Health education competence and rare disorders

-An online and collaborative academic course on bachelor-level

Introduction:

This poster will present a new academic course, Health education competence and rare disorders. The course aims to provide professionals with increased knowledge and improved health education competence when providing services to people with rare disorders.

Studies show that competence in health education is crucial for ensuring that patients and service users benefit from self-management programmes (Vågan et.al., 2016). Frambu Resource Centre for Rare Disorders and Inland Norway University of Applied Sciences have therefore developed and successfully launched a new academic course targeting professionals.

The course was first made available to students in 2019, and because of a high number of course applicants, it is now fully booked for a second semester in 2020.

Background:

The term «Health education competence » has been developed in dialogue with people with rare disorders and professionals that deliver self-management programmes. It focuses on the interaction between professionals and people that receive their services.

These self-management programmes have a different goal than treatment in that they are intended to boost the self-management abilities of the individual patient or next of kin programmes (Vågan et.al., 2016). This is important in order to increase empowerment for people with rare disorders so they can participate in, influence, control and hold accountable institutions that affect their lives (article in Eurordis by Appanah, 2008).

Method:

The academic course is structured into five modules.

The modules are:

- What is a rare disorder?
- Different types of rare disorders and specific challenges
- Health education competence when facing rare disorders
- Lifecycle Perspective and long-term planning
- Ethics

Each module consists of video lectures by leading experts, personal stories, selected readings, podcasts and webinars. There are a few assignments throughout the modules, and all students must do an exam at the end in order to complete the course.

Conclusion:

A survey was sent out to students that completed the course in 2019. The survey report showed that the students highly valued the course and would recommend it to other professionals. Based on this feedback Frambu Resource Centre for Rare Disorders and Inland Norway University of Applied Sciences decided to relaunch the course in January 2020. The course is fully booked.





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