



SURVEY ON THE SOCIAL SUPPORT AND COUNSELLING GIVEN TO RARE DISEASE PATIENTS IN SPECIALISED HEALTHCARE

Rare diseases entail a range of problems in everyday life. The lack of information and limited understanding of challenges in everyday life are common in rare diseases. Social workers and rehabilitation counsellors at hospitals are in a key position in providing guidance and counselling on issues of everyday life. They also may play a key role in assessing when social support is necessary and what kind of support, services and benefits the rare disease patients and their families need.

Background

In Finland, most of the rare disease patients are diagnosed in specialised healthcare, usually at university hospitals. The Finnish Network for Rare Diseases carried out a survey on social support and counselling given to rare disease patients in five university hospitals. The survey was sent to 220 social workers and 136 rehabilitation counsellors (n=356). A total of 73 replies were received, so the response rate was 20.5 %. This was the first survey of this kind to be made.

Results

In general, the work of the rehabilitation counsellors is more specialised and more specific than that of social workers. However, the survey results show that there is regional and institutional variation in the operating policies. Social workers and rehabilitation counsellors meet rare disease patients relatively seldom: 77 % reported monthly or less frequent meetings.

The services of a social worker or rehabilitation counsellor are offered automatically or when needed to most of the rare disease patients (figure 1).

require more time and effort, and the guidance was considered laborious in comparison to other patient groups.

The lack of medical information made it difficult to understand day-to-day life with a rare disease. On the other hand, compared to other diseases, providing information on services and support was considered similar in nature.

In the counselling process, in over half of the cases the role of the family was considered significant (figure 2).

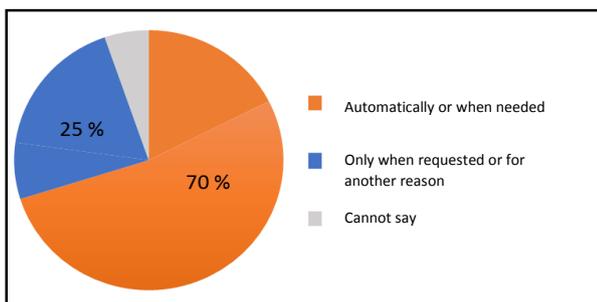


Figure 1. How often are the services of a social worker or rehabilitation counsellor offered to rare disease patients?

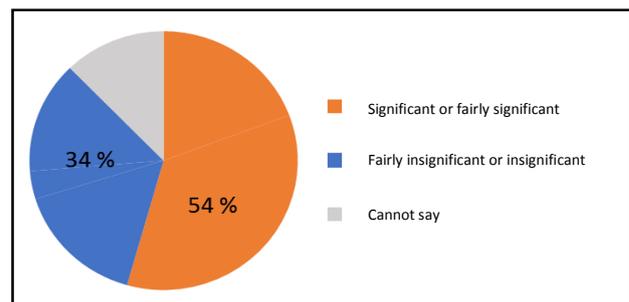


Figure 2. In counselling process, what is the role of the family with rare disease patients, as compared to other patients?

Since information available to professionals and rare disease patients is limited, rare disease patients

Nevertheless, in one third of the cases the role was considered fairly insignificant or insignificant.





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One reason why the opinion is divided might be the amount of information available: the less information there is, the more the role of the family is emphasized.

Almost half of the respondents were well aware of the services the patient organisations offer to people with rare diseases and their families.

They were most familiar with peer support activities and different rehabilitation services like adaptation training courses. The least known were web services and recreational activities.

Evidently, the more the professionals meet persons with rare diseases, the better acquainted they were with the services and activities offered by patient organisations.

Still, most patients were guided to services and a suitable organisation was usually fairly easy to find. The activities offered by organisations were considered important, particularly the peer support and the provision of up-to-date information. Still, there are always some patients who are not interested in the activities and services provided by the patient organisations.

Summary and conclusions

Social support and counselling given in special healthcare by social workers and rehabilitation counsellors is important to people with rare diseases. The role of social workers and rehabilitation counsellors is essential. However, there is a need for further surveys. Although there is a common framework, practices seem to vary from place to place. The results of the survey provide a good basis for discussions on how the care and service pathways should be planned to better support the everyday life of rare disease patients and their families.

The results show that the social workers and rehabilitation counsellors are in a key position in providing guidance to rare disease patients. The more the professional works with rare disease patients, the more familiar he or she is with the field concerned. Furthermore, it is noteworthy that diagnosis related guidebooks and brochures produced by patient organisations are widely used by the professionals in specialised healthcare. The services provided by patient organisations may play a significant role as the issues of everyday life are important in finding ways to support the rare disease patients and their families.

Although the response rate was low, the results of the survey are in line with the experience of the patient organisations. There is no need for additional or more extensive services for rare disease patients, but rather a more intensive and methodical approach. Also, a genuinely multi-professional approach is needed. A patient should get access to professionals who can assess the need for social support when a diagnosis is made or when the living conditions change and/or the course of the disease changes.

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The survey was carried out by the Finnish Network for Rare Diseases, which consists of 17 independent, non-governmental organisations and foundations that work for the interests of rare disease patients. The main goal of the network is to improve the conditions of people with a rare disease or disability by raising awareness and sharing information, and by influencing and co-operating with decision makers, professionals and experts both nationally and internationally.

