

ORIGINAL ARTICLES

Factors influencing the quality of life of people with rheumatic disease

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Abstract

Aim

Several factors affect everyday life of people with chronic rheumatic illness. A systematic study has been conducted to investigate the most severe problems aggravating the quality of life of these patients, and the role of support and assistance from their family members/acquaintances. An analysis of the characteristics of economic situation influencing everyday life of a risk group of the Estonian society is also presented.

Methods

A national sociological survey called 'Chronic Rheumatic Patients 2006' was carried out by the Rheumatic Association of Tallinn with support from the Ministry of Social Affairs of Estonia. Data were collected from 808 respondents using a questionnaire. The quality of life data was analyzed and compared to results of the population survey 'Estonia 2008'.

Results

The respondents indicated their state of health and shortage of money as their most severe problems, followed by dysfunctional family relations, poor living conditions, etc. The problems were more severe for those who lived alone and had been coping with illness for over 10 years. In most cases, occasional assistance was received from family members or acquaintances to cope with daily life. On an average, every tenth respondent did not have anyone to turn to for assistance. The respondents have also reported the lack of sufficient information on the nature of the illness, effect of medication, options for obtaining assistive devices and rehabilitation.

Conclusion

Need for attention during the initial period of the development of the illness and to increase awareness in the society to provide better conditions for the affected are highlighted based on the results.

Introduction

It is well known that elderly people face different health problems with the advancing age. It has been estimated by Mudege and Ezech that only 14% of those above 65 years are free from chronic illnesses.¹ The World Health Organization's mandate to promote health globally includes improving the well-being of those living with chronic conditions.² The 'Eurobarometer 2007' survey revealed that Estonian citizens, on an average, perceive considerably more discrimination based on disability and age than others in Europe.³ These two

aspects, chronic rheumatic disease and discrimination, usually occur together in elderly people of Estonia.

A society is as strong as its weakest link. In order to improve the situation of the elderly who form the weakest link, attitude towards them in the society needs to be changed. An important step in this direction is collection and dissemination of specific knowledge about the situation of chronic rheumatic patients. Previous studies on chronic rheumatic patients have confirmed that chronic illnesses influence all aspects of the life of

patients – they suffer great losses in the areas of work, material security, family life, and in the psychosocial sphere.⁴ As a consequence, the prevalence rate of depression in these patients is approximately 20%, while that of general population is about 5-9% for women and 2-3% for men.⁵ Depression and physical consequences of the disease influence the quality of life of rheumatic patients since they are confronted with pain, fatigue, stiffness, functional limitations of mobility, and problems with daily living activities. In addition, people with chronic rheumatic disease often express concern, fear, and insecurity about their future.^{6, 7} The present study aims to analyze the characteristics of health of long-term patients with rheumatic illness in Estonia, factors influencing their health, and their coping with the illness and activities of everyday life. Additional objectives include the effect of hardships of life on the development of stress and psychological tension, and identify the support rheumatic patients receive from family members and acquaintances to cope with their daily life.

Materials and Methods

The data collected in two national surveys have been analyzed. The first 'Chronic Rheumatic Patients 2006 (CRP-2006)' survey was carried out in cooperation with the Rheumatism Association of Tallinn and the Ministry of Social Affairs in 2006.⁸ In this study people suffering from rheumatic disorders in different Estonian towns were questioned on their quality of life, economic status, and assistance being received. Respondents were chosen for the study on the basis of being diagnosed by their clinicians. During this survey, 1450 questionnaires were distributed to chronic rheumatic patients in health centres and hospitals in various regions of Estonia. The quality of life of people with chronic rheumatic illness has been compared with that of general population using the data from 'Estonia 2008' population survey. This survey covering the entire Estonia was carried out by the sociologists of the Institute of International and Social Studies of Tallinn University (TU IISS) in 2008. As a part of this survey, 1541 respondents in the age group 16-69 were questioned.

Results

Eight hundred and eight questionnaires received from respondents of CRP-2006 survey yielded a response rate of 56%. Among the respondents, a majority were women (87%) and chronic illness was a characteristic of the retirement age (> 56 y) (65%) rather than younger years (< 46 y) (20%). Every third of the respondent was working, including 8% of those who were in retirement

age. Majority of the respondents had a long history of rheumatic disorders, at least 5 to 10 years, and every second respondent had the disease for more than 10 years. In the present study, 'coping with the illness' has been interpreted as a state of well-being and the reasons preventing the respondents' well-being have been analyzed. The feeling of well-being can be measured using several indicators. A Finnish sociologist Erik Allardt has distinguished three components of the notion of well-being: living standard, economic coping (*Having*); social relations, assistance from the family (*Loving*); and physical condition, health state (*Being*).⁹ Results of the survey on each of these factors are summarized in the following paragraphs.

Economic situation

On an average, 29% of the respondents reported poor economic conditions. According to them, all of their income was spent on food and housing, or it was not sufficient for food alone. It may be presupposed that strong economic stress affects various aspects of life of patients with rheumatism, and they may have to forego some of the comforts to accommodate for their essential requirements. An overview of restrictions they had to impose upon themselves, as represented by respondents' answers to the question: "What have you had to give up due to economic reasons within last 12 months?" is given in table 1. The options provided for response were 'often', 'sometimes' and 'never'. Comparison of the responses 'often' and 'sometimes' has been taken up in the present study.

The mean percentage of restrictions by the respondents with rheumatism was higher in all areas (Table 1), compared to Estonian population. The data confirms that due to economic reasons, the respondents had problems even to meet the needs of daily life, e.g. eating what they would like to eat. It was shocking to note that more than half of the respondents, for whom receiving medication was vital, had to *often* or *sometimes* give up medication. One in five patients with chronic rheumatic illness reports loneliness as an essential difficulty of personal life. It would be necessary for them to socialize with friends and acquaintances. Unfortunately, sometimes they had to give up receiving friends or visiting relatives/friends due to economic reasons. There were also material limitations to pursue their cultural interests, since many of them had to give up going to the theatre and cinema, buying books, and subscribing to newspapers and magazines. However, these were not the only restrictions. Besides medication, people with rheumatism also require rehabilitation and expensive, assistive devices.

Table 1: Activities given up by chronic rheumatic patients within the past one year due to economic reasons (responses *often* or *sometimes*)

Activity	People with chronic rheumatic disorders* (%)	Estonian population* (%)
Buying some necessary foodstuffs	60	48
Going to the theatre and cinema	73	62
Buying books, subscribing to newspapers and magazines	80	68
Receiving guests	63	46
Visiting relatives/friends	76	66
Buying medication	59	40

Sources: *Survey of chronic rheumatic patients 2006

#Population survey 'Estonia 2008', TU IISS

The assessments of the accessibility of treatment are also critical and are shown in table 2. Around 40% of the respondents considered the opportunity to get an appointment with a specialist as *good*, whereas only 15% considered the accessibility of rehabilitation as *good*. When expensive treatment opportunities were considered, the accessibility of treatment was often considered *poor*. On the whole, 40% of the respondents assessed their financial resources available for buying medication as *poor*. A majority of people with rheumatism lacked funds for rehabilitation.

Social relation

Hardships of life cause tensions, which in turn aggravate daily problems. In order to understand these aspects, respondents were asked whether social support can alleviate the stress level, i.e. whether social support can act as a buffer during stressful situations and contribute to the feeling of well-being, in spite of the presence of stressors. Chronic rheumatic patients experience many problems to cope with life, and support from the society is not always sufficient. The present study also investigates the extent of support/help the rheumatic patients received from their families, including the younger generation and parents, relatives, and friends.

The responses reveal that children and relatives/acquaintances help the patients to a considerable extent. In most cases, children support the patients in emotionally difficult situations by listening to their worries, and help them in practical activities like renovation, construction, transport, etc. To a smaller extent, assistance has been provided in household work such as cooking, laundry, etc. Other

relatives and friends provide assistance less frequently compared to children. However, some questions do arise, despite providing the rheumatic patients with benevolent and supportive atmosphere. Firstly, it appears that support is provided, mostly occasionally, but not continuously. For example, only 4% of the respondents have continuously received material assistance from their children, and 20% of them received it occasionally. In case of assistance in household tasks, the respective ratios were 18% and 28%. Unfortunately, 29% of the respondents lived alone.

Secondly, asking for help may be stressful for a person with chronic rheumatic disease, even when help is sought from family members including children. This is more pronounced when the person asking for help has experienced humiliation or unfriendly attitude on an earlier occasion. Therefore, chronic rheumatic patients try not to show their helplessness, do not wish to be a burden for children, and wish to cope with their life as independently as possible. Thirdly, it is apparent that chronic rheumatic patients experience financial hardships. In spite of this, 63 - 67% of the subjects claimed that they had not asked for financial assistance from their children or relatives and acquaintances. In some families, there could be problems helping chronic rheumatic patients because it takes much time, dedication, understanding and patience on a daily basis. The reason may also be that their dignity does not allow them to solicit help, or they try to do so only in an emergency.

Fourthly, it is evident from the survey that primarily those living alone do not have any one to assist them. In the present study, every sixth to eighth patient living alone

Table 2: Assessment of accessibility of treatment and resources

Resource	Accessibility* (%)			Total (%)
	Poor	Average	Good	
Appointment with a specialist	23	37	40	100
Financial resources for buying medication	40	44	16	100
Rehabilitation	55	30	15	100
Material resources for receiving rehabilitation	65	25	10	100

Sources: *Survey of chronic rheumatic patients 2006

referred to this lack of assistance with household chores and emotional support. Other authors have also referred to the lack of assistance and patients with chronic rheumatic disease for at least five years essentially need help with their daily activities such as housework, laundry, gardening, and doctor visits. Although most patients received such assistance, 24% of the respondents did not receive help with one chore or the other.⁷ The support received was also not necessarily positive at all times. In order to differentiate 'problematic support' from positive support, even the term 'double-edged sword' has been applied in literature.¹⁰ Previous studies have also provided data proving that critical remarks from their spouses may cause stress in chronic rheumatic patients.¹¹ The authors have asked patients and their spouses to assess the functional ability and pain level of the patient separately. The assessments diverged considerably from each other, and both maximization and minimization of the illness had a negative influence on the patients. Maximization led to negative consequences, such as increased dependency, lowered competence, and greater depression. Minimizing the seriousness of the situation may give the patient an impression of not being taken seriously, and if the spouse makes critical remarks, it may also have a negative effect on the health of the patient.¹²

Researchers point to an extremely important connection: social support at the initial stage of the illness has an effect on the occurrence of functional disability and pain in 3-5 years time, i.e. a higher level of support at the initial stage of the illness predicts its progression in the longer term in a positive way.¹³

Children do help their parents often, but briefly and superficially. This does not provide any improvement with the situation of patients, especially with their feeling of

psychological well-being. Children are healthier and have their own life and interests, and that is probably why they do not always understand the needs of elderly sick persons. Taking into account the results of other studies, it has to be emphasized that the fact that they need assistance from the family is already stressful for chronic rheumatic patients. In addition, there exist data proving that people with little assistance from the family display twice the stress levels as those with better support from their family.¹⁴

Physical condition

Health situation of the patients has been assessed using a 2-point scale. The level of satisfaction was described on a scale such that one end marks complete satisfaction and complete dissatisfaction on the other. Options were *totally satisfied* and *mainly satisfied* on one end, and *mainly not* and *not at all satisfied* on the other. A huge contrast between the two populations has been observed, in that only 29% of respondents were satisfied with their health among chronic rheumatic patients - several times lower than that of general population of Estonia (71%).¹⁵

In order to better characterize their health situation, the respondents were asked to report the prevalence of certain medical disorders, i.e. in the recent past, how often they have suffered from headache, (over) exhaustion, sleep disorders, depression, indigestion, irritation, heart problems, etc. Health disorders and their prevalence (Table 3) indicate that the incidence was higher for rheumatic patients than general population. It has been noted that 60% of chronic rheumatic patients suffered from frequent sleeping problems and (over) exhaustion. Many of them also suffered headache (45%) and heart problems (40%). One in three patients suffered from irritation, depression, and indigestion. Corresponding

Table 3: Frequency of health problems (responses almost every day or 1-2 days in a week)

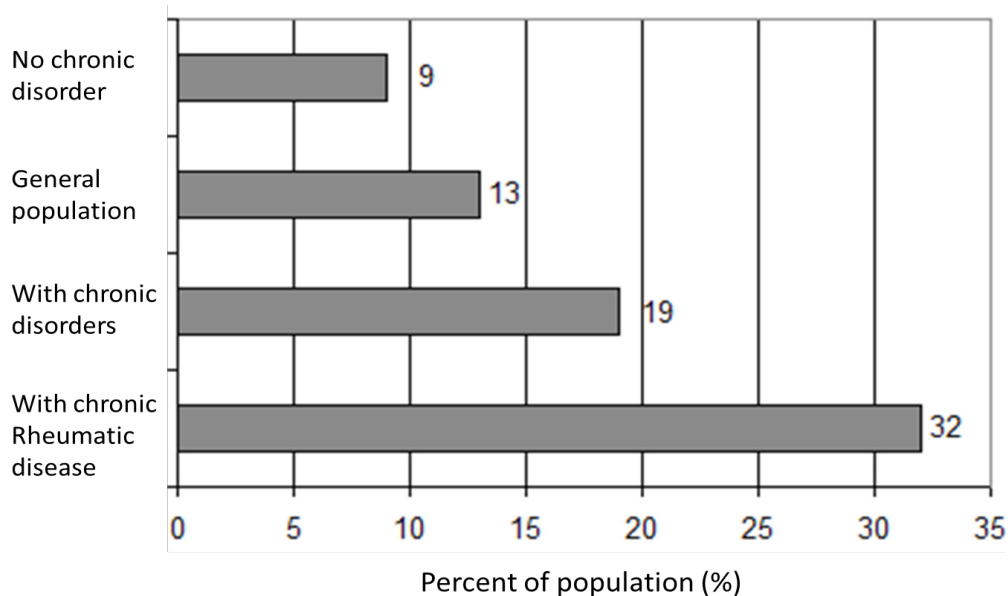
Health problems	People with chronic rheumatic disorders* (%)	Estonian population* (%)
(Over) exhaustion	63	44
Sleep disorders	60	33
Headache	45	23
Heart problems	40	11
Depression	33	25
Stomach ache, indigestion	35	13
Irritation	39	36
Dizziness	28	10

percentages for the general population were considerably smaller for all these symptoms, as shown in table 3. Another important aspect the present study has revealed is the manifestation of accumulated stress as symptoms in chronic rheumatic patients. A strong correlation was observed between the responses indicative of mental stress and the probability for frequent headaches, sleep disorders, agitation, fatigue, heart complaints, and depression.

The inter-relationship between coping with ill-health and the challenges of life is also illustrated by the responses. Although problems of life do exist for many people in

Estonia, their level of difficulty depends, to a large extent, on how stressed and tense they feel. In the present study, this aspect has been studied by the question, "To what extent do you feel that things are overwhelming?". Percentage of responses to this question depicted in figure 1 shows a stepwise increase in the proportion of people who were stressed. Among those who did not have chronic disorders, 9% felt that life was overwhelming, while the percentage for the overall population was 13%. Among people with chronic disorders, 19% were stressed, but this percentage was the highest among chronic rheumatic patients (32%).

Figure 1: Frequency of chronic disorders and level of stress (answer: Feeling that life is overwhelming is felt once-twice in a week or more often)



Sources: Population survey 'Estonia 2008', TU IISS;
'Survey of chronic rheumatic patients 2006'

Chronic rheumatic patients experience many difficulties while trying to cope with their lives. High level of stress characterizes their lifestyle or, in other words, they pay a price for coping. Most people make adjustments to their life due to health problems, and if these adjustments are not too burdening, they learn to live with them. At the same time, the chronic illness can be so serious that it affects day-to-day coping. The status of Estonian chronic rheumatic patients was characterized by their answers to the question, "Has the chronic disorder decreased your ability to work and learn?" It has to be stressed here that the question was answered only by respondents who worked or studied. The disease *very much* affected the coping and working ability of people with chronic illnesses (37%), which was much higher than the population average of 17%.

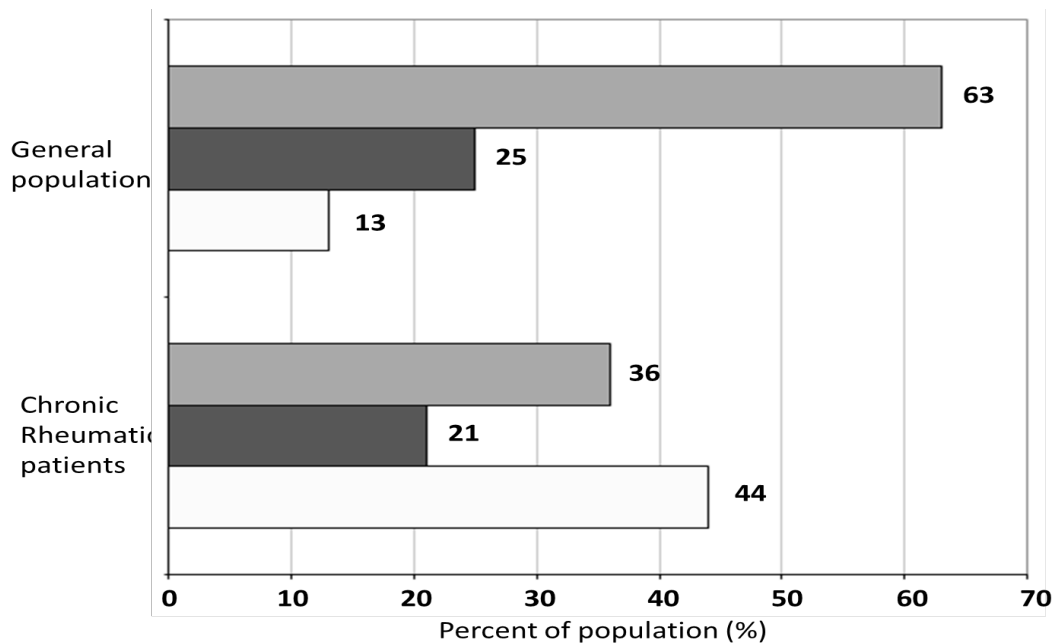
The chronic illness not only decreases the ability to work, but results in situations where it is not possible to work at all. This situation was revealed by their responses to the question "Have you been away from work (school) due to illness during the last 12 months?" as shown in figure 2. Comparison of the answers to this question by rheumatic patients with the general population revealed that the situation was worse for rheumatic patients. In general population, 63% answered that they have not been away

from work at all during the last year due to illness, compared to 36% among rheumatic patients. Only 13% in general population did not attend work/study for a long term. In contrast, more than thrice the number of patients (44%) could not attend to work/study during the same period, and a majority of them had the illness for a month or more.

Satisfaction with life

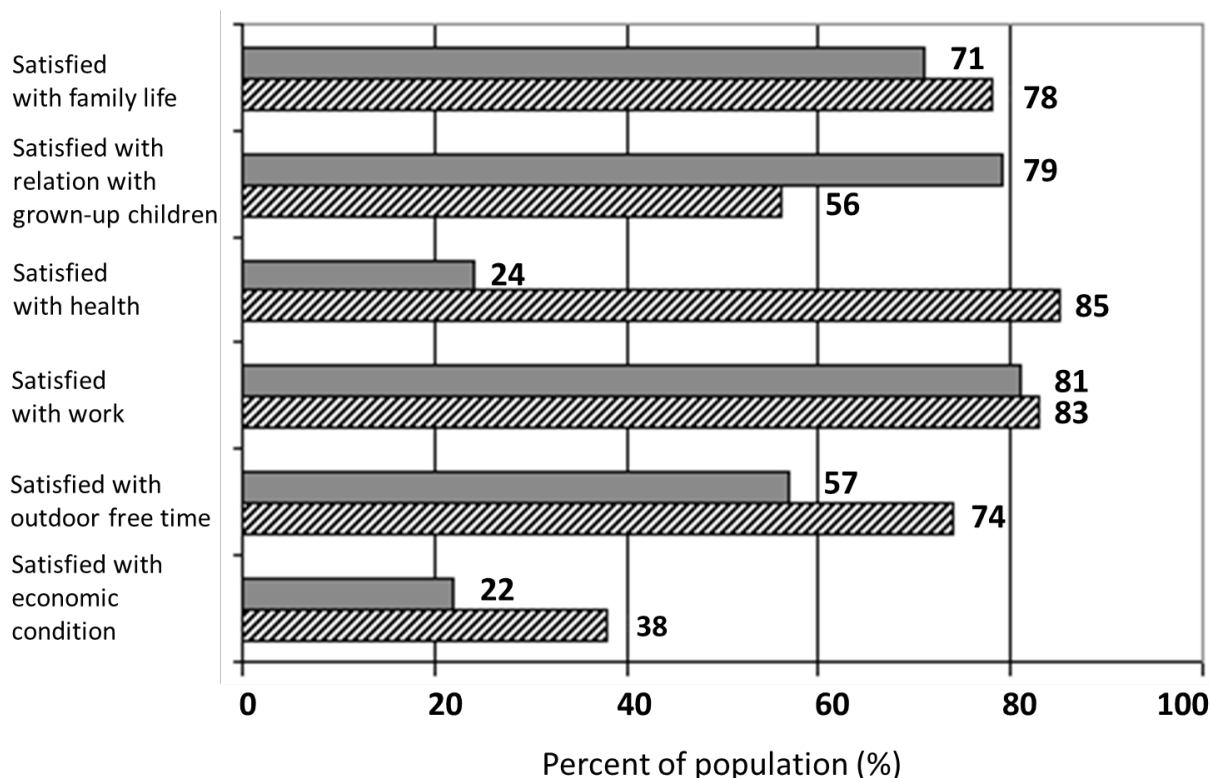
Health and well-being are major determinants of satisfaction with life and all aspects of a person's life are reflected in health. Development of overall satisfaction with life depends on the level of satisfaction with different aspects of life. Figure 3 shows the level of satisfaction with different aspects of life in general population as well as in people with chronic disorders. Satisfaction with health was much reduced among chronic rheumatic population than general population due to obvious reasons. However, there was no significant difference between the two populations when satisfaction with family life and work was considered. Estonian population is generally characterized by high satisfaction with family life and this could be the reason for the proportion of satisfied respondents to be almost equal in both the comparison groups. It is noteworthy that respondents with chronic disorders were equally satisfied (81 vs. 83% for general population) with their work. The

Figure 2: Frequency of absence from work due to chronic rheumatic disease (answer to question: "Have you been away from work (school) due to illness during the last 12 months?")



Sources: Population survey 'Estonia 2008', TU IISS;
 'Survey of chronic rheumatic patients 2006'
 (■ Not at all, ■ 1-2 weeks and □ up to a month or longer)

Figure 3: Satisfaction assessments (totally or mainly satisfied) with different aspects of life depending on the prevalence of chronic disorders



Source: Population survey 'Estonia 2008', TU IISS
 (■ No chronic disorders and // with chronic disorders)

fact that being able to go to work, in itself, is a basis for satisfaction, especially when disabled people have to work.

It is surprising to note that respondents with chronic disorders were more satisfied on relationship with their children (79%), compared to those without disorders (56%). This can be attributed to the fact that grown-up children help them materially (26%), in everyday tasks (48%), and practical tasks (67%) as well as they offer emotional support and advice in difficult situations (70%).

The level of satisfaction with the economic situation was relatively low in the Estonian society – only 38% was *totally or mainly satisfied*. As expected, this number was even lower for people with chronic disorders when they have to deal with additional medical expenses (22%). Likewise, satisfaction indicator for spending free time outdoors was lower (57%) than general population (74%) due to restrictions on physical activities imposed by the chronic disorders, especially with rheumatic disorders.

Other limitations

Rheumatic patients need rehabilitation and technical

aids that may be expensive and unaffordable for many of them. In addition to the economic problems (64%), lack of information regarding the possibilities for rehabilitation (mentioned by 27% of respondents), services and benefits available (18%), healthy eating (17%) and institutions providing rehabilitation (16%) hinders and/or slows down the treatment of rheumatic patients in Estonia.

There was also a relatively large and statistically significant ($P < 0.05$) difference between the groups of rheumatic patients and general population in terms of the existence of personal problems. The contrast between the groups was highlighted when *very serious* responses for some of the personal problems were considered. These include the shortage of money (60% for rheumatic patients vs. 51% for general population), own health (71% vs. 23%), health of a loved one (43% vs. 32%), and fear of losing a job (25% vs. 22%). The question of loneliness emerged very frequently as an important concern among the disabled people as approximately one fifth of them (19% vs. 14%) lived alone, and almost every fifth was widow(er) or divorced.

The occurrence of severe problems is also accompanied

by a cumulative effect when these problems pile up. The occurrence of a problem is likely to trigger other problems. The situation may be described as a wheel of problems. The wheel turning in a positive direction reduces the occurrence of problems in one's life. It may also turn in a negative direction causing a series of hardships.

Conclusions

The present study demonstrates that the health and wellness of Estonian people with chronic rheumatic disease are considerably affected, throughout the course of the disease. Not only the pain accompanying the illness, but depression significantly affects their self-esteem and hinder coping with life. The main factor that could improve their health and wellness is financial prospects for buying medication and receiving rehabilitation. A negative aspect concerning Estonia, frequently pointed out by respondents of this study, is the lack of information about the nature of the disease, the need for treatment, the effect of medication, and opportunities for obtaining assistive devices. Respondents call for essential improvements to take place in creating work opportunities adapted to the needs of the disease, professional re-training and quality of social services. A significant role of the state is emphasized as legislative basis, state aid and financial support are needed to bring about these improvements.

In view of the economic limitations and negative emotions related to the disease, a decrease in the quality of life of respondents is expected. However, the respondents are found to be relatively satisfied with their life (an average rating of 3.34 on a 5-point scale). Satisfaction with life is found to be higher in younger respondents with higher education and in women. Although the level of psychological stress is high, and the respondents suffer from pain, fatigue, and depression, it is seen that the patients have accepted their situation and deal with it in a composed manner, while continuing their efforts towards recovery. As 'agents of change', it is important to enhance the awareness of rheumatic diseases in the society and help establish better conditions for those affected by rheumatic disabilities.¹⁶

Competing interests

The author declares that she has no competing interests.

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