

Dementia and Fall Risk: Exploring appropriate screening and assessment of fall risk for people living with dementia and understanding the informal caregiver's perspective in Saskatchewan, Canada.

Background: Falls are the leading cause of injury and hospitalisation for older adults in Canada and the second leading cause of unintentional injury deaths worldwide. For people living with dementia (PLWD), falls have an even greater impact. PLWD are at a much higher risk of falling than the general older adult population with an annual fall rate of 60-80% compared to approximately 30% in the general older adult community-dwelling population. There are standard practices and guidelines for conducting fall risk screening and assessment for older adults, but these are often not practicable for this population.

This project is an offshoot of a larger study entitled “Be Proactive, Not Reactive: A Collaborative Approach to Fall Risk Identification, Prevention and Post-Fall Care for Older Adults in Saskatchewan” with the objective of exploring how its findings were applicable to PLWD and how their informal caregivers are impacted by fall risk.

Project Overview: The project consisted of three research elements, a scoping review, an online questionnaire and semi-structured interviews. The scoping review aimed to explore the current literature on fall risk screening and assessment for PLWD, and to identify any recommendations on the most appropriate tools. An online questionnaire aimed at informal caregivers of PLWD was designed and distributed province wide, which collected quantitative data on fall events, demographics, opinions and experiences. Participants were then recruited via the questionnaire to take part in qualitative semi-structured interviews, which delved deeper into their questionnaire responses and explored more personal and emotional factors from the informal caregiver's perspective. Following analysis of the data, knowledge translation activities were carried out including a conference poster session, an online presentation, submission of papers to academic journals and production of a resources list for public use.



WHAT DID WE FIND OUT?

Scoping Review:

The purpose of the scoping review was to identify and summarise recent research, practice guidelines and grey literature which have considered fall risk screening and assessment for PLWD. Extensive analysis of six electronic medical databases was carried out, along with wide-ranging searches for grey literature publications and online material. The process revealed that there is a very limited amount of research in the area, with a total of 27 publications selected as being suitable for investigation. Five combination fall risk screening and assessment tools were identified, along with 23 individual tests which focused on the assessment stage. This scoping review established that not all fall risk screening and assessment tools are suitable for use with PLWD. The literature explored in this review also indicated that the most meaningful assessments for PLWD are those which replicate 'Activities of Daily Living' such as getting up from a chair and 'Dual-Tasking' activities such as walking and talking at the same time.

Although fall prevention was outside the scope of this project, we argue that if fall prevention interventions are to be successful, they must be built on a solid foundation of knowledge regarding the individual needs of the PLWD. This can only be achieved if appropriate fall risk screening and assessment methods are identified and utilized.

Questionnaire:

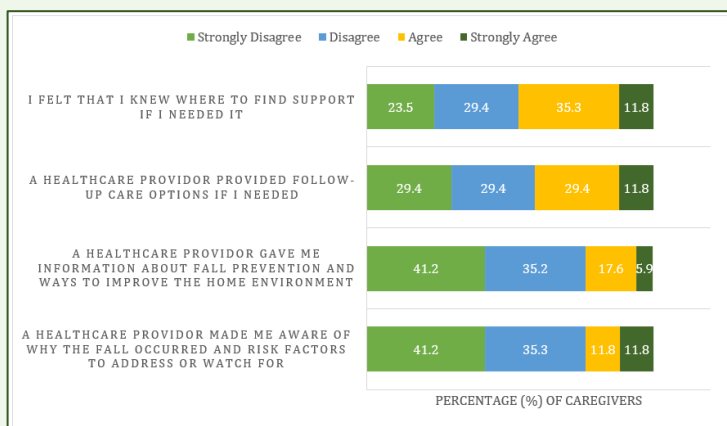
The purpose of the questionnaire was to obtain information regarding the number and circumstances of falls in PLWD, demographic information and the resulting experiences of the informal caregivers. Data was obtained via an online questionnaire which was distributed across the province. For the purposes of this study, an 'informal caregiver' was defined as any relative, partner, friend or neighbour who provides assistance for someone living with dementia. This may include such things as personal care, help with shopping, companionship and meal preparation. The caregiver may live with, or separately from, the person receiving care.

The demographic data showed that 54% of the caregivers lived with the PLWD and that 'spouse' was the most represented group of caregivers at 36%, with 'child' close behind at 28%. The fall event data revealed that 62% of falls in the last 12 months resulted in injury, and that 41% of these falls resulted in hospitalisation of the PLWD. The caregivers reported that 65% of the PLWD had no recollection of the fall event or understanding of how it happened. This could have significant effects on the reliability of fall risk screening and assessment along with any prevention measures.



The caregiver experiences data identified potential health impacts, with 43% of caregivers reporting that they lost sleep because of the fall event and 33% indicating that they noticed a deterioration in their own health after the PLWD fell. Fear was also a common response for caregivers surrounding the fall event, with 76% being scared by the fall event and 67% remaining in a fearful state for a long time afterwards at the thought of the PLWD falling again. These physical and mental disturbances have the potential for significant impacts on the caregivers own health, and should not be ignored.

The questionnaire also explored the caregiver's opinions of the support they received from the healthcare system following the fall event, and a section of the results is shown below.



The results revealed that 53% of the caregivers did not feel that they knew where to go to get help after the fall event. They also showed an absence of assistance and education from the healthcare system with regard to how the fall may have occurred and ways to prevent another fall occurring. The provision of follow-up care was also perceived to be lacking.

Semi-Structured Interviews:

Participants for the interview stage of the study were recruited via the questionnaire in order to expand on their responses, with the aim of exploring the caregiver's experiences, opinions and emotions in more depth than is possible with a questionnaire. The interviews were carried out online via a video conferencing service, which allowed them to be carried out at any time and from anywhere, enabling participation throughout the province including rural and remote locations.

Through analysis of the interviews, several themes emerged such as concern that the PLWD may be suffering with an unknown injury, that they will be moved into long-term care, and the importance of ensuring that the PLWD continues with their routines and activities as much as possible. When discussing the effects on themselves, many caregivers noted physical pain (e.g. sore back, neck and shoulders; headaches) and negative effects on their mental health (e.g. stress, frustration, guilt, loneliness and feeling overwhelmed or trapped). These factors can also combine to create other broader issues such as loss of sleep, exhaustion and burn-out, which are then cycled back into a complex causal loop of effects on the caregiver. There were however, some positive narratives such as enjoying new hobbies together and making new friends through community support groups.

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Executive Summary

When asked about their interactions and experiences with the healthcare system, the responses from the caregivers were mixed, with some having largely positive experiences and others less so. Many caregivers noted that they felt confused and overwhelmed by hospital processes, hierarchies and staff titles which added to their anxiety when attending with a PLWD. Several also reported that during interactions with emergency care providers they had felt ignored or discounted when attempting to communicate information regarding the PLWD. This has potentially serious consequences as PLWD often have very specific needs, and it may not even be obvious at first that the person is living with a form of dementia. One caregiver recalled a scenario where the PLWD was giving incorrect information about their medication to the emergency healthcare provider. If the caregiver had not been able to correct them, the consequences could have been serious.

The interviews produced some very powerful comments, some of which are reproduced below:

“Absolutely running on empty. That’s the way I describe it. You’re just putting one foot in front of the other ... all of us were exhausted.”

“If she did fall, she could probably, quite easily, walk around on maybe a broken ankle or something and not even realize it”

“It took me probably 45 minutes before I could get her up off the ground because... she couldn’t get her mind around what she was supposed to do”

“The facility didn’t tell me that’s why he fell”

“It has been extremely stressful”

“I feel very alone”

“Some days I don’t want to have to do it all by myself”

“Looking ahead is really frightening”



“I am slowly morphing into the two of us... my identity has started to become more with his. When he’s no longer here, how do I put myself back together?”

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KEY MESSAGES

- Our scoping review found that not all fall risk screening and assessment tools and tests are appropriate for PLWD. The most meaningful fall risk assessment tests are those which replicate Activities of Daily Living and Dual Tasking.
- 65% of the PLWD in our study did not remember falling or understand why it happened. This must be taken into account when using fall risk screening and assessment tests and designing fall prevention interventions.
- Many of the informal caregivers of PLWD who took part in our study disagreed that they received assistance, education and follow-up care from the healthcare system in Saskatchewan following a fall event.
- Several of the informal caregivers of PLWD who took part in our study had felt ignored or discounted when attempting to communicate information regarding the PLWD to emergency healthcare providers. This could result in vital information about the PLWD being missed.
- All of the informal caregivers of PLWD who took part in our study were, or had, experienced a wide range of negative impacts on their physical and mental health. Support systems such as respite care, community activities and family/social networks were highly valued where they were available. However, some also reported positive impacts which should be recognised.



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