

Understanding Caregiving Challenges in Canada

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What does interRAI data reveal about caregiving in Canada?

- interRAI data provides a **strong evidence basis** for understanding caregiving in Canada.
- Robust data for decision-making combines evidence from clinical assessment data with the voices of caregivers.
- Together these data can be used to inform **system change**.

interRAI Collaborative Research Network

- Roughly 37 countries, 100 researchers.
- Provides standardized and detailed clinical assessment tools.
- Conducts multinational collaborative research to develop, implement, and evaluate standardized clinical instruments and their applications.
- 4.9 million assessment records across Canada.

What has interRAI data revealed about caregivers in Canada?

- interRAI data was used to **create a screener to “flag” caregivers** of seriously ill home care clients in Canada who are starting to feel burdened.
- The screener identified that 65% (69,638) of caregivers are in the high/very high-risk group for experiencing caregiver burden.

How can these data be used to support caregivers in Canada?

- The screener is an important **decision-support tool** for home care clinicians.
- It can help identify caregivers that may need additional care, education/training, or supports.

What have interviews with caregivers revealed about caregiving in Canada?

- Data from individual interviews were analysed to look for common themes and sub-themes.
- Common themes included:

Caregiver as anchor

- Part of the team
- Trapped by the system
- Lack of respect
- Loss

Bewildering System

- Expectations vs. reality
- Staffing
- Crisis response
- Exceptional experiences

Patient, caregiver, and family-centered care

- Psychosocial and spiritual aspects
- Patient choice/voice/advocacy
- Access to care
- Life outside diagnosis

Implications

For clinicians

- interRAI data provide solid evidence to support clinical **decision-making** and **care planning**.

For decision makers

- Data can support broader decisions related to **system changes** and **quality of care**.

For family members or other caregivers

- Caregiving is a difficult task and caregivers need **ongoing support** as they navigate a complex health care system.

Conclusion

- This research is meant to help people who are providing care.
- The goal of this work is to provide support and acknowledge the lived experiences of those involved with the system and to understand their needs and experiences to improve care for all.

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