P1 - Authoring of Peer-Reviewed Articles on the Experiences of Patients with Rare Diseases by Patients and their Caregivers: A Rapid Review

Leventhal P - PPD Clinical Research Business of Thermo Fisher Scientific
Drachmann D - Evidera, a business unit of PPD, a Thermo Fisher Scientific company
Schinner R - Evidera, a business unit of PPD, a Thermo Fisher Scientific company
Skovlund S - Evidera, a business unit of PPD, a Thermo Fisher Scientific company

INTRODUCTION

Partnering with patients and caregivers as authors can help improve the relevance and reach of peer-reviewed publications, especially when they describe patients' experiences. Here, we examined the practice of including patients and caregivers as authors of peer-reviewed publications on the experiences of people with rare diseases.

METHODS

Embase and Medline were searched on June 20, 2024 for peer-reviewed articles in English on the experiences, views, and values of patients with rare diseases using a validated search filter. Articles with patients, caregivers, or patient organizations as affiliations were selected automatically using search terms and then screened manually.

RESULTS

197 articles with patients, caregivers, or patient organizations as author affiliations were identified. Since the first published in 2004, numbers have increased. The 197 articles represent 13% of the 1494 total peer-reviewed articles found on the experiences, views, and values of patients with rare diseases published in 2004–2024. The proportion increased steadily with time to 22% in 2021 but has fallen since. The most frequent article types were qualitative study/survey (31%), consensus/guideline/recommendation (22%), and reviews (16%). 95% of authors identified as patients or caregivers were affiliated with rare disease associations. The term "patient author", promoted recently, was listed as the affiliation for only a single article.

CONCLUSIONS

Patients and caregivers are increasingly visible as co-authors of peer-reviewed articles on the experiences, views, and values of patients with rare diseases. A consistent way of identifying patient and caregiver authors in databases is needed to better understand their role and impact.