

clinic in Helsinki, Finland. [cited 2023 Oct 27]; Available from: <http://dx.doi.org/10.1016/j.jpsychores.2024.111776>

doi:10.1016/j.jpsychores.2024.111776

## 111777

### **Integrating experience sampling methodology in clinical practice for fatigued children with a chronic health condition: A qualitative study on future implementation of PROfeel**

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### **Background**

One in five children with chronic health conditions experiences severe fatigue, influenced by biological, physical, and psychosocial factors. Experience Sampling Methodology (ESM) enables personalised insight into factors, preferably modifiable (i.e., lifestyle), that are associated with fatigue and related disabilities. Despite its potential, no ESM-intervention has yet transitioned from research to paediatric clinical practice. This qualitative study assessed implementation factors from the perspective of end-users for an ESM-supported eHealth intervention called PROfeel, to understand implementation needs for ESM-interventions in paediatrics.

### **Methods**

PROfeel starts with smartphone-based ESM for personal fatigue insights, followed by shared decision-making with a professional on insight-based and tailored lifestyle goals. For this study, we conducted semi-structured interviews and used inductive thematic coding for analysis. Respondents were end-users; health care professionals (HCPs,  $N = 20$ ), patients ( $N = 11$ ), and their important others ( $N = 11$ ). Patients, aged 13 to 21, had followed PROfeel in a research setting. Ten patient-parent dyads and two singletons (one partner, one patient) were separately interviewed. This study was classified as exempt of the Medical Research Involving Human Subjects Act (file number: 22/833).

### **Results**

HCPs agreed that the lead clinician, specifically the paediatrician, should identify patients for PROfeel after excluding medically treatable causes for fatigue. However, opinions on the most appropriate professional to deploy PROfeel varied based on differences in care pathways for specific diagnostic groups and differences in HCP's perceived scope of responsibility. This scope ranged from disease-focused to holistic (i.e., excluding or including fatigue). The expected added value for patients determined HCPs' enthusiasm for PROfeel. Generally, HCPs anticipated patient benefits, but doubted the feasibility of the intense ESM-period and lifestyle change subsequently. Preconditions mentioned were efficacy, practitioner's skills, time, and financing.

For patients, the severity of fatigue primarily determined feasibility of PROfeel compliance. Both the absence of complaints

and severe fatigue-related restrictions were barriers for use. Facilitating factors were: gaining insight, experiencing effect, the right timing, and aligning with values. Patients largely followed PROfeel independently, seeking autonomy. They barely involved peers, but felt supported by parents and the PROfeel professional.

### **Discussion**

Carefully selecting patients who could benefit and are motivated to comply is essential. Embedding PROfeel in a universally applicable care path might not be feasible or desirable, given the heterogeneity of working structures and HCPs' perspectives on responsibilities. This heterogeneity is a known barrier to implementation in clinical practice. HCPs, both as subscribers and deployers of PROfeel, play a vital role in its implementation. Since HCPs' support for PROfeel mostly depends on added patient value, consequently, aligning with patient preferences is crucial. The results should be interpreted in light of interviewed end-users, recognizing that stakeholders like insurers or managers might foresee more preconditions.

### **Conclusion**

Although PROfeel is feasible for carefully selected patients, to bridge the gap between research and clinical practice for an ESM-supported blended care trajectory such as PROfeel, involving patients in the future development and implementation steps is key. Besides, for embedding the intervention into existing care paths and assigning responsibilities to HCPs, these should fit the heterogeneity of clinical practice.

doi:10.1016/j.jpsychores.2024.111777

## 111778

### **Refractory persistent somatic symptoms: A survey about estimated prevalence, characteristics and needs among general practitioners**

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### **Background**

Persistent somatic symptoms (PSS) are highly common in all health care settings. Despite several evidence-based treatments, some patients suffer from 'treatment-resistant' or 'refractory' PSS. In these patients, 1. symptoms expand or worsen during treatment, or 2. patients do not receive treatment at all. Patients with refractory PSS are a heterogeneous group with high complexity due to co-occurring problems like somatic or psychiatric comorbidity, dependency on opioid medication and iatrogenic harm, resulting in feelings of helplessness among patients and their healthcare providers. Often, only the general practitioner (GP) is involved, lacking sufficient expertise and resources to manage these patients. As far as we know, refractory PSS has not been described in scientific