

Navigating services in a context of mistrust: family perspectives

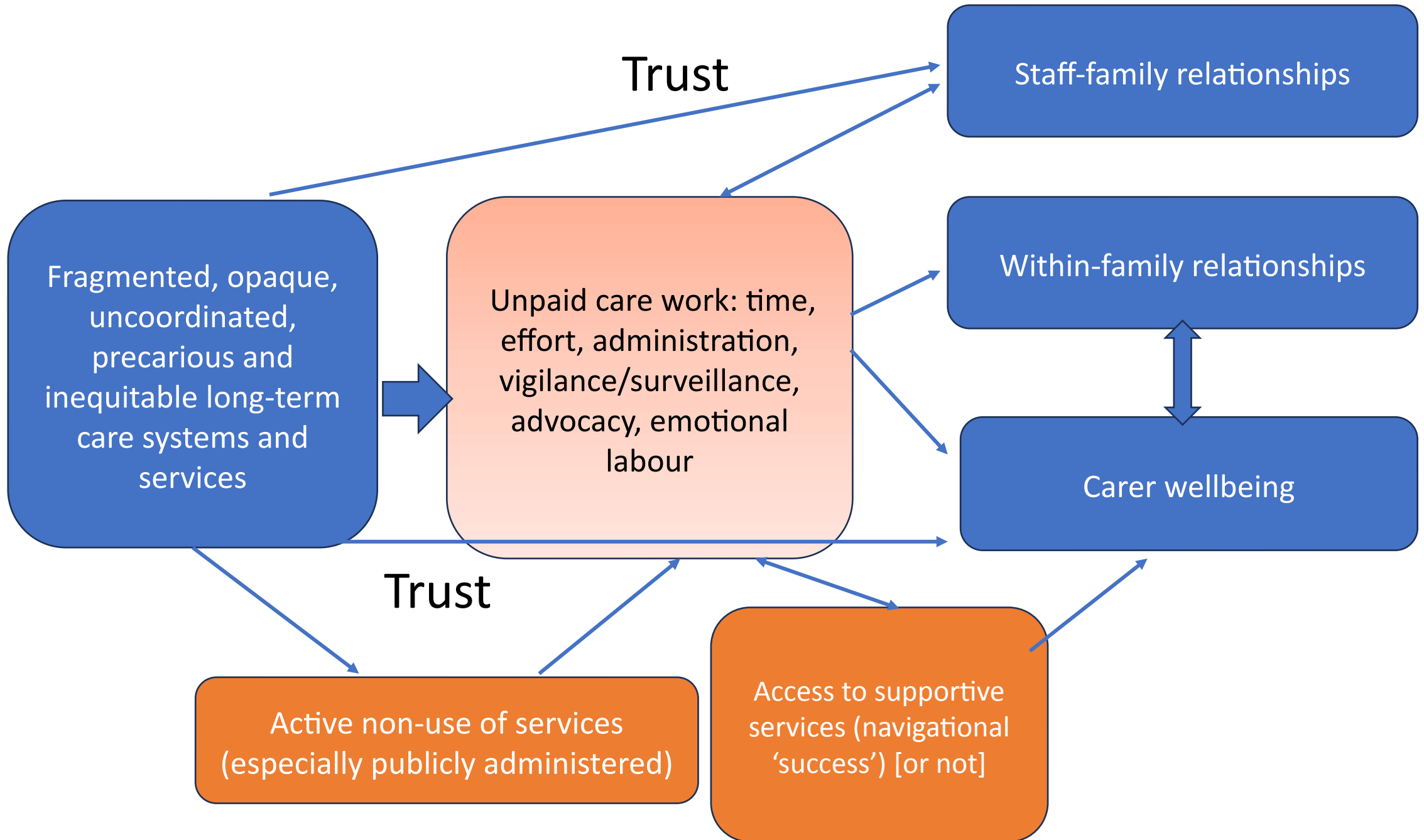
Professor Laura Funk, Sociology, University of Manitoba

Friday April 19th

*Demand and Supply of LTC Services: New perspectives from
economics, sociology and political sciences (Montreal, QC)*

Introductions

- Sociological, social and critical gerontological background
- Qual research – family/friend care of older and dying persons (BC, MB, home + LTRC)
- Complexities of interpretations, emotions, processes over time; contextual and discursive analyses
- Chappell & Penning, Marshall on economic globalization – [effects on older adults, family]; feminist sociology
- Theorizing pathways/processes involved in system navigation for older adults - structural burden (Taylor & Quesnel-Vallee, 2017), ‘candidacy’ (Koehn, 2009), ‘administrative burden’ (Herd & Moynihan, 2018)



Manitoba Caregiver Consultations, 2012

System navigation the most frequently mentioned 'biggest struggle' in a survey of 311, with 36.1% wishing for 'a lot' or 'quite a bit' more help.

- Accessing, monitoring and coordinating health and social services

"I as a caregiver would not need support if I wasn't constantly needing to: make phone calls, spend inordinate amounts of time documenting, arranging and attending meetings, and writing letters in order to access necessary services for my mother" (p.14).

Qualitative interview study (2014-2016)

Funk, Dansereau & Novek (2019); Funk & Hounslow (2019a)

32 family/friend carers of older adults in Winnipeg

- **Structural antecedents:** opaque and fragmented health and social services
- **Individual strategies:** digging/hunting; pushing through/working around; coordination/oversight = time, skill, emotion work, social capital
 - *Interpretations* - frustrating work they did not feel they should be doing
- **Consequences:** Demands on time/energy, alongside emotional responses enhance stress, distress, system dissatisfaction (+ activism inclinations)
 - Inequities are reinforced

Example (IRPP report)

“I e-mailed them and they sent back an auto-reply saying, “Thank you for this and it takes seven days before we even look at your request.” Finally somebody gets back to me and they said, “Oh, the application has to come from your home care case coordinator, and according to our system your [mother’s] file is open with the home care case coordinator....”

It turns out my home care case coordinator was on maternity leave and they hadn’t filled the position....So I waited basically two months before they assigned [my mother a home care case coordinator]. So all I’m basically asking is for the application form [for family-managed care]. Just send me an application form for the thing.

And then, of course, because it had been six months, whatever, and [the case coordinator] was new..., they’d have to come and do a reassessment. Okay, fair enough....So basically they did that. Then they have to meet with their team manager and meet with their team and do that; get a letter of support from the doctor. Okay, fine, so I have to do that, blah, blah, blah. I have to get her into day hospital; okay, I do that, blah, blah, blah....

So then they sent out the application process and the application was nine typewritten pages, budget-wise, this, that and the other thing. So I’d say it probably took me, and I know the system, 10 to 12 hours to complete the application; send it away. They send me back, “Thank you, it’ll be 8 to 12 weeks before you hear from us. Don’t call us. We’ll call you.”

Examples

(Funk, Dansereau & Novek,
2019)

“I was supposed to get the compression stockings. Well you need the referral, but you don’t need this and you need that and you’re constantly going in one big circle because (public) home care didn’t want to be responsible, and then you wouldn’t get what you needed because it was a walk-in doctor and not a regular doctor, and then you had to go and get the pressure tension done to make sure that the skin could handle it. So you couldn’t go and just fill the prescription for the stockings.”

Examples: emotion and identity

work

(Funk & Hounslow, 2019a, using full longitudinal set of interviews with the same carers)
Concern that navigation work will change self or does not fit with identity

“I don’t want to get bitter and I don’t want to get angry or frustrated, but I’ve seen it with my aunt – because she was a caregiver to my grandparents for 20 years...”

“My mother looked at me and said ‘it’s really too bad because you don’t have the personality for this [navigating the system]’ (laughs). I suppose I could have been offended by it. I thought it was hysterical. She’s absolutely right. I completely don’t”

Examples: emotion and identity work

(Funk & Hounslow, 2019a)

Interactions with care providers/representatives of systems

“My mom says I have a cold heart, but it’s not that. I take any feelings that would really bring me down and make this a lot harder and I just kind of put them aside in a box and I close the lid...”

“I work in customer service and I don’t like being a bitch to other people.... But at this point, I’ve been calling you guys for three days. You said you’d call me back. You don’t call me back.” She added “it makes me seem like a bad person because now I’ve become an angry person over something that shouldn’t have been this complicated at all, right”?

“I’m going to be 73 in September. I figure, how many more years have I got? I’m not going to be a doormat. I know what my rights are. And I’m not going to take it... that’s not my personality from before. I used to, if somebody would say something I’d like [timid voice] ‘oh ok.’ No, no more. I’ve become an advocate for my husband because I feel I have to.”

Examples: moving towards activism?

(Funk, Dansereau & Novek, 2019; Funk & Hounslow, 2019a)

“How do you navigate it when you’re by yourself? How do you navigate it when you’re not at ease making six phone calls or you can’t figure out how to do it or you don’t have access to a computer in your home so that you can go online and figure it out? It’s so not transparent and because of its not being transparent it’s so inequitable.”

*“I’m not very interested in opening doors that only [we] can get through. The whole idea is to **blast open the doors because there’s a problem with the doors.**”*

IRPP report (2019)

System navigation is a public, structural issue, not an individual level problem of information, skills, learning

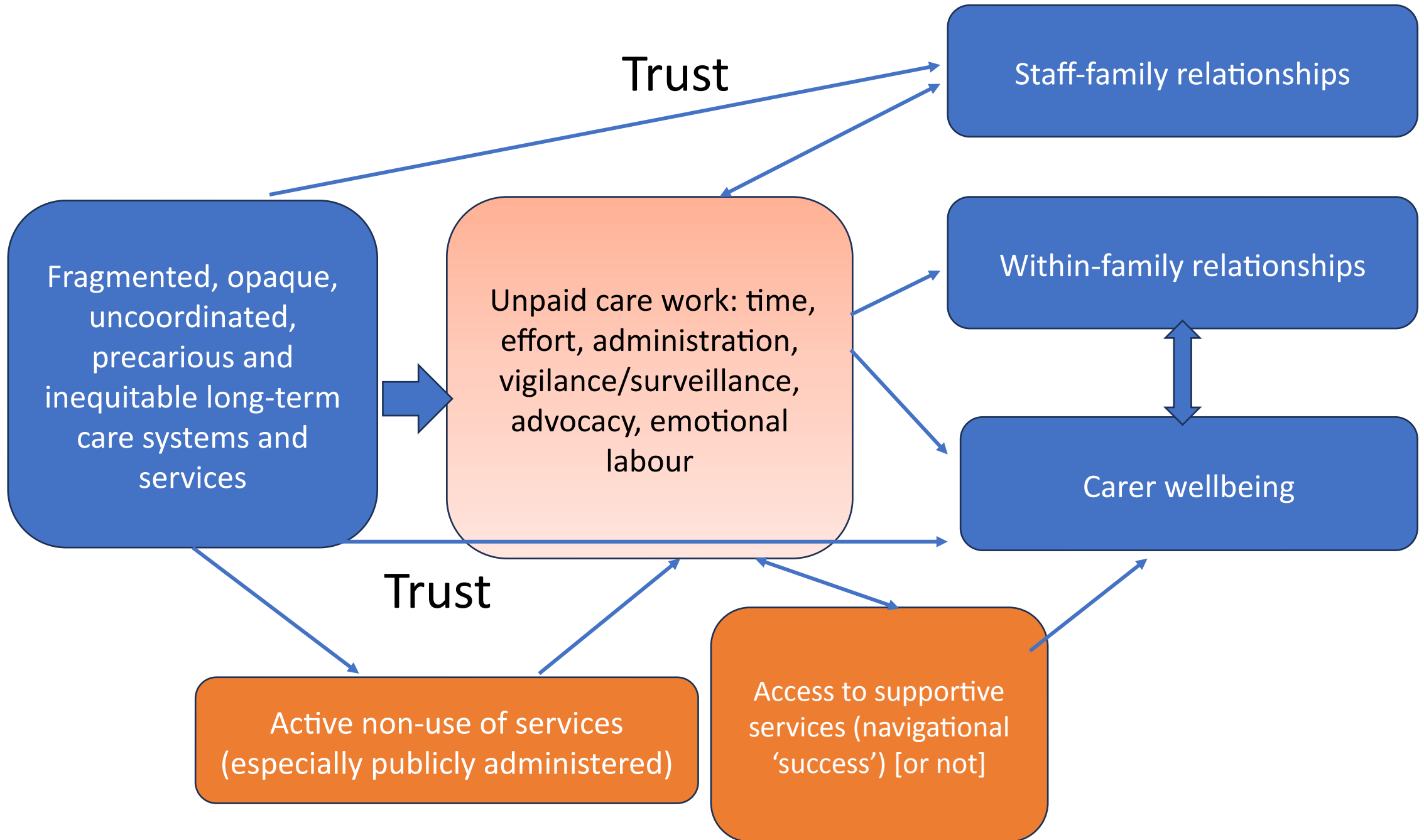
- ‘Three pronged approach’
 - Information
 - System navigator roles (building on research on ‘patient navigators’ in health care)
 - Integrated systems
- Formal system navigator programs are expanding and diversifying but tend to focus on specific conditions or transitions.
- Promising early evaluation of some professional and volunteer models, but difficult to pinpoint what it is that works and how
 - Caregivers not usually a focus, but some evidence of benefit
 - Nonprofits may be better able to focus on family goals vs system needs
 - Nonprofit/volunteer models can be be strained by turnover, time and resource constraints, limited reach/scope.
 - Formal navigators grapple themselves with system complexity

22 formal system navigators – role interpretations (Funk & Hounslow, 2019b)

- Empowering people through providing info, skills, education about services (reinforcing as 'individual problem')
- Public system navigators - tempering expectations and/or supporting organizational goals
- Reactive approach dominated. Rarely able to initiate or advocate given workloads/lack of time.
- Rarely interpreted their roles as addressing inequities in service access, though some had insights into systemic features of systems that made them difficult to navigate

Future steps...

- Explore added navigational complexity and challenges faced by marginalized families (new immigrants, low SES) in inequitable and culturally inappropriate or unsafe systems
 - Koehn et al., 2009; Koehn & Badger, 2015; research on cultural brokers
- More research into processes by which system navigation reinforces and amplify existing inequities in care outcomes
- Comparative research between countries
- Administrative burden is a policy choice and change requires political will, administrative capacity and creative design (Herd & Moynihan, 2018).
- Integrated care



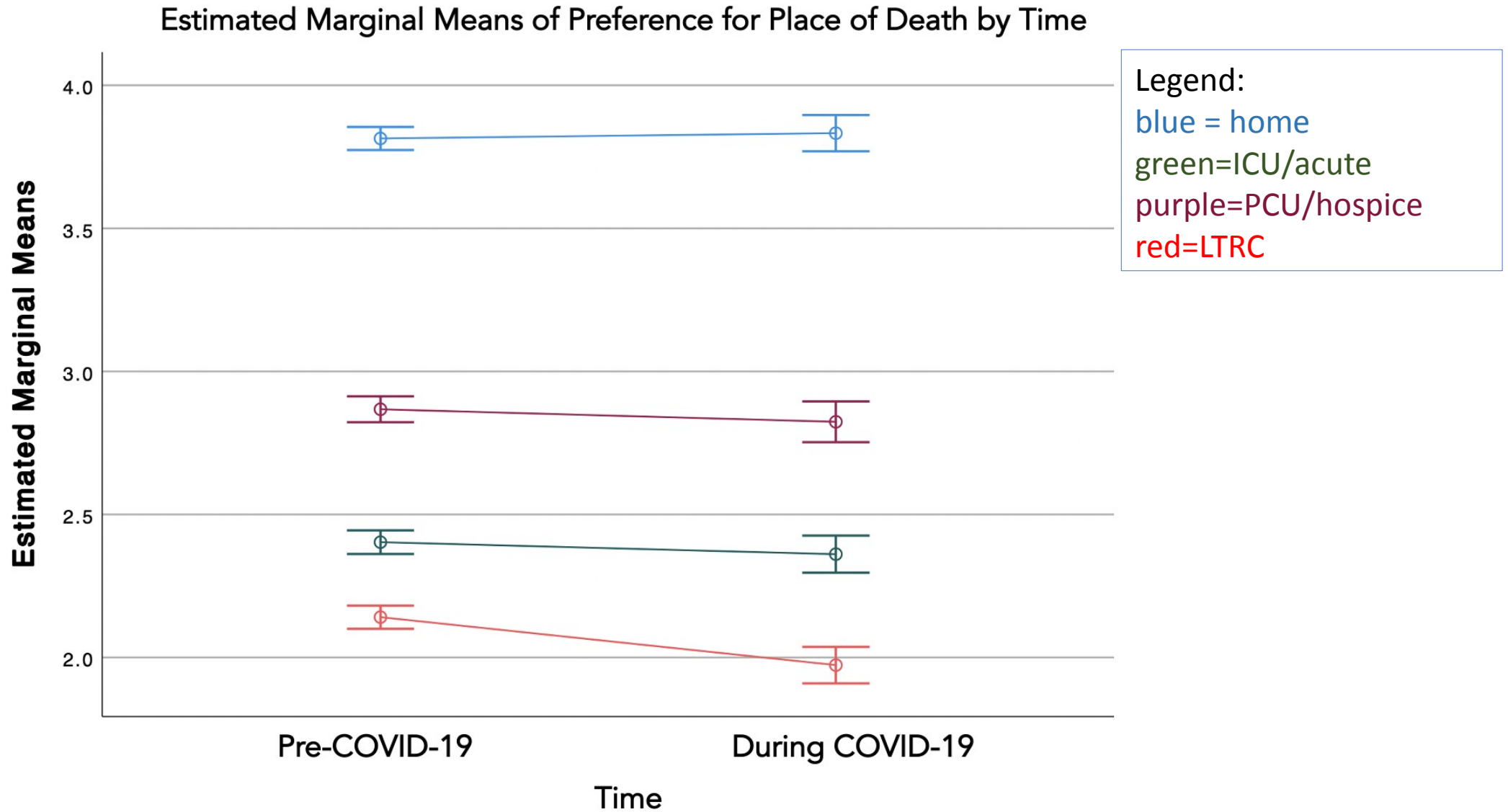
Erosion of Trust (pre-pandemic)

- *“I was just trusting that... I was letting the system just unfold and I realize now that you can't do that”* (Funk, Dansereau & Novek, 2019; p.430)
- *“My question was, why wouldn't a personal care home know that?”*
(IRPP report)
- *“Courtney ...was told [by Ministry of Health] to take her father to the emergency department and refuse to take him home, which meant he would be prioritized 'as an emergency placement.' [In the interview] she expressed frustration, stating that 'it's not right and that's really hard on him. So why would I do that to him when **your system is broken.**'* (Scott & Funk, 2023: my emphasis)

COVID-19 - widespread erosion of trust in LTC

- Early pandemic: especially in early context of high fear of contagion, lack of trust in system/workers led some to voluntarily decline home care (or withdraw from LTC) Funk, Penner, Dansereau, Kuryk, 2021, and others
- COVID-19 death rates, isolation/neglect in residential care = increased aversion to, fear of LTC in particular
 - Genevieve Thompson's study in Manitoba (to be published)
 - Dying at home study (to be published)
 - Various others (Holahan et al., 2022, etc.)
- Broader context of lack of trust in governments, public administration of services, but in LTC, also for-profit ownership.

Fall 2019 (n=2500) compared to Fall 2020 (n=1009)



Yamamoto et al. (2023) – 56 news articles (March 2020-March 2021)

- Examined representations of home care in mainstream news media
- Care as something older adults as a group were ‘deserving of’ (versus human right of citizenship); language of ‘apocalyptic demography’
- Home care commonly positioned as progressive future, panacea to undesirable LTRC alternatives. Portrayed as a uniform whole system across contexts.
- In contrast to coverage of LTRC which tended to highlight issues of profit, coverage of home care did not clearly distinguish nor present profitization in the sector as potentially problematic
- “Inequities of homes paces and impacts on families are obscured, with homes characterized as idealized places of dignity and (relative) safety.”

Trust and Long Term Care

- Trust in individuals or systems is inextricably interconnected each other and with trust *in various other social systems* (Meyer et al., 2008).
- Trust is important for managing sense of risk related to social vulnerability within systems – but conferring trust enhances vulnerability through reliance on the trusted, making trust even more important - Gilbert (2021)
- More research needed into differing experiences of risk awareness and conditions and processes (experience, knowledge, a ‘leap of faith’) that shape trust (Meyer et al., 2008)
 - Family carers of persons most likely to be harmed within systems: LGBTQ, racialized [Hendrix Rogers et al., 2021], advanced dementia, end of life care

Impacts of lack of trust, for carers

- In absence of trust in service providers/systems, carers take on added responsibility and stress of ‘constant vigilance’ and advocacy (Manitoba Caregiver Consultations, 2012)
- Eroded trust has negative effects for carers, both through emotional distress and increased time and energy overseeing and monitoring services (Funk, Dansereau & Novek, 2019)
- *“You need to be an advocate. Because they've done some things - and I don't want to say she's in a bad place. No she's a good place. But you know, like, there's staff and there's staff right. Not everybody's like 100%. But you still have to follow up.”* (Current SSHRC funded study)

Current SSHRC-funded study of diverse family carers (2023-2024)

*I just kind of let go a lot when he lived with [foster home lead]? I didn't try to interfere, with her. Once I knew that he was placed, and the finances were in order, he had the right clothing and all that, **then I let go. I still stayed in contact, but, I didn't feel....I didn't feel RESPONSIBLE?** [Interviewer: less as a caregiver...] Yes. More of a sister. And I had that with [foster home lead]. I had that with [Gary's previous room-mate]. Like I didn't worry about whether he was eating? Like, sometimes I wondered **WHAT** they had (laughs). But they were **OKAY**. it was just keeping them tidy and everything. But once that was in place, it was kind of like, what can I do to help them, and would help me too. **So you just get that in place and then you have to step back. You still watch, like and now, even with (current group home), I go over there once a week but I TRUST that they're doing, you know.***

Navigation challenges + mistrust

- Unpaid work, time and emotional energy = burnout
- Distress/worry, apprehension about future care needs or carer roles
- Avoid LTRC or care services *if possible* (Amilon et al., 2022; Achou et al., 2022).
Advantaged families hire privately (profitization), direct managed care, retirement residences or A/L, private navigators, paid companions = two-tiered care system and diverging trajectories
 - Distress/guilt/shame if family member needs service
- Strained relationships with paid care workers (vs. solidarity); effects on certain outcomes or goals of care? Comfort with care provision?
- Dissatisfaction and political behaviour - -reduced support for for-profit LTRC? For public services? Advocacy for equitable and relational care?

Nurture/preserve trust through quality, relational, equitable systems - interpersonal, management, governance levels

- Address system navigation challenges (as previous)
- Demonstrating 'caring about' and embodied, non-verbal communication
- Culturally sensitive, trauma-informed, and inclusive approaches
- Staff continuity/familiarity, time (Gilbert, 2021).
- Promising practice: Nonforced care policies (Herron's SPAC study)
- Laws, regulations and protocols can enhance trust OR can backfire if overly focused on 'accounting' or used in rigid/prescriptive way (Gilbert, 2021; Banerjee, 2023, Armstrong, 2018).
- Democratic engagement (advisory councils, etc)
- Equity lenses, disrupting power relations

References

- Achou, B., et al. (2022). Nursing home aversion post-pandemic: implications for savings and long-term care policy. *Journal of Economic Behavior and Organization*, 201, 1-21.
- Amilon, A., et al. (2022). Trust in the publicly financed care system and willingness to pay for long-term care: A discrete choice experiment in Denmark. *Social Science and Medicine*, 311, 115332.
- Armstrong, P. (2018). Balancing the tension in long-term residential care. *Ageing International*, 43, 74-90.
- Banerjee, A. (2023). Social imaginaries and the application of feminist care perspectives to nursing home reform. *International Journal of Care and Caring*, 7(4), 750-755.
- Funk, L. (2019). [Relieving the Burden of Navigating Health and Social Services for Older Adults and Caregivers](#). IRPP Study 73. Montreal: Institute for Research on Public Policy.
- Funk, L. (2012). [Manitoba Caregiver Consultation Final Report](#). Seniors and Healthy Aging Secretariat, Ministry of Healthy Living, Seniors and Consumer Affairs. Winnipeg, MB. 44 pages.
- Funk, L.M., Penner, J., Kuryk, K., & Dansereau, L. (2021). [Caregiving during COVID in Manitoba: Report of Survey Findings](#). Winnipeg, Manitoba.
- Funk, L., Dansereau, L., & Novek, S. (2019). Carers as system navigators: Exploring sources, processes and outcomes of structural burden. *The Gerontologist*. 59, 426-35
- Funk, L., & Hounslow, W. (2019a). The emotional landscape of accessing and navigating formal supports for older adults in one Western Canadian city. *International Journal of Care and Caring*, 3, 531-48
- Funk, L., & Hounslow, W. (2019b). How formal navigators interpret their roles supporting families. *Quality in Ageing and Older Adults*, 20, 10-9

...continued on next page

Gilbert, A.S. (2021). Conceptualising trust in aged care. *Ageing and Society*, 41, 2356-2374.

Hendrix Rogers, A., Epps, F., Hendricksen, M., Roach, A., Akunor, H.S., and Palan Lopez, R. (2021). Trust of nursing home staff caring for residents with advanced dementia: A qualitative descriptive study of family caregivers' perspectives. *Geriatric Nursing*, 42(6), 1362-1366.

Herd, P., & Moynihan, D. P. (2018). *Administrative burden: Policymaking by other means*. New York, NY: Russell Sage Foundation.

Holahan, T.J. et al. (2022). Building trust in post-acute and long-term care: Strategies for sustainable change. *JAMDA*, 23, 193-196.

Koehn, S. (2009). Negotiating candidacy: ethnic minority seniors' access to care. *Ageing and Society*, 29, 585–608

Meyer, S., Ward, P., Coveney, J., & Rogers, W. (2008). Trust in the health system: An analysis and extension of the social theories of Giddens and Luhmann. *Health Sociology Review*, 17:2: 177-186.

Scott, E., & Funk, L.M. (2023). Cumulative disempowerment: How families experience older adults' transitions into long-term residential care. *Journal of Gerontological Social Work*, 66(3), 433-455.

Taylor, M. G., & Quesnel-Vallée, A. (2017). The structural burden of caregiving: shared challenges in the United States and Canada. *The Gerontologist*, 57, 19–25.

Yamamoto, C., Funk, L., Ethier, A., Carrier, A., Contandriopolous, D., & Stajduhar, K. (2023). Painted in broad strokes: English-Language news media coverage of home care in relation to the COVID-19 pandemic in Canada. *Journal of Canadian Studies*, 57(2), 205-232.