# A Scoping Review of Family-reported Outcome (FRO) Screening Programs in Chronic Disease Care

Sylvie Lambert<sup>1,2</sup>, RN, PhD, Li-Anne Audet<sup>1</sup>, RN, MSc, PhD Candidate, Lydia Ould Brahim<sup>1</sup>, RN, MSc(A), PhD Candidate, Jamie Schaffler<sup>2</sup>, RN, MSc(A), Cecilia Garcia Ramirez<sup>1</sup>, RN, MSc, Francesca Frati<sup>3</sup>, BFA, MLIS, Sonya Sangha, RN, MSN, Fuschia Howard<sup>5</sup>, RN, PhD, Leah Lambert<sup>4,5</sup>, RN, PhD

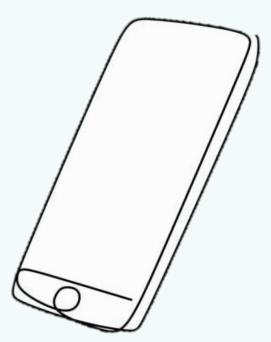
## **BACKGROUND**

Screening for patient-reported outcomes (PROs) like symptoms, distress, or quality of life is a cornerstone of chronic disease management. Screening for PROs supports:

- Patients in **learning to self-monitor** (a self-management skill critical to targeting behaviour change)
- Allows clinicians to identify priority issues and tailor their interventions

Caregivers (unpaid family members or friends) provide most of the care for those with chronic conditions.<sup>1</sup> However, with limited formal support, caregivers often experience negative health consequences themselves.<sup>2</sup>

Despite this, limited attention has been paid to similar screening for caregivers, called **family-reported outcomes (FROs).** 



# **OBJECTIVES**

Identify the extent to which FRO screening programs for caregivers of patients with a chronic illness have been developed, evaluated, and implemented, including types of FROs and effects of using FROs on caregivers.

## **METHODS**

A scoping review to identify FRO screening programs for caregivers of adults with chronic conditions was undertaken following guidance by PRISMA-ScR<sup>3</sup> and the Johanna Briggs Institute (JBI).<sup>4</sup>

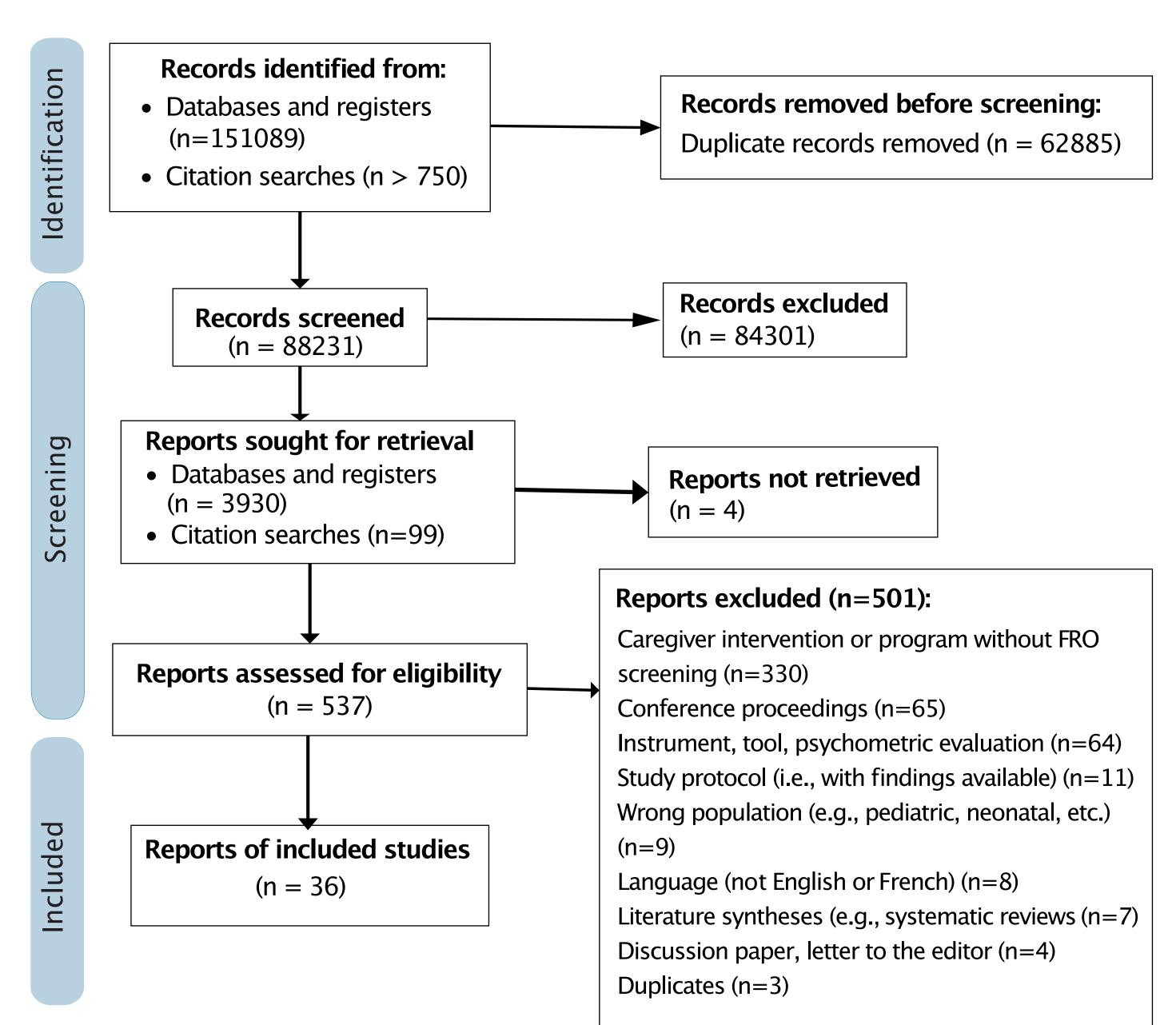
FRO programs were defined as planned collections of FROs from caregivers, which were reviewed by a healthcare professional (or dedicated interventionist) with the goal of tailoring their follow-up care/interventions to the results.

Iterative searches included four electronic databases, ProQuest dissertations and theses, reference lists of included articles, and citations of included full texts in Scopus, Web of Science, and Google Scholar.

Inter-rater reliability was established for screening and data were extracted and verified by a second author. Data were summarized using frequency counts and quantifying text.

# **Consolidated PRISMA Flow Diagram**

Identification of studies via databases, registers, and secondary citation search strategies



## PRELIMINARY RESULTS

#### **Overview of studies:**

- 36 manuscripts detailing 17 unique FRO programs that included over 4000 participants were included.
- Studies were published between 1999 2024 most frequently from Australia (n=17) and United States (n=6).
- Most common study designs were qualitative (n=11) and pilot/feasibility studies (n=8)
- Most caregivers were women spouses of care recipients who were primarily diagnosed with cancer

#### Types of FROs screened

- Caregiver needs (e.g., Information, practical support) (n=22)
- Emotional distress, anxiety, depression (n=10)
- Global mental and physical health (n=1),
- Readiness for caregiver role (n=1)
- Burden of care (n=1)

#### Timing of FRO screening

- Nearly all studies (n=22) screened for FROs 1-3 times; prior to interventions/clinical responses to tailor them and during final data collection.
- In two studies, screening was time-based (weekly, bimonthly) rather than timed with intervention.

### **Components of FRO screening programs**

Follow-up interventions were primarily delivered by nurses and included a combination of a) providing relevant information/resources, b) referrals, c) individualized real-time sessions with an HCP, and d) skills training (e.g., problem solving). Four electronic screening programs offered automated follow-up (e.g., automated referrals).

#### **Acceptability**

FRO programs were generally found to be acceptable.

#### **Efficacy**

- Proximal variables: Programs demonstrated positive impact (e.g., preparedness)
- Distal variables: Impacts of the programs on other outcomes (distress, strain, anxiety, depression, unmet needs, quality of life) were mixed with minimal improvement reported across the sample.

# **DISCUSSION**

The main findings suggest:

- FRO screening was mainly used to tailor interventions rather than monitor symptoms (common for PROs)
- Programs demonstrated positive impact on proximal variables (e.g., preparedness) but this did not translate to more distal outcomes (quality of life, anxiety).
- Future research on timing of screening, caregiver engagement, and efficacious follow-up interventions is needed.



# **ACKNOWLEDGEMENTS**

This study was funded by the Canadian Partnership Against Cancer and a Canadian Institutes of Health Research (CIHR) Canada Research Chair.

## **REFERENCES**

- 1. The Change Foundation. (2019). 2nd Annual Spotlight on Ontario's Caregivers.
- 2. Geng, H. M., et al. (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. Medicine, 97(39), e11863.
- 3. Page, M. J., Moher, D., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & McKenzie, J. E. (2021). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. BMJ, 372.
- 4. Peters, M. D. Jet al., (2020). Chapter 11: Scoping reviews (2020 version). In Aromataris, E. & Munn, Z. (Eds), JBI Manual for Evidence Synthesis, JBI, 2020





<sup>1:</sup> Ingram School of Nursing, McGill University; 2: St. Mary's Research Centre, Montréal, Canada; 3: Schulich Library of Physical Sciences, Life Sciences, and Engineering, McGill University; 4: British Columbia Cancer Provincial Health Services Authority, Vancouver, British Columbia; 5: School of Nursing, University of British Columbia, Vancouver, British Columbia