Psychological and Social Factors in Rheumatic Diseases

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Abstract: *Rheumatic diseases are major causes of different degrees of pain, disability and deformity. They have strong impact in patient's lives, especially in psychological and social dimensions, as a result of their healthcare needs. The present study has a qualitative nature and is based on the evaluation of the impact of changes related to the progression of rheumatic diseases and on how the disease affects patients, namely at psychological, professional and social level. We conducted a focus-group to understand how illness could limit the daily life of these adult patients, women and men, with rheumatic diseases. Along the analysis and discussion of the results, we found out that the patients with rheumatic diseases have a health condition extremely complex, particularly in a psychological and emotional dimension. They have suffered severe changes, associated to emotional disturbances, related with demotivation, anxiety, nervousness, and physical limitations of multiple sorts, which lead to frustration or dissatisfaction. The rheumatic diseases can strongly affect the profession and social activity of the patients, but the family and friends support was proven to have a positive impact in the individuals, softening some negative effects of the illness. Our study emphasizes that it is recommended that nurse practitioners participate in the evaluation of these patients, in order to provide the adequate healthcare that they require, and aiming to promote their wellbeing.*

Keywords: *rheumatic diseases, health, illness, social dimension, psychological dimension, nursing*

1. Introduction

In our western societies, the major cause of morbidity is the rheumatic diseases, which reflect the overall impact of musculoskeletal illnesses. It is estimated that approximately 10% of the general population suffers from these chronic diseases (Cardiel, 2011; Cardiel & Rojas-Serrano, 2002; Lucas & Monjardino, 2010). There are about one hundred rheumatic diseases that produce varying degrees of pain, disability and deformity.

In general, these diseases do not increase short-term mortality and therefore, are not taken into account as health priorities. However, their influence on the deterioration of the quality of life is increasingly recognized. Rheumatic diseases can be defined as functional alterations of musculoskeletal system without traumatic source (Queirós, 2002). These are chronic and degenerative diseases, that impose major challenges on life and health of the patients, their families and even, in a larger extent, on the health systems, so, these reality needs all attention because it implies an enormous cost on healthcare systems (Woolf, 2003; Silva, 2000). Among these diseases, the most common are, first of all, osteoarthritis (OA) and rheumatoid arthritis (RA).

Their causes are frequently unidentified, but it is well-known that they are progressive, with an uncertain prognosis. Almost all rheumatic disorders have treatment that in a certain extent can be controllable, though they are incurable and a major cause of disability (Queirós, 2002). The osteoarthritis, in particular, has a prevalence that increases steeply with age (Faustino, 2003). Nowadays, about 12% of people over the age of twenty five years old are affected; and 60% of people over the age of sixty five years old have at least one joint with a moderate to severe deformation.

In fact, 38% of the Portuguese population (circa 2.7 millions) suffer from some form of these illnesses (approximately 1.7 million men and 970 thousand women) (LPCDR, 2004).

A rheumatic disease restricts people's ability to perform some tasks, social and occupational roles. It is the single greatest cause of disability in the elderly. More than 53% of adults over the age of 65 years complain from this health problem (Pimm & Weinman, 1998). Moreover, the aging of the Portuguese population, associated to the increase of rheumatic diseases, triggers profound implications, especially in plans caring for older people with rheumatic problems (Lucas & Monjardino, 2010).

The chronic degenerative diseases develop gradually, affecting health and welfare, provoking pain, disabilities and constraints in all kind of activity. These diseases inflict undoubtedly, a limitation to the autonomy and independence of persons, compromising their wellbeing in every sense (Hill, 1999).

In face of the strong psychosocial impact of rheumatic diseases, the World Health Organization dedicated the years from 2000 to 2010 as the 'Bone and Joint Decade', created by an initiative of the United Nations. The main objective is to highlight the importance of musculoskeletal diseases, and their impact in all areas of human life, in different regions of the world (MS, 2004). Another objective is to invert the increasing tendency of rheumatic illnesses and this demands a comprehensive and global approach, by the health services, to reduce the risk of contracting this disease and promote their adequate treatment and rehabilitation, all over the world, including in Portugal (DGS, 2007).

All rheumatic diseases may play important roles in shaping the cognitive, emotional and behavioural processes, underlying the each person's symptoms and subsequent adaptations. Patients with rheumatologic problems, whether they are mild or severe, will be affected emotionally, physically, psychologically, sexually and financially. Some may have to give up work and become dependent on their companion; the chronic pain can cause problems in relationships, several activities, and even the simple things may become too difficult. As a result the ill person can feel isolated, lonely, depressed and even guilty (O’Donovan, 2004).

Pain is the predominant complaint of those who live with a rheumatic condition. We usually associate pain with some kind of injury, but the rheumatic chronic pain challenges these beliefs, and patients and physicians find it hard to understand how it can arise from apparently nowhere. In the rheumatic diseases, pain and joint stiffness are the first symptoms to appear, first of all in the hands.

As the disease progresses, other joints such as the shoulders, elbows, wrists, hips, knees and ankles, are affected (Olivier, 2004; O’Donovan, 2004). This kind of pain is almost permanent, in day and night, and sometimes changes to patients’ sleep pattern. It is often brought about by a combination of pain, fear and anxiety about their disease and their future (Hill & Hale, 2004; Bourguignon, Labyak & Taibi, 2003). Sometimes, the loss of the normal range of movements results in loss of independence and mobility, causing a negative impact on psychosocial status of the individual.

The chronic symptoms of rheumatic disease can cause psychological impact. The variability of good and bad days makes it difficult to plan any event, and younger patients report this as their greatest difficulty in dealing with the symptoms of arthritis (Straughair, 1992; Hill & Hale, 2004). These uncertainties can contribute to depression and patients' anxiety. In fact, pain and fatigue are major factors that contribute to depression and these may become complex to evaluate. Fatigue and feelings like anger, fear, and worthlessness are common between these patients, who often also have to deal with anxieties about their dependence upon the others.

Rheumatic diseases are also responsible for the degradation of joints and for profound changes in the physical appearance, so the patients may feel that they are no longer attractive with their 'new body'. The truth is that alterations to body image pose a problem to which young people are particularly vulnerable, because they truly worry about their image, associating it to the difficulties to have meaningful relationships. Sometimes, as the patients become too much centred on people’s perception about their (physical) image, they also may become socially isolated (Ryan & Olivier, 2002; Boyington et al, 2008). At physical and psychological levels, the sexual problems can occur, as sexual intercourses may become painful and functionally difficult. This can place a strain even on lasting relationships (Hill, 2004; Hill & Hale, 2004).

On the social domain, the rheumatic disease affects the patient on his work and social activity. Patients are less likely to be employed or be as well paid as their healthy peers, and this is another factor of anxiety (Packham, 2004; Hill & Hale, 2004). Of course the disease also affects the family and is responsible for some alterations and financial changes. In spite of everything, patients with chronic diseases are sometimes little aware of the social and psychological consequences of their disease, or about their subsequent needs.

There are methodological problems to evaluate the impact of rheumatic diseases. There is information about some aspects such as the impact of quality of life like pain, suffering, progressive deformity and inability to perform activities of daily living. It is also important to understand other variables such as social and psychological problems, undesirable changes at work or in life plans.

The traditional ways of providing healthcare is almost exclusively based on the medical model of diagnosis, and sometimes fail to recognise common issues that affect individuals with a chronic disease. There are several factors that may lead the individual to experience a loss of self-esteem and, ultimately, a feeling of disempowerment in negotiating their healthcare needs (Olivier, 2004).

Without an understanding of the internal and profound implications of the rheumatic diseases, the healthcare professionals could hardly achieve a real perspective of the situation, in order to identify what are the repercussions of this illness. The perceptions of the patients suffering from this illness are essential to understand what they feel and what they have to face, daily, in every domain of their lives.

In this sense, the **main objective** of the present study is to understand how rheumatic diseases can limit the life of patients, namely at psychological, family and social dimensions.

2. Methodology

2.1. Population

Our sample consisted of 10 participants, patients with rheumatic diseases, six (6) women and four (4) men, from 30 to 60 years old.

2.2. Instrument of Measure and Procedure

We conducted a focus-group with all the participants. They were asked about:
How rheumatic disease can limit your activities?
What implications the disease has brought to your social life and to your relationships with your family and friends?
How do you usually feel?
This last question is related with another: 'In what extent can pain limit your daily activities, at a social, professional and psychological level?'.
We let the participants talk and discuss about these topics. We also collected some socio-demographic data about the participants (e.g. gender, age, marital status, etc.), as well as some other indicators about less relevant issues.
All the data was collected at the Portuguese League against Rheumatic Disease (LPCDR, 2004) and was analysed through content analyses (Bardin, 1977).

2.3. Ethical Considerations

The patients were informed that their participation in the study was anonymous and voluntary. Accordingly, we obtained a written consent from each participant. The permission to record the interviews and the group discussion, as well as the confidentiality and anonymity, were assured by us.

3. Findings

When we asked the participants to talk about 'How rheumatic disease can limit your activities?' all of them said that the main problem is the pain, many times severe and incessant, provoking suffering, disability and several restrictions. Participants reported that pain essentially commits their ability to walk and, above all, they have difficulty climbing up and go down stairs (cf. Table 1).

Women, in most of the day, have difficulty in carrying out household tasks such as shopping, to treat clothes and preparing food for cooking. Men denote more difficulty to drive the car, work, practice their favourite sports, and in addition they complain that the pain affects their social relationships. Most participants consider the pain they feel as moderate or intense. Considering the gender, women say they suffer from an intense pain in the joints, while men argue that the pain is moderate and really affects several joints, throughout all the day and by night, it may even imply difficulty falling asleep, or sleeping disorders.

Table 1. Activities, feelings and social limitations related with rheumatic disease (by descending order of importance/frequency)

Activity limitations	Social limitations	Feelings
Mobility in community Mobility at home Climbing up and go down stairs Household tasks Shopping	Working Hobbies Changes in the social life Visiting family or friends	Anxiety Constant worry Depression Tension Restlessness

Cooking Treat clothing Working Hobbies Difficult to sleep, or Rest deprivation (and Fatigue)		Nervousness Sadness Lack of courage Unselfishness Discouragement Hopelessness Low self-esteem Uncertainty regarding future

To the question ‘What implications the disease has brought to your social life and to your relationships with your family and friends?’, the responses of both, men and women, suggest that their social life is compromised in consequence of the disease.

It was observed that the disease has brought important restrictions in several common daily activities, such as leisure activities, work or hobbies, and in go out home, even to do some shopping or to visit family or friends (cf. Table 1).

The participants reported that the support given by family and friends is essential. They often say that most of the times the family ‘would be present if they needed help’, because family 'shows an interest in their problems' and they are aware of their 'personal needs', and that is why they are 'sensitive to the effects caused by arthritis'.

As we already mentioned, the social life of the patients is compromised by illness, so, leaving home for leisure activities or hobbies sometimes becomes particularly difficult, and relatives or friends are also very affected for this situation. They often maintain regular contact with family by telephone, using it most days. And this is a way to feel somehow accompanied or close to someone, and not isolated or in loneliness.

The male participants still have a paid job and are professionally active. The women, in general, are housewife; among women, the most affected by illness and with more than 50 years old, are now retired. Some of the men reveal that when they feel especially tired or uncomfortable it becomes difficult to concentrate and to do their job. Some also refer that in some days they need to reduce the working hours, because of the pain and fatigue they feel.

In reply to another question, ‘How do you usually feel?’, participants said they rarely feel calm or relaxed. In fact, they point out that they frequently feel nervous, sad or depressed. They also mentioned that they do not appreciate many of the things they have to do and they do not habitually feel much enthusiastic. But, in general, they also reported that even when they feel very sad, and despite their limitations, they like to live (and do not have a wish to die), despite their usual pain and suffering.

4. Discussion

According to what we found, many authors highlight the impact caused by rheumatic diseases on the life of the patients, affecting them at different levels, in the way they usually feel and on their daily activities (e.g. Carr & Higginson, 2001). In this context, the physical limitations due to changes in any joint function and some kind of functional disability, may gradually lead to loss of independence of the individual in particular in the common activities of daily living (Hill, 1999). In this respect, Melanson & Downe-Womboldt (2003) reported that mobility in general, whether at home, in the community, in travels on foot or by transport, in care of personal hygiene and in the household tasks, may be seriously affected.

In a study that addressed the impact of rheumatic disease in women in relation to their domestic life, when compared with others (considered healthy), were found significant changes in this activity for those women, for example in what concerns to cooking, cleaning and ironing, among others (Rebelo, 1996).

As we verified, a rheumatic disease can strongly contribute to important impairments at a physical and psychological dimensions of a patient, and this can be noted in some symptoms as fatigue, morning stiffness, inability to activities of daily living (like doing some actions, eating, dressing, and hygiene habits, among others) (Melanson & Downe-Wamboldt, 2003). Our study also showed that there are some components affected, in particular movements involving flexion and extension of joints, both in terms of the lower limbs (such as walking, climbing and descending stairs) or of the upper level (as the movements associated to hands, fingers and arms).

In summary, the rheumatic diseases are recognized as a health problem that mostly affects women. Along time, there is a progressive evolution to severe disability. And this is reflected on the difficulty to perform the activities of daily life and the tasks that are culturally more associated with women.

The pain is a major cause that affects the lives of individuals with rheumatic diseases, and this is a very complex issue, both for patients as for health professionals. In fact, most patients with a rheumatic disease, especially with rheumatic arthritis, have pain in almost all joints, ranging from moderate to very strong (Davis, 2003). In the population that we studied the majority of the patients evidenced this pattern.

There is also a relationship between pain intensity and some sleep disturbances. The rheumatic pain may interfere with sleep and affects the performance of many activities and tasks, such as those that are related with hygiene, dressing up and undressing, household chores, the shopping or the writing. Thus, we can say that the capacities of people with rheumatic disease are usually reduced in many ways, limiting their quality of life.

It is evident that the family is very important for the respondents. However, nowadays the families have more difficulty than in the past to give direct support to any member that may be sick for long periods - including personal care, household tasks, basic needs, etc.

It is therefore normal that other resources may be used to contact someone or to maintain a good relationship, which is really valued by our subjects, but this does not overcome the social isolation felt by the patients. Frequently, in addition to a strictly biological disorder, emerges a certain social isolation. This was evidenced by our participants with the decreasing of their social contacts, either in visits to family and friends, or in carrying out recreational activities and hobbies.

Rheumatic diseases have a huge social importance. They also have a great impact in work. The progressive increase in disability linked to rheumatic diseases, is the main cause of early retirement. Our participants described some changes that affected their work rate (decrease in the number of hours of work). Women, in particular, perform the domestic tasks but, in both sexes, it is necessary an adaptation to accomplish even the more simple actions, learning to live with severe physical limitations.

Regarding the emotional aspects, we should remember that a chronic disease triggers of anxiety and depressive reactions, varying from person to person. Any healthcare professional that takes care of these patients, should consider that each person is unique as has a own way to experience the illness and the way how it changed his life, family and social interactions.

Our participants revealed tension, restlessness, nervousness, changes of humour, and a certain degree of negativity to face the day-to-day activities, reinforced by some sadness, lack of courage, unselfishness, discouragement and hopelessness - as predictors of a low self-esteem.

In a study with a population of 137 patients with rheumatoid arthritis, 42% was depressed, and chronic pain was considered the main cause (Nicasio & Wallston, 1992). In this regard, Teixeira (2002) states that depression is often associated with rheumatic diseases in general.

Another aspect that could lead to the onset of depression is the change of body image, resulting from physical deformities caused by the disease, and this implies constraints on the work and in social life.

5. Conclusion

We can say that pain becomes really meaningful, as a form of suffering, when it is continuously present, even if its intensity varies over time. This is what happens in rheumatic diseases, as chronic illnesses. The pain and the suffering affect the individual, in all his areas of action.

In particular, the psychological repercussions of the rheumatic diseases are considered very negative by most authors, and it is natural that, with increasing age, its effects become more serious (e.g. Jackobsson & Hallberg, 2002; Hyunsoo & Whasook, 2003). There are several aspects that can contribute to it. The pain and functional disability often cause anxiety, insecurity and depression.

If we take into account the isolation, so usual, of the older people in our societies, then it becomes more obvious the importance of the psychological condition in the case of the older people, so often retired or away from their family (e.g. Gaião, 1990).

Pain can really have a tremendous impact and limit the daily activities of anyone with a rheumatic disease. This is why it was so valued in our study. It can be viewed as a multidimensional phenomenon that affects the person at different levels, namely behavioural, emotional, psychological and social, implying a great personal suffering, with heavy costs to the individual and family, and having inevitable social and professional consequences.

The physical and functional effects of the disease may be more or less severe, and it is known that there is a tendency for their increase with disease progression, and the increase of age.

The ‘physical illness’ has clear implications in affective, family and social interaction, contributing to emotional disturbances related to a high level of tension, fear, insecurity, physical limitations, and this situation leads to a profound dissatisfaction or frustration, in different areas of personal life. It should be noted however, that the social support, and especially family and friends, it turned out to have a positive impact on the subject, decreasing in part, some of the negative effects of the disease in these dimensions.

The decrease and even the loss of some capacity or functionality, has a negative influence on the individual performance, particularly at a professional domain, implying important limitations on any activity.

Knowing the physical, functional and emotional difficulties and the limitations of the patients, health professionals may have a better understanding of patients' priorities and improve their strategies to deal with them, providing the adequate care to help them facing the everyday life, contributing as much as possible for their wellbeing.

In this sense, this study may contribute to understand how it is to live with rheumatic disease, and how can we help someone suffering from this chronic disease, to face the day-by-day positively and with more hope.

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