

The IDEAL Study



SPRING 2018

SITE 3 Report

INVITING
DIALOGUE on
EXPERIENCES of
ACTIVE involvement in
LONG-TERM CARE

What is the purpose of the study?

The IDEAL study was a **four-year** project which began in 2013.

Information was collected through interviews & time spent at three different long-term care (LTC) facilities.



1 urban not-for-profit LTC facility
Data collection: April 2014 - April 2016



1 suburban not-for-profit LTC facility
Data collection: February 2016 - September 2016



1 rural not-for-profit LTC facility
Data collection: March 2017- September 2017

The IDEAL study sought to understand the ways **residents, family members & staff** work together in LTC facilities. This understanding will help inform policy and practice in this area.



Findings presented in this report represent the group data from Site 3 & what we heard most often.

In Canada, family members contribute over **44 million hours** of care work in LTC facilities, but are often absent from research that informs & shapes policy & practice.

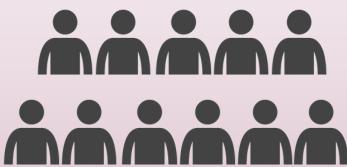
By 2038, families are expected to be contributing over **107 million hours** of care work in LTC in Canada.

There is a marked need for an in-depth examination of the negotiation & sharing of care responsibilities among **family members, residents & staff** in LTC to improve the safety & quality of care in this sector.

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Who Participated at Site 3?

11 family members



10 staff members



- 27 hours of interviews
- 10 hours of observations

family
see want to come
staff
care right
know
get think time got
going mom

Most frequent words from Site 3 data

Positive Feedback at Site 3:

From Family Members:

"I see they're run off their feet. So I think they do very well, you know, dressing her and putting a scarf around her neck and all those funny little things that I like done." (FM304)

"[Staff] always ask me, 'what do you think? What do you think might be going on and what would you like to happen here? What aren't we doing right here?' (FM306)

"P: Oh, the staff here are just wonderful.

P1: We've had to, you know, discuss things with them and figure some things out but they are really trying to help really well. The staff are great." (FM301)

From Staff:

"They [most family members] understand what we're doing and they're pretty much like... 'I trust you guys as care aides and nurses that you are doing the best for my mother.'" (S304)

"...well that's why I'm here, is to provide [the residents] with some quality... We know that this is the last phase of their life so for me, it is being able to provide them with some quality of life while they're here. So I like to focus on humour and laughter and you know, because it's a home but we all know it's institutional as well." (S306)

"We're lucky to have so many family members that are so involved. I know I have said to them 'thank you for being involved.'" (S305)

Family Members

Expectations for staff to individualize resident care & maintain residents' emotional well-being.

Families felt frustrated at the perceived lack of person-centred care practice.

Staff and Families:

Perceptions of each other's roles impact how the relationships between staff & family evolved.

"I'd just like to see the staff have 5 more minutes a day to be able to sit on her bed and say, 'You know, how many kids did you have again? Where were you born?' You know. I'd like to see that." (FM303)

"It's a busy, busy day. I mean we do everything from toileting them to cleaning them to making their beds to brushing their teeth. So if you spend anything more than 15-20 minutes on one person, you're already behind." (S301)

Front-Line Staff

Staff experienced difficulty when they felt family members had unrealistic expectations of care work & workload.

What were the Findings at Site 3?

Communication Challenges

"I didn't know, what is that level of expectation we should have. Because no one tells us what their job description is. No one says, 'This is the person that's supposed to be doing this, this and this. This is the person that's responsible for this, this and this.'" (FM308)

"A more realistic admittance to the facility... Because I know one person I spoke to said, 'I was promised this and I was promised that and I was promised this.' And I said, 'Sorry, I didn't realize.'" (S305)

"... just giving you information is huge... like if you had somebody in the hospital, you know you talk to someone in the hall and they say, 'oh, she had a bad night last night.' It's similar here. Just because they live here doesn't mean you don't want to know a daily update." (FM317)

"...technically, we're not allowed to talk to families about anything. Everything has to go through the LPN [nurse]...whether they question how their resident slept or how their health is, how she eats." (S301)

"...there's a lot of restrictive rules when a resident wants to make their own choice. And I think that it's become easy for families to just speak on behalf of them and then you know, it's like we're talking over this person. They're just the person in the bed. And often they forget that this person still makes a lot of choices throughout the day when they're not there. Whether it's something as simple as 'I want toast with breakfast', 'I want to wear the green shirt today', and 'I don't want to go to bed until 10:00 o'clock tonight. Maybe I wanted to go to bed at 7:00 yesterday but this is my choice today.'" (S307)

"Some days it's really hard to go in that room, knowing that the family's going to be in later that day and they're going to have a complaint no matter what you do" (S301)

Balancing Person-Centred Care & Workload

"It's all care. It's all, 'How are you today, [R302]? Can we do this? Can we do that?' It's lovely...they're gentle & they're sweet...But do [staff] talk to her like she's got an identity and a personality? No, not really." (FM303)

"But when push comes to shove and they've got fourteen residents to take care of, they've got to get their job done and they're really pushed and they're in a hurry. So getting the job done in a standard way, of course is much more efficient than doing it in a more individual way. So that's when things fall by the wayside." (FM302)

Juggling Multiple & Competing Demands from Residents & Family

"The summer's really difficult because they have so many casuals. They have a tough time getting staff...as soon as they hit long weekends...it's a crapshoot. You just don't know...who's going to be on" (FM303)

"I think [family] expect a lot. And we say, 'Well, great. If we had an extra person, it would be done.'" (S304)

"I would love for them to have more help. I feel like they're under-staffed... it's like they're just kind of trying to keep their heads above water..." (FM304)

"Part-time versus casual...they'll be on the floor for a while and then all of a sudden...they've gone to a different pod and it's like, oh, really? You were just starting to get to know my mom." (FM308)

Consistency of Staffing & Having Sufficient Staff (exacerbated by rural location)

Appreciation of Relationships with Families & Residents & of Care Provided

"So as I say, when I go to [Site 3], the staff are very, they're very kind, they're very attentive." (FM310)

"...I just look at [residents] as part of my family and it just feels like a little family." (S304)

"It's like a family here... They want you to feel like you're part of the family... They care about us too." (FM301)

"They're more than just my mom's RCAs. They are friends. We consider them family." (FM302)

"I just want them to know how much I appreciate them being here because without them, I might be dead! [laughter]" (FM306)

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How do the Three Sites Compare?

- Unlike Sites 1 & 2, no residents were interviewed at Site 3.
- At Site 1, participating family members were mainly spouses, while at Sites 2 & 3 they were primarily adult children.
- While Sites 1 & 2 are located in urban settings, Site 3 is situated in a more rural setting, which creates some staffing challenges.
- Although there were overlapping themes, each site also had unique concerns. At Site 1, concerns centred around responsive behaviour & resident-to-resident aggression. At Site 2, concerns existed regarding conflict arising between family members when negotiating care. At Site 3, staffing concerns played a central role in families' experiences.

Questions about the Study?

Contact Us!

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Tips & Suggestions from Families & Staff

- Have staff wear easy-to-read nametags that include their position (e.g., RCA, LPN).
- Put up a small whiteboard on each unit that notes which staff members are on-shift & for which residents they are responsible.
- Include a brief summary of a resident's personal preferences & biographical details in a visible area in their room to assist in personalizing care
- Ensure RCAs are present at resident care conferences.
- Offer workshops/in-services:
 - For families and staff: on interpersonal communication (e.g., facilitating communication between staff & families)
 - For families: on how families can safely assist residents when transferring residents (e.g., out of a wheelchair) or helping at mealtimes
 - For staff: on the latest in dementia care approaches



Next Steps

Publishing papers & research findings in relevant journals.
Developing & providing educational workshops for family caregivers in long-term care facilities.



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