Chronic disease: Working together

Sir,
I enjoyed reading the editorials on Dr. Rita Levi-Montalcini as well as on patient centered care,[1,2] and I would like to share a story about an admirable Estonian woman Maire-Liis Hääl. She is not as famous as Dr. Rita Levi-Montalcini. She is an ordinary woman, but ordinary persons can also achieve extraordinary feats.

One autumn several years ago, a woman introduced herself as chairwoman of Tallinn Rheumatism Association and explained her wish to study the problems and needs of people with rheumatism. In order to collect and analyze data in a scientific manner, she needed the help of specialists. She talked energetically and passionately, and since her inner strength and wish to act were so enormous, I did not need a lot of convincing to take part in the study.

Maire-Liis Hääl formed a maximally effective research group. In addition to herself, who suffered from rheumatism and knew all the problems related to this disease, she included one of the best rheumatism doctors, a professor emeritus of University of Tartu, and me, a sociologist. My task was to carry out the data analysis.

This multi-disciplinary research team facilitated a holistic study of the life of rheumatism patients. We studied not only the problems related to the illness itself, but also their life in general, including their coping skills, strengths and weaknesses. Data collection took place in cooperation with Rheumatism Associations, rheumatologists and general physicians all over Estonia. 1450 questionnaires were distributed, out of which 808 were filled and returned. As a result of this cooperation we published a book, coping with life and availability of treatment for people with rheumatism in Estonia”.[3]

Maire-Liis Hääl was able to see the situation on a wider scale – apart from the biological aspect of disease, she calculated its economic impact as well. In healthy people, 90% of all health-related expenditure was on health promotion like nutraceuticals, rehabilitation, and hobby sports (massage, pool, tennis, gym). In people with illness, expenses on rehabilitation were very small (7%), due to which 64% said the possibility of achieving rehabilitation was poor.[1]

What did we learn from this cooperation and why am I writing to you?

First, reviewers said the composition of the research team was good and optimal. Because what one lacked, the other contributed. So it was research and practice all together, combining clinical care, sociology and patient perspectives. The team was led by a person with rheumatism, not by a clinician. Second, we studied more thoroughly people who suffered from one type of disease. This focused approach helped us achieve more tangible results. Furthermore – we translated the shortened version of the questionnaire into Finnish, as the Vantaa Rheumatism Union and also Nordic Rheumatism Unions thought that it would be important for them to carry out a similar study. Thirdly, it should be emphasised that our work had major practical implications. The society is unaware of what people with rheumatism and their families have to suffer in order to cope with everyday life, their expenses, and changes in quality of life. However, people who are ill sense the negative attitude of society, due to which it is necessary to change the opinions of the public, patients and specialists about people suffering from rheumatism.

We showed what mistakes people with rheumatism had made themselves (go to the doctor too late, stop taking medicine
when they felt their health had improved). There were also shortcomings in how information was distributed to the patients, because people did not know where to get help, what services are available. It appeared that general practitioners were not always able to diagnose rheumatism early enough. We showed that training courses would be needed for support persons, and family members as well. Based on these findings, we made suggestions at the level of state, doctors and patients. We emphasised the need for continuing such sociological studies, including qualitative and mixed methods research. As our reviewers stated, it is often the patients who know the answer to how their situation could be improved.

A similar situation prevails with endocrine diseases such as diabetes and hypothyroidism. I hope this letter will inspire endocrine researchers to continue working for their patients, with their patients, while collaborating with sociologists. Endocrinologists must not neglect to involve the state, society, and family members of their patients in the management of disease.

Look at what one simple person achieved, in spite of a serious illness. This happened because of her great vision, a large-hearted and helpful nature, knowledge of the problems of ill people, and her inspirational ability. To carry out this kind of work there has to be a leader who longs to help other people, whose sparkling eyes, ideas and energy attract others who come into contact with her. This was Maire-Liis Hääl!

**Prayer sign in diabetes mellitus**

Sir,

Limited joint mobility (LJM) is a condition characterized by hand stiffness resulting from flexion contractures of the fingers and thickened, tight, waxy skin.[1] It is seen in approximately 25-50% of diabetics, equally common in both sexes; and commoner in patients on insulin, juvenile onset, and longer duration of the diabetes.[1,2] It begins as contractures in the distal interphalangeal and proximal interphalangeal joints. Gradually, it increases to involve metacarpophalangeal joints, wrists, and other peripheral joints of both upper and lower limbs [Table 1]. It is usually asymptomatic, but later in the course of illness, the patients complain of stiffness, weakness of grip, clumsiness, and decreased dexterity due to reduced ability to perform fine movements. Typically LJM is painless; however, patients with coexisting neuropathy may report pain.[1-3] Clinically, it is detected by performing the “prayer sign”[3] by asking the patient to put his or her hands together in a praying position with the fingers fanned and to press together the palmar surfaces of the interphalangeal joints and the palms. Normally, an individual is able to oppose both hands together, but a patient with LJM fails to do so as in our patient [Figure 1]. Prayer sign correlates well with goniometer in detection of LJM. Another test to detect LJM is the “tabletop test” that is conducted by asking the patient to place his hands palms-down on a tabletop with the fingers spread.[1] A normal individual should be able to make contact of palmer surface of hand; however, a patient with LJM will not be able to do so. In case of positive test, the examiner may confirm limitation of joint motion with passive extension of the fingers. Differential diagnosis includes Dupuytren contracture, tenosynovitis of the finger flexor tendons, reflex sympathetic dystrophy, palmar fasciitis, and scleroderma.[1]

Results of laboratory (erythrocyte sedimentation rate, antinuclear antibodies and rheumatoid factor), radiographic

---

**Table 1: Classification of LJM[3]**

| Stage | Stage | Description |
|-------|-------|-------------|
| 0     | No limitation | Includes equivocal or unilateral findings |
| 1     | Mild or slight limitation | Involvement of one or two interphalangeal joints or only the metacarpophalangeal joints bilaterally |
| 2     | Moderate limitation | Involvement of three or more interphalangeal joints or one finger and one large joint bilaterally |
| 3     | Severe limitation | Obvious hand deformity at rest |

LJM: Limited joint mobility
