From Alternate Level of Care to Person Centred Care: Perspectives from Multiple Stakeholders

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Keynote for GTA Rehab Best Practices Day
\textit{May 3, 2019}
Presentation Outline

• People and System Complexity
  • Opportunities to Improve Care Quality

• A Key Care Quality Issue: Alternate Level of Care

• What is Known about ALC?

• A Deeper Look at ALC Experiences

• How do we Move Forward?
  • Strategies Co-designed by Patients, Caregivers and Providers
People and System Complexity

Opportunities to Improve Care Quality
Complexity of Patients

Mental Health, Addiction, Cognition

Social Determinants of Health

Multiple Concurrent Complex Conditions ± Aging

Slide created by Jason Nie
Let’s Keep in Mind…

• The majority of factors that influence health lie *outside* the health care system
System Complexity

Slide created by Jason Nie
Continuity of Care
Haggerty, Reid et al (2003)\textsuperscript{35}

**Informational Continuity** - information on personal histories, events so that current care for patient is appropriate

**Relational Continuity** - an ongoing therapeutic relationship between a patient, care partners and care team

**Management Continuity** - a clear and consistent approach to the management of a persons multiple, fluctuating care needs
Value-based healthcare

Outcomes that matter to patients and caregivers

Costs throughout the patient journey

Adapted from Michael Porter and Canadian Foundation for Healthcare Improvement (2018)
A Key Care Quality Issue: Alternate Level of Care (ALC)
“Are YOU still here?”
Delayed Hospital Discharge or Alternate Level of Care (ALC)

Hospital care is complete but the person is stuck in a hospital bed while waiting for their next point of care.
Alternate Level of Care is a care quality issue that impacts health systems worldwide.

16% of inpatient hospital beds in Ontario are occupied by ALC patients.

35% of inpatient hospital beds in Northwestern Ontario are occupied by ALC patients.

Wait period usually exacerbates an already heightened risk of:
- Functional decline
- Falls
- Hospital related adverse events, e.g. medication errors, exposure to infectious diseases

$2.5 million/day in Ontario
What is Known about ALC?
Characteristics of ‘ALC Patients’

ALC patients have been classified as having a number of demographic\textsuperscript{6-8}, functional\textsuperscript{2,3,9-15}, and social\textsuperscript{16-22} characteristics:

- Older age
- Psychiatric diagnoses
- Physical impairment
- Aggressive behaviors
- Social isolation
- Multi-morbidity
- Female
- Requiring assistive devices
- Depression
- Cognitive impairment
- Neurological disorders
- Lacking insurance coverage
- Caregiver stress and capacity concerns
- Homelessness
- Having Medicaid status
- Having Medicaid status
But...ALC is predominantly a systems issue

- Hospital process issues\textsuperscript{24,30}
- Assessment delays\textsuperscript{29}
- Lack of available services on weekends\textsuperscript{18}
- Lack of (and long wait lists for) long-term care (including those that align with religious and cultural preferences)\textsuperscript{3,15,13,19,20}
- Lack of (and long wait lists for) post-acute options (rehab, homecare)\textsuperscript{9,21,23, 25-28}
- Need for housing adaptations
• Systematic review of experiences of ALC from the patient, provider and hospital perspective (35 studies)
• ALC associated with mortality, reduced mobility, infections and depression
• Staff stressed and their inter-professional relationships were negatively impacted
• Extra bed days associated with cancelled surgeries and treatment delays
• Costs ranged from $356-$980 per patient per day
## Alternate Level of Care Options

*Sutherland and Crump (2013)*

<table>
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<tr>
<th>Some Options to Address ALC</th>
<th>The Challenge</th>
<th>The Ideal</th>
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<tr>
<td>Build More Option</td>
<td>Often default to <strong>Long-term Care</strong> and <strong>Hospital Beds</strong> but once filled problem remains</td>
<td>Consider community care spaces like supportive housing</td>
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<td>Integrated Care Option</td>
<td>Downward substitution and sharing resources difficult in a siloed system</td>
<td>Coordinated Care Models with Shared Governance (e.g., PACE or PRISMA models)</td>
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<td>Financial Incentives Option</td>
<td>Activity Based Funding in Hospitals as a lever to “push” patients out of hospital in a predetermined period</td>
<td>Does not adequately consider complexity and social care needs. Patient journey much longer than a ‘care episode’</td>
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<td>Bundled Care to capture acute and post acute period</td>
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A Deeper Look at Alternate Level of Care Experiences
Care Providers – Identified Key Areas of Care Transitions

- Relationships as the Foundation of Care
- Desired Processes and Structures for Care
- Barriers and Workarounds for Desired Care

Relationships as the Foundation of Care

- Time to build trust and rapport with patient/client and family
- Understand factors that influence willingness to engage and accept services
- Empower patients by asking them where to start

“So it would be good to have a person that you can spend time building that rapport. So even if he [client] just opens the door a crack and that person has that in, and then you start off with a 5, 10 minute conversation, and then you get the person to agree to meet you again. And maybe the next time you meet, it’s a 20 minute conversation. And you build that trust. And you’re able to take that time.”
Desired Processes and Structures of Care

• Comprehensive assessment of needs and capacity

• Supporting formal and informal caregivers in providing complex care

• Having the right people on the team working across sectors (e.g., include peer and personal support workers)

• Integrating health and social care proactively (before a crisis and preparing for decline)

• Interim care options and Service Co-location
“I agree though that when you’re starting with the **client**, if you begin there, you should be doing a proper psychosocial and medical assessment. So that doesn’t just include the physical demands, the mental demands, **but where are their passions, where’s the spark in their life, what are the things they like to do, what gives them meaning?** All those things need to be included in the picture right from the beginning. Because they …improve quality of life.”
“But it’s not like a transitional care program where, for example, someone’s in hospital and then we discharge them and then there’s, you know, we make sure we have best practice in transitions where you have like: someone meets them at home and does the medication review and then contacts the family physician, aligns the goals from hospital with the goals at home, you know, and does all that work. That is not something that exists here.”
Barriers and Workarounds for Desired Care

• Ending up in the wrong place (perverse incentives/quicker/sicker discharges)

• Multipronged access issues (eligibility, availability, ability to get to service, etc.)

• Misaligned measurement/performance targets

• Missed opportunities (providing care after crisis)

• Bending the rules (workarounds)
“...we don't have any service code for caregiver support. But so much of what we need to do is caregiver support. But we have no way to capture that. And then we have to meet these service targets in order to continue to get the funding. So you have to be really creative with how you’re delivering those services so that you’re capturing and responding to the needs that you need to respond to.”
“What does this individual need to be successful? And it’s sometimes so unique. And then we have to maybe bend a bit, be flexible rather than being very rigid and working in silos. But at the same time, for that small thing, you can’t, you know, find somebody to come step in and do it. Because these services which are already involved, they need to take one extra step to make it a success. Because they don’t do that one extra step, the person is again put back into the system to go back to the ER and all those kinds of things.”
Summary of Provider Experiences

- **Authentic and consistent relationships** between providers and families and **ongoing communication** is required.

- Attention to **non-medical factors** including culture, personal goals and expectations, can provide insight into care preferences and levels of engagement.

- Teams that **recognize and support less formalized roles** of families, personal and peer support workers, are critical to the delivery of supports to this population.

- ‘**Enabling levers**’ such as performance measures tied to measuring **what matters to people** and incentives for cross sectoral working is required.
Caregivers in Canada

- Over 8 million (3/10 people) provide unpaid care to their family members or friends
- $25 billion in unpaid labor/year
- Caregivers provide 7 hours of help for every 2 hours of professional care
- 60% of caregivers are employed
- 1/4 are “sandwiched” between caregiving and childrearing
- Higher caregiver hours associated with worse health outcomes

80% of homecare provided by family and friend caregivers. What about hospital care?
“And she was just lying in bed for 3 days, a little 86 year old. Like no, I wasn’t very happy. But once I asked the questions, I wasn’t angry, I wasn’t upset. Once I asked the questions, I got the best services. The nurses were awesome. Just nobody seemed to know what was happening next.”

Kuluski, K., J. Im, and M. McGeown, "It's a waiting game" a qualitative study of the experience of carers of patients who require an alternate level of care. BMC Health Serv Res, 2017. 17(1): p. 318.
“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)
Community Gaps
Caregivers want care that is...

Flexible
- Timing and type of care is tailored to needs of clients and caregivers

Reliable
- Organized (System Navigator)
- Assessments (determine capacity)
- Care providers are consistent
- Services are predictable

Available
- Easy access to services and information
- Housing/retirement homes/long-term care homes are available
“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 Province
“There's a lot of different things that are needed. Number one, if they want to look at keeping people at home, they’ve got to help out with the caregiver burnout. And the biggest thing that they can do is if they are going to have a support worker come into a house, for them to actually work for 8 hours [for] cooking, you know, cleaning, laundry, these kind of things.

- Caregiver for her father
What Caregivers *Observed* while Patient was ALC

<table>
<thead>
<tr>
<th>Patient over Person</th>
<th>Sub-Optimal Process</th>
<th>Inconsistent Care Quality</th>
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<td>Acute Needs over Personal Needs</td>
<td>Not on the same page</td>
<td>Providers and care of mixed quality</td>
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<tr>
<td>The Person Behind the Patient</td>
<td>Unfair and Uncertain</td>
<td>Communication issues</td>
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<tr>
<td>Person-Environment Fit</td>
<td>Multiple moves</td>
<td>Lack of Trust</td>
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“There is no regular toileting[...] that’s where she get agitated. There seems to be a link between needing to go to have a bowel movement. But we’ve been there long enough now that there's more frequent toileting. But as I say, she started off being fairly continent. She’s not anymore.”

- Caregiver for her Mom
“Yeah. 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 [her 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.” - Caregiver talking to her son about her husband (ALC patient)
“I said even if she were to fall, break her hip, get pneumonia die...And that may sound harsh but that’s the reality. That’s quite often what happens. I think in a lot of cases the reason why she’s screaming and all this sort of stuff is because she can’t get out of her chair. You guys have her buckled in. She’s used to being independent and walking around. I’d much rather see her fall with her walker than be bound to a wheelchair.”

- Caregiver for her Mom
What Caregivers *Did* While Patient was ALC:

- Fill in the Gaps
- Pay out of pocket
- Advocate/Makethings happen

Caregiver Roles and Expectations
“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).
“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. 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 LTC bed… when I explained to them that it was really difficult 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.”

- Caregiver for her Mom while working full time in a different province
Emerging Insights/Questions

1. Many different trajectories, but key concerns are common (uncertainty, ongoing caregiver involvement, communication challenges, etc.).

2. The role of the ‘formal’ (i.e., paid professional) versus ‘informal’ provider (i.e., family member) not always clear or considered fair
   - What is the role of the hospital versus the family?

3. Ethical trade-offs need to be discussed/reconciled

How do we move forward?
Moving Beyond Collecting the Story….

Working with patients and families with ALC experience to co-design service improvements
Roles and Activities

Patient and Caregiver Advisory Group
- Facilitated by a caregiver (Ida McLaughlin)
- Created a terms of reference, plan research activities
- Reduce barriers to engagement

Research Activities
- 2 focus groups (one with patients and caregivers and one with providers)
- Co-design activity with all parties on a commonly identified issue

Liaise with Decision Makers and Share Knowledge
- Share change ideas, identify implementation opportunities and barriers
- Briefing notes, podcasts, presentations, etc.
- Build on the work through future grants and evaluations.
Insights from Patients and Caregivers
Focus Group (n = 11)

How They Feel During their Care Journey

- Supported
- Threatened
- Scared to be alone
- Shamed
- Rushed
- Grateful
- Uninformed
- Relieved
- Powerless
- Impatient
- Mixed emotions
- Guilty
- Exhausted
- Valued
- Unsupported
- Confused
- Safe
- Broadsided
- Angry
- Understood
- Hopeful
- Surprised/encouragement
- Lack of communication

Lunenfeld-Tanenbaum Research Institute
Good Health System
If Patients and Caregivers had a *Magic Wand* they would want to improve:

**Communication**
- Open and transparent
- Empathy and compassion
- Tailor communication (dementia, non-English, learning styles)

**Supports for and Acknowledgement of (Family) Caregivers**

**Hospital Processes and Programs**
If Providers had a *Magic Wand* they would want to improve:

- More Housing with Care options
- Policy Changes
- Better Communication (with patients, caregivers, other team members)
- Greater respect for/ options for people with behavioral challenges
Co-Design Session
With Patients, Caregivers, Front Line Providers, Educators

Station 1: Having the Initial Conversation about ALC

Station 2: Questions during ALC Phase

Station 3: Determining the Basket of Care during ALC Phase
Balancing Capabilities of the System with the Needs/Preferences of Patients and Caregivers
Having the Initial Conversation

Suggested Questions for Providers to ask:
“What is your understanding of how you’re doing right now?”
“How have the last few months been like for you?”
“What are you hoping will happen right now?”

Suggested question for Patients/caregivers to ask:
“Now that I’m here waiting for [next setting] what will my day look like? Who will come see me? Will I still have some connection to the clinical team?”

In cases where patients did not meet pre-determined goals or have plateaued, a provider can say:
“We all wanted [patient] to get better. We are sorry we couldn’t do more with the tools we have. The goal has shifted”
Health Care Workforce
Brave Leaders

“A brave leader is someone who says I see you. I hear you. I don’t have all the answers, but I’m going to keep listening and asking questions.”

Brene Brown (p.195)
The Answer is Not Having the Answer
Just ask more questions

“Have more ‘back stage’ conversations ‘on stage’ with patients and caregivers. It's ok not to know the answer. Being open about it creates partnerships that have everyone looking for it and goodwill to keep going if the first solution isn't the right one.”

- Clinical Director

• Being vulnerable together sparks creativity (Brene Brown)
Questions During ALC

Topics

• Long-term care (tailoring choices)
• Social network
• Caregiver/Family concerns
• Expectation management
  • Change in Volume of Care
  • Uncertainty
  • Changing Course
“There’s no set plan, it keeps evolving. I understand that, but I mean, but you don’t, if you had a weekly, some sort of weekly update, just a quick one…it doesn’t matter who it is as long as somebody that has the information can say, okay this is what’s happening for this week…”

- Son caring for his mother who needs long-term care
Examples of What Should Go Into the ALC Basket of Services

Aim
For ALC Patients to Receive a Basket of Services

Physical Stimulation
1. Assigned provider to help patient out of bed each day
2. Group Exercises
3. Use of community day programs

Mental and Social Stimulation
1. "My Story’ Board Communication Page for each patient
2. Link ‘like’ patients together (shared culture, language, interests)
3. Pet and Music Therapy

Life Skills and Logistics
1. Find/make appointment with GP
2. Manage prescriptions and other appointments
3. Financial paperwork (ODSP)
4. Meal planning/cooking group

Assign a “go-to” person for ongoing patient contact (who can connect with other providers)

Volunteers and trainees
Use/ share resources with community partners
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?”
HOW do we advance this?
Creating Engagement Capable Environments

Enlisting and Preparing Patients

Asserting patient centered care and experience as a key goal

Communicating patient experiences to staff

Ensuring leadership support and strategic focus

Engaging Staff to Involve Patients

Supporting teams and removing barriers to engaging patients

HOW do we advance this?
Creating Engagement Capable Environments

• Focus on *not only creating but sustaining* engagement capable environments

• Consider the role of geriatricians in championing some of this work

• Consider impact on provider workload
  • Trade-off between time taken to collect data and patient care?

• What do we do with the information we collect?
  • Avoid *cynical placation*

• Use mixed methods (to capture needed context)
Learning Health System
Informed by Patient and Caregiver Experiences

The Blue Arrow.
How we usually do things. Collect information, analyze it and reflect on what it means.

The Red Arrow.
The most important (but neglected part). We need to feed the information back to appropriate stakeholders, try something new and continue to tweak it)

Friedman, 2014
http://www.learninghealthcareproject.org/section/background/learning-healthcare-system
Next Steps

• Create a tool-kit of strategies from the co-design session

• Share with patients and caregivers across Ontario for feedback

• Capture ALC experiences of patients, caregivers, providers, managers and decision makers in other Ontario regions (Co-PI, Dr. Sara Guilcher), in partnership with HQO

• Test new strategies through a rapid cycle evaluations/feasibility study

• Apply for grant to conduct a full scale evaluation

• Examine international and local leading practices
In Summary

• Key Care Quality Issue - poor care transitions/ALC

• More Known about ALC Patient Characteristics and Risk Factors and Less about Experiences

• Patient, Caregiver and Provider ALC Experiences and Change Ideas sheds light on best practices

• We have an ALC Best Practices Tool-Kit in development that we are willing to share!

Contact me at Kerry.Kuluski@sinahealthsystem.ca
Acknowledgements

North West ALC Study

• Health System Performance Research Network [http://www.hsprn.ca/]

• ALC Research Funded by the Ministry of Health and Long-term Care (the Applied Health Research Question Program)

• The North West (NW) CCAC was a key partner (requested the research and provided access to the sample). An acute care and post acute care facility in one community in Northwestern Ontario played a key role in connecting the research team to ALC patients.

• Research team for NW ALC study:
  • Dr. Mary McGeown
  • Jennifer Im (recent U of T Graduate Student)
Acknowledgements

ALC Co-Design Study

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Support from:
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Shawn Tracy
UHN Open Lab (Craig Madho, Melissa Frew)
Kristina Kokorelias
Sarah Carbone
Acknowledgements

These projects are funded by:

- Ontario Ministry of Health and Long-Term Care
- Bridgepoint Sinai Health System
- Strategy for Patient-Oriented Research
- Toronto Central LHIN
- Canadian Institutes of Health Research
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