Characteristics of Qualitative-Based Patient Experience Data Publications in Rare Diseases, Neuroscience and Oncology

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BACKGROUND

- Patient experience data (PED) are defined as "information that captures patients' experiences, perspectives, needs, and priorities."[1]
- Based on previous research, most PED publications in rare diseases, neuroscience and oncology appear to use a qualitative study design.[2]
- These are all disease areas in which active patient engagement and involvement in research has taken place.[3]

OBJECTIVE

- Our objectives were to characterise the approaches used to collect PED and identify gaps in reporting qualitative-based PED studies in these disease areas.
- We investigated:
  1. Year of publication
  2. Publications available in open access
  3. Study methodology and data collection methods
  4. Content related to patient experience mapping
  5. Inclusion of plain language summaries (PLS)
  6. Patient or caregiver authors
  7. Use of reporting guidelines for qualitative research
  8. Pharmaceutical company funding.

LIMITATIONS

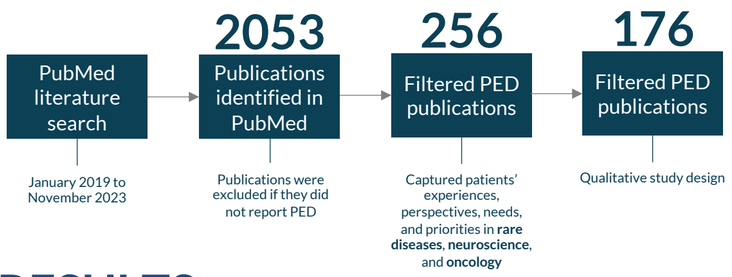
- Restricted search of PubMed (eg, specific disease search terms).
- Only the abstract was available for some publications, so we were not able to fully assess the characteristics of all publications.
- Pragmatic review methodology (ie, non-systematic review search strategy and process).
- Author affiliation searches that were limited to specific terms, potentially excluding other relevant affiliations (eg, patient organisations); however, additional manual searches are likely to have addressed this limitation.

CONCLUSIONS

- Although qualitative-based studies are the most common type of PED publications, often articles do not clearly describe the qualitative methodology and data collection methods used in the study.
- Interviews were the most common method used to collect PED.
- Few publications included a PLS or patient/caregiver authors.
- Improved reporting, including use of validated reporting guidelines, could be helpful.

METHODS

- We searched PubMed to identify PED publications in rare diseases, neuroscience and oncology that used a qualitative study design (January 2019 to November 2023).
- PED publications in rare diseases, neuroscience and oncology were identified by searching the title/abstract search for key terms and limited to English language.
- Publications were filtered to only include PED.
- PubMed index terms were used to identify publications with PLS and patient or caregiver authors.
- We conducted a manual search to further characterise PED publications according to our objectives.



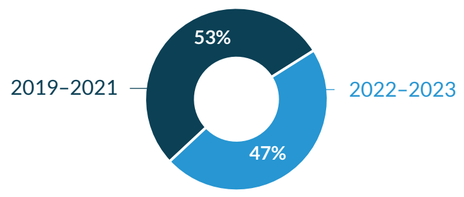
RESULTS

1. Year of publication

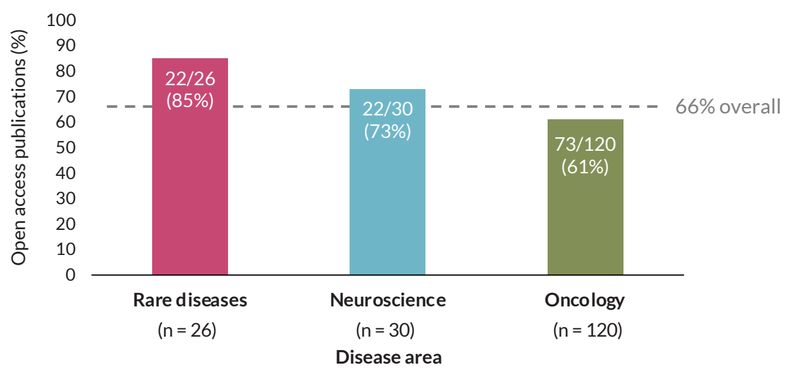
Qualitative study design

176

publications



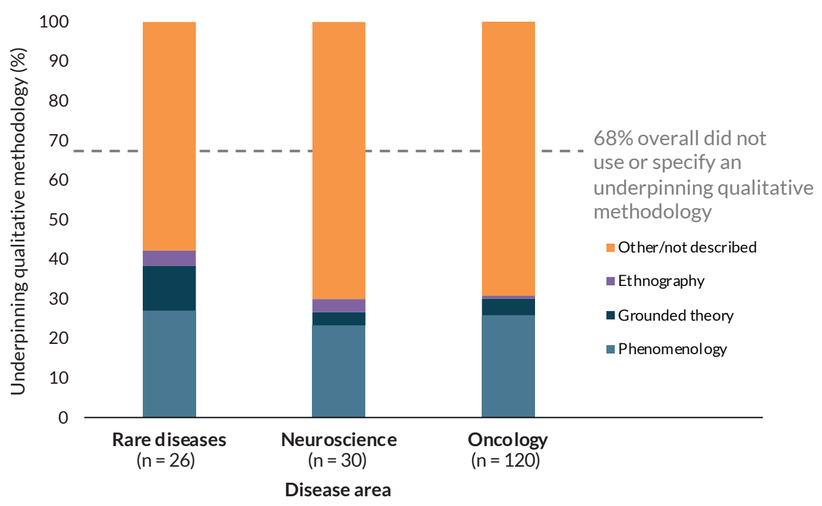
2. Publications available in open access



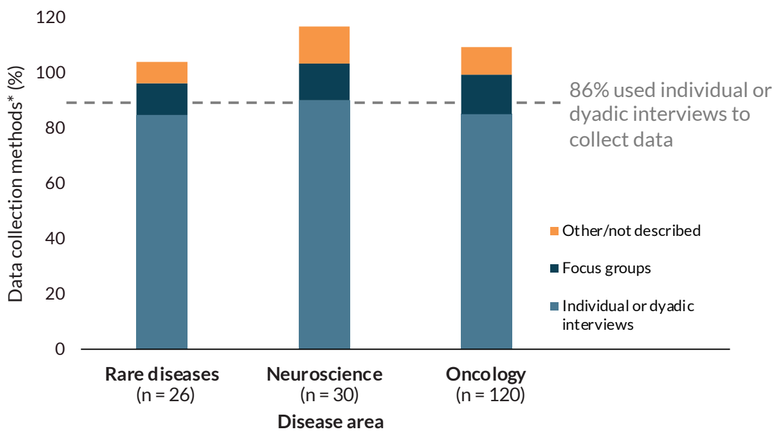
Most PED publications were available in open access (66%)

3. Study methodology and data collection methods*

- Where specified, phenomenology (the study of an individual's lived experiences) was the most common methodology (26%) across diseases.



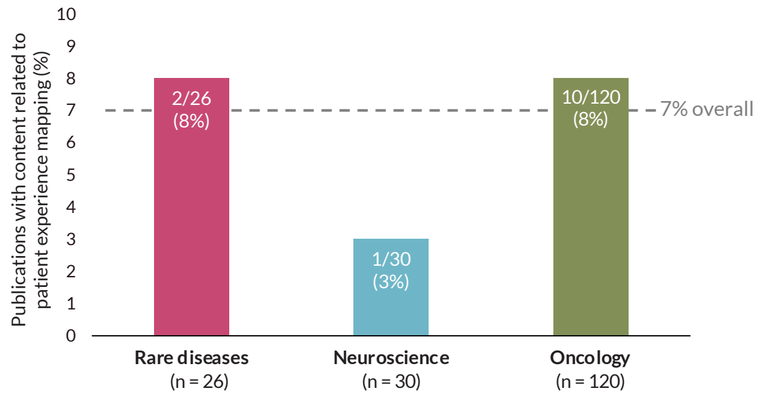
Most qualitative PED studies did not use or specify an underpinning methodology (68%)



*Studies using multiple methods are included in each separate methodology, so totals add up to more than 100%.

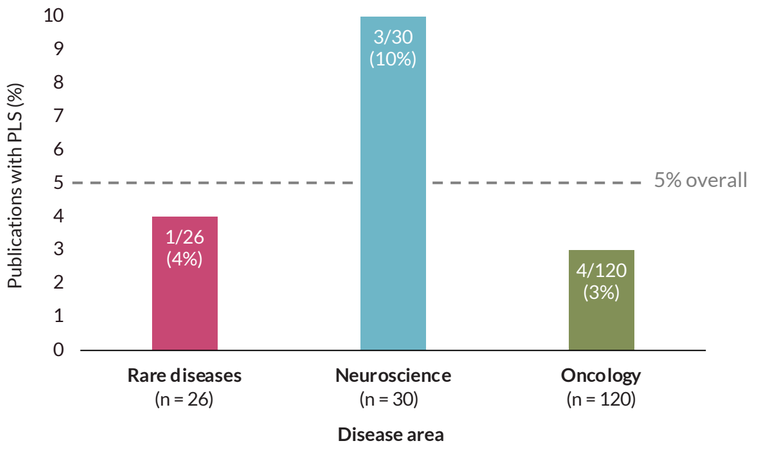
The most common data collection method was via interviews (86%)

4. Content related to patient experience mapping



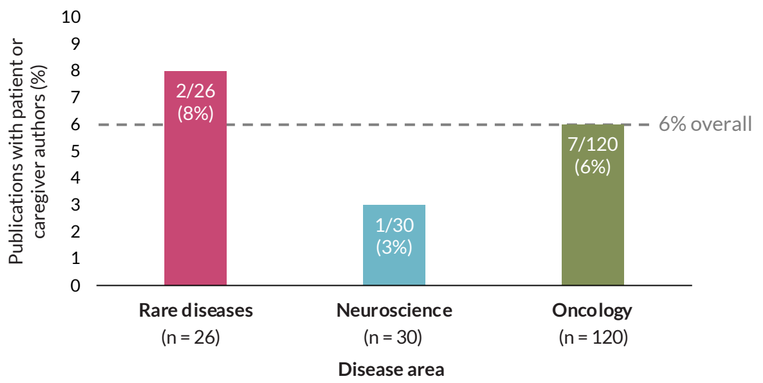
Few PED publications include content on patient experience mapping (7%)

5. Inclusion of PLS



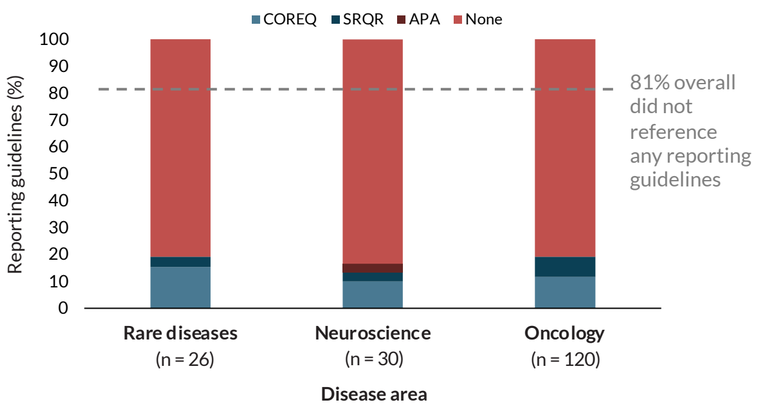
Few PED publications included PLS (5%)

6. Patient or caregiver authors



Few PED publications included authors with patient or caregiver experience (6%)

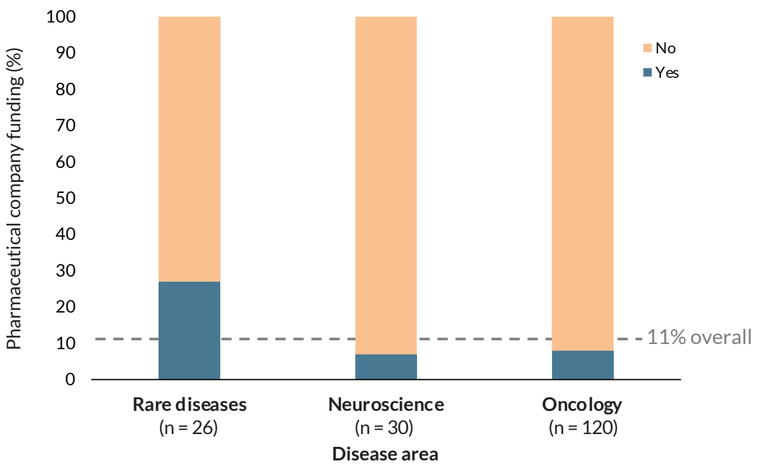
7. Use of reporting guidelines for qualitative research



Few PED publications referenced reporting guidelines (19%)

APA, American Psychological Association's guidance for reporting qualitative research; COREQ, consolidated criteria for reporting qualitative research; SRQR, standards for reporting qualitative research.

8. Pharmaceutical company funding



Few PED publications declared pharmaceutical company funding (11%)

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1. U.S. Food and Drug Administration. Available from: https://www.fda.gov/drugs/development-approval-process-drugs/patient-focused-drug-development-glossary. Accessed January 9, 2025.
2. Stones SR, Oliver J, Gorbenko O, et al. Curr Med Res Opin 2024;40(Suppl 2):12–3.
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