

#### Is it Time to Stop Searching for a Magic Bullet? Re-examining the Role of Family-Staff Relationships in Quality Continuing Care

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#### About me...

- Researcher in the area of interdisciplinary health ethics (since 2004)
  - Relational Ethics perspective
    - Relationships are at the core of ethics
    - · We live in an interdependent world
    - Often looking for the "fitting" response
    - But, ultimately, we are always uncertain and vulnerable.
- Limited experience working in continuing care
  - 5 years working with not-for-profit organization
  - Quit due to moral distress
- 7 family members have been in continuing care
  - 1 currently facing the prospect
- I believe it is important to consider both family and staff perspectives when looking at issues in continuing care

# The Changing Continuing Care Landscape of Canada

- Aging population, increasing demand for continuing care services
- Increased level of client acuity
- Increasing treatability of certain conditions, but also increases in dementia and mental health issues
- Extending life for both the aged and the young
- The continuing care sectors is more complex than ever before
- As a system, we respond with:
  - Strategies and recommendations
  - Standards of Care, which are regularly measured
     Ongoing collection of demographic, satisfaction, and quality indicator data
     Investment in innovative programs, practices, and models

In short, we are controlling, tracking, assessing, and trying to improve all aspects of the system constantly.

But are we missing the forest for the trees?

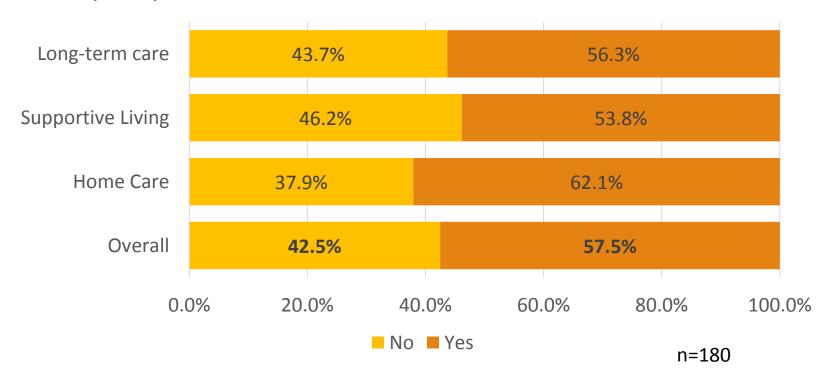
Some healthcare workers have seen so much change in our system that, rather than embrace new ideas, they view them as momentary trends in a system that overall unwilling and unable to change.

For others, there is a desire – and at times a desperation – to find something, anything, that works.

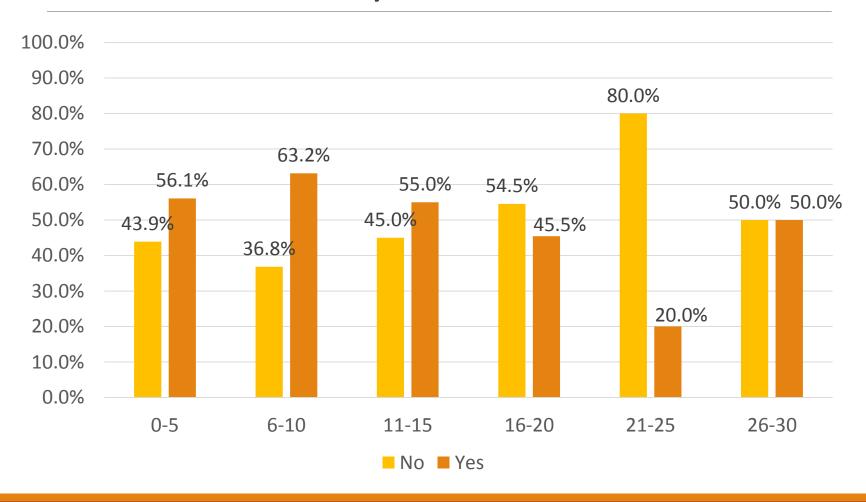
Because what we have often sees like it isn't working.

# Survey of Alberta HCA working in Continuing Care (2016)

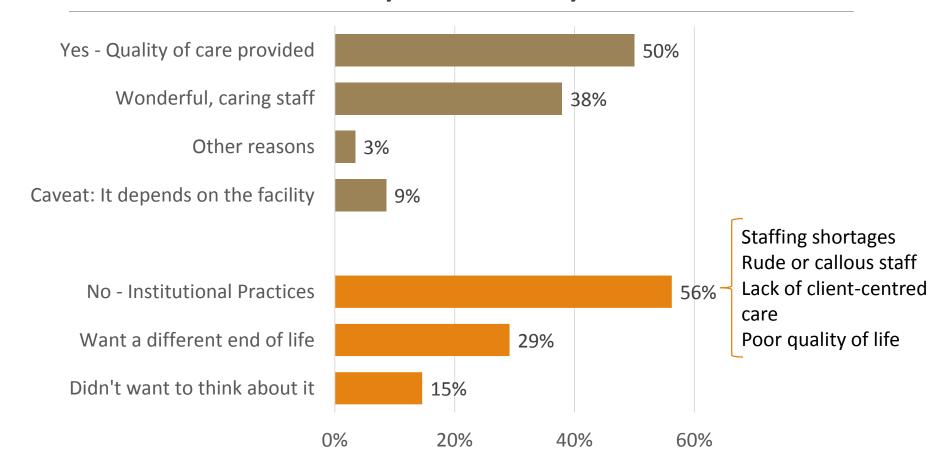
 "Thinking about the different continuing care facilities and service providers you have worked with, would you want to be a client? Why/Why not?"



#### Preference by Years of Service



#### Reasons Why & Why Not



### Moral Distress Among PICU Teams (2007-2016)

- The question of patients' quality of life post-complex life sustaining treatment is a major source of moral distress.
- Ruth's Story (Registered nurse):

"We had a patient who attempted suicide... it was touch and go...

It's years later now, and we nurses still talk about this boy, that case. 'I wonder how he's doing?' I'll ask.

Somebody will say, 'I have friend who works over there and he doesn't get any visitors...'

'We did this to them.' That feeling is awful."





#### Canadian Health Professionals' Experience of Compassion Fatigue (2007-2011)

Bente (Social Worker)

"It used to be that homecare was all in one place. So if you came in at the end of the day, you would see the case manager... Now, we are very isolated. We don't have contact with each other very often. We work on our own which is really difficult."

Dahlia (Occupational Therapist)

"I had loaned a gentleman a wheelchair until we could get him his own. Because it was more of a transport chair, he couldn't push himself but had to have his wife push him. I saw them at the grocery store, and I felt crappy because it had been at least six months since I promised him I would get him his own wheelchair, one that was fitted to his needs. This made me feel really horrible. I wanted to duck around an aisle... I felt bad. I felt guilty because they are struggling and couldn't get what they needed."



# Supporting Relationships Between Family & Staff in Traditional Continuing Care Facilities (2004-2009)

- Resources: Fall-out of (at that time) recent cuts to funding
  - Staff shortages
  - Limited time
  - Limited services to improve quality of life
- Staff rotations
- Process issues: Laundry
- Personal issues: Coping with Loss
- "Good staff" vs "Bad staff", "Good family" vs "Bad family": what our language codes



#### Behaviours that Support Relationships

Demonstrated by families	Demonstrate by staff
Understands the resident's illness and the behaviours that accompany it.	Understands the resident's illness and is aware of the resident as a person.
Acknowledges staff by name.  Speaks respectfully.  Takes the initiative to engage in small talk.	Acknowledges family by name.  Speaks respectfully and communicates resident's status to family.  Engages family in small talk.
Is <b>consistent</b> in frequency of visits and attitude.	<b>Consistent</b> ly works with the same resident and uses same care plan.
Attends and <b>adapts to the changing needs</b> of their family member.	Attends and <b>adapts to the changing needs</b> of the resident.
Brings extra "little things" for their family member. Replaces ruined belongings.	Does the "little things" for the resident. Shows respect for resident's belongings.
Understands when things go wrong at the facility & appreciates the care provided.	Meets basic care requirements no matter what is happening at the facility.
Has realistic expectations. Agrees on care to be provided.  Cooperates with staff.	Orients family to <b>realities of facility</b> .  Staff are well-trained as caregivers; know care plan. <b>Cooperate</b> with family.
Tells the care manager about the good as well as the bad. Is respectful of other residents.	Is willing to listen to concerns.  Responds and follows up.

#### Behaviours that Undermine Relationships

Demonstrated by families	Demonstrated by staff
<b>Refuses</b> to work with staff to establish the best care plan. Refuses to acknowledge the expertise of staff.	<b>Refuses</b> to give the family a role in the resident's care, including considering care alternatives suggested by the family.
Is verbally abusive to staff or residents.	Responds "I don't know" to requests for information.
Complains about staff.	Treats all concerns as complaints.
Constantly changes care routine.	Is inflexible in how care is provided.
Ignores or <b>denies the needs</b> of family member.	<b>Disregards</b> personal and medical <b>needs of resident</b> . Does not pay attention to details.
Has unrealistic expectations of staff and facility.  Demands more services than are feasible	Provides poor care. Does not recognize when less care becomes negligence or abuse.
Brings extended family issues into the facility.	Does not communicate what works with other staff.
Is judgmental of other families.	Is competitive with other staff.
Shows prejudice, racism, or sexism.	Shows prejudice, racism, or sexism.
Ignores the staff they do not know.	Shows favoritism among residents and families.
Interrupts the care of other residents to speak with	Runs and hides from family members.

staff.

# Family & Staff Perception of the Butterfly Care Home

#### • Purpose:

To understand how family and staff were experiencing the implementation of the Butterfly Care Model, identify observed changes in self, others, and residents, and identify any concerns.

- 17 family members interviewed
- 22 staff (HCAs, LPNs, RNs, RTs, Rec. Assistants, & Housekeeping staff)
- Participation was voluntary and confidential

### Prior Knowledge & Initial Reactions

- 15 family members were familiar with the BCM before implementation
- None of the staff knew about it
- 4 family members had reservations about it
- Staff had initial mixed reactions to it

"My first reaction was...not really shock... but scared, [I was] thinking about more work. More demands from management. More demands from co-workers." (staff)

 All family and staff felt that the model had brought about at least some positive changes to the facility

#### Perceived Changes

The facility became less institutional

"Before... it was like a hospital setting" (HCA).

Staff engaged more with residents and family

"After it was started, I noticed the difference in the atmosphere. It seemed to be calmer. The nurses spent more time visiting with the residents, where before it was...they were still given really good care. But it wasn't hands-on. I feel it gave them permission to hug them and sit and read a book with them or sit and read a magazine, whereas before they had to do their tasks. It was more task-oriented... So I would say the difference would be, more one-on-one care after the Butterfly Model was implemented..." (family)

Care became more individualized

"Their care is a lot more intentional with each person, as opposed to just a group" (family).

#### Perceived Changes in Clients

 10/17 family members saw changes in their loved one, mainly in disposition

"She's a little more settled there. Like I said, she talks less about moving home. And once she did mention that 'this is my home.' I was shocked. I think she likes it – she still complains but there are things that she likes." (Family)

- The remainder of family saw changes in other residents
- All staff saw positive changes in residents

"A lot of changes, for sure. Behavior wise, a lot less. Aggressiveness. Physical...it's still there in some, for sure. But in general, they are much brighter, more responsive. Easier to take care of. It [the model] has changed a lot." (staff)

#### Perceived Changes in Staff

- Increased teamwork amongst staff, and a flattening of power
- Improved disposition

"I get the impression that they now have more of a purpose than just keeping these people alive and caring for them on a daily basis." (family)

• Improved staff-client relationships

"Your approach with to the residents changes, because you learn how to be more patient with the residents." (LPN)

"The staff is more attuned to the residents. They might walk up to mom, and mom will say 'I love you.' They'll hug her, put their arm around her, grab her arm and say 'I love you too! So what's new with you today?' They're job is to be more in-tune with the residents, not to do the paperwork. Not to make sure that residents' hair is combed perfectly, or you know, they've got matching socks on or whatever." (family)

#### Perceived Changes in Staff cont.

Improved family-staff relationships

"The staff were happier, more pleasant, easier to deal with, more satisfied in what they were doing." (family)

Better communication

"I felt when they talked to me and I felt like when I asked them questions they weren't annoyed that I was calling - which I really expected. They are busy – they are very busy people – but they were calm and told me exactly what was happening," (family)

### Perceived Changes in Family

8 staff saw significant changes in family

"They're laughing. They're just happy. You're not seeing them depressed when they come. [Before] they looked depressed, just like the residents. [Now] they come in, they're laughing. They're smiling before they enter. Somebody's – they're smiling. Family members, they're smiling. Visitors, they're smiling. Leaving. When they see us eating with the residents, they say, 'Wow!'" (HCA)

 5 family members noticed a personal change, some felt guilty about no longer worrying

"I feel less stressed and more relaxed. Because when I'm not there or I leave I really don't have anything to worry about. Everything is fine; everything has been taken care of.... Whereas before I felt ... I knew that she was being cared for, but you are still kind of wonder how this is going. It was always in the back of your mind, but now it is not so much in the back of my mind. I don't have to worry..." (family)

Increased trust in the facility as a whole

#### Challenges

Becoming less task-oriented in a system built on tasks is hard

"Sometimes [the tasks] are pulling us. ... Not most of the time. Just some of the time. ... But sometime the care is pulling us to – not to stop, but interact less with them. For my part, I'm trying hard to engage as much as I can with them, but sometimes that's my problem." (HCA)

"So basically, in my position, you're always thinking about standards and audits. And all those things. I don't really worry too much about it anymore." (nurse supervisor)

- For LPNs and HCAs, in particular, learning to let go of professional barriers is challenging
- Team-work become essential, as does coercing those not fully committed yet

"We have to divide up our time just to make the program work." (HCA)

#### Unexpected Impacts

Families see staff treating residents like family members

"The relationship between the staff members and the residents is quite different. It feels much more like a family. It's not like they are just doing what they have to do. I get the feeling that they are doing it because they want to do it and that they care very much about what they are doing." (family)

18/22 staff reported a change to their professional sense of self.

"I realized while taking Butterfly, that it's not about only work. You have to do your best for them. Tell them how's the weather outside, because they don't go outside. Tell them what happened outside has big impact on them. It's like they're out, too, because they know what happened outside." (housekeeping staff)

 Staff describe how it has changed how they interact with others outside of the facility – at other workplaces or with their families

### What can be learned from the Butterfly Care Model Study?

- Giving space for family-staff and staff-client relationships is essential in continuing care.
- We need to do this, even if it means that not all of the tasks will get done and some of our checklist remains incomplete
- The facility is still meeting required standards of care
- It has introduced a few large, but many more small things that are bringing about significant changes
  - For clients
  - For staff
  - For family members

#### Then what?

- 95% of innovation is incremental
- Even providers that are unable (or willing) to engage in major changes can support and improve relationships
  - Starting with small changes
  - With the familiar and comfortable
  - Building on what works for you and your organization
- As a society, we need to balance control and tracking with support for meaningful human relationships

It is time to stop looking for a magic bullet and start making the changes that support family-staff-client relationships.

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