

Person-centred care: Patient/family experience and expectations from the health system

Sienna Caspar, PhD, CTRS

Care4u 2019

Sienna.caspar@uleth.ca

B.Sc. in Leisure Services—Therapeutic Recreation: University of South Alabama

- Tough lessons from my first job in long-term care (LTC)
- American Therapeutic Recreation Association's Dementia Practice Guideline
 - Nonpharmacological treatment of disturbing behaviours
- Geriatric Healthcare Consultants
 - Dementia Care Specialist

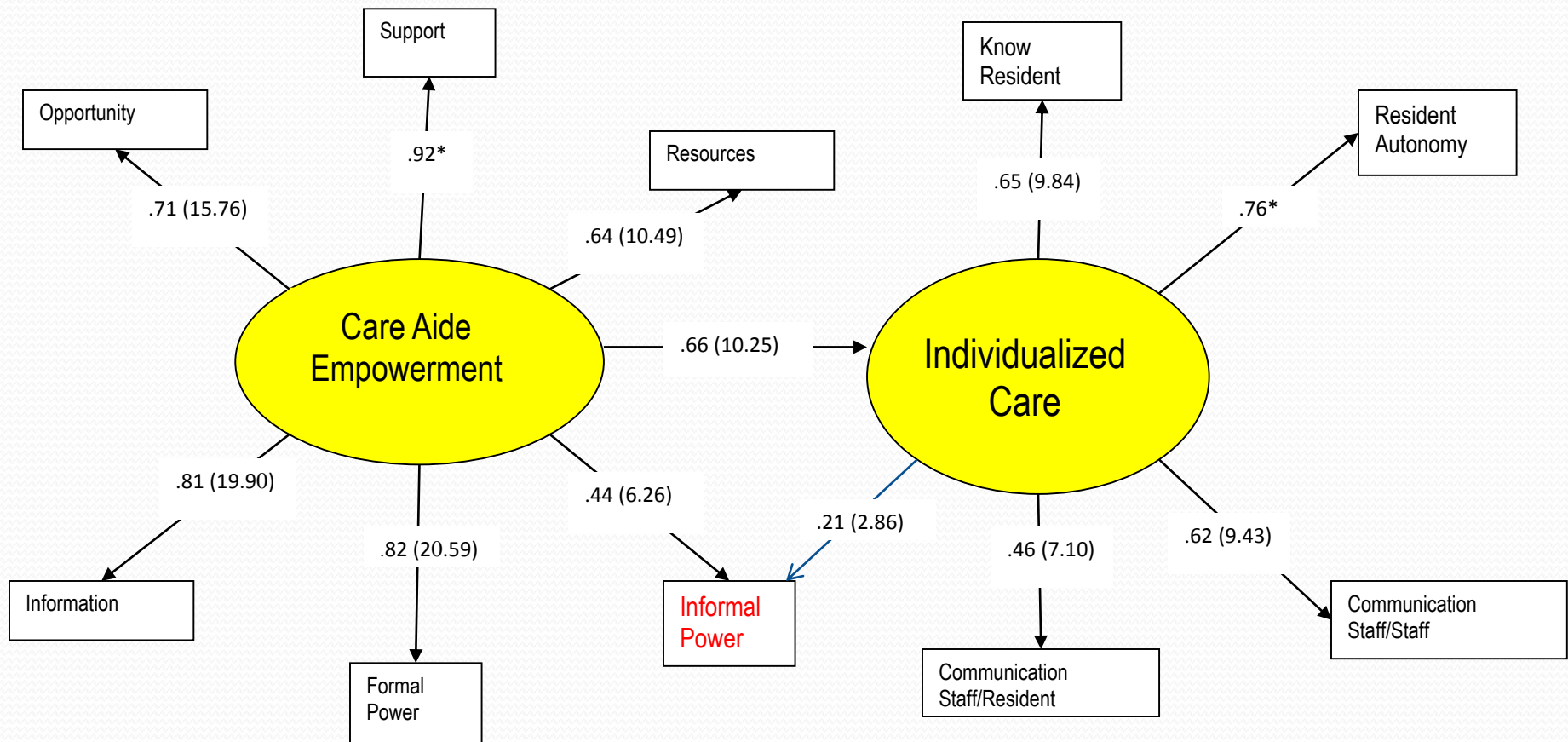
My burning question....

- Why is person-centred care so hard to consistently implement in long-term care facilities?
- Person-centred care:
 - A care philosophy that respects the care recipient's preferences and life history, honours identity, enables engagement in meaningful activity, and encourages an overall sense of well-being (Fazio, 2008).
- I believed the answer might be found through studying the organizational systems in long-term care facilities.

MA in Gerontology: SFU

- Explore the relationship between long-term care (LTC) staffs' access to empowerment structures and their perceived ability to provide person-centred individualized care.
- The 568 Participants from 41 LTC facilities (across 3 health authorities) were divided into two groups:
 - 242 RNs ($n=177$) and LPNs ($n=65$)
 - 326 care aides

Results



Caspar, S. & O'Rourke, N. (2008). The influence of care provider access to structural empowerment on individualized care in long-term care facilities. *Journal of Gerontology: Social Sciences*, 63B(4), S255-S265.

PhD in Interdisciplinary Studies: UBC

Comprehensive Exam

- Realist review of 87 interventions designed to change practice in long-term care facilities.
- What works, in what circumstances, and why?
 - Predisposing, Enabling, and Reinforcing Factors

Life Happened....



My personal story.....





The profound intersection of
my professional and
personal experience

Personal lessons....

- Family members are often the person with dementia's most valuable resource
- They are also the most vulnerable resource

Professional lessons....

- On being an advocate....
- Permanent resident assignment...
- Person-centred care is dependent upon care staff's access to, and application of, individualized care information.

Institutional Ethnography

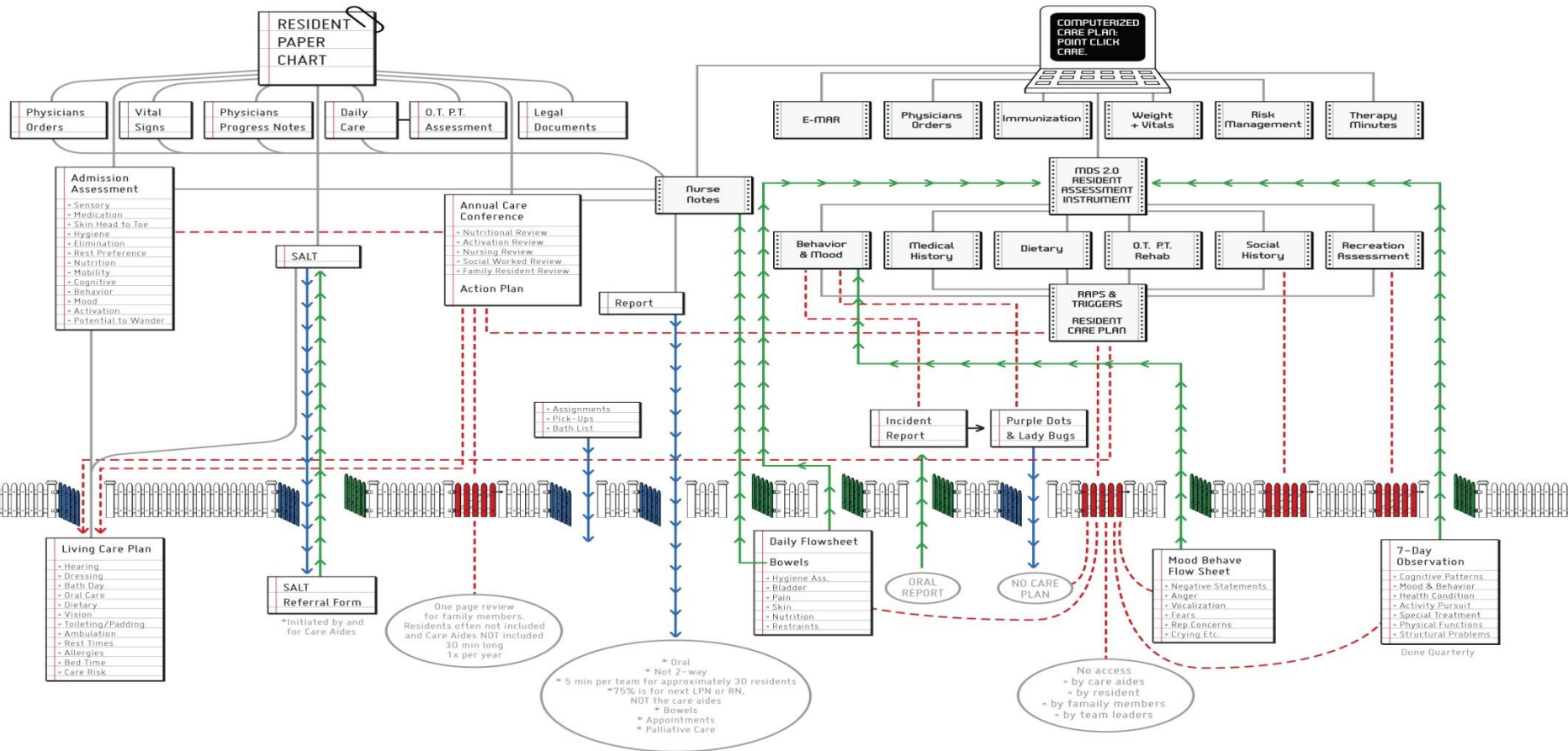
- Three LTC facilities:
 - Similar is size and admission policy (150 residents with complex care needs)
 - Represented three different ownership statuses (private for profit, private not-for-profit, and public not-for-profit)
- Participant Observation (83 hours)
 - Standpoint: care aides. Shadowed days, evenings, nights
- In-depth Interviews (76)
 - “360°” interviews
- Textual Analysis (100+)

- In LTC there seems to be a fence with two sides....
- On one side of the fence the work is “textually mediated”.
 - “If it’s not documented it didn’t happen!”



- On the other side of the fence the work is “socially mediated”.
 - Very little of the knowledge, information and intimacies of the work gets documented

Facility #1



What I learned....

- **Manager [09]:** *So, some RNs will allow them, some facilities will allow them [the care aides] to read histories. Many facilities say it's not their right to read a chart. So, therefore, they're terrified to go and to get them so that they can know more about the residents that they're getting into the personal space of. And, even if they actually can go read them, they don't have time.*
- **RCA [06]:** *You just get used to going in blind.*

What I learned....

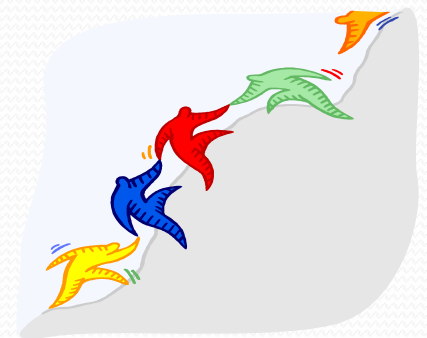
- The only two institutional texts that the care aides had practical access to that were regularly and systematically updated were the bowel lists and the bath lists.
- **RCA [01]:** *We don't have the responsibility of the RNs and the LPNs and the pills and all that stuff, but I think our job is equally important. And lots of people don't know that, because they just think that we're professional ass-wipers. Really, that's not near what it is.*

What family members and care recipients need.....

- We need to ensure that *all* care providers have practical and feasible access to individualized information about the people they are caring for.

What I learned.....

- Health care aides turn to their personal beliefs and values combined with their experiential knowledge when making daily care decisions.
- Individualized care information obtained through working directly with the residents is stored in their minds (and hearts).
- It is primarily shared orally
 - Usually on the fly or on their own time



What I learned...

- The care aides' process of orally sharing information was largely dependent upon the quality of their working relationships with one another and especially with management.
- **RCA [12]:** *If two of the girls don't like each other, one great tip that one had that could save us all time and injury doesn't get shared.*

What family members and care recipients need.....

- We need to ensure that greater emphasis is placed on team work and the climate and culture of care in health care settings.
- Supportive leadership is key!

What I learned...

- Health care aides also lacked practical access to their team leaders and supervisors.
- There was not a clearly defined time for two-way, open communication.
 - On the fly
 - While passing meds
 - Little to no feedback or follow-up
 - Giving up and staying silent



- **RCA [03]:** *I find that because stuff is missed, it looks bad on you, to family, to residents, to staff, to just...in general. If your resident is in pain and you can't do anything about it, then you feel awful, and you can't do anything. And, I can ask and ask and ask, but it doesn't mean anything is going to happen.*

What family members and care recipients need.....

- We need to ensure that all care staff feel empowered and engaged in their workplace.
- Person-centred care is dependent upon galvanizing our greatest resource—our care staff!
- Responsive leadership is key!

What I learned.....

- Unattended sorrow in the workplace impedes person-centred care.
- **RCA [16]:** *Patients will steal your heart, patients will make you cry. I've seen a male RCA cry when a patient died. ...they become your family, they really do. And sure that's bad, in aspects, but it's great. When you come to work and you're working with [a resident who feels like] family.*
- **Researcher:** *How do you think it's bad?*
- **RCA [16]:** *I think because it's not really encouraged to have these relationships.*

What family members and care recipients need.....

- We need to recognize that person-centred care required the creation of relationships between the caregiver and the care recipient. And we need to acknowledge that this relationship has been formed when the care recipient dies.



Thank You!!!