facilitated people in their initial interaction during the official chats:

*“Online you don’t have to show up physically, even if the disease is not visible, but in any case online there is no this direct confront. I would feel much more embarrassed to participate on a real meeting, but if there is another one online with the experts I would participate with a pleasure. (...) in a real meeting you cannot be mute, instead on the computer you can also not write if you don’t want. And I think that this helps you to start chatting, especially for somebody like me who is not used on that..” (Livia, 42 years old)*

Another patient pointed out that the anonymity facilitated the initial stage of the communication, helping her to start chatting:

*“You have the anonymity online – you are there, but at the same time you are not. And so you let flow the words in a different way, especially during the chats with the doctors I found it more easy to start..”(Angela, 55 years old)*

The anonymity made easier the initial stage of the communication during the *official* chats where patients discussed more practical issues, but when it came to the point to open themselves on more personal and deep level, patients evidenced the need to establish a visual contact with the others and they stated that the computer blocked them. That explains why once the official chat with the experts was finished almost nobody took the initiative to contact somebody else or to continue the interaction on

a more personal level. Angela evidenced the less success of Oneself in creating a deeper level of interaction only between patients due to the lack of visual contact:

*“If the aim of the site was to create a kind of union between patients, I don’t think it was very successfu..There was not that interaction only between us – we were talking or with the doctors or with you.(...) It is already difficult to talk about your personal stuff. So why I should open myself with somebody that I don’t even know? Sometimes you need to see the face of the other, the facial expression, I need the visual contact. Especially when you are going to talk about personal things. And may be this is the point where the computer blocks me – if I am going beside certain level, I need to see, to feel the person. You know, opening yourself completely without seeing the other one is not so easy”(Christiane, 60 years old)*

➤ *The moderator*

The presence of a moderator who was establishing a personal contact with each of the patients and who was directing the chats was a strong incentive to interact. The moderator was seen as a *guide* who was keeping the focus on the specific topic during the chats with the doctors and was inspiring people to interact:

*“You were our guide, otherwise I wouldn’t have participated. The fact that there was a connection with you, that there is somebody who inspired and guided you was stimulating..(Nicole, 42 years old)*

*“I think what your (the moderator) role was very important because you were intervening when the discussion was going beyond. (...) you have also other possibilities online like Facebook or some forums where you can talk about whatever you want, but these meetings (on Oneself) were on a specific topic and I think it’s important to have a coordinator. (Gerardo, 60 years old)*

***Intrapersonal and social dimensions of the illness experience***

The way patients were experiencing the illness inside and outside of them was another important factor that impacted their need and usage of the online tool. The *acceptance* of their disease, the reaction of their *social context* and their actual *social network* were crucial factors that impacted differently the way they approached the virtual communication and as a consequence the way they has been impacted.

➤ *Intrapersonal dimensions*

The way people perceived the disease and their level of acceptance influenced their use and need of the virtual communication. For those who were avoiding and denying their condition interacting online was seen as a reminder of the problem they wanted to avoid and so they were more reluctant to chat as one patient said:

*“I don’t accept this illness; I am telling myself that I don’t have it. I know it sounds weird, but this is my way to face it. So meeting people online who are talking about the pain and about things that I want to avoid is a bit useless for me, it’s like you make official your role of the sick.” (Morena, 35)*

Instead those who were on a more advanced stage of acceptance and for whom their disability was not perceived as a *taboo* or a shame, Oneself was seen as a source of practical assistance in facing the illness.

We observed that people with a deeper awareness and acceptance of the disease were more open towards alternative methods of support, as the online one and were more willing to share their experiences as one patient pointed out:

*“For me my illness is not a taboo or a reason to be ashamed. I think that the openness, the confront with the others cannot be other than a positive benefit. So I’ve never experienced my illness as a closure or as a fear to show it to the others – it’s exactly the opposite, it’s something that I accept! I share my experience and I want to learn from the others’ experiences too, because I can only benefit from that.” (Martino, 53 years old)*

➤ *Social dimensions*

Another factor who affected patients' virtual interaction was the way they experienced their disability within their real social environment. Those patients who didn't feel enough comprehended and understood by their surrounding environment were the one who were more willing to interact and to search for a virtual support. For these patients the online space was offering them the consideration that they were missing in real life and the chats helped them to externalize their "anxieties" that were difficult to be shared with the others:

*"It (Oneself) helped me to externalize all the anxiety of my disease, my neurosis..to have the chance to talk about my illness, to feel considered first of all..Because don't forget one thing: when you are outside, when people look at you and tell you: "Go better to work, instead of stealing money from the health assurance!" It's not nice.. Even when you talk with your closest person, they tell you that you don't have anything. And also with your doctor is the same - I don't want to play the victim, but from my experience during some medical visits, you feel like you are more, like a burden. Instead on the website you talk with one doctor and you make a question, then you make another question to the other one and so on..it helps you to calm your mood, what torments you..."(Gerardo, 60 years old)*

Patients evidenced that their actual *social network* and perceived support in real life affected their need of online support. Obviously those people who had a satisfying and rich social network and who perceived more support outside were less willing to establish new contacts or to enter in a deeper level of interaction with the other patients. As one of the patients pointed out, Oneself was perceived more as a tool to obtain practical advices, instead of creating social network and this can explain why our site had less success in creating an online community on a lay level:

*"I was going online especially for the meetings with the doctors. It's not that I was not interested to see what the others write, how do they live with the disease – this is interesting, but it didn't give me the push to say "ah, I really want to establish a contact with that person!" Then I have also my friends, I have many people coming to visit me at home, I have many contacts – so this kind of saturation probably made*

*me less willing to go on a deeper level..but for people who don't have a lot of friends, I find it (Oneself) ideal!" (Marlene, 48 years old)*

### ***Illness dimensions***

Also some dimensions related on the illness as *time of suffering* and the *level of severity* determined the need of online support and the engagement in the virtual interaction. Those patients who were less impacted from the disease and who were not suffering so much the pain, felt less *authorized* to give advices and to interact on a chat with people who were more heavily impacted by the illness. That was a reason, because some of the patients were more passive during the online chats:

*"May be the level of my disease is not so serious and that probably stopped me to contact somebody else. I felt myself involved, participative but in a more humble way, less severe then the others..Because who am I in front of somebody who cannot stand up or is in a wheelchair? My pain was ridiculous in comparison with the others, so what experience could I bring?" (Roberto, 65 years old)*

Also the current stage of severity of the pain influenced the need to search for a help – passing currently through an acute episode of pain make patients need more the support online:

*"When you feel well, it's easy to not think about it (RA), but when you feel pain, the more symptoms and problems you have, the more probably is that you need to navigate, to talk with somebody who makes you feel better". (Elena, 39 years old)*

### ***Personality type***

The personality type was one of the most important determinants about the way patients interacted online – generally the online behavior was a reflection of the way they interacted in real life. We evidenced two types of participators: the lurkers – who were more passive and were mainly reading the others' comment; and the active

users who were more initiative to use the interactive parts of the site as the chat and the forum. These two categories were strongly connected with the personality of the participants: those who described themselves as open and interactive in real life were actually the ones who were more interactive also online; the participants who described themselves as more shy were the ones who were more passive during the chats.

As one of the patients pointed out:

*“It’s a question of how you really are, I think it’s as when you are in a real group: there is who is listening and who is talking; there are these two categories. It’s a question of personality. But who is just listening, doesn’t mean that they don’t have anything to say. May be they are more introvert, more shy. I am more open, I am not reserved, but there are others who are different. I think it’s a matter of character. (Benedetta, 58 years old)*

One of the participants explained her less intervening in the chats with her introvert and reserved personality:

*“I liked the chats, even if I didn’t intervened so much, I am not a great chatterer, I don’t freely chat with everyone. I am more listener then orator. I keep my things inside, I don’t like to share them so much.. but also only reading the others, you recognize in their stories“ (Marlene, 48 years old)*

## **Discussion**

In this article we evidenced patients’ views and experiences with the online tool Oneself that we designed for the study with the idea to provide social support online. The general purpose of the article was to explore RA patients’ perspectives of the usage of such an online tool, evidencing the factors that affected their online engagement. The general purpose of the article was to explore from patients’ point of view the factors that determine their engagement in online communication in order to maximize the efficiency of online support in helping people to deal with the pain.

Considering our quantitative and qualitative results it became clear that Oneself helped patients more on a *practical* level, increasing mostly outcomes that are related on the everyday management of the disease as reducing the impact of the stress and the pain on the quality of their lives, and increasing the level of health literacy and self-efficacy. The online communication was less successful in changing more *deep* and internal mindsets as the perceived social support, the acceptance of the disease and the psychological empowerment. On a first stage the effect of the tool only on a certain outcomes could be explained with the general patients' usage and consideration of the site - Oneself was perceived as a tool for obtaining more professional advice and for seeing how other people deal with the disease, but it failed in incentivizing more personal levels of interaction and in creating an online support group between patients. This helps us to understand why our intervention was more successful in changing concrete and daily experiences with the disease. Returning to the health empowerment model, we can see that patients took more advantage of those facets of Oneself that were likely to help with the health literacy element of that model. For example, discussions with and advice from medical professionals helped patients in areas like pain and stress management. By contrast, patients made less use of the peer interaction opportunities offered by the site, and these were designed particularly to boost the psychological component of the model. Because the tool did not become a space for intensive interaction, it was less able to impact upon mindset variables like acceptance and empowerment.

The strongest benefit that incentive people to interact on the website was the *double interaction* with doctors and patients. Definitely our study shows that one of the most important factors in shaping patients' engagement online was a site moderated by health professionals. The organized virtual meetings allowed patients to share their concerns and to benefit from both experts' advices and personal real stories of other people. During the virtual meetings patients felt considered and heard and interacting online was a way to put in words their problems and to externalize it. Sharing the



concerns and worries about the disease with experts was a way to deal with the stress related on the future evolution of the illness and that explains why in our quantitative evaluation the management of the stress was actually one of the most positively affected variables.

Our results are aligned with those of the previous study on Oneself with chronic back pain patients, where was actually proved that the chats with experts was a fundamental part of the virtual interaction that helped users to “construct their personal frame of reference about the nature and the course of their disease” (Schulz et al., 2010). In that sense Oneself became a tool to obtain professional advice, but succeeded less in incentivizing a virtual support group only between patients that lasts over the time.

The failure in shaping Oneself as a virtual space of lay support between patients could be explained with some cultural factors related on the Swiss context. Some surveys shows that only a small part of the Swiss population use Internet as a source of support (only 10% of the Swiss patients searched health information and help online) and especially in the Italian part of the country the usage of Internet as a tool of health support is surprisingly low (Froidevaux & Täube, 2006; Ammann, 2000; Jeannot et al., 2004). Even if these results are all the more surprising considering the similar pervasiveness of Internet in Switzerland to other northern European countries, it is a fact that the use of Internet as a source of support among Swiss patients is much lower in comparison with other European countries (where 30% of patients search health information online) and with the United States (rate of 40%) (Froidevaux & Täube, 2006). The smaller success of our intervention in incentivizing a deeper and more personal communication among patients could be explained also in the light of the way Swiss patients trust and consider the different source of health support. For the Swiss population physicians still represent the most trustable and preponderant resource of health information and so the idea of a virtual community only among patients is not valued as a potential method of support (Seematter-Bagnoud & Santos-Eggimann, 2007; Ammann, 2000). Considering these results we

can assume that the idea of establishing an online network only among patients is not still seen as enough reliable source of support for the self-management of the disease among the Swiss-Italians.

Even if some studies evidenced the facilitating role of the *anonymity* in online interaction among chronic patients (Berger et al., 2005); in our study that anonymity had an ambivalent effect in relation to the nature and the stage of the communication. Not showing physically and keeping the own privacy was a facilitating factor on the initial stage during the official chats with the doctors, as patients felt free of any obligations and less judged. But moving on a deeper and personal level of interaction, the lack of a real, visual contact with the others impeded patients to open and share more private problems, which partly explains why our intervention was less successful on a personal level.

Of course the need and the way patients interacted online depended also on the way they perceived and experienced the disease in their selves and lives. The *acceptance* of the illness was a condition of being more open in sharing the disease and to search for alternatives of support, whereas patients who were still in a stage of avoidance were less willing to talk about their pain. Other studies confirmed that people who had a deeper awareness of the disease benefit more from online support, as they used it in a more personalized and selective way for their particular needs (Caiata-Zufferey and Schulz, 2009).

Together with the internal experiences of the disease, also the external, *social experience* of the condition was an important factor that affected the need of online support. It has been proved that patients who participate most in online forums are those suffering from conditions that are not well understood and more prejudiced from the society (Davison et al, 2000). RA patients often complain the lack of enough understanding from their significant others as family and doctors and some of them feel even prejudiced and diminished in their suffering (Kostova et al., 2014). It has been shown that the negative social reactions to the pain endorse the experiencing of internalized stigma that in turn impacting negatively the sense of

personal control over the pain, reinforcing pain catastrophizing (Waugh et al., 2014). Indeed in our study exactly these kinds of sufferers who felt stigmatized and had less the support from their real social context were those who were more engaged on the web discussions, where they felt considered and understood without any conditions.

Also some factors related on the illness as the *length of suffering* and the *experience with the pain* determined patients' online behavior. Our study revealed that those patients who had greater control over their disease and who didn't experienced acute episodes of pain felt less authorized to interact and to give advices to others who were more heavily impacted. Indeed some studies confirmed the fact that patients who experienced greater problems with their disease and those suffering from a longer time are the one who use and benefit more the virtual support (Caiata-Zufferey and Schulz, 2009; Grande et al, 2006; Voerman et al, 2007).

Patients felt that their online behavior was affected by the "real" *personality*. In fact they felt that the way they behaved online was the reflection of their style of interaction in real life: those who perceived themselves as more open were the ones who were more interactive during the chats and those who were more passive, described themselves as more reserved. Similar results have been evidenced in other studies, where the phenomenon of the so called "lurkers" online is explained with a similar behavior in real life (Davison et al, 2000).

### ***Limitations and practical implications of the study***

The results of our study have to be considered in light of some limitations. The first concerns generalizability to other diseases. We should acknowledge the possibility that the nature of RA is such that patients have more need of practical support from the major sources (such as family and doctors) and less need of interaction and emotional support from sources such as online groups. Life-threatening or severely stigmatized diseases like cancer or AIDS are perhaps likelier to send patients to additional or anonymous arenas like online support groups. Second, our sample of

the qualitative evaluation was not representative for all of the users, but the interviewed participants were the one more willing to chat and to talk about their experiences. Third, some factors as the social context and the computer abilities of the participants should also be considered, as in our study many of the patients complained the lack of familiarity in using Internet.

Nevertheless, sites as Oneself, monitored by health professionals, have the potential to help patients in managing the consequences of the pain. Online communication reduces significantly health care costs and could be an additional tool for patients to share the concerns related on the unpredictable character of the pain.

The practical implications of our study lies first of all in understanding the circumstances under which online social support could work better - something crucial not only for the patients but also for those people who aim to provide social support online. Internet interactive applications can be considered a promising form of support benefitting the health system. Although, it is important to acknowledge that online social support could become a real support only when considers patients' needs related on the specific disease. Our study evidenced the importance of including interactive features involving health professionals as the most reliable source of health information and support. All of the patients in our study appreciated the possibility to communicate with experts who were available online, without the restrictions during the medical consultations, where some of the personal concerns are not discussed (Ogden et al, 2004; Patel, 2004).

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## **CHAPTER V**

### **GENERAL CONCLUSION**

## **Conclusions**

The studies described in this thesis have two parallel sets of objectives. The first set is specific to Rheumatoid Arthritis. We sought a deeper understanding of the struggles that RA patients face, to identify whether and how they receive adequate support, and which types of responses from their social environment tend to help or hinder patients with this unpredictable and invisible condition. We also designed and tested an RA-specific online tool and evaluated it from both supply and demand sides: can the kind of social support that RA patients need be provided by online interactions, and which types of patients profited more from those interactions? The second set of objectives is broader and more theoretical – and, as such, applicable to those researching other chronic diseases and to those using the key concepts in other contexts. Identifying gaps in the literature, we sought a fuller understanding of acceptance as a process and traced the ways in which multiple sources of social support can facilitate or impede that process. We also used the case of RA as a kind of acid test of the potential of online interaction to generate positive health outcomes, and provide more general guidance about the willingness and ability of patients to make good use of online support.

In the concluding discussions that follow, then, we provide new insights both for academic researchers and for practitioners, and recommendations both for policy and practice and for further research. The implications of our findings for research and practice are importantly intertwined. Our findings about the recurring and lingering effects of late diagnosis on the acceptance process are of obvious relevance to medical professionals – but they also highlight for academics the complexity and non-linearity of that process. Our findings about the dangers of over-reassurance give clear guidance to doctors and, via educational materials, to families too – but they also help to explain the sometimes meagre correlations between quantitative measures of social support and of acceptance in the research literature. And our findings about the limited effects of online interactions on RA patients are of use to

those planning and designing tools like Oneself – but they also modify the optimistic conclusions of academic studies investigating the health benefits of online support.

### ***A definition of a model of acceptance and its complexity***

In the first paper, we identified the main difficulties RA patients face during their fights with the chronic pain, delineating a new model with five main ‘key moments’ of acceptance. We defined some key experiences that are common for RA patients, starting from the struggles to find the right diagnosis until the moment of realizing that the illness is chronic and that the only way to live with it is to accept it. Following the suggestion of McCracken that acceptance is not “a single belief or thought, but a process”, we model that process, tracking patients’ struggles over time. The key contribution of the study therefore lies in presenting a new model of acceptance, organizing key experiences and moments. Our model adds to the literature by building on and extending the work of LaChapelle et al. (2008), first by introducing key moments that were missing from their own framework but also – as indicated by the use of the term ‘key moments’ rather than stages – by emphasising the complexity, non-linearity and general haphazardness of the acceptance process. The contribution of the study lies in depicting a model, adding to the literature of acceptance a definition of a process, that organizes some key experiences in stages over the time. Following the suggestion of McCracken that acceptance is not “a single believe or thought, but a process”, we describe this process, comprehending patients’ struggles over the time. While any such model is inevitably a simplification of a more complex process, with RA it was particularly hard to impose a chronological order. The phases lacked clear beginnings and ends and often overlapped; moreover, some patients more or less skipped a phase while others got stuck in it for years. Moreover, and crucially for practitioners as well as academics seeking to define and understand the concept, acceptance is a permanently ongoing process and not an end-point. Even when patients achieve a high level of



acceptance, they are not ‘safe’ – even someone engaged in integrating the illness can still regress into previous phases. However, exactly by identifying the reasons why some patients stall or relapse during the acceptance process, we were by extension able to generate new insights into how some patients succeed in their struggles with the pain and achieve acceptance.

And those insights are applicable not only to RA but also to other chronic conditions. While we argued strongly that certain aspects of RA made acceptance harder to attain, the broad model that we set out seems highly likely to apply in the case of other conditions that, through significant physical and psychological damage, cause similar ‘biographical disruptions’. For example, Schaefer (1997) in her study with women suffering from fibromyalgia describes the experience of avoiding some personally important activities because of the fear of pain and discomfort. She depicts a moment when patients feel “down in the dumps” (p.568) since they were no more doing anything they wanted to do and that significantly impacted their past lifestyle. This is like a less extreme version of what we defined as “hitting the bottom”, describing a similar pattern of losing the connection with the own values and goals and feeling as a passive victim of the disease. Similarly, Afrel et al. (2007) describe the process of “living with a body in pain”, evidencing the experiences of patients suffering from non-specific musculoskeletal pain. They define a period of rejecting the new limitations of the body, of refusing to accept the pain and denying the need of help. This is similar to our stage of “resisting the illness”, where patients struggle to retain their pre-pain identity. Denial is also a common reaction in other chronic diseases as cancer, where patients use it as a coping strategy against the stress, especially during the terminal phase (Vos and Haes, 2006). However, denial is more self-defeating in cases like RA where the unavoidable outcome is a life of pain rather than death.

We can see that these studies highlight some key themes that describe more general processes as adjustment or adaptation. They look at acceptance as part of these

processes, saying more about the nature and the consequences of it. In this sense, the innovative part of our study lies in looking at acceptance as a process and in explaining how actually patients achieve it.

Another significant contribution of the study, adding another layer of complexity within the simplifying model, is to highlight circumstantial factors that make the acceptance process different for each person. The paper places heavy emphasis on one of the most important of these: the timing of diagnosis. So far in the literature, diagnosis has not been studied as a factor shaping acceptance, and so our study has fresh implications for researchers as well as practitioners and policymakers. So far in the literature, diagnosis hasn't been studied as a factor shaping acceptance, and with our findings we highlight the importance of the diagnosis for the initiation of the acceptance process. This plays a crucial role in patients' struggles to achieve acceptance. Diagnosis proves an especially tortuous period in the case of RA, where some patients struggle for years to discover the real name of their pain, living in a state of uncertainty. In addition to the medical difficulties to diagnose RA, in the first paper we identified some structural reasons for late diagnosis. Having initially ignored the pain themselves, patients when later searching for a medical consultation tend to feel distrust from the doctors and diminished in their suffering. We showed that the late diagnosis has not only physical but also psychological consequences, affecting both the initiation of the acceptance process and the smoothness with which patients pass through it.

Those findings mean that the first paper contributes to an interesting stream of research which considers diagnosis itself as an activity and a process, indeed proposing diagnosis as a topic for sociological enquiry (Jutel, 2009; Brown, 2011). These studies take in consideration some extra-medical factors as social, political and economic ones, arguing that nowadays diagnosis is not just an interaction between patient and doctor, but could involve more complex dynamics as commercial interests and commercialism. It has been shown that, in cases of uncertain illnesses

(such as but by no means only RA), patients struggle to prove their illness in front of doctors and insurance companies, which leaves them struggling to be identified as a patient and even at risk of being deemed “crazy” (Dumit, 2005). In his study, Dumit (2005) shows how insurers have an interest in denying the existence of chronic diseases, which makes even an ultimately successful process of diagnosis into a battle during which patients feel distrusted and dismissed. Our study of the private healthcare system in Switzerland tends to corroborate those findings. We argued – and certainly patients strongly felt – that GPs are conditioned within the system to keep costs low, which among other things meant a reluctance to undertake the more expensive tests that could more reliably diagnose RA. Given the long-term damage wrought by delayed diagnosis, this could be a costly error for patients and a false economy for the healthcare system as a whole.

The clinical implications of this are clear and important. General practitioners and health policy makers should be aware of what prompt diagnosis can do both for physical and psychological outcomes. This applies not only in the case of RA but also to other chronic pain diseases as fibromyalgia, chronic fatigue syndrome or chronic back pain. When there is not a particular cause of the pain and when the patients’ suffering is initially reported rather than evident, there is a risk that doctors will underestimate that suffering. This is liable to delay diagnosis with the unwelcome consequences described above. On the other hand, as GPs might well retort, a wholesale willingness to accept patients’ self-reports could lead to unnecessary expense. There is a balance to strike between scepticism and credulity. That point highlights the fact that our study involves only the patients’ perspectives on the struggles for diagnosis – and hence some selection bias in that only those eventually established as RA sufferers were interviewed. Further research, exploring the causes of late diagnosis from the point of view of doctors, would be very useful. More generally, we echo the calls referred to above for a more specific scrutiny of the diagnosis process. Given its centrality for the acceptance process, the customary call for further research is a sensible one.

On the policy side, the study contributes in highlighting some implicit incentives of the specific Swiss health care system that might exacerbate difficulties in pursuing acceptance. Health policymakers could profit from our insights in considering how to reshape these incentives to accelerate diagnosis and treatment, decreasing in that way the physical and psychological costs of the late diagnosis.

Our grounded theory approach also enabled us to make a new contribution to academic debates about the conceptualisation of acceptance, clarifying that it has a more specific meaning than that of broader concepts such as adjustment or coping. By uncovering the meaning that patients give to the process of acceptance, we are able to extend the definition of McCracken (2005): “a willingness to experience continuing pain without needing to reduce, avoid, or otherwise change it”. At the heart of our definition is the combination of two processes: grieving the losses of the past and the pre-pain reality, but at the same time maintaining a connection with – and the pursuit of – the personal values and goals that were important in that pre-pain life. These two conditions can appear conflicting because, while from one side patients are supposed to accept the losses and the limitations, they need not and should not accept passive victimhood. Certainly the word “acceptance” seems to have indicated passivity among many of the interviewed patients, who insisted that they will never accept the disease, but “learn how to live with it”. However, that reaction, and the way our patients described the process more generally, was consistent with the ideas of LaChapelle et al. (2008). They argue that the willingness to maintain valued activities, while at the same time acknowledging that the way they manage those activities has to be changed, may be the ‘opposite sides of the same coin’.

From a practical point of view, it is important to reflect patients’ notion of acceptance, in order to facilitate the communication between health professionals and patients. Doctors can find it useful to have a deeper understanding about patients’

meaning of acceptance and the way they achieve it, so they can support and facilitate the entire process.

This brings us back to the theoretical starting-point. Since acceptance thus involves the realization that important life goals can and should be pursued, we can see its place as one key outcome within the psychological component of the Health Empowerment Model. Like empowerment, acceptance also reflects the perceived ability to deal with the secondary impact of the disease over patients' lives, and so has a place in the model as an important self-management behavior. In turn, given the structure of that model, it is unsurprising that acceptance is one of the outcomes that can be fostered by social support. We turn to that relationship next.

### ***The concept of social support and its integration in the acceptance process***

It is well established that the support which chronic patients receive from their social environment is fundamental for the way that they face their disease (Affleck, Pfeifer, Tennen, and Fifield, 1988; Gil et al., 1987; Osborne, Jensen, Ehde, Hanley, and Kraft, 2007). Nevertheless, previous research had provided only limited information about the nature and contingency of the relationship between social support and the specific concept of acceptance. The insights from the first paper about the intricacy of the acceptance process already gave a hint about why the impact of social support might itself be complex and conditional. With the second paper, we add three more clear-cut contributions to the literature in question: (i) identifying a link between social support and acceptance considering the two concepts in their multifaceted character; (ii) defining the conditionality of such support over acceptance, (iii) and giving suggestions about finding the balance for the right social support that RA patients need in order to better deal with the pain.

Acceptance is a multiphasic concept with different stages and also the concept of social support is multidimensional, comprehending different sources and types. One

of the chief innovative contributions of the second study is that we took full account of this dimensionality in assessing the relationship between the two concepts. While one purpose of the study was to identify how the importance of the different sources of support varied across the key moments in the acceptance process, many of the patients' histories argued against such clear patterns. A reliable and trusted source of support, whether it is a family member, a friend or a GP, was likely to be useful throughout the process. From an academic point of view, this reinforces the complexity and subtlety of our core variables and the relationship between them. It also highlights the methodological advantage of qualitative research which teases out nuances that statistical correlations can conceal. From a practical standpoint, it means that support of different types is not something that can be phased in and phased out as patients reach certain milestones, and that medical professionals need to be mindful of patients' support needs well beyond the realm of diagnosis and medication. That said, some patterns could be discerned. We have already seen the crucial (and not invariably positive) role played by doctors at the diagnosis stage; they were also crucial in helping patients to interiorize the new implications of the disease, providing information about its evolution and being empathetic towards patients' personal concerns. Meanwhile, family was the main provider of support during the entire path of acceptance and especially during the most difficult moments of "hitting the bottom", when patients need the right emotional and practical support.

The second contribution of the study was to describe when and why social support failed to help patients, defining the facilitators and the barriers that respectively may help or hinder acceptance. What emerged from our findings is that providing social support might be a difficult task due to the *invisible* and *unpredictable* nature of RA, and we showed that distrusting and sceptical responses from the social environment served to inhibit acceptance rather than promote it. This problem is highly likely to arise also in the case of other chronic pain diseases whose cause and evolution are uncertain (Åsbring & Närvänen, 2002; Eccleston et al., 2007). Werner and Malterud (2003) show how women with chronic pain complained of being met with scepticism

and a lack of understanding by their doctors. Feelings of being ignored, rejected and belittled proved to be common and often patients even felt blamed by their doctors. Pain is socially invisible and, especially in conditions where there is no obvious treatment for it, it is natural enough that other people struggle to comprehend patients' suffering. Yet reactions of scepticism, which are typical from people who don't suffer from chronic pain, are perceived by patients as lack of empathy and endorse the experience of *internalized stigma* that in turn affects negatively patients' pain behaviour (Waugh et al., 2014).

Of course, if sceptical reactions are understandable, then that raises the question of how this problem might be solved. One immediate answer, drawn directly from our findings, is that no one should lurch to the opposite extreme and offer nothing but sympathy and reassurance. We found that, in their different ways, neither scepticism nor excessive reassurance were productive in fostering acceptance. The problem with reassurance is clear if we return to the definition of acceptance as the recognition of certain losses. Put simply, if patients are told that "everything will be OK" then they will not reach the twin realizations that there is ultimately no cure for their pain and that they will therefore have to accept the new limitations of the body.

One of our contributions to the academic literature and is therefore to give a clear notion about what is the right type and amount of social support from patients' perspective. So far, social support has been assessed more from a quantitative perspective using general measures that reflects less the different dimensions of this concept, and may conceal the effects of 'over-support'. This is why, in our study, we looked at social support from different perspectives, giving more specific insights about the right formula of support, balancing between scepticism and excessive reassurance.

In terms of the Health Empowerment model that underpins this thesis, our specific and original contribution in the second paper is to highlight the conditionality of the relationship between social support and positive psychological outcomes. What

appears as a solid arrow in Figure 1 is, in reality, not quite so solid. We should not overstate the case: our interviews yielded numerous examples of social support contributed to acceptance and, more generally, to feelings of competence and self-determination. But there were counter-examples, emphasising the contingency of the kinds of relationships involved in a model like that of Schulz and Nakamoto (2005). This is not intended as a criticism of the model itself because, as noted above, any such model is necessarily a simplification. But it argues for research to understand where the simplifications come in, and the conditions under which the model applies.

One source of conditionality, implied in our results but not something which our data were well suited to investigate, is the patients' personality traits. It is arguable that some patients would be helped by a considerable degree of reassurance and support, while others might be better served by being prepared for and aware of the uncertain future evolution of the disease. Personality psychologists have identified traits like need for closure (Webster and Kruglanski, 1994) and intolerance of ambiguity (Furnham and Ribchester, 1995) that are likely to condition the effectiveness of different types of social support, and indeed have already been shown to shape processes akin to acceptance such as goal adjustment and successful ageing (Brandtstädter and Rothermund, 2002). We advise future research into the moderating role of personality type in the relationship between social support and acceptance, which would ultimately assist the tailoring of support to individual patients' needs. Meanwhile, acknowledging that personality factors may be harder for doctors to judge than more obvious characteristics such as severity of condition, age, length of time since diagnosis and so on, we should emphasise that these too may shape the type of social support that is appropriate to a patient.

The findings of our study in understanding the sources of social support, and the conditionality of their help, is important also from a clinical point of view and for exactly those groups that we have seen can offer such support. Knowing the importance of the early diagnosis, the negative effects of skepticism and over-



reassurance, and the need from patients' side to be considered in the psychological impact of the disease may help physicians to improve their relationship with the patients. The same contribution can be referred also regarding the support from the family, giving practical suggestions for the family members on their helpful and unhelpful responses.

One final point, applying to both the first and second papers, relates to the small-N qualitative methods used. These should not be regarded as a limitation of those studies, given that a central purpose was to ground new theories in rich data and to identify and explore complexity and contingency. However, qualitative studies like this tend to generate hypotheses that cannot then be tested given the small numbers available. For example, our suggestion that personality traits will moderate the usefulness of social support will remain speculative pending a quantitative survey study including measures of the variables involved. Larger-N studies can investigate conditionality more systematically, and more generally add robustness and generalizability to the findings from our in-depth interviews. This is why an iterative combination of qualitative and quantitative methods is often to recommended, and indeed was used in the project on which the third paper was based. We turn back to that study now.

### ***The potential of online social support on patients' self-management***

One clear message from the first two studies is that RA patients were quite likely to have some key support needs unfulfilled. Hence, for the third study, we produced and evaluated an alternative means of offering support – via an online environment. Previous research had painted an optimistic picture about the possibility of *transferring* social support online in such a way as to deliver positive health outcomes. Again, as in the other papers, a principal contribution of our study is to add some nuance and contingency to those studies, providing a more detailed

understanding of the factors that determine the efficacy of online support. This is again facilitated by the qualitative interviewing approach, which allowed us to get patients' perspectives on the things that made them more or less engaged in online communication.

From a practical point of view, the primary innovative feature of this study is the attempt to operationalize social interaction online. We created a website for RA patients that were entirely based on the previous needs assessment. The design and the contents of the website were the reflection of what patients needed to know and to receive in terms of informational, practical and emotional support. In this sense, the online tool that we created contained tailored and personalized information, which is fundamental to making these kinds of sites supportive.

Our qualitative findings were consistent with those from a quantitative analysis of Oneself which found that the online tool was more effective on a practical level than on a more deeply personal level. This pattern is reflected in patients' perceptions of the site as a practical tool, on which patients could obtain suggestions from experts and other patients in managing their disease from a more "technical" perspective. Any impact on the psychological component of the Health Empowerment model was, at least from patients' standpoints, confined to the short-term utility of expert advice in calming down their concerns about the numerous uncertainties that are typical for RA. Nevertheless, the tool was less successful in creating an online support group in which patients shared their emotional and personal problems with the disease, and it did not seem to shift deeper mindset variables like acceptance of pain or psychological empowerment. At least based on our findings, then, the principal impact of online social support will be on the Health Literacy component of the model: gaining information and obtaining practical advice.

This pattern is not unique to the case of RA, either, judging by a study of chronic lower back pain patients that was based on a previous version of the Oneself site. This again showed that the site helped patients to increase their knowledge, to

manage better their pain, and to take fewer painkillers (Schulz et al., 2010). In a qualitative evaluation of that version, Caiata-Zufferey and Schulz (2009) showed that interacting online helped patients to better understand their disease and to acquire more confidence in the ability to manage it.

Another significant finding of that study was that patients who already had high levels of awareness and self-management of their pain were the ones who benefited more from online support, in part because they were better able to select the information appropriate to their needs. We found a somewhat similar pattern whereby patients who had already achieved high levels of acceptance were the most willing to use the website. This suggests that the *demand* for support is not just a matter of information levels but also has a psychological component. Those who are yet to achieve acceptance, for example those still resisting or denying the illness, are also less ready to acknowledge their need for support.

This last point highlights the general and important consideration that the potential for a more durable impact of online social support depends not only on the characteristics of the site but also on a range of factors at the level of the patients themselves: demographic and clinical factors such as age and the severity and duration of the disease, the way in which patients have experienced their disease, and the kinds of personality factors alluded to already. Several of these are worthy of further consideration, not least because they may help to explain the limited use of the site and, in turn, its limited effects on the key psychological variables of interest here.

A crucial experiential factor regards the way in which society treats the disease in question. Those who feel more stigmatized by and perceive more prejudice in their 'real' social environment will be more willing to search for alternative sources of help such as online interactions and support (Hay et al., 2008). As the study of Phoenix and Coulson (2008) points out, patients suffering from stigmatized and life-threatening conditions like AIDS use online support groups as a means of both

offering and receiving social support. They show that the online model offers the right environment for individuals suffering from AIDS to express the emotional impact of the disease as well as their feelings of anger, fear and frustration. Davison et al. (2010) argue that conditions which are unexplained and invisible, like RA and other chronic pain diseases are also the kind that could encourage openness to establishing online interactions. However, the nature of the stigma is of course rather different in the case of RA than in a more dramatic context like AIDS. What is clear, pending future research is that the benefits of online tools will be maximized by considering how societal reactions to patients' conditions will shape demand for those tools. This last point leaves some open questions about how much RA patients actually need online support. Our study seems to indicate that RA patients need practical and medical support, in terms of advice regarding their concerns, but are less in need of supportive online groups on a more personal level – something needed by those suffering diseases like AIDS which cause deeper psychological discomfort.

When it comes to personality factors, the most striking aspect of our results was the similarity between patients' online and offline behavior. Those who described themselves as more social and open in their real life were also more participative and interactive virtually. At the other end of the spectrum, our findings confirm those of some previous studies showing that the phenomenon of "lurkers" can be explained with a similar behavior in real life (Davison et al, 2000). It might initially be thought that this constrains the effectiveness of online interactions because those who have the sparsest social networks will also participate least in and profit least from online interactions. Yet it has been shown that "lurkers" benefit from online support in the same way as posters do. This indicates that reading is in itself a sufficient factor to benefit from the online environment, and this makes sense in terms of outcomes like health literacy. However, although there is evidence that reading others' stories can also have an empowering effect (van Uden-Kraan et al., 2008), it nevertheless seems

likely that the self-imposed constraints on participation in online interactions help to explain Oneself's more limited impact on psychological outcomes like acceptance.

There are also probable interactions between patients' background and personality on the one hand, and the nature of online interactions on the other. One obvious point concerns the age profile of participants and, by implication, their computer skills and experience. There is evidence that younger age and higher education are predictors of health-related Internet use among chronic pain patients (Dutta and Feng, 2007). By contrast, in our experimental study, fewer than one in ten of all participants was between 18 and 40 years old, and many of the interviewees complained of their limited computing abilities and their lack of familiarity with the Internet as a mode of social interaction. In the study of van den Berg et al (2006) with RA patients, the authors suggest to be cautious in extrapolating results from people who have low Internet skills, and we should repeat this warning. Specifically, if it is the case that those less familiar with the Internet have used it primarily for gathering information, while social interaction is a kind of 'next level up' in Internet familiarity and usage, then we can again expect a site like Oneself to influence the informational more than the psychological components of the Health Empowerment model. From a practitioner standpoint, designers of such tools should bear in mind the limitations of their target users. From a research standpoint, we would propose a more rigorous comparison of effects that considers not only usage of the online tool itself but also everyday use of the Internet.

Of course, those less familiar with the Internet more generally are also likely to be more alert to the differences between face-to-face interaction and a tool like Oneself. Many of our participants explained their reluctance to open themselves and share their private stories by the faceless nature of online interaction, which doesn't transmit all the non-verbal symbols and cues that help people to feel more comfortable in exposing their personal problems. This has already been highlighted as one of the main disadvantages of online interaction, limiting participants' capacity

to read and respond to – and thus ultimately to trust – other users (van Uden-Kraan et al., 2011). That said, while a certain lack of personal connection is inevitable in the online environment, designers of tools like Oneself can mitigate these factors. One key means of doing so is with moderators, who act as the bridge between the people and the virtual environment, incentivizing and inviting them to participate. In our study, the presence and participation during chats of a moderator who had already established a personal connection with the patients was perceived as an incentive to interact, giving participants the feeling that there is somebody who “cares” about them and that is constantly available. Other simpler means of “personalizing” online interaction are things like the use of visuals and videos, and the encouragement and facilitation of offline interaction among participants. Indeed, another suggestion for future research is to compare the modes of interaction more directly, assigning participants randomly to either face-to-face or online support groups and investigating the relative efficacy of the two.

Finally, from our findings emerged that familiarity with the Internet is something that varies across countries and cultures as well as across individuals. We pointed out that, perhaps surprisingly, Switzerland is a context in which online support is less common. The Swiss population still considers the doctors as far and away the main and most trustworthy provider of support (Froidevaux & Täube, 2006; Ammann, 2000; Jeannot et al., 2004). By contrast, in some other societies, notably the US, the Internet is more readily considered as a potential source not only of information but also of support – online groups of the kind assembled by Oneself are much more common (Fox, 2006). This difference again helps to explain why, in our study, the online tool was perceived more as a means of obtaining expert information and less as a source of the type of social support that could deliver psychological benefits. Since a site like Oneself, once designed, is relatively easy to export to other contexts, it would be well worth replicating both the quantitative and qualitative evaluations of that intervention in other countries.

We have now considered quite a long list of individual and contextual factors that moderate the efficacy of online social support. Together, they provide a number of plausible reasons why the effects of Oneself were more limited when it comes to the deeper psychological changes that are of principal interest in this dissertation. Before concluding, we should acknowledge a more practical limitation of that study which may also help to explain the pattern of effects. The Oneself study involved two months of online interactions and this is arguably too short a period in two key respects. First, it seemed to be insufficient to create the feeling of a real group that could persuade enough patients to share their personal problems freely and openly. Second, as we saw in the first paper, acceptance is often a very long and slow (as well as an erratic) process. It is therefore not surprising that a two-month intervention is insufficient to generate – or at least to observe – shifts in deeper internal and external perceptions such as the perceived social support or the acceptance of pain. By contrast, two months is plenty long enough to provide patients with more factual information about the disease and practical advice on medication and treatment.

We should conclude our discussion of the third paper, and thus the dissertation, on a more upbeat note. Although we have focused on barriers to participation and difficulties in bringing about genuine online interactions, we should emphasize that Oneself also generated several of the positive effects that were reported by others attempting to deliver social support to patients online. Patients widely recognized the practical support that they can gain from such a tool. The dynamic interactions with both experts and other patients was a way to *externalize* and reframe the concerns about their disease – something that as our quantitative results confirm decrease patients' levels of distress and increase their self-efficacy. We thus make a specific and significant contribution to the literature on online support, highlighting the importance of health professionals being involved and present online. They are a reliable means of encouraging participants to use the tool and also of incentivizing patients to share their anxieties, both important channels to a sense of support. That

said, it was not only the dynamic interactions with health experts but also the possibility to chat with people in the same situation that was appreciated by the participants. For many, it made them more aware of their need to be listened to and understood, and tools such as Oneself undeniably offer the incentive as well as the opportunity to be part of a group and to share their concerns. What emerges from our results is that the therapeutic value of these kind of websites lies in giving the space to express the own concerns and fears and to feel that other people have find their ways to manage the pain.

It is worth reiterating that these points apply as much to other chronic diseases as to RA. Patients suffering from a lifelong illness will rarely find all of their support needs met in their normal social environment, and a tool which offers tailored information and the opportunity to interact with medical professionals and fellow sufferers is a precious and important additional support. As emphasized throughout this dissertation, living with a chronic disease has many injurious psychological consequences. A reliable, open and “24/7” space can help to mitigate these consequences, allowing patients to express their unspoken concerns and to ‘learn to live with the pain’. As one patient concluded:

*“It is one thing to be alone in fighting this disease, and is another thing to be in a group of ten people, discussing and knowing that you are not alone (...) this site helped me to express my fears, to talk about my disease and to feel considered.”*

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## **APPENDIX**

Table 1: Mean differences on various dependent variables among experimental participants (paired-samples t-tests, N=113)

Dependent variable (length of response scale)	Pre-test mean	Post-test mean	T statistic
Social support (1-7)	5.49	5.36	-2.04
Acceptance (1-7)	4.73	4.63	-1.54
Psychological empowerment (1-7)	5.07	5.13	0.48
Stress management (1-5)	3.23	3.49	4.10***
Pain management (1-11)	6.81	6.94	0.69
Health literacy (0-15)	7.42	7.75	1.75*
Self-efficacy (1-11)	6.64	7.14	3.11***

Asterisks denote significant improvement: \*  $p < 0.1$ ; \*\*  $p < 0.05$ ; \*\*\*  $p < 0.01$