

CONFERENCE ABSTRACT

Are we measuring what matters to people? A review of PROMs and PREMs used to evaluate self-management interventions.

21st International Conference on Integrated Care, Virtual Conference – May 2021

Marta Ballester¹, Monique Heijmans, Carola Orrego, Lyudmil Ninov, Jessica Beltran, Ana Isabel González, Marieke van der Gaag, Rosa Sunol

1: Research Institute – UAB, Spain

Introduction

In past years, the urgency of putting people in the centre of health care research has clearly been established in the public discourse. However, the depth of patient inclusion is still limited.

In our COMPAR-EU project (Horizon 2020) we aim to move forward by investigating effectiveness of self-management interventions (SMIs) through the lens of the patients themselves. We do so developing of core outcome sets (COS) for SMIs for adults living with type 2 diabetes, obesity, heart failure or COPD. We now go one step further by reviewing if and how the RCTs on SMIs are reporting on those outcomes, with a focus on which patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) are being used.

Methods

After developing our COS we searched Pubmed, Embase, Cinahl, PsycINFO and Cochrane for RCTs on SMIs for people of 18 years and older living with TYPE 2 DIABETES, COPD, HEART FAILURE and Obesity. Articles and abstracts were screened by two independent reviewers and information extracted for, among other, outcomes (guided by the four COSs) and the PREM and PROM instruments used.

We analysed whether all outcomes included in our COS were measured in the literature and the variability and concentration in the use of specific PREMs and PROMs for each outcome and disease.

Results

PREMs and PROMs were both highlighted by patients as being important.

For type 2 diabetes we reviewed 697 RCTs on SMIs, which used PROMs for 17 of the 23 outcomes in our COS (some were not susceptible to be measured by PROM/PREM or they were not reported in the literature).

For obesity, we reviewed 517 RCTs on SMIs, which used PROMs for the 10 of the 15 outcomes included in our COS.

For heart failure we reviewed 288 RCTs on SMIs, which used PROMs for the 19 outcomes in our COS.

For COPD we reviewed 252 RCTs on SMIs, which used PROMs for the 10 outcomes in our COS.

Ballester: Are we measuring what matters to people?: A review of PROMs and PREMs used to evaluate self-management interventions

PREMs were less used in the literature.

Discussions

Our research confirms that the use of PROMs, is extensive, but some outcomes relevant to patients are still not regularly included in effectiveness research, specially those related to experiences of care (PREMs).

Conclusions

There are significant advances in the use of PROMs, the use of PREMs is still more limited in self-management research.

Lessons learned

The way in which research measures effectiveness often is mismatched with patient preferences. Our COMPAR-EU COS for type 2 diabetes, obesity, heart failure and COPD, and literature review can help align research with patient preferences.

Limitations

As any literature review, ours could face limitations in search and extraction and our participatory process due to the small sample of patient and other stakeholders. Several mitigation strategies have been applied.

Suggestions for future research

We suggest expanding the measure of the relevant outcomes to patients in effectiveness research, and the specific PREM and PROM instruments to do so, therefore facilitating comparability.