



Phoenix Project for Improving the Quality of Life in Rheumatic Diseases: Preliminary Results.

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Abstract

Rheumatic chronic diseases (RCD) are among the most common chronic non-communicable diseases. They are the leading cause of disability in developed countries, and consume a large amount of health and social resources.

The purpose of this preliminary study (PHOENIX PROJECT) was to evaluate changes in the quality of life of patients suffering from RCD followed by talks in Group Counseling for emotional support. Group Counseling talks for emotional support is a behavioural intervention to facilitate patients adopt and sustain their own health related goals. The Counseling Group talks have been divided into eight meetings for a period of four months according to the cycle of the Gestalt contact, each meeting lasted two hours. During the first and the last meeting it is given the self-assessment questionnaire SF-36, in order to make measurable the results obtained.

In patients there was a significant improvement in quality of life, without any change of the treatment set by the specialist; patients have expressed great satisfaction with the procedures of the meetings and for their given opportunity to express their emotional state linked to the basic chronic disease. Our preliminary study suggests that Group Counseling talks for emotional support could be extremely effective in patients with chronic rheumatic diseases.

Introduction

In our society there are many people having to cope with chronic illness, whether it is their own or a loved one's. It is a highly emotional impact event, which alters the balance of the person. Rheumatic chronic diseases (RCD) involve the body and the person as a whole: his feelings, his thoughts, his being with others, his own priorities. Daily life with RCD has been identified as a full of "uncertainly" relating to patients being uncertain about their own interpretations of their symptoms and whether they would be able to receive adequate help to master their disease and manage their everyday lives. Living with RCD in day to day life also means having to relate, over time, to an increasingly non-compliant body: a body with RCD does not move as desired. Several studies have been found that patients with rheumatic diseases have a significantly higher disability, higher prevalence of anxiety symptoms and they have been more often hospitalised and had more home support needs compared to persons without RCD. Comparison and sharing with people living similar experiences to their own is a very important resource [1].

In recent years there have been enormous developments in the treatment of rheumatic diseases: the advent of new synthetic and

biological DMARDs (Disease modifying antirheumatic drugs), the synthesis of different COX 2, the new vasodilators or the different SYSADOA (Symptomatic slow acting drugs for Osteoarthritis) [2]. Clinical results were exciting, but the downside was the exorbitant increase in health expenditure and side effects. The drug centered therapy made us slightly neglect the fundamental goal of every therapeutic intervention: improvement of the patient's life quality [3].

The patients' quality of life is severely reduced by chronic illness and emotional support through counseling techniques is a very effective approach for chronic diseases. Professional counseling is an activity whose goal is to improve the quality of life of clients, supporting their strengths and abilities for self-determination. Counseling provides a space for listening and reflection, in which clients may explore problems related to evolutionary processes, phase transitions, and states of crisis and strengthens the capacity of clients to choose or change. Counseling is an intervention that uses various methods borrowed from different theoretical orientations, it caters to individuals, families, groups, and institutions. Counseling can be provided in various settings such as private practice, education, health, business (AssoCounseling definition of counseling adopted in 2011). The purpose of this preliminary study (PHOENIX PROJECT) was to evaluate changes in the quality of life of patients suffering from RCD followed by talks in Group Counseling for emotional support.

This project is posed as a journey that sees its port in the enhancement of the person and their individuality, with their own way of reading what is happening, facing the difficulties, getting excited, thinking, projecting into the future. Of course, the main objective is to acquire information, new skills and insights in order to facilitate and support the patient's empowerment through a path of strengthening their personal resources and acceptance of their condition in the awareness that they are more than the disease, but our project would have also a significant impact on improving the quality of life both individually and socially.

Patients and Method

For our project 24 patients suffering from various rheumatic diseases (osteoarthritis, arthritis, fibromyalgia and inflammatory connective tissue) were invited. Patients were informed of the purpose of the study, of the treatment program organized and of the way in which the Counseling Group talks for emotional support would be carried out. All patients gave informed consent to participate in the study and to the treatment of personal data.

The Counseling Group talks have been divided into eight

meetings according to the cycle of the Gestalt contact, each meeting lasted two hours:

Phase 1 - pre-contact

Meeting 1: At this first meeting it was administered the SF-36 questionnaire to all participants (Figure 1), the same questionnaire used in other studies for evaluated health status [4]. Then the counselor has dealt with each other to present the patients for an activity of knowledge, every patient presented to others.

Meeting 2: During this second meeting, the theme of “disease impact” is addressed. The impact of the disease represents both an objective (change of everyday life, work, sexuality, joint deformation, pain), or as emotional (intra and extra family relationships, body image, realization of their expectations). In this meeting we wanted to highlight how patients live the “here and now” of their disease. The instrument used was that of photography. Through the choice of a photo they are recovered emotions related to the experience of illness. Each individual patient has then shared with the group his emotion and this has facilitated the recognition of their emotional world.

Phase 2 - initial contact

Meeting 3: This second stage startup to contact focused on intra and extra family communication processes. Through the use of role plays patients were able to experience the different stages of communication and especially the emotional state in different situations. It has explored the verbal and nonverbal communication, brief training on empathy, assertiveness, message transfer. Patients during the workshop were able to experience the pleasure of effective communication to be played in the daily reports.

Phase 3 - full contact

Meeting 4: This third phase began with a training of patient education, essential for patients with chronic diseases. Patient education means increasing its health literacy, implement compliance for therapeutic treatments, help keep a proper lifestyle and support them in times of acute illness. A good patient education is only possible thanks to a team work in which the patient is an active participant. A therapeutic education fundamental goal is to share the plan of care, involving the patient, the professionals and the family team; necessary for this purpose to succeed in creating a strong “therapeutic alliance”.

Meeting 5: In the fifth meeting we have addressed the issue of social support. We have focused on how the patient perceives his own body and the outside world. It emerged because patients have fear of judgment and stigma. They feel that others see them only as sick and not as people. During the meeting we have been used body techniques. The work focused on to bring to patients that they are

rich people to resources and opportunities, and the disease is only a part of their lives.

Meeting 6: The sixth meeting was focused entirely on personal resources and strategies. The focus was exclusively patient empowerment. Also in this meeting it is an art-therapy technique with paper and colors were used. Through the rediscovery of creativity will be the way to an internal process that leads a person into a state of awareness of the present moment. The use of color greatly reduces the stress connected to the experience of the disease by the patient recover the joy and the desire to try again even outside the protected environment one stretched positive emotion of serenity.

Phase 4 - post contact

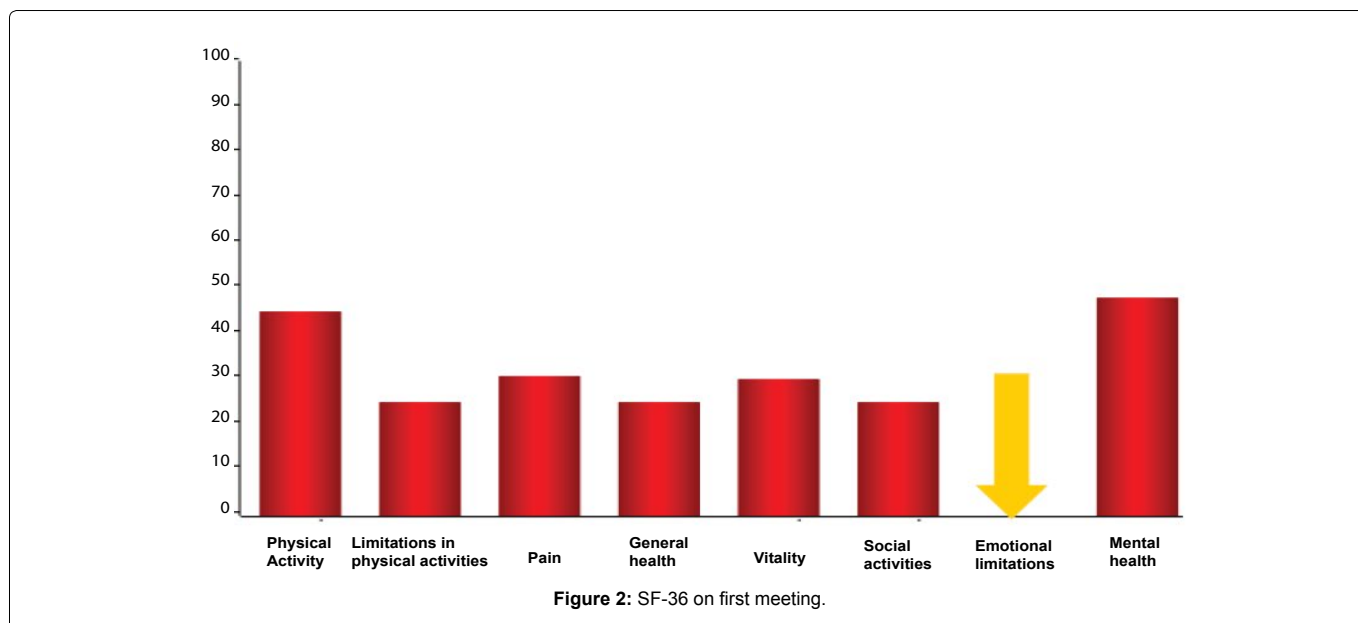
Meeting 7: In this seventh meeting he worked on starting the post-contact and the closure. It has made the point on what had been experienced in previous meetings and the importance of a successful conclusion of the route. All this in order to metabolize to patients than done. It was shared in groups from each individual patient what he would do in everyday life with what we learned during the meetings. Also in this phase the sharing and comparison have enriched the rose of possibility of every single person. It was precisely the strength and unity of the group had donated to individuals new opportunities for self-perception, acceptance of their disease and recognition as a person and not as sick.

Meeting 8: The meeting focused on the wishes of each individual patient to the group. Each chose their mode by creating a climate of full of emotions game. In the last part of the meeting patients have the SF-36 questionnaire filled in again. During the study period patients were asked not to change current treatment unless absolutely necessary, and on the rheumatologist of confidence’s advice.

Results

Out of the 24 patients enrolled, 18 patients completed the study. The project is divided into eight group meetings in which themes such as: Impact of disease; intra/extra familiar communication; Therapeutic adherence; social support; resources and strategies are discussed.

The techniques used during the eight meetings refer to the school of “Pluralistic Integrated Counseling” [5], each meeting lasts two hours, and the protocol used is structured according to the cycle of the Gestalt contact (pre-contact, initial contact, full contact, post-contact). During all the eight meetings artistic techniques and/or bodily techniques inspired by the art-therapy and theater-therapy were used to facilitate and enable the path of self-knowledge through expression and creativity.



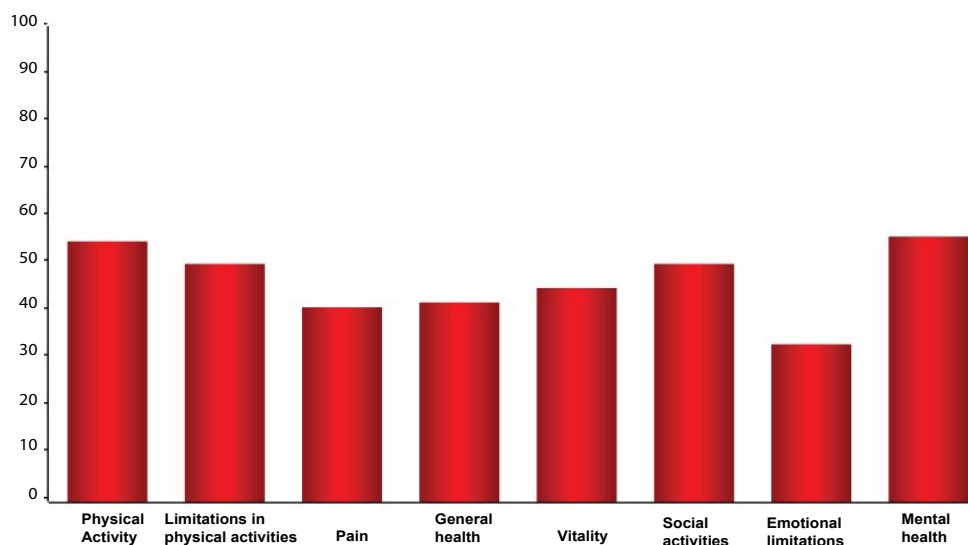


Figure 3: SF-36 after eight meeting.

In patients there was a significant improvement in quality of life, without any change of the treatment set by the specialist, as demonstrated by the statistically significant reduction in the SF-36 overall score (Figure 2 and Figure 3). The positive effect of the therapy on the “Emotional limitations” has produced a significant benefit on other areas evaluated with the SF-36 questionnaire, such as “Mental Health” and “Physical activity”. The results of this beneficial effects on physical and mental health has produced an important reduction on pain perception.

In particular there has been a notable improvement in item 1, 23-28 and 32. Patients have expressed great satisfaction with the procedures of the meetings and for their given opportunity to express their emotional state linked to the basic chronic disease.

Conclusions

Rheumatic chronic diseases are among the most common chronic non-communicable diseases. They are the leading cause of disability in developed countries, and consume a large amount of health and social resources [6]. The overall effect of RCD on individuals’ valued life activities appears to affect their psychological well-being. Loss of the ability to engage in recreational activities and social interactions in particular has been reported to significantly increase the risk of new onset depression. Several studies indicate that some rheumatic patients would benefit from patient education programs to ensure they are aware of when and how to seek help for their disease flares. Various self-management interventions have been developed to improve patients’ ability to cope with the complexity of symptoms related to CRD. There is a growing consensus that emotion regulation, in terms of acknowledging and dealing with negative emotions associated with chronic illness, can contribute to adjustment [7]. However, today few interventions explicitly address patients’ emotional response to their disease in clinical practice.

Some interventions that focus on the promotion of healthy habits include two essential aspects: complexity and use of health coaching. Health Coaching is a behavioural intervention to facilitate patients adopt and sustain their own health related goals, change attitudes, decrease attitudes, decrease unhealthy habits, improve the management of chronic diseases, generally increase health related quality of life and can improve treatment adherence in chronic patients [8]. Group Counseling talks for emotional support is a mode of Health Coaching and it uses the motivational talks between patients to improve patients’ health status and ameliorate therapeutic adherence.

In this pilot study, the Group Counseling talks for emotional support have proven extremely effective in patients with chronic

rheumatic diseases, with a significant improvement in quality of life and at very low cost as demonstrated to other groups [9]. Thanks to the path of counseling patients have learned useful techniques and information to deal with more awareness their disease state. Through the training of health literacy and patient education have learned more clearly the nature of their problem, the need for long-term therapy and the importance of sticking to the agreed directions, avoiding errors and variations of the route. The patients have experienced since the condition of health literacy has a negative impact on their life also as induction factor of a state of anxiety and, to a lesser extent, of depression. To reduce the anxiety caused by a low level of health literacy, the best investment was to boost alternative communication strategies and management of care pathways.

Patients have improved their use and access to screening and preventive services and have increased their level of adherence to the requirements. Moreover, their emotional state has changed significantly increasing the desire to be in relationship. Similar results have been found in other researchers groups; in fact Cognitive Behavioural Therapies are growing in application within health care systems. In fact these therapies have been positive in the reduction of depression, helplessness, fatigue and enhanced the use of active coping strategies. Acquire the skills needed to take care of yourself is an act of great responsibility that allows the individual to move from the diseased condition to that of someone with a disease.

Through these instruments it is improved in patients perception of self-efficacy and health conditions. This is currently the only way to significantly reduce the costs of the health service.

It will be very useful a study with a greater number of patients divided by groups of pathologies in order to assess the effectiveness of the Group Counseling in different rheumatic diseases. It would be interesting to deepen and also to evaluate the variable linked to the compliance of the subjects, since the path of the eight meetings provides an internal training of health literacy and patient education that have considerable repercussion on the therapeutic adherence and the containment of health care costs.

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