THE PSYCHOSOCIAL CARE OF THE RHEUMATIC PATIENT

Pirkko Kiviniemi*

1. Wakening interest in psychosocial aspects
The comprehensive, somato-psychosocial approach in diagnosing and treatment of the rheumatic diseases has its roots in the history of mankind. Every culture and nation have their traditions and beliefs. Ethnologists and historians could tell us about old habits, rituals and healing methods which show us that the comprehensive approach in the treatment process is very old. We have only forgotten or perhaps neglected during the fast industrial and technical progresses these immaterial characteristics of human life. We have, however, always had openminded persons who have on the one hand admitted that intelligence and technical skills are important factors in human life, but on the other hand they have emphasized the value of emotions, the person's historical background and his living conditions in creating a mature, integrated and balanced life style.

In rheumatology we have also had authors who have seen the importance of psychosocial factors in the rheumatic diseases. The first authors examined the problem from the etiological point of view. They tried to find psychosocial factors contributing to the onset of the disease such as emotional shocks and persistent emotional or social stress. Over the years, increasing attention has been devoted also to the sick person's experiences and his/her environment as well as to the psychosocial approach in therapy.

2. Clinical situation and psychosocial factors
The most prominent clinical characteristics of rheumatic diseases, restricted movement and reduced physical strength form a natural basis for emotional reactions to the disease. They alone may cause restrictions and conflicts in human relations and, because they foster dependence, the passive sick role becomes easily the patient's predominant behaviour pattern. This very practical approach in examining the psychosocial factors in rheumatic diseases forms a promising point of departure for many research hypotheses. It motivates us to make research which can be easily applied for treatment purposes. In addition, it creates a com-

* Rheumatism Foundation Hospital, 18120 HEINOLA 12, Finland
prehensive connection between experienced symptoms and emotional reactions to the disease.

On the basis of the clinical experience and before the scientific verification, I dare make the following conclusions about connection between the experienced symptoms and emotional reactions to them (Fig. 1): Pains, tiredness and the decreasing of energy cause easily anxiousness and depression in the minds of the patients. The patient becomes also emotionally vulnerable and very self-conscious. Swollenness on joints, clumsiness and the experienced ugliness, may strengthen these reactions. He feels that the circle of life is getting smaller and the tempo of living slower. He fears that the doors to the outside would be closed to him partly because of his limited functional ability and partly on the basis of his changed appearance.

Interruptions in the normal working (Fig. 2) because of the treatment periods and the weakening of working ability caused by the disease increase anxiousness and depression. In addition, the patient can hardly help feeling insecure, inferior and different when comparing his abilities with those of the healthy people and with his/her own capacities before the illness. Isolation is a very understandable behaviour pattern in the situation like this.

Besides the psychic stability and self-confidence there are two more psychic factors which are deeply involved in the disease situation. The diffuseness in diagnosing and the unpredictability as well as the chronicity of the illness rise the demand of high energy consumption and that of flexibility in long-lasting and variating situations. The balanced use of energy and sensibility and elasticity in handling frustrations are very helpful skills during the long disease process. The only problem is that people often loose the balance and flexibility in difficulties. In addition we must always remember that our living conditions, the environment we live in, give the basis and the frames for our skills and possibilities to solve the arisen problems.

3. Critical remarks on the treatment connected research

The fifty years research work performed thus far has also given us new ideas. It has indicated the direction we can follow in future studies. It has given us applicable knowledge for practice. I think we have perhaps criticised too much the earlier work. We should try to evaluate positively the findings we already have. We should also make trials (of) for application. The physicians in the late thirties and in the early forties2,3,6,7,11,26) used observation in the treatment situation as a research method (Fig. 3). They tried to define the psychic diagnosis of the rheumatic diseases. As the theoretical basis they used psychoanalysis, anthropology and psychosomatics. The results have been collected using observation, interviews, and the description of individual cases and that of the small groups as a research methods. We have accepted the main results revealed by these studies nearly as a fact and often as a point of departure of our own research work: the constriction and control of emotions, conscientiousness and sensitivity to other people's expectations. We know, however, that the reliability of these studies is at least questionable in the modern sense of the statistical significance. In every case, these research results are
practical and easy to take into consideration in the treatment situation.

The aim of the statistical studies (Fig. 4), started in the late forties, has been diagnosing different disease group. As the basis of their studies the authors have used trait theory and factor analysis. The results can be regarded as statistically significant. The practical value of the studies of this research area could be greater than it now is considering the great number of the studies performed.

Clinicians who use projective tests and statistical methods (Fig. 5) together have also tried to define the psychic diagnosis of the rheumatic patients. Their work has been partly based on psychoanalysis, partly on testing methods used in different studies. These results have revealed the blocking in the use of the psychic energy and in social relationships among rheumatic patients. The result may be regarded as statistically significant and they could also be quite valuable in practical treatment situation.

Modern psychological research of the somatic diseases is widened to different areas (Fig. 6). The scientists are interested in diagnosing, treatment situation, progression of the disease as well as in the etiological factors of rheumatic diseases. Theoretical basis has regained its importance, methodological approach is sounder and wider than it has been during the last 30 years. The comprehensive view in scientific approaches has been reaccepted.

The research results of today do not give very much new information, but the greater reliability of the studies and the wider interest in psychological aspects of the disease among the different specialities seems to make it possible to form steadier theories and to perform more valuable as well as more applicable psychological research from this on.

4. Social environment and the rheumatic patient

Only a few studies have been carried out on the environment of the rheumatic patient from the time before the onset of arthritic symptoms and during the course of the disease process. It has been suggested that rheumatic patients come from heavy working groups with low incomes and a low level of education, and that this socioeconomic background is common to all the rheumatic disorders, including rheumatoid arthritis.

Whilst it is easy to understand that the frequency of arthrosis and soft-tissue rheumatism increases when the working conditions get worse, it is difficult to believe, so far as inflammatory arthritis is concerned, that the nature of the work as such could provoke the disease. It could well be that the apparent relationship is due to a sampling error resulting from a different pattern of use of private and medical services by people from different socioeconomic groups and differences in availability of services.

Some writers have suggested that there is a connection between arthritis and unsatisfactory housing conditions. There are also data which suggest that the frequency of divorce is greater among arthritics than it is in the normal population.

Unfortunately, up until now all the research carried out on social factors in rheumatic diseases has been fragmentary and without a clear theoretical background.
We are still asking: “Does the socio-economic status of the family have an effect on rheumatism and, if it does, what is that effect?”

5. The atmosphere of the ‘rheuma family’

Research workers have been more interested in the interaction between family members and in the tension caused by the discrepancy in social background factors than in pure social facts. Halliday commented on the arthritic female’s sacrificing conscientious way of looking after disabled relatives. Booth, on the other hand, stated that rheumatoid arthritis patients could sacrifice themselves for their family but that charity was pursued to avoid moral criticism and accusations. As a matter of fact, sacrificing behaviour is a sign of dependence. Johnson et al. agreed with the earlier writers’ dependence theory. They added to the image of the rheumatoid arthritic woman the tendency to domination and to masculine protest reaction. Booth, on the other hand, had reported earlier that rheumatoid arthritis patients were unwilling partners in the sexual act, and Halliday had reported that rheumatoid arthritic women were sexually frigid.

According to later research workers, characteristic features of the rheumatoid arthritis family were indirect expression of emotions, especially that of negative ones, and tension between family members. Aggression felt against the spouse was directed at the children. Communication between family members was artificial and poor. It was suggested that tension within the family was caused by the discrepancy in the status of the parents or spouses. Vague identity, a tendency to dependence and other peoples’ expectations might also be reasons for tension in human relationships within the family.

Research work dealing with the emotional climate of the rheumatic patient is methodologically sounder than that on socio-economic factors affecting the ‘rheuma family’, and the results obtained so far provide a useful basis for future research and for treatment development.

6. Age, family and disease

One reasonable way to examine the problem is to use age as a link between the family situation and disease: the disease means different things in different ages and the family means different things in different ages (Fig. 9). This fact is very important in planning the treatment system.

The childhood

In childhood, joint disease may mean limited possibilities to the diseased child: (a) in playing with other children because of the functional disability, (b) in trying different role models because of the isolation resulting from the disease, hospital care, and overprotection, and (c) in testing independently his or her limits and possibilities in building one’s identity.

The parents want to protect the child, to take care of him and to make life for him as easy as possible. They may be ashamed that they have a crippled child, and deep down in their minds may be a desire to reject the abnormal offspring. At the same time, they may have
strong feelings of guilt. The brothers and sisters may be jealous and feel neglected if they do not understand why one of them has privileges.

<The youth>
Diffusion, questioning, striving and insecurity of the youth make the diseased young person very vulnerable. His developing independence is threatened by many things. The dependence on parents may last longer than normal. The hospital care may break contacts with classmates and other friends. The disease makes the young person different, perhaps abnormal; the functional disability makes him weak.

There is a danger that the young person's growth to an adult person with full responsibilities for work, family and society is stopped. He continues living in the shelter of the childhood home, seeking support from medication, medical staff and trivial time-consuming things. As a person and as a representative of his sex he remains immature. Within the family, there is a risk of an emotional explosion, but the blocked or indirect communication hampers open discussion and clarification of the situation.

<The adult>
Adulthood (Fig.10) is the time of activity, responsibilities, psychic, sexual and somatic maturity and parenthood. The diseased young person feels that he did not gain what he wanted, but the adult person may consider that he has lost everything in the midst of the active striving. The loss experience takes hold of the whole life. Feelings of insecurity and anxiety come first: "I shall lose my job, my status. I am no longer capable of taking care of my family. I must be sexually unattractive. I feel impotent. I am no longer an acceptable model for identification for my children. Is there any use going to see a doctor? Can anybody cure this illness?" The fears and questions go round in the heads of the spouses.

In the first place, facing up to the disease means adaptation and seeking medical help. After that come the problems of money, housing conditions, technical aids, occupation, etc. The task of the family is to support the patient in clarifying the situation. Every member of the family can take care of his share of the tasks and responsibilities and can make everything easier for everybody.

<The aged>
The disease is, in a way, a natural characteristic of old age. However, a crippling disease such as rheumatism does not inevitably belong to the latter years of life. When it occurs there is a danger that helplessness, insecurity and loneliness increase and begin to dominate the whole life situation of the old person. The need for active help becomes greater. Expectations directed both at society and at the family are seldom expressed openly by the aged.

In many countries, the social services are quite satisfactorily organized but the patient's own family and the nearest neighbours are still the most important support for the old. Vigilance, tactfulness and patience are necessary when people act for the benefit of their old relative or for other aged persons living in their neighbourhood.

7. Summary of findings and experience essential to creating a psychosocial therapeutic model
As the basis for the psychosocial therapeutic model of the rheumatic patient presented here are
1. Conclusions based on the clinical experience
2. Information collected from studies concerning the psyche of the rheumatic patient
3. The results from social studies
4. General theory of the sick role

Clinical experience indicates that pain-connected anxiousness, depression and vulnerability of self-confidence are the most prominent emotional reactions in the disease situation. During the illness process the need for psychic elasticity and that for balanced use of energy joint to the essential psychological factors of the rheu-
Main therapy-related research findings of the psychological studies are characterized by tension, insecurity and difficulties in open, relaxed social relationships.

There are findings2-7,11-14,18,19) telling about constriction, emotional reactions, social isolation and insecurity, neurotic reactions, anxiety, resistance to change, blockage in close personal relations and difficulty in expression of emotions. (Fig. 11 and 12).

There are also results (Fig. 13) which tell about a diffuse, neurotic, blocked and stony anxiety and conflicts characterizing the patient's emotional life3,15,24). These conflicts exist between the need for autonomy and for dependence, between seclusion and sociability, and between the need to be submissive and experiencing the nurturing as a pressure.

Available information is not nearly sufficient for the research worker to ascertain with any certainty the original basis on which these reaction patterns rest. It does seem logical to assume, however, that the disease itself has had a contributory effect towards the reinforcement of these features. The experience of loss brought on by the illness—and especially the helplessness and ebbing of strength that accompanies rheumatoid arthritis—together with the new and strange situation that the disease brings with it, produce anxiety, dependence and perhaps also an emphasized need for autonomy.

8. Sick role—rehabilitee role development

Documented in all the results mentioned above are the components of the sick role described by Parsons22), prominent among which are the passive acceptance of help and liberation from social obligations. In a chronic illness the sick role is gradually transformed into the disabled role. The question of the disabled role alone provokes uncertainty, calling up, as it often does, the need for forming a new identity. All of these various factors bearing on the sick person causes her/his behaviour patterns and her attitudes to become conflicted and tense.

In Figs. 14 and 15 can be a schema, drafted by Kasl and Cobb (1964)23), of the unfoldment of the sick role through the different phases of disease. The identity and role performance schemas have also drawn on data that are part of Gordon's8) disability concept. The important point in this combined pattern of thought is the function and influence of the sick role in different types and phases of illness. If the illness is brief, the sick role implies seeking help and ends with recovery. If the illness is chronic, the sick role may become permanent, with the result that regression may take place in the individual's personality, and his chances for an independent adult life might be reduced.

When the disease threatens to become chronic, the central role becomes that of the rehabilitee (Figs. 16 and 17), a role studied in Finland by Rantalaiho23). This investigator's views conformed with those of Goffman and Gogswell. Vital to the successful adoption of the rehabilitee role is that the patient's own activity and participation will be continually expanded, so that her/his need to accept help is reduced and her own contribution to the implementation of different measures is correspondingly increased.

The rehabilitee role is one that undergoes transformation. Important phases are (1) the meeting and handling of the disease process and situation itself; (2) the open encounter and recognition of the disability and incapacity; (3) the minimization of the stigma attached to the disability, i.e. of "spoiled identity", so that the labelling resulting from the disability cannot gain the upper hand over the individual herself or over her environment.

Beginning this process of transformation and the persisting in it requires readiness on the part of both the rehabilitating individual and his environment. Training and learning are essential, so that the traumatized and diseased person can start to rehearse his new role. Gradually he learns to integrate his new identity
with his other roles and to relate it to reality, without either exaggerating or belittling the importance of the stigma.

9. Therapy process

If the above-mentioned results of research as well as the general laws that govern psychic behaviour and role formation in disease are to be taken into account, then the approach of therapy must be all-inclusive. A possible course that the therapeutic process might take is outlined in Figs 18, 19, 20. Basic to my thinking about disease, and therefore taken into consideration in the planning of this course of therapy, is the joint effect of soma, psyche and social factors. It is difficult to think that, in chronic illness, successful long-term therapeutic results could possibly be achieved without such an all-inclusive view.

Whether it is a question of the somatic, the psychic or the social sector, the first and most important step must be the establishment of a therapeutic relationship. That such a relationship is important to the rheumatic patient is evidenced by findings that the patients were more anxious, had a neurotic need for achievement and were blocked in their emotional expressivity. These are the reactions that point to insecurity. The value of the therapeutic relationship is further increased by the opportunity it offers for an alleviation of the uncertainty and helplessness associated with the disease itself. This therapeutic relationship must be safe, honest and open, so that reciprocal communication is possible on a horizontal level, and not just from the higher (professional) to the lower (patient) level.

Laying the groundwork for practical therapeutic measures, i.e. offering the patient appropriate information, is just as important as establishing the therapeutic relationship. Patient education today does not deal effectively with the problems of eliminating uncertainty and clarifying identity. Once the sick person is given adequate information about her/his illness, and about herself and her possibilities, she will be better able to organize her own new self-image and new role. She will know how to define her goals and will become familiar with her own limitations and capabilities.

However, simply passing out information is no more effective in patient education or therapeutic work than it is in any other type of education and counselling. Information must be organized to be useful, and the patient must learn how to use it profitably. Feedback, and the reinforcement of knowledge and skills that have been learned are an important part of therapy whether medical, physical, surgical or psychological. The same basic principles underlie all forms of treatment. The

![Diagram](attachment:image.png)

Fig. 15 Role development 2.

1. GIVING A NAME TO THE DISEASE

Initial depression

2. ACCEPTANCE OF THE SITUATION

Initial depression

Adaptation

Denial

of the sick rehablee roles

Fig. 16 Two extreme models of acting during the rehabilitation process

3. ACTING IN THE SICK, REHABILITEE ROLES

Minimizing the stigma

The acceleration of stigma

of independence

of denial

4. CONCEPT OF ONE'S SELF AS AN INDIVIDUAL

Positive

Negative diffuse

Integrated

Static

Flexible

Restrained

Fig. 17 Rehabilitation process

various forms merely employ different techniques and differently worded concepts, but always inherent in long-term therapy itself is the process of learning.

In the treatment of a chronically ill patient the objective is optimization not only of physical capacities, but also of psychic functioning and of autonomy. Such an objective can obviously only be attained through lengthy training and maturation. To avert anxiety and insecurity in the initial phases of treatment it is
important that the patient has somebody whom she is able to take recourse with and whom she can trust to be always prepared to give help. Patients differ widely in their dependence and in their need for help. For some, a child-like dependence may last long. Such dependence should not be forcibly severed, but rather the patient should be given a chance to attain independence at her own pace. When she is ready she will assume responsibility on her own initiative, provided she has not been guided authoritatively or indifferently.

Even at more advanced stages of her illness, the chronically ill patient will not be able to manage without some expert support. She can, however, learn to judge when she needs the help of professionals and when she is able to manage on her own. Once such a realistic autonomy has been achieved, therapy can be regarded as having been successful and the likelihood of the person becoming a serious invalid, averted.

The tools of therapeutic process include not only the therapeutic contact, and the various methods by which information and education are dispensed, but also an expanded social interaction, which can be achieved by making the environment less hostile to the disabled, either individually or through community planning.

Social interaction can be also encouraged and guided through the use of various types of group-therapy and role playing, settings which offer the patient an opportunity to try herself out and to thereby learn to know her limitations and capabilities and to find a reasonable balance between dependence and independence. This "realistic autonomy" is the goal of the psychologically oriented therapeutic model.

The goal presented here is not very easily gained. The health professionals need (Fig. 21) more education in team work and in understanding the psychosocial aspects of the disease. We need also well organized plans for patient education that the patient could learn the responsibilities needed in rehabilitation and when he lives as a disabled person.

10. Therapy process in action

In the following I have a few suggestions for a behaviour model in treatment situations. They all have been useful in practice.

1. At the beginning of the disease and later during critical phases of the disease the patient has to face many difficulties and frustrations (Fig. 22). The coping process is often long and inconsistent. Both the helper and the client need a lot of patience and flexibility that they were able to meet the fluctuations in the illness process and in the conditions of life. Even accepting one swollen joint as an organized part of one's body may take time for months. We can only imagine what is needed in facing all other changes of life caused by the disease.

2. The helping people, also the professionals, are often full of good advice. Trusting in their own competence they may be blind to see things from the patient's point of view. The means for solving this problem is empathy, in other words the readiness to listen to other people and the ability to hear what they really say. Also the disabled person has right and obligation to make his own decisions and to go his own way. The professionals' task is to help the patient to see what he wants, how he can get it and how the patient's desires are interrelated with the surrounding reality and with the patient's resources.

3. In case of severe disability (Fig. 23) patience and cleverness are needed for solving all problems in transport, ADL, working conditions etc. Winning the prejudices among family members, neighbours and in the public opinion takes time and energy as well as this fight tries one's self confidence.

4. During difficult phases the patient may experience
his life as a hopeless, black reality. He loses his energy and his capability to be active in the midst of mourning, anxiety, insecurity and self pity. In the situation like this the helper needs maturity and capability to empathy that he could see the crucial points and were able to offer sensible and effective keys to the patients for their solving the problems. The helper should also be properly active when supporting the patient, not too much pushing or too little distant and passive.

REFERENCES


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