

Learning to Live with a Chronic Illness, without Thinking about Death

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Doi:10.5901/ajis.2013.v2n9p326

Abstract

Chronic diseases are characterized by continuous pain and suffering, affecting the personal well-being, emotional, family and social. Patients experience moments of disruption, in face of alterations or deformations in their body image, and the need to change their habits and social roles. Some patients accept their situation, having good practices of self-care, adapting to their limitations and seeing the future with hope, while others represent the disease with sadness, negativity, fear and worry. The suffering but particularly death, emerges as a possibility that they prefer to ignore. This study aims to contribute to the understanding of how patients perceive their chronic disease, as well as life and death. Data were collected through a focus-group conducted with the consent of ten participants - adult and aging patients with rheumatoid arthritis. Among the various questions discussed, we highlight these: 'How do you envisage your illness?', 'How do you feel towards life?', 'How does illness affect your life?', 'How do you envisage death?' All participants recognize the disease as incurable, associating it with suffering, loneliness and grief. Women complain especially of the limitations imposed by the disease, which hinder the achievement of household tasks, while men emphasize the constraints they experience at a professional level. Patients reveal resignation or intention to learn to live with a persistent pain, but they all tend to ignore death. They believe in therapy, although they see it as excessive and with a temporary effect. The most important thing they consider is to be alive, hoping to get better.

Keywords: *chronic illness, rheumatic diseases, pain, body, life, death*

1. Introduction

Rheumatic diseases are an important (and global) public health problem, resulting in limitations in the daily living activities of the patients that often reduce their familiar meetings or social participations.

Most of the inflammatory joint disease (e.g. arthritis) results directly from pain and disability, affecting the well-being, in numerous aspects (Symmons et al., 2002; Silman, 2001; Zink et al., 2004). These diseases are very common and only in Europe it is estimated that there are over 103 million patients (Lucas & Monjardino, 2010; Faustino, 2003; Queirós, 2002).

All diseases of this kind no matter the etiology - can undermine the musculoskeletal system, causing pain and changes, especially at the joints, causing deformation of the body - as well as functional disability by limiting the movements, autonomy, independence and the social involvement, committing welfare (Lucas & Monjardino, 2010). In

fact, rheumatic diseases have a profound effect on functional status, interfere with activities of daily living, reduce physical mobility and may, secondarily, increase mortality (Majitria et al., 2009).

Historically, rheumatic diseases¹ have received relatively little attention, and their impact have been minimized (Hootman et al., 2002), considering that they affect only older people, for which nothing more can be done. Gradually, these attitudes are changing. About 60% of the patients with these diseases are under 65 years old, and an appropriate management of the situation can make a real difference² (e.g., Lucas & Monjardino, 2010). Due to these problems, emerged in 2000 the 'Bone and Joint Decade (2000-2010)' that is a global initiative endorsed by the World Health Organization (WHO), whose goal is to improve the health quality of life for people with musculoskeletal disorders, including rheumatic diseases.³

Although therapeutic options have improved over the last decades, these chronic illnesses affect the economic situation, work status, family and social relationships of a significant number of patients. These outcomes are clearly related to functional disability, and we are now aware of an increased mortality associated with the inflammatory rheumatic diseases, like rheumatoid arthritis (Goodson & Symmons, 2002).

It is now clear that mortality in rheumatic diseases is strongly influenced by the disease activity and can be reduced by effective treatment (e.g., Krause et al., 2000; Zink et al., 2004). The way to face the disease is essential in the patients' routine. The disease can be a source of great pain, constituting a real or imagined threat to the integrity of the person, confronting it with its fragility and the idea of death. Suffering can enhance the value of life and contribute thereby to self-regulation and reconstruction of the person (Gameiro, 1999).⁴

Knowledge of disease characteristics influences the patient behavior, emotions, and management of symptoms (Correia, 2006; Pimm & Weinman, 1998). When the reaction to disability is not adaptive, fear can become in denial, evidencing a defense mechanism or anxiety, in face of an irreversible disease, and many patients think even in death (e.g., Marques et al., 2012).

Death has always been a part of human development and any person that is faced with this, questions his own life, confronting his fears and anxieties (e.g., Kastenbaum, 2001; Kastenbaum & Aisenberg, 1983; Oliveira, 2008, 2011). When it comes to chronic diseases such as the rheumatic diseases, death emerges as an issue since the diagnosis, not only by its gravity, but essentially by the loss, pain and suffering, associated with the illness, and by the threats of the unpredictability of disease itself (Bromberg, 1998; Alcântara et al., 2011).

In Western society that drives us to the accumulation of goods, medicine and new technologies offer us (the illusion of) an increasing life expectancy, trying to delay or hide the confrontation with death. Became almost a shame share feelings related with death, pain and suffering, particularly in the case of chronic diseases (e.g., Oliveira, 2008, 2011).

The idea of dying will be better accepted by the elderly, because most people in this age group is already in the final phase of its life cycle, and has done what is expected by society - has worked, married, had children, and became old, so, may die (Boemer, Zanetti & Valle, 1991). The fact is that it is also more likely that death occurs among the elderly, than in other age groups. However, the fear of dying is not linear, is an individual experience that can be aggravated by the disease.

The modern way of living, inciting us to 'look happy' at any moment and at any cost, to cultivate pleasure, image, fashion and material goods, separates us from reality. We pretend or run away, ignore or reject the death, thinking that certain setbacks only happen to others, and that certain diseases can only be diagnosed to the others. However, we know that death does not differentiate status, position or class, after all, we are all equal in the end (e.g., Oliveira, 2008, 2011).

¹ E.g., inflammatory rheumatic disease, like rheumatoid arthritis.

² E.g., medications, new techniques of joint replacement surgery.

³ This goal is being achieved through the following measures: i) raising awareness of the growing burden of musculoskeletal disorders on society; ii) empowering patients to participate in their own care; iii) promoting cost effective prevention and treatment; iv) and advancing the understanding of musculoskeletal disorders through research to improve prevention and treatment (Woolf & Ákesson, 2001; Woolf, 2003, Woolf & Pfleger, 2003).

⁴ This reconstruction can be positive and is only possible if a person has the ability to use her personal resources (self-esteem, competencies acquired) and external resources (family support, social support, sociocultural values) to deal with suffering, and others, like the motivation for the search for meaning, motivation for others, and the openness to faith and hope (McIntyre & Vila-Chá, 1995).

Death is seen as the darkness, the unknown and therefore awakens on us the fear, anxiety and other feelings of malaise. However, when we deny death itself, such position causes us discomfort and unwanted feelings, as if we did not want to face our own life.

In Portugal, we do not find studies that address the representations of the disease, and its relation to life and death, among people with rheumatic disease, so we consider the present work as relevant.

2. Main objective

This study aims to contribute to understand how patients perceive their chronic disease, as well as life and death, among adults and aging with rheumatic diseases.

3. Method

We conducted a focus-group with 10 participants - patients with rheumatic diseases - nine women and one man, from 56 to 80 years old, all married, diagnosed with rheumatic diseases for four to thirty years - all of them are retired and live in Lisbon.⁵

The participants were asked about:
'How do you envisage your illness?'
'How do you feel towards life?'
'How does illness affect your life?'
'How do you envisage death?'

We let the participants talk and discuss about these topics. We also collected some socio-demographic data about them (e.g., gender, age, marital status, and time of disease), as well as some other indicators about less relevant issues.

All the data was collected in a hospital inpatient and were analysed through content analysis, to determine the relevant categories and main units (e.g., Bardin, 1977).

4. Results

The analysis of the interviews revealed themes, such as: reactions to rheumatic disease; feelings and emotions centered on the person; impact on the person, the family and society, impact of disease on the perception life and death.

When we challenged the participants to talk about "How do you envisage your illness?", from the analysis done, two categories emerged. The first is related to negative aspects associated to difficulties of everyday life - the subjects were unanimous in connote illness as chronic and as a problem that impedes the realization of fundamental tasks in day-to-day. The second is linked to positive aspects, where reactions of adaptation and acceptance are obvious (cf. Table 1).

Table 1. 'How do you envisage your illness?' (Categories and items - or units of analysis)

	Difficulties in Everyday Life
Negative reactions due to the rheumatic disease	I cannot do simple tasks I was an active person I cannot do my chores I cannot do the cleaning I cannot put things in order is difficult to do simple things in life I cannot accompany my family purchases are difficult to make I have no strength, the disease took my energy sometimes even in bed is difficult to stay our life depends on others

⁵ Ethical considerations: the patients were informed that their participation in the study was anonymous and voluntary; accordingly, we obtained a written consent from them. The permission to record the interviews and the group discussion, as well as the confidentiality and anonymity, were assured by us.

Positive reactions due to the rheumatic disease	Adaptation / Acceptance
	I live one day at a time I think that what happened had to happen there are worse diseases, there are people worse than me we have to accept we have to learn to live with the disease I no longer feel revolt I'm used I accept my situation, I have to accept I am resigned, I live in the present at first it was a shock, could not believe

4.1 'How do you feel towards life?'

When we asked the participants to talk about what they feel about life, emerged sentiments centered on the person - 'what I feel' - but also attitudes with impact on family dynamics and on a social level - what others think of the patient himself.

4.2 'What I feel'

Most spoke of the sadness of feeling they are different persons. When talking about themselves, they wept with ease and spontaneity. Some said they were afraid of the future, and expressed dismay, once the disease is a source of pain and suffering.

Besides fear, hope and uncertainty also appeared frequently, with the perspective of having to depend on others and become a burden to the family. The doubts about the future increase as time passes. Faith comes as an inner strength that helps in confronting the disease and contributes to its acceptance and adaptation. For them, it is worth continuing to invest and learn to live with the disease (cf. Table 2).

4.3 'Impact of disease on family and social dynamics'

With the evolution of the disease also occur changes in family and social dynamics. These can be positive - as the support, understanding and help - or negative - for most subjects, the family members show disinterest and misunderstanding. Family life suffers major alterations because it implies changing roles and functions; when the patient is the wife or mother, the lack of female figure implies domestic difficulties to their husbands. All subjects felt that most people do not believe that the disease may cause so much discomfort and has so strong impact on their lives (cf. Table 2).

4.4 'How does illness affect your life?'

Patients report that the disease affected their life, in all dimensions, given the suffering caused, and the fear of losing health. They feel vulnerable, distressed and anxious, what can lead to isolation and loneliness, not wanting to talk to anyone and, sometimes, forgoing social activities. The implications that the disease has on the health and well-being are especially evident in the changes on the routines and daily plans, in complaints, signs and symptoms, and also in sleep disturbance and anxiety, due to the stress caused by the emotional weight that the disease causes. One aspect that also has changed, affecting the lives of the subjects, was the changes on the body and in physical appearance (cf. Table 3).

Another aspect mentioned was the management of the disease itself, in terms of (adherence to) therapeutic, symptoms and energy. For this it is important to have accessible information and understand the characteristics of the disease to be able to manage it. They say that they have little information about the disease and this is due to health care professionals who do not report them what they have, and even worse, do not listen the patients complains. They also consider that the proper management of the disease depends, especially, of the adherence to the therapeutic. However,

some individuals do not feel informed about this. Others argue that even without this knowledge, they follow all directions given by healthcare professionals (cf. Table 3).

4.5 'How do you envisage death?'

From the response to this question it appears that some of the subjects, despite the pain, complications and difficulties in living with this type of disease, don't have fear to face the death, saying that they would not mind dying, since suffering is too much. Some patients do not even want to hear about this issue, stating that prefer to take medication and live with the complications of therapy and the pain, than to die (cf. Table 4).

Table 2. 'How do you feel towards life?' (Categories and items - or units of analysis)

What I feel	Fear	I do not reach an old age I'm afraid of becoming a burden to my family nobody will take care of me I do not want to bother anyone I'm afraid to get worse I have the consciousness that in the future I will be worse I fear the disease, it always comes back sometimes I am afraid to lie down I fear tomorrow
	Sadness	I am no longer the same I feel sad no one understands me I cry a lot the disease takes me the joy of living it is not easy to live like this, I feel a great sadness it gives me little will to live the disease takes it all from me
	Uncertainty	I do not know what will become of me I do not know if I'm here tomorrow I see the future black
	Discouragement	I do not know, I am very discouraged ... I lost all hope I feel trapped and limited I have no desire for anything the disease takes me from myself I'm out of patience has been very difficult to accept all of this revolt me
	Suffering	I have a lot of pain, some days I cannot stand this sometimes I'm afraid to go to bed, because when I wake up I am worse, and afraid of tomorrow I have a lot of pain I'm afraid of suffering
	Hope	I always hope to improve, I hold some hope I see life in a positive way, I am an animated person hope is the last thing to die I take medication to relieve me, is the magic box I believe in tomorrow, with hope and faith I want to get better
	Will to learn	I learned to live with pain I was an active person now I cannot do nothing modifies the pace up, I feel very tired we must do tasks differently and one thing at a time, not to get tired
Impact of disease	Positive attitudes	who helps me and who understands me is my sister, it

on family dynamics		has the same disease that I my family knows what is wrong with me and helps me the family believes in me
	Negative attitudes	my husband does not understand me they think I'm feigned the persons say that I have a habit to complain of diseases
	Changes in family roles	is my husband who does the shopping .. is my daughter who helps so me, it is my right arm
Social role	Face to others	the persons do not realize that I have pains as they usually say ... you look well, you look so good

Table 3. 'How does illness affect your life?' (Categories and items - or units of analysis)

Social dimension	Social isolation	there are days that I do not want to see anyone, they knock on the door and I do not open I may not have patience for people I have no desire for anything I do not even feel like getting out of the house I do not have will to get dressed and leaving I isolate myself very much I feel very lonely there are times that I feel useless I do not leave home I feel lonely, I cannot explain
	Changes in many activities and leisure	I cannot commit myself to anything I cannot combine to go to any party I do not accept any invitation for fear of not being able to go
Physical dimension	Sleep disorders	I sleep very badly the pain will not let me sleep
	Pain	I have pain I need my hands to work... and I have pains I need my legs and feet to work... and I have pains I am desperate with pain it hurts the whole body
Psychological dimension	Anxiety	we have the nervous system changed depression is chronic I feel very nervous I feel anxious
	Body changes	is revolting, my body is different now I look at my body with sorrow my body does not respond to my head, my head does but the body does not
Disease management	Therapies	we have too much medication I take cortisone, relieves me and keeps me on my feet I have a need to know what they give me to take the medications bring many complications
	A need to talk to others	I like to talk to other patients when I'm in hospital talking with others helps me to better understand the disease
	A need to have support and comprehension	I accept the advice of health professionals I'm afraid to be operated doctors do not understand us it would be very important if the physicians could understand us

Table 4. 'How do you envisage death?' (Categories and items - or units of analysis)

Death	Acceptance/ Resignation	I do not care, I'm tired of suffering I do not mind that death come from the heart, I want her to come
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	No acceptance	I am not able to talk about death I want to live I do not want to accept the idea of dying I prefer to take the whole medication to prevent death
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5. Discussion

Rheumatic diseases, being chronic and degenerative, arouse negative perceptions of patients. The pain is always present, accompanied by great suffering. These diseases have an enormous emotional and social impact. However, some subjects show a good adaptation, but many showed great displeasure and concern.

Social changes caused by chronic disease are associated with not only the difficulties that people have in participating in social events, but also in the domain of work and stigmatization by society (e.g., Rolland, 1987, 2004). The participants show concern with the severity of disease, suffering and death, and so it is natural that reveal fear, insecurity, discouragement, distress or despair, but also have positive feelings of courage and hope.

Many are the feelings experienced by the subjects, from the tears and the fear, to changes observed in the body, which eventually reveals their physical limits and losses. The degradation of the body, persistent physical pain, the physical limits and losses, feed the person with a deep sense of sadness and fear (Phaneuf, 2002). The fear, as well as hope and uncertainty, are common emotions on the chronic patients (e.g., McNamara, 2001).

The uncertainty about the future, common among all of us, is increased with the presence of the disease, which in essence has unknown prognosis (Fleming, 1997). McNamara (2001) highlights the uncertainty as a process that begins with the lack of information about the disease and its causes, and is aggravated by the lack of knowledge about the therapeutic treatments and symptoms of worsening of the disease.

The subjects reported that the problems related to the disease are not limited only to themselves, but consider that the family is also affected by the disease, which leads to changes in everyday life - in the roles and functions performed within the family.

The disease and suffering may also be an opportunity and motivation to reorganize a new life, in which the patient could mobilize their personal capacities, family and social, to seek new ways of being in life (Guerra, 1998). The appearance of a disease can have a positive side, if the implied changes lead to a evolutionary character. What, with no doubt, will help to accept the disease and learn to live with it as part of their existence, and not as an obstacle in personal development (Hegelson, 1999).

It is important that each person understands the meaning of the experience of being ill, to herself, as this will help it to surpass herself and learn from the situation, regardless of the suffering and losses that the disease causes (e.g., Pio Abreu, 1997).

6. Conclusion

Living with a rheumatic disease is not easy, by the impacts and significant changes in each patient, affecting him at physical, psychological and social levels. All participants recognize the disease as incurable, associating it with suffering, loneliness and grief. Given the disease, subjects reveal negative feelings, such as fear and revolt, but also show capacity of adaptation and acceptance, with due support.

In this study we considered the experience of patients with rheumatic disease, what are their concerns as well as their feelings and emotions, the meanings of illness, and how they deal with their illness and also with death.

Faced with the disease, the subjects turn to themselves, analyze their feelings and frighten themselves with the reality that surrounds them. They show sadness and anger for the situation they live, and fear they cannot cope with the disease and the consequences of it in the future.

The patients feel worried about the impact of the disease on themselves, but they seek to have the strength, hope and faith to keep fighting. Sometimes they feel discouraged or distressed, given its condition and suffering. They may reveal intention to learn to live with their condition, but they all tend to ignore death. They believe in therapy, although they see it as excessive and with a temporary effect. The most important thing they consider is to be alive, hoping to get better.

Health professionals should pay attention on the needs of people and value them. Only then will better understand the problems and needs of patients, to guide and improve their practice, as regards, in particular, the planning of their intervention and care, helping them live with greater dignity, experiencing the day to day, with an awareness that everything we experience is important, giving value to life, without fearing death.

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