

## Poster

### The quality of life and stigma experienced by children with rare diseases and their families in Romania

**Shir Grunebaum** Oxford Brookes University

**Dr Liana Nagy** Oxford Brookes University

**Purpose and aims:** What is the quality of life (QoL) of children with rare diseases (CwRD) in Romania and how does this relate to their family's experiences of stigma? There are over 900,000 CwRD in Romania (Puiu and Dan 2010) who are often excluded from the literature and health care services (Detiček et al 2018). This study aims to measure the QoL and experiences of stigma in CwRD and their families in Romania.

**Design and methods:** A questionnaire consisting of demographic information, and two validated questionnaires – Paediatric Quality of Life (PedsQL) and adapted Parental Perception of Public Attitudes Scale (PPPAS) – were used. Eighty participants (parents/primary caregivers of CwRD aged 2–16 years old) were recruited and accessed the survey online via Qualtrics between October and December 2022. Data analysis through SPSS is ongoing.

**Results:** Initial analysis has indicated that the average QoL on a scale of 0–100 is 36.04. Data suggests that 60.5% of children 'always' or 'often' have problems with their social functioning. Additionally, 70% of parents indicated that they regularly experience stigma because

people believe that rare diseases are the result of parental sin.

**Conclusions:** Initial findings suggest that there is a need for increased support and interventions aimed at CwRD, their families and communities in Romania to address their lower QoL and heightened experiences of stigma. Occupational therapists may be uniquely positioned to address these needs. However, the availability and efficacy of occupational therapy services in Romania are significantly unexplored.

#### References:

Detiček A, Locatelli I, Kos M (2018) Patient access to medicines for rare diseases in European countries. *Value in Health*, 21(1), 553–560.

Puiu M, Dan D (2010) Rare diseases, from European resolutions and recommendations to actual measures and strategies. *Medica*, 5(2), 128–131.

#### Conference theme

Breaking through

#### Keywords

Long-term conditions, Children and families, Health inequalities

## **RCOT Career Development Framework Pillars of Practice**

Evidence, Research and Development;  
Professional Practice

### **Ethical approval**

Ethical approval was provided by Oxford  
Brookes University (HLS/2022/VI/73).

### **Author information**

Shir Grunebaum is a graduating MSc  
Occupational Therapy student at Oxford  
Brookes University with experience  
conducting international research on  
people with rare diseases, seeking to  
improve the lives of those with rare or  
orphan conditions through research,  
innovation and occupational therapy.