

Social services and psychological counselling as dual pillars of an integrated case management approach for people living with a rare disease

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Background

Social services can help rare disease patients deal with the complexity of the disease by providing information, support and guidance on various social, medical and financial aspects of living with their disease.

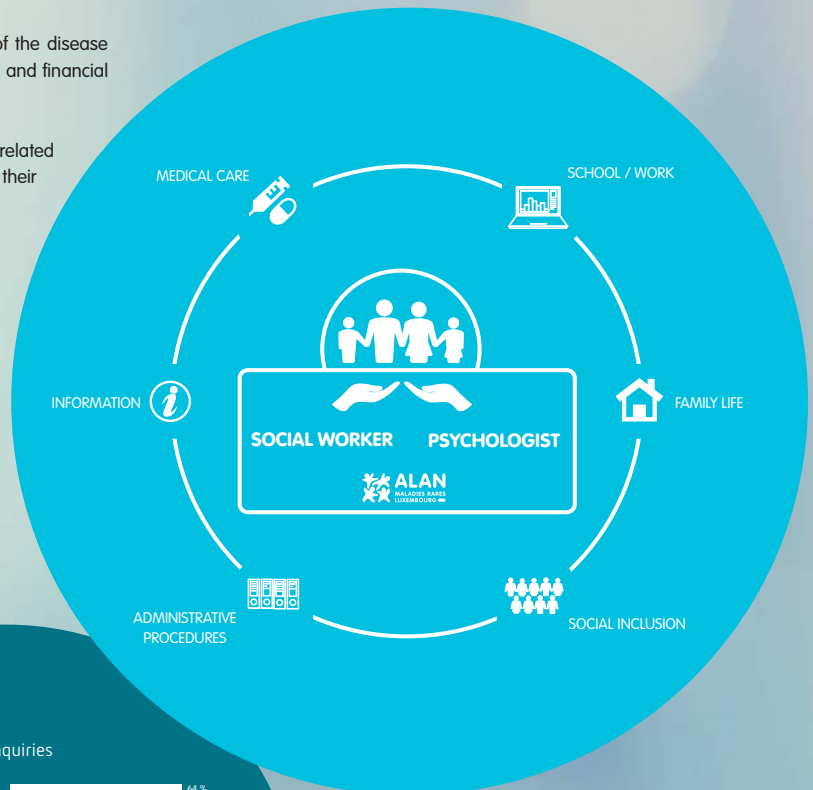
But, patients and their families often experience anger, anxiety or stress related to the delay in diagnosis, the diagnosis itself, the prognosis, the change in their independence, social isolation or financial issues.

The mental challenges of living with a rare disease mean that patients risk developing depression or other mental health disorders and that most patients would also benefit from psychological counselling throughout the different stages of their disease.

Method

Based on feedback from patients, their families and medical professionals, an integrated case management approach with a combined foundation of psychological support and social services was developed.

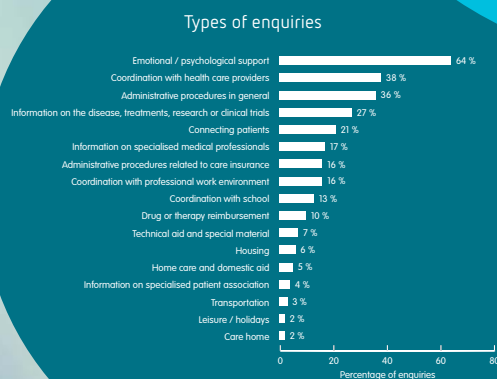
The case management team is composed of social workers and psychologists who bring their specific expertise and unique point of view to jointly support and empower the patients in their life plans.



Results

This dual case management system is employed to guide the patients in six different aspects: helping them obtain adequate medical care, facilitating integration at school or at work, preventing social isolation, providing information regarding clinical trials and registries, helping with administrative procedures and improving the quality of family life (e.g. housing, finances, transportation).

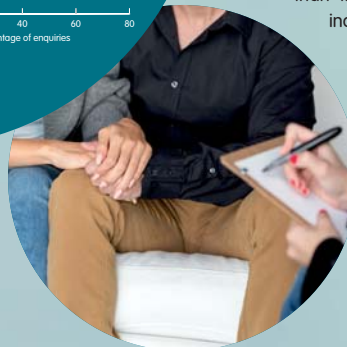
The case management team responds to a wide range of enquiries from rare disease patients. In 2017, the need for emotional or psychological support was by far the most common request (64%), followed by requests for help with the coordination of their health care (38%) and help with administrative procedures (36%).



Discussion & conclusion

A recent study showed that chronic illness, poor health perception, disability and the related inability to work were among the most important risk factors for depression in the Luxembourgish population.¹ Further, people living with a rare disease consistently report worse mental health than the general population, putting them at an increased risk of developing a mental health disorder.^{2,3}

Psychological support, starting as early as possible, may reduce this risk and improve the patients' quality of life. Combining psychological counselling with social services, rather than viewing it as a separate entity, further reinforces the traditional integrated case management approach.



References

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