

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

Research shows that rareness brings with it a range of problems. The lack of information on and experience of rare diseases also causes problems in different everyday situations. Those who are experts in the everyday rare disease-related challenges are scarce in social welfare and healthcare; moreover, expertise and a rare disease patient may not necessarily always come across. The social workers and rehabilitation counsellors employed at university hospitals are in a key position in providing guidance and counselling on support and services offered by society. They also play a key role when considering when the social support is necessary and what kind of support the rare disease patient and his or her family needs.

Background of the survey

The Finnish Network for Rare Diseases carried out a survey targeting the social workers and rehabilitation counsellors' at all five university hospitals in Finland in order to find out what kind of guidance and counselling rare disease patients receive, and how these differ from the guidance and counselling that patients with more common diseases are provided with. The online survey was sent to 220 social workers and 136 rehabilitation counsellors, i.e. altogether to 356 professionals. A total of 73 replies were received: 39 from social workers and 34 from rehabilitation counsellors. The response rate was thus 20.5%. The survey answers give an indication of what kind of guidance and counselling rare disease patients receive from social workers and rehabilitation counsellors. A similar survey has not been previously conducted. The results provide a good basis for reflections on how the care and service pathways should be realised to support the everyday life of rare disease patients and their families as comprehensively as possible.

Results of the survey

The role of the social workers and rehabilitation counsellors varies depending on the hospital and disease group concerned. The survey confirms that the professionals in question meet with rare disease patients relatively seldom: 77% reported monthly or less frequent meetings. The survey also confirmed the assumption that the work performed by rehabilitation counsellors is more specialised and their target groups more specific than is the case for social workers. The rehabilitation counsellors focus more on finding solutions to specific issues than on identifying general challenges that pose a threat to everyday life and solutions to these.

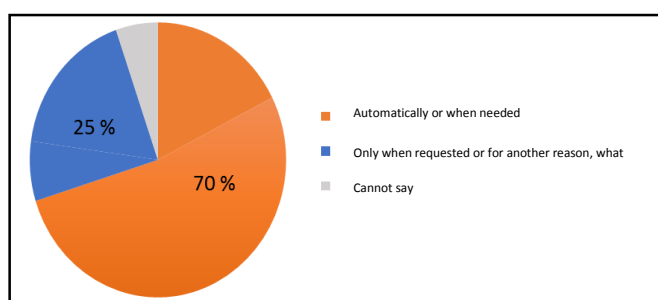


Figure 1. How are the services of a social worker or rehabilitation counsellor offered to rare disease patients?

Over half of the respondents (54%) was of the opinion that, due to the rareness of the disease, those close to the rare disease patient have a significant or fairly significant role in guiding the patient (figure 2). The role of close ones was deemed particularly significant as far as searching for information was concerned. Rare disease patients and those close to the patients were in many cases regarded as experts in the disease concerned, and it was also stated that they actively searched information on the internet.

Social workers and rehabilitation counsellors who work with children assessed somewhat more often the role of family more significant, as regards searching for information, than is the case for other diseases.

Almost half of the respondents were well or very well acquainted with the services the patient organisations offer to rare disease patients. The respondents were most familiar with the adaptation training courses and peer support activities, and the least familiar with web services and financially supported holidays. The more the respondent was in contact with a rare disease patient, the better acquainted he or she was with the services offered by patient organisations.

Many indicated that the counselling provided to rare disease patients is labour-intensive: rare diseases often seem complex, and gaining deeper knowledge of them is laborious. Since information geared towards professionals and rare disease patients is limited, rare disease patients require more guidance than others.

In 70 % of the cases the services of a social worker or rehabilitation counsellor are offered to rare disease patients automatically or when needed (figure 1). The survey does not, however, provide more detailed information on how the need for services is determined. It is mentioned that a client is referred to a social worker or rehabilitation counsellor particularly for the following reasons: the disease is in its initial stage, there are changes in the disease condition or the medical staff expresses their concern.

Guidance provided to rare disease patients was considered laborious in comparison to other customer groups. The main differences lay in determining the symptoms of the disease and their effects, whereas providing information on services and support was considered similar in nature.

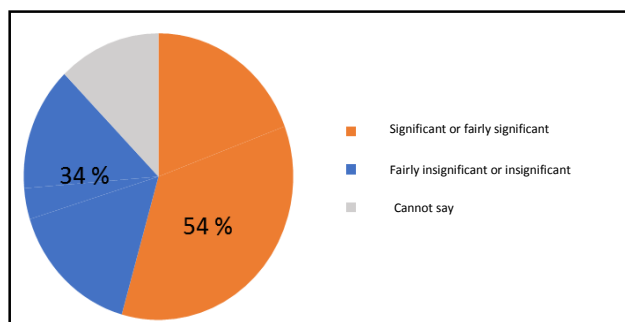


Figure 2. What are your experiences: how great is the role of the family or close ones when rare are concerned as compared to other diseases?

The majority of the respondents stated that they for the most part referred patients to services offered by patient organisations, and that they usually also were able to find a suitable organisation. Many respondents felt that the activities offered by organisations were important, particularly the peer support and the dissemination of up-to-date information. However, many mentioned that not everyone is interested in the activities arranged by organisations.

Summary and conclusions

In conclusion, the survey shows that the social workers and rehabilitation counsellors are key figures in providing services guidance to rare disease patients. Particularly the role of the rehabilitation counsellors was emphasized. The guidance practices should, however, be specified and harmonised. The more a professional works with rare disease patients, the more familiar he or she is with the field concerned. On the other hand, the guidebooks and brochures on diagnoses produced by the patient organisations are also widely used in specialised healthcare. Since coping with everyday life was by far the most important theme regarding the guidance of clients, the role of the NGO seems particularly significant: the services provided by patient organisations play a vital role in supporting everyday life.

Although the response rate was low, the results of the survey are in line with the experiences accumulated in the organisations. Rare disease patients do not want additional or more extensive services but a more intensive and methodical approach to the work performed: the professionals should adopt a genuinely multi-professional approach, and they should have up-to-date contact information to patient organisations. A patient should get access to social support, when he or she is diagnosed with a rare disease or when the living conditions change and/or the course of the disease changes.

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