

The IDEAL Study

September 2016

Interim Report

Inviting Dialogue on Experiences
of Active Involvement in LTC

About IDEAL

The IDEAL study is a four-year project, which began in 2013. Data were collected at Site 1 from April 2014 to April 2016.

In February 2016 data collection began at Site 2, and is ongoing until October 2016. One more long-term care facility will be included in the study before its conclusion in 2017.



What is the purpose of the study?

We are collecting information for the study through interviews and spending time at participating facilities.

We will be at three different LTC facilities.



1 urban not-for-profit LTC facility



1 suburban not-for-profit LTC facility



1 rural not-for-profit LTC facility

The aim of this study is to gain a better understanding of how families, residents and staff work together in long-term care facilities.

The IDEAL study seeks to understand the ways individuals work together in long-term care facilities through learning about the experiences of **residents**, **family members**, and **staff**. This understanding will help inform policy and practice in this area.

Who participated in the study at Site 2?

Fourteen



Family Members



Seventeen



Staff Members

Four



Residents



Four

Residents



33 hours of interviews

70 hours of participant

observations

Why is the study important?

- In Canada family members contribute over **44 million hours** of care work in LTC facilities, but are often absent from research that informs and shapes policy and practice.
- By 2038, families are expected to be contributing over **107 million hours** of care work in LTC in Canada.
- There is a marked need for an in-depth examination of the negotiation and sharing of care responsibilities among **family members, residents** and **staff** in LTC to improve the safety and quality of care in this sector.

Positive Feedback at Site 2:

Family members expressed appreciation for all members of staff—from nursing, to cleaning, to management—and felt better knowing their loved one is at Site 2.

“The care here is extremely good, I'm very happy with [it]. And their reputation's good.”

Residents said that they enjoyed all the activities and opportunities to socialize.

“I like it here. There's so much to do.”

Staff felt that the best part of their jobs are their relationships with the residents.

“My fulfilment here is seeing my residents smile back at me.”

Potential Areas of Improvement at Site 2:

Family members wanted more social activities for residents, and further opportunities to connect with one another—especially on evenings and weekends, for those who work. Residents desired independence that aligned with their individual capacities. Staff wanted higher levels of staffing in order to spend more quality time with residents.

What ideas came up at Site 2?

Family members and residents balance maintaining family traditions and identity while coming to terms with an evolving disability or disease in the context of LTC. There was more of an emphasis on the former.

"I've learned not to expect her to be in my world. You have to be in her world, wherever, whatever that is, and you just go." -FM0205

"Oh, we talk. We go out and sit in the garden. We take her for lunch if she's up to it, feeling it. We go for drives." -FM0225

"So she doesn't have a lot of hobbies. So it's more a matter of just being with her. And she just loves that. Yeah, she loves the company." -FM0219

"[when he visits]...we'd have a game of cards on the bed and talk, go down and have a cup of coffee together." -R0204

Families maintained traditions and identities through decorating residents' rooms with photos, art, personal objects and celebrating holidays together. But more important were the little, frequent ways family members sustained relationships by being involved in residents' care, most often in a social or instrumental capacity.

The staff and organization's role in caring for residents and keeping them safe was at times at odds with family priorities. Most discussed among staff members was the importance of interdisciplinary communication between staff members.

"Sometimes, if the resident is pureed and they [family members] [...] gave them different food... So, as long as we tell them that they're not supposed to do that, and if they really insist on doing it, they have to sign the waiver ... Because they want, they wanted the resident to eat what she *used* to eat, right, and what she *used* to love to eat." -S0211

"The family members want them [residents] to do the activities or do exercise. [...] we can't force them to do it. But the recreation people will bring them down for exercise and that. But sometimes they refuse, but the family members want them to do the things." -S0215

"I think families have a hard time dealing with that too, about how dementia changes people." -S0204

"...aggressiveness most of the time comes because they cannot express anymore like they used to do, right? It's same like us. "Oh, I used to do like that. I cannot do it anymore." Of course I'm getting agitated. I'm getting... It's same for them, right? [...] don't treat them like children. Don't treat them like they are sick. Treat them like normal people." -S0207

How the care environment influences the experiences of residents, family members, and staff. A main focus for staff was on managing unsafe behaviours or situations, through initiatives like the Purple Project or accident prevention.

going
time right
care good
know want
think come family

The 10 most frequent words spoken during interviews at Site 2

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How do Site 1 and Site 2 compare?

- Although data collection at Site 2 took place over a shorter amount of time than at Site 1, there were more interview participants at Site 2 (Site 1 had 12 family member interviews, 11 staff member interviews, and 3 resident interviews.)
- At Site 1 the majority of family members who participated were the spouses of the resident, while at Site 2 the majority of family members who participated were the sons and daughters of the residents.
- While there were many overlapping themes, each site did have unique concerns. At Site 1, seven family members were concerned about responsive behaviours that can lead to resident-to-resident aggression. At Site 2, four family members were concerned about the conflict that can arise when negotiating care within families.

Next Steps

- Data collection at Site 3.
- Presenting research findings at the 21st IAGG World Congress of Gerontology and Geriatrics (July 2017).
- Publishing papers and research findings in relevant journals.
- Developing and providing educational workshops for family caregivers in LTC facilities.

Questions about the study?

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