

“Mom, I think we’ve been railroaded”

***The Experience of Caregivers of
Alternate Level of Care Patients***

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Mount Sinai Hospital

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Circle of Care

Program of Research

Overarching Goals

1. Build a database of Patient and Caregiver Experiences Related to Alternate Level of Care.
2. Use these data to understand the critical health system performance issue of ALC and how it can be addressed.
3. Engage with patients and families to actively build solutions to the ALC issue using “co-design” methods.
4. Test these patient and caregiver informed solutions in interventions/trials.

ALC Statistics

<https://www.oha.com/CURRENTISSUES/ISSUES/ERALC/Pages/eralc.aspx>

14%

Hospital beds in Ontario occupied by ALC patients

28%

Hospital beds In Northwestern Ontario occupied by ALC patients

44%

ALC patients in Ontario waiting for a long-term care (LTC) bed

63%

ALC patients in Northwestern Ontario waiting for a LTC bed

What do we know and what are the gaps?

- Small proportion of patients account for substantial # of ALC acute hospital days.
 - Morbid obesity, psychiatric diagnosis, abusive behaviors and stroke (made up 4.3% of all ALC patients but 23% of ALC days)¹
- ALC patients are at risk of rapid functional decline and adverse events.²
- ALC results from “system” issues (ease of discharge arrangements, community capacity).^{3,4,5}
- The patient and family experience regarding ALC has received very little attention to date.^{6,7,8}

Objectives

- To share the experiences of caregivers of ALC patients (targeting those who are waiting for long-term care from the hospital).
 - To share areas of unmet need and perceived risk factors for ALC from the perspectives of family caregivers.
 - To explore ways in which capacity can be built in the community to minimize ALC risk.

Methods

- **Design** - Exploratory Descriptive Qualitative Study
- **Setting**- Northwestern Ontario (2 hospitals: 1 acute and 1 post-acute)
- **Recruitment**
 - List of eligible participants provided by the North West Community Care Access Centre (CCAC)
 - Care coordinators contacted them to seek permission for researcher to follow-up
 - Researcher followed up to obtain consent and schedule interview

Methods (continued)

- **Sample – 20 participants (7 patients and 13 caregivers)**
 - *Inclusion Criteria (patients)*- in hospital waiting for LTC, on CCAC case load but not on wait-list prior to hospitalization, English speaking, can provide consent
 - *Inclusion criteria (caregivers)*- caring for someone who meets the above criteria *in addition* to those who cannot provide informed consent.
- **Data Collection**- Semi-structured one-on-one interviews*, audio-recorded and transcribed verbatim.

* Two conducted with multiple caregivers (family members) of one patient

Methods (continued)

- **Data Collection Tool-** Self Designed Interview Schedule
 - Hospital Experience
 - Homecare Experience (if Applicable)
 - Social Supports
 - Long-term Care Wait Process
- **Analysis** – Identify key categories in the data, open thematic coding within and across categories (capturing expected and emergent themes).
 - Methodological rigor ensured by coding simultaneously during data collection until saturation of themes occur; 2 coders to reach consensus on coding framework, themes and definitions (ongoing).

Caregivers

Variable	Number of Participants (n = 13)
Sex	7 Female, 6 Male
Relationship to Care Recipient	Spouse = 2, Child = 7, Parent = 1, Other = 2
Employment Status	Employed = 5, Retired = 3, Not Working = 1
Type of Hospital of Care Recipient	Post-Acute = 10
Lived with Care Recipient?	Yes = 3, No = 7
Length of Hospital Stay	< 1 year = 6, 1-3 yrs. = 3; 3+ yrs. = 1
Reason for Hospitalization	Fall = 5, Stroke = 1, Frailty = 2, Mental Illness = 2, Cancer = 1
Community Services Prior Hospitalization	Yes = 6, No = 4 (1 refused services)

Key Categories

**Unmet
Community
Needs**

Hospitalization

- Reason for Hospitalization
- Admission Experience

**Long-term
Care Process**

**Caregiver
Challenges**

**Hospital
Challenges**

(Reason for) Hospitalization ***More than a single isolated event...***

“Yes, two years ago March, he fell in the driveway along with our mother. They both went down. But they both had an injury but his was more. Like she put her shoulders out and he took the knee out. He went to surgery. There was difficulty with the surgery. There was difficulty with the recovery. Which led to more problems because of the dementia, because of the medication, because of no routine. It led to him being diapered mainly.”

- Caregiver for her father (in hospital) and mother (at home)

Her Brother (also a caregiver) added: *“Yeah, well, he had the dementia happening. And he was walking very slowly. And an accident was ready to happen. You can tell, you know, from the way he was walking.”*

Hospitalization Experience for Patients

Two Caregivers Share Their Aunt's Perception of Being Hospitalized:

“But in fact, she still believes to this day that she took a boat to the hospital... Yeah, overseas, she was kidnapped overseas. The story she told us was they came in, they wrapped her in a blanket, they covered her face. And then when she got off the boat, the person didn't even speak English at the point. And then the hospital ended up in it but at first it wasn't even a hospital. She said that she took a boat to Florida, is what it was. And then she said they punched out her teeth. But meanwhile what had happened was she's had lots of teeth removed over the years.”

Caregiver Challenges

- Balancing Multiple Roles
- Caring While Aging
- Time to Look After Self
- Living Apart from Care Recipient

Caregiver
Factors

- Dealing with Care Recipient's Complex Illness
- Dealing with Feelings of Guilt
- Care Recipient Refusing Care

Care
Receiver
Factors

- Being Kept in the Dark/ Future Uncertain
- Filling in Healthcare System Gaps
- Experiencing Pressure from the Healthcare System

Health
System
Factors

Balancing Multiple Roles

“It’s too much. It’s too much. It’s him and it’s her. I don’t know if that’s a proper thing to say or a proper way to describe it but I just feel like, you know what, when you take a piece of meat and throw it into a lion’s den, and the lions are...Tearing it apart, this side, that side. I just feel like I’m right in the middle of it.”

- Caregiver for her Daughter and Neighbour

“But to me, what it is, it's the stress. I have to admit, I’m in a busy job. I teach. And then some days, it depends on how it goes, you’ve got to put up with my mother.”

- Caregiver for his Father (in hospital) and Mother (at home)

Care Recipient Refuses Care

“Like when I used to come and bring stuff to her, you know, like stop and get groceries or if I made something good to eat or something like that, I would get it ready and jump in the car and wheel it over to her. Well, our visit was between my car and her door. She never let me in.”

Apparently I was told that when she was offered to be helped, she refused the help. When they made a phone call and said that they were coming in and stuff like that, she sort of didn't answer the door. Another thing, I got several phone calls from the nurse that was bathing her. She also couldn't get in. She'd be ringing the doorbell and stuff like that, and [daughter] wouldn't answer the doorbell, she wouldn't let her in. And so of course, there's no bath. I mean she can't be hanging around forever. She's got to get [daughter] bathed and off she goes to other places.”

- Caregiver for her Daughter and Neighbour

Refuses Care/ Living Apart from the Care Recipient

“So looking back, it’s hard to say because unless somebody actually goes to the GP and tells the GP what your concerns are, nothing happens. Because the first time I called [community agency], the person on the phone was really helpful in that you need to get her to the doctor and get a geriatric assessment. Well, getting her to the doctor was...she refused to go. So it’s really hard because you have to respect her. You can’t force her to do things. I think the only difference would have been if I was living in town, I might have been able to get things assessed sooner.”

- Caregiver for her Mother, Works Full Time, Resides in a Different

Filling in Healthcare System Gaps

“Or I also find that as family members, we are the ones that are helping other clients – opening up their milk and their trays. Which to me staff should be doing that. Or maybe volunteers. Maybe you need more volunteers. I don't know how you can get volunteers in there. Maybe for breakfast, lunch and supper to make sure that they have everything opened and make sure that they have, you know, their bibs and just their set-up routine every day. So it will alleviate maybe the nurses to do that and go somewhere else when Mr. so and so needs to go the bathroom or he needs care.”

- Caregiver for her Father (in hospital) and Mother (at home).

Hospital Challenges

- Deconditioning
- Lack of time
- Trade-offs
- Person-Environment Fit
- Not Enough Stimulation
- Misalignment of Routines

Deconditioning

“And I find that [post-acute care facility] deconditioned my dad. And you know, not taking him to the bathroom as often, and finding him like on the side of the bed with his cast almost down to his knee or past his knee because that’s where his injury was, because he had to go to the bathroom. And he didn’t know better to ring. So I don’t know how long. He had to have been there for quite a long time because his knee was swollen and the cast had been pushed down.”

- Caregiver for her Mother (at home) and Father (in hospital)

Lack of Time

“The staff here are wonderful but they’re just over-worked. They don't have the time to sit with each person that’s on that floor to help them with their meals... Just to remind her that there's some food there, eat...A little guidance every so often to make sure that she eats. And the staff, as I say, they’re wonderful.”

– Caregiver for his Mom

Trade-Offs

“So she’d be up until 3 in the morning, trying to go into people’s rooms, yelling, screaming. So it was hard on the nurses. And I mean I’m realistic. I know it. I understand. I mean I’ve been there. I worked in long term care for several years as a registered practical nurse, actually specializing in Alzheimer’s dementia. So I know what it’s like. And that’s why even when she was at the [post-acute care facility], they said, “Well, we had to put her into a wheelchair and put a seatbelt on it.” I said, well, that’s fine but even when she was at the hospital, she might have the occasional fall but she was still able to keep her strength in her legs. And I said that’s what I’d really like to see.”

- Caregiver for her Great Aunt

Person-Environment Fit (Example 1)

“But she hates it here. She hates it here. She hates the old people here because she said they cry out in the night, they disturb her sleep. You know, there’s too much of an age difference. You know, like [daughter] is in here with people that are... You know, like [daughter]’s body is... I would say [daughter]’s body is broken. It’s broken. It’s not healthy. But her mind is sharp. She’s as sharp as can be. Maybe if her mind was gone then maybe she could accept a lot of this stuff.”

Person-Environment Fit (Example 2)

“that’s the beauty of my mom having Alzheimer's, is in the moment she kind of understands that this isn’t...like I’m in a room with 3 other women, for somebody who’s been so private all of her life. But it hasn’t been a... Because she can’t... Every day it’s, “Where’s the bathroom?” It’s only in the moment. And so she hasn’t had a big problem in that environment. Thank heavens for dementia.” caregiver 8

Lack of Stimulation/Decrease in Care

Interviewer: *“So you’re paying for long term care in the hospital setting...”*

Caregiver (Daughter): *“With no services.”*

Interviewer: ... *“without the service level that you would get in a long term care facility.”*

Caregiver: *“And oftentimes they’ll come and say, ‘[Mother], would you like to go for a walk?’ ‘No.’ ‘Okay, bye.’ Coax her. Give her a reason. Right?”*

Misalignment of Routines

“And it was really only an issue recently...And it’s a bit of my own selfishness, if you can put it that way. This one nurse’s routine was to give mom her medication as soon as she came on shift, which is 7:30. By the time I get there at 8:15, mother is now in la-la land. So that half hour or hour that I would always have with my mom to feed her, to do the hugs and kisses, oftentimes I clean her up and get her dressed in the morning, I couldn't have that because the meds that she has knocks her out. So it was simple. All I had to do was say family requests that we give the medication with breakfast. So end of problem.”



Caregiver for her Mother while Working Full time

Long-term Care Process

- Long illness process led up to hospitalization when it was then decided long-term care was needed
- When the “wait at home” option was explored there family caregivers tended to resist due to:
 - Not living in the same community
 - Not living in an accessible home
 - Fear
 - Not getting the home support needed to provide care
 - Unable to because of other roles (working)
- Sometimes the caregiver appeared willing but the *right* supports were not available

Sometimes the Caregiver Was Willing but the Services Were Not There

“And then they came up with the suggestion that she wouldn't be able to stay by herself. She said her memory is too short. Because we don't know, maybe she might get up and go out. I said, I can't see that. But she said you never know. She said her long memory might be starting to go too. That's what they were saying. That's what they said - we can't keep her by herself. I said, well, can we get somebody to come in? And they said, well, the only thing that they would be able to do is for 8 hours. That's it, that's the max, she said. But there's nobody there for the night. So that was the hard part.”

- Caregiver for his Wife while Working and Dealing with Personal Health Issues

Long-term Care Process

- Some **positive experiences** (family meetings, ongoing communication and flexibility in switching bed options)
- While patients and families were able to choose a preferred LTC home they don't have a say in the **#of moves** beforehand
- Some felt that the process was full of **uncertainty** and characterized by **perverse rules**
- Some felt that the hospital was **pushy** and was assessing the patient before they had a chance to stabilize

Many Moves Before “the Move”

“But I just didn’t think it was fair for my dad having dementia or Alzheimer’s to go from... And you would know too. You go from one unit and you’re settled, and you’ve got these nurses. Then you go from there, you go to 3-south, to 2-south, to 2-north, to 4 and then 5. So he went for 5 moves. And then they just say to me that it’s all to do with the... Because my dad didn’t need the rehab anymore. So he went from the rehab to a different stage, right. A different unit.”

- Daughter Caring for her for Mom (at home) and Dad (in hospital)

“Basically at the end there, it’s just like he doesn’t suit our needs at [post-acute care facility] here, he’s got to go somewhere else. Right now we’re going to put him in [post-acute care facility site].” - Son Caregiver

Hospital (at times) Perceived as Pushy...

“Well, they seemed to be very pushy in, you know, getting him out of there, out of the [hospital]. I guess they needed the beds or something. And he [son] says, “Mom, I think we’ve been railroaded.” We didn’t like the way it was going. They were suggesting that he come home. And we said no because I don’t know if I could cope with that and I think it would have been too much for me. And they suggested that he come home for 90 days. And it would make a difference of how fast he gets into the nursing home because he would be getting...he wouldn’t be getting any care in a hospital...And we didn’t want him to come home because I knew I couldn’t handle him. Because like if he passes out in the night, and if I don’t hear him or something...”

– Caregiver for her Husband (in hospital) and mother (at home)

Lack of Alignment between LTC Process and Patient and Caregiver Realities

“And so they did phone and say that they had a bed. It was on a Thursday, and that it was available on the Tuesday. And so I checked and I could get out there Tuesday night. So I said let’s go for it. And then Sunday night she fell and broke her elbow, and ended up in hospital and had to have surgery. So now I’m sitting back at the [hospital]. And my poor mom hasn’t been out of bed in 2 ½ days. She hasn’t had the surgery. And I’m about to lose her long term care bed... So when I explained to them that it was really difficult for me to take my mom physically over and bring her back when she could get called to the OR any minute, and I don’t want to miss that either. So she got her surgery that afternoon. She was discharged Friday. And I just went over anyway and moved all her stuff in anyway, even though the bed wasn’t there. It was assigned to her but it was unclear. And I moved her stuff in anyway. [laughs] And then got her in, and she’s been in there since.”

- Caregiver for her mother while working full time in a different province.

Unmet Community Needs

- Some shared positive community care experiences but many gaps were identified.
- What's Needed?
 - Flexible Care (Time- evening care, Type- socialization, meals)
 - Predictable Care (fewer cancellations)
 - Home Adaptations/ More Accessible Housing
 - Greater Capacity in Retirement Homes/Supportive Housing
 - Having a Point Person (Coordinator)
 - More long-term care beds (to reduce long waits)
 - Assessments that better determines decision making capacity
 - Greater assistance in determining the right setting/care package

Some were Satisfied with Community Care

“...it was really going well. And we enjoyed the ladies that were coming. And then there was a gentleman that was coming too. And you know, like he’s in his early 80s, and I’m in my late 70s. And a lot of our relatives and friends have passed away. And we enjoyed that company every day. We looked forward to it.”

- Caregiver for Husband (in hospital) and Mother (at home)

Greater Flexibility (Time)

“But as far as extra care, as I said, the only thing I can think of is a longer day for laundry and for showering days, stuff like that. You know, just so they’re not rushing them. Because with the dementia and everything, if you start rushing them and making demands on them, they get all flustered.”

- Caregiver for his Father

Greater Flexibility (Type of Care)

“So I wanted activity. I wanted something that... Because her social circle is small. She wasn’t getting out. So what I wanted was somebody to come and take her for a walk, walk down the hall, little activities, it doesn’t matter. Because dad was doing everything. Dad was killing her with kindness, right. Dad was doing the laundry. Dad would do the food. Everything. And she is/was capable. Still is capable on some levels. But he was doing it all. So it was like was there someone who could come in and socialize, exercise, that sort of thing?”

– Caregiver for her Mom while Working Full Time



Issues of Reliability and Communication

“Well, [lead community agency] had contracted out to [community agency]... They were supposed to show up at a certain time, and they never showed up. Now, you can’t blame them. They had like 20 people at the [retirement home] they’re supposed to service by one person. And the day that she fell, they never even showed up. And she was lying on the floor for several hours before [retirement home] staff found her.”

Caregiver for his Mother

Assessing Capacity

“And the last time when she had gotten out, when all these things happened with my parents, they had gone ahead and done the assessment on her, and they said that she was borderline capable of making her own decisions. So it kind of came up that she would make quick rash decisions. She didn’t have the thought process to be able to think things through. And so there was a lot of issues with all that sort of stuff.”

- Caregiver for her Great Aunt

Key Insights

- Caregivers shared potential community based solutions that *may* address ALC or at least create a more supportive experience.
 - E.g., Night care, supports for socialization, meals
- Lack of capacity in hospitals impact patients (deconditioning), and caregivers (who fill in the gaps and are getting burnt out).
- The patient only tells part of the story (important context provided by caregivers). Passive patients may not self-advocate.
- Many trade-offs in busy (post) acute care environments comprised of increasingly medically complex patients

Key Insights

- Many challenges identified have no clear/easy answer
 - Trade-offs between **security** (providing homecare services) and **autonomy** (patient refuses care despite need).
 - Trade-offs between **health** of busy hospital staff (using a Hoyer lift as a quicker option and to protect back) and **health** of patient (who, as a result, may not ambulate as often and start to decondition).
 - Trade-off between **safety** targets of hospitals (minimize falls/adverse events) and **autonomy** (patients want to move around freely).

Key Insights

- By the time patients become ALC, caregivers are already burnt out and patients are quite complex.

Three key questions:

- *“Can we begin to develop mechanisms to identify those at risk in the community sooner?”*
- *“How can we make the long-term care waiting/ALC process more tolerable for patients and families?”*
- *“How can we begin to openly discuss and address the many trade-offs that occur during the transition/ALC process?”*

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Thank You!

Questions?

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