

Informal Caregiving for People with Life-Limiting Illness: Exploring the Knowledge Gaps

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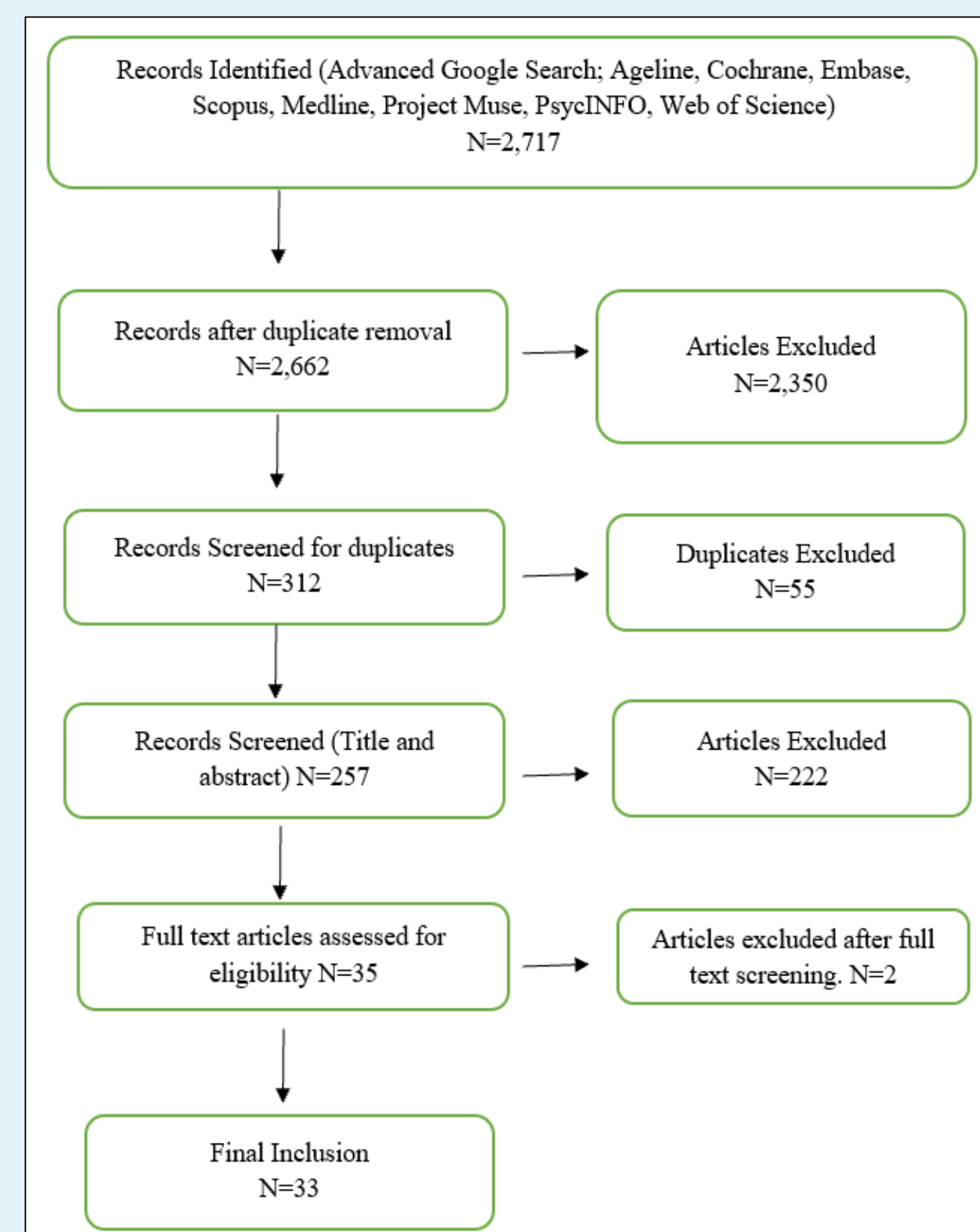
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Introduction

- ❖ People with life-limiting illness are increasingly having more care provided to them by informal caregivers (ICs) such as family members and friends.¹
- ❖ Although there is a substantial amount of literature surrounding informal caregiving, there is a paucity of research from a hospice palliative care angle.
- ❖ To address this knowledge gap, this scoping review explored the effects of and challenges to informal caregiving at the end of life in Canada.

Methodology

Figure 1: PRISMA Flowchart

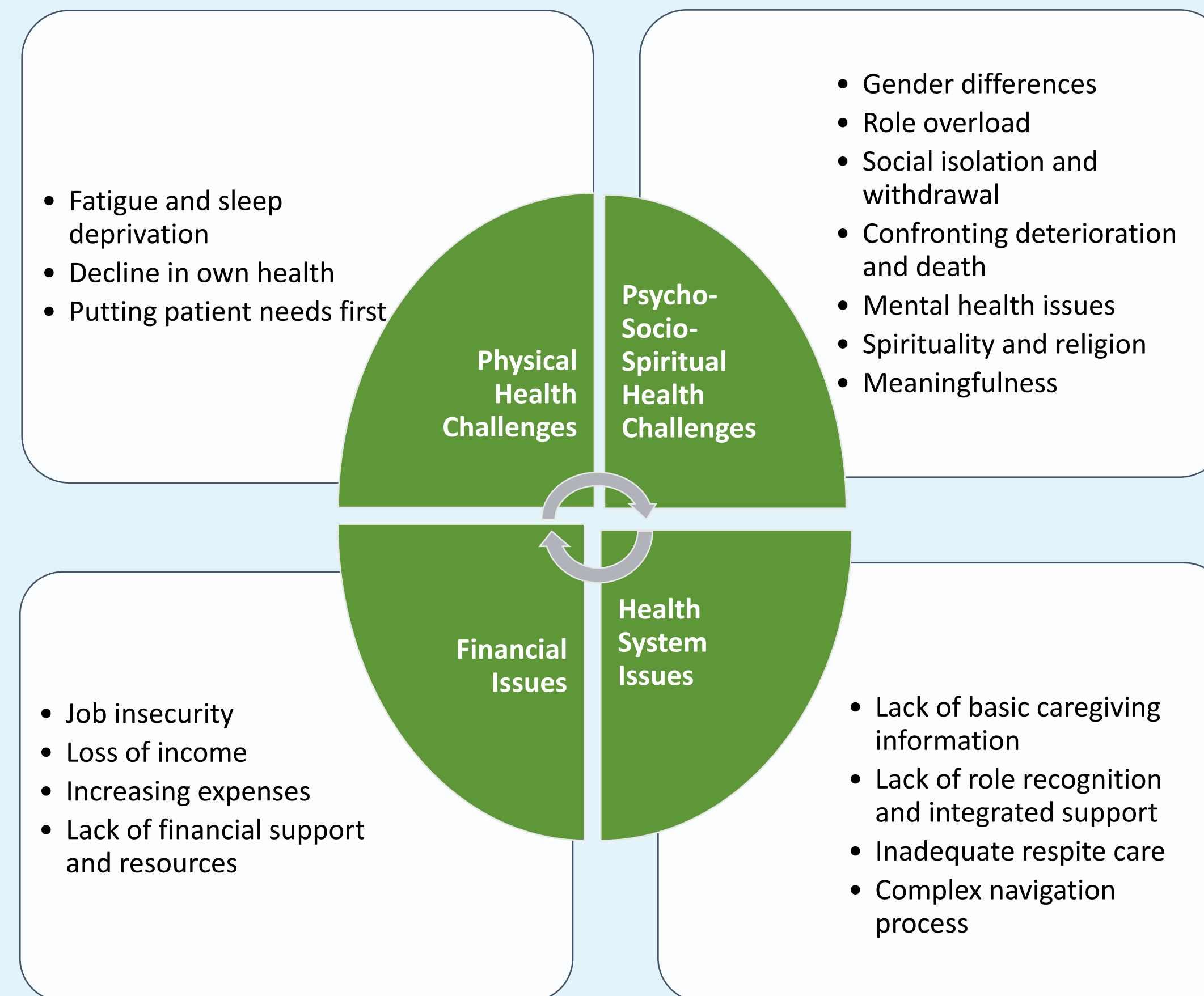


- ❖ A scoping review of the literature was conducted following Arksey and O'Malley's five step framework.²
- ❖ A thematic content analysis was employed to summarize key findings.³

Results

- ❖ There were 2,717 initial search results. After de-duplication and article screening, 33 articles were included in the final article selection.
- ❖ Four major themes were identified after extraction including:
 1. Physical Health Challenges
 2. Psycho-Socio-Spiritual Health Challenges
 3. Financial Issues
 4. Health System Issues

Figure 2: Themes and Sub-Themes Emerging from Scoping Review



References:

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Implications

- ❖ **Practice:** Our findings align with existing literature that support the contributions of physical, psycho-socio-spiritual, financial, and health system burdens to informal caregiver distress. Holistic and integrative interventions are required to support the health and well-being of informal caregivers.
- ❖ **Policy:** Current caregiver supports are inadequate. While European countries are actively developing programs such as the Integrative Palliative Care Initiative (IPC-I), Canada is lagging behind in this field.⁴ Robust policy change is required to empower informal caregivers.
- ❖ **Research:** To explore the effects of hospice palliative care between a diverse range of caregivers providing care to a wide spectrum of patients. To clearly re-define the roles of caregivers, identify their needs, and develop solutions or strategies. To better translate and disseminate resources available to caregivers. To explore the unique experiences and the challenges of minority caregiver populations providing hospice palliative care in Canada and beyond.

Conclusion

- ❖ Informal hospice palliative caregiving leads to and is exacerbated by numerous physical, psycho-socio-spiritual, financial, and health system challenges.
- ❖ Health providers and authorities need to acknowledge the complexity of the issue and work towards systematic policy reform to empower caregivers.
- ❖ Application of the knowledge gained from this review will pave the way to a meaningful end of life experience for both the dying and their caregivers.
- ❖ Scoping Review II on "Supporting Informal Caregivers in Hospice Palliative Care: Are We Doing Enough?" under way.