Implementation of the Dementia Isolation Toolkit in long-term care improves awareness but does not reduce level of moral distress amongst staff

Think Tank on Moral Distress in LTC, Research Institute for Aging
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CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

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cpsi icsp Canadian Patient Safety Institute / Institut canadien pour la sécurité des patients

Canadian Foundation for Healthcare Improvement
Fondation canadienne pour l'amélioration des services de santé

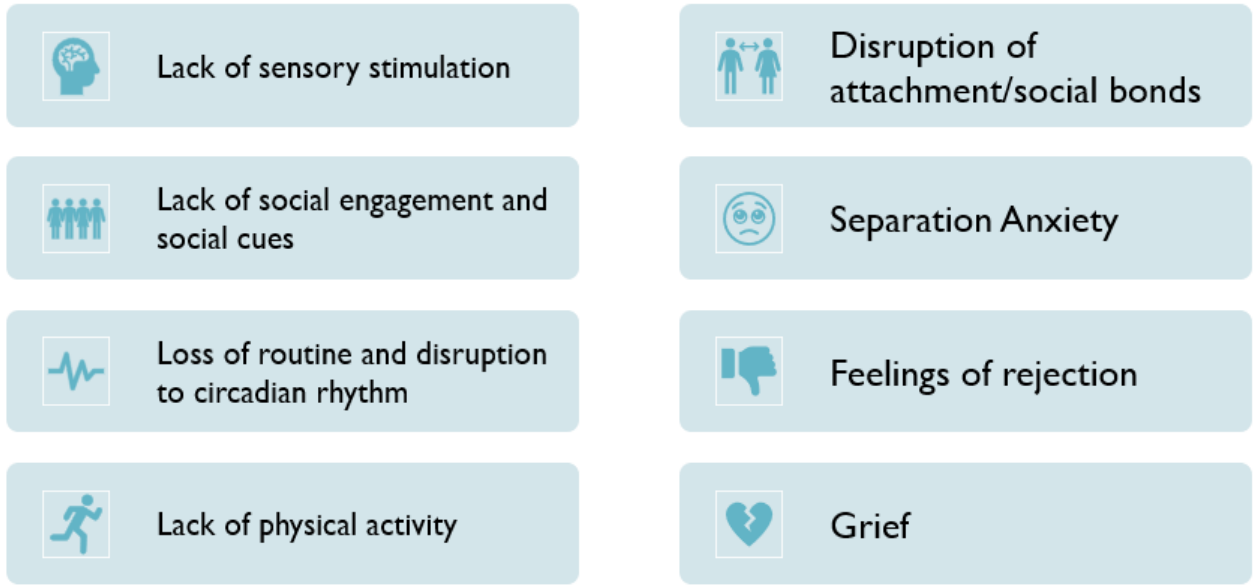
Moral Distress

When you know the right thing to do for a resident, but for some reason, you are unable to do it.

Examples

- When infection control measures conflict with what we think is best for an individual
- Seeing care suffer because of a lack of resources
- Inadequate support

Impact of isolation on residents



https://www.nsmsgs.ca/47/Confinement_Syndrome/

Dementia Isolation Toolkit

www.dementiaisolationtoolkit.com

Primary aim

To support the compassionate, safe, and effective isolation/quarantine of residents of LTC

Secondary aim

To support moral resilience in LTC staff during the COVID-19 pandemic

1. Ethical guidance tool
2. Ethical decision-making tool
3. Communication tools
4. Person-centred isolation care planning tool

2. Person-centred isolation care planning tool

Reframe the problem

How can we make her stay in her room?

How can we support her needs to help her stay in her room?

RESIDENT NAME OR INITIALS: _____ COMPLETED BY: _____ DATE: ___/___/___

Person-Centred Isolation Care Plan

DIT Dementia Isolation Toolkit

PERSONHOOD:

What information do we know about this person? (e.g. likes, dislikes, values, previous roles/professions, their capabilities, relationships/family)?

What kinds of needs/reasons bring them out of their room?

What helps them return to their room?

ENGAGEMENT:

What activities do they enjoy?

What activities can the resident engage in while in their room?

What do they like to talk about?

Who do they enjoy spending time with?

SUPPORTING NEEDS:

What do they need help with?

What are their favorite foods or drinks?

What things and/or people bring them joy and pleasure?

REMINDERS:

What do they understand about the need to stay in their room?

What kinds of reminders are effective? (write exact words to use)

What other kinds of reminders work? (Signs, barriers, alarms)

PLANNED APPROACHES/STRATEGIES:

1) _____
2) _____
3) _____
4) _____
5) _____

Training materials

DIT Dementia Isolation Toolkit

HOME OUR TEAM DOWNLOADS TRAINING VIDEOS CONTACT US

DIT Training Videos

We have prepared two training videos to help you use the DIT. After viewing, we would love to hear your feedback! Please provide us feedback in the form below the videos.

Ethical Guidance Tools

Person-Centred Isolation Care Plan

Subtitled Languages

French
Chinese
Hindi
Portuguese
Spanish
Tagalog
Tibetan

Research Questions

What is the impact of the DIT on the self-reported moral distress amongst LTCH staff?

What factors (i.e., organizational culture, management, resources, external policies or directives) influence the adoption, use, and impact of the DIT on moral distress amongst staff.

Participants completed a one hour semi-structured interview plus the Moral Distress in Dementia Care Survey (MDDCS), both pre- and post-implementation of the DIT

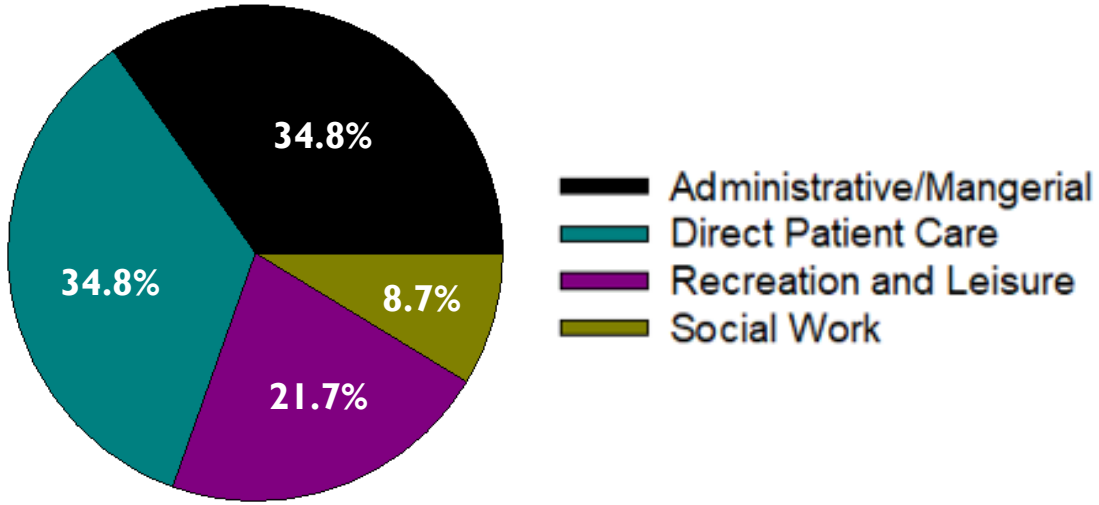
Awosoga, et al., (2018). Development and validation of the Moral Distress in Dementia Care Survey instrument. Journal of Advanced Nursing, 74(11), 2685–2700.

Participants

87% of participants were female

Average time working in LTC = 11 years

Average time in current role = 5 years



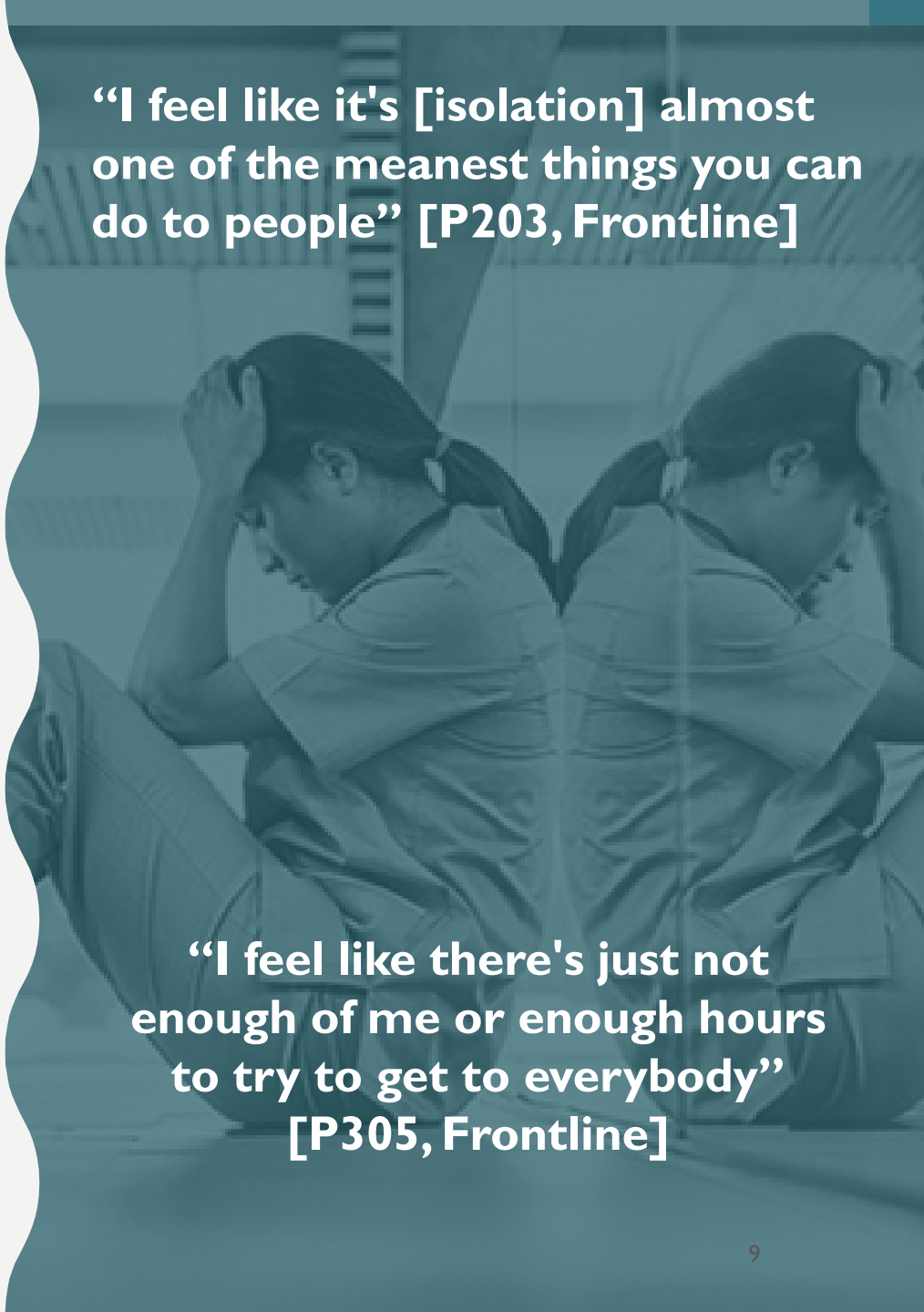
	Total[a]	LTCH01	LTCH02	LTCH03
	% (N=23)	39.1% (n=9)	30.4% (n=7)	30.4% (n=7)
Gender				
Female	87% (20)	26.1% (6)	30.4% (7)	30.4% (7)
Male	13% (3)	13% (3)	0% (0)	0% (0)
Age				
20-29	21.7% (5)	4.3% (1)	8.7% (2)	8.7% (2)
30-39	26.1% (6)	13% (3)	4.3% (1)	8.7% (2)
40-49	21.7% (5)	13% (3)	4.3% (1)	4.3% (1)
50+	21.7% (5)	0% (0)	8.7% (3)	8.7% (2)
Unknown	8.7% (2)	8.7% (2)	0% (0)	0% (0)
Education				
College certificate or diploma	43.4% (10)	8.7% (2)	21.7% (5)	13% (3)
University certificate or diploma below bachelor level	8.7% (2)	4.3% (1)	4.3% (1)	0% (0)
Bachelor's degree	26.1% (6)	8.7% (2)	4.3% (1)	13% (3)
Master's degree	17.4% (4)	13% (3)	0% (0)	4.3% (1)
Unknown	4.3% (1)	4.3% (1)	0% (0)	0% (0)
Job category				
Managerial/Administrative	30.4% (7)	8.7% (2)	13% (3)	8.7% (2)
Frontline	69.6% (16)	30.4% (7)	17.4% (4)	21.7% (5)

Moral Distress in LTC during the Pandemic

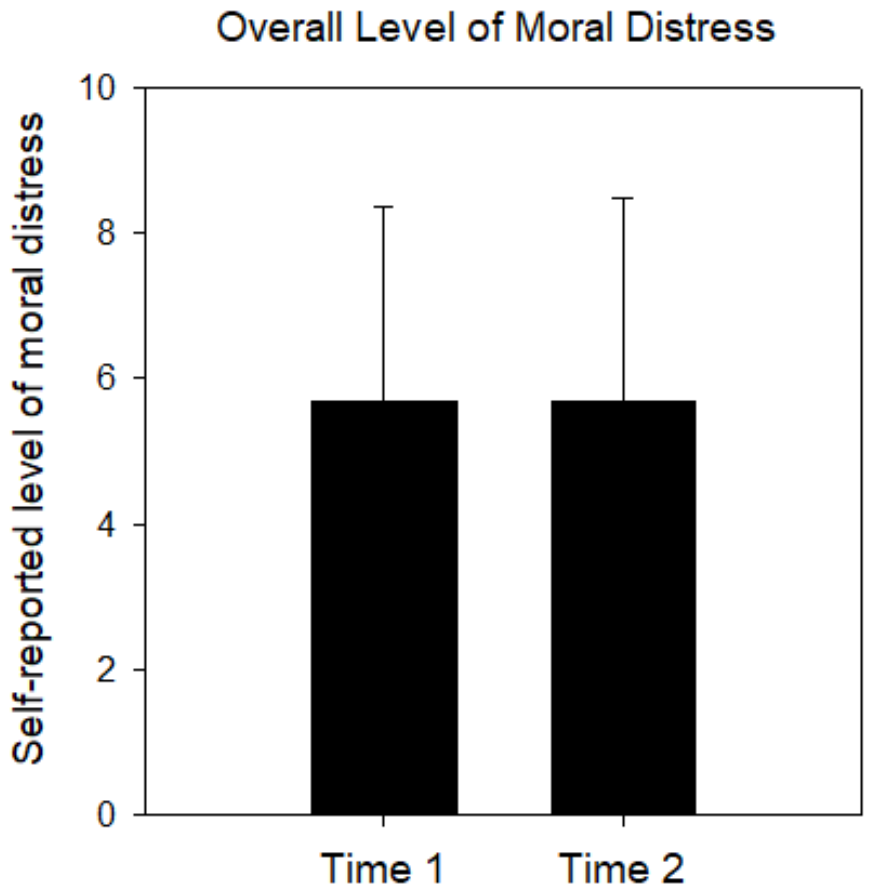
"A few staff said they felt useless because they can't do the program that they used to. They don't feel effective" [P301, Managerial/Administrative]

"To be honest, there were times when people didn't follow the rules…imagine having two spouses that they couldn't get together at the same facility and one is dying and the other one can't come say goodbye" [P303, Managerial/Administrative]

"I feel like it's [isolation] almost one of the meanest things you can do to people" [P203, Frontline]



"I feel like there's just not enough of me or enough hours to try to get to everybody" [P305, Frontline]



On a scale from 0 to 10, what is the overall level of moral distress that you have felt providing care to residents with dementia over the last year?

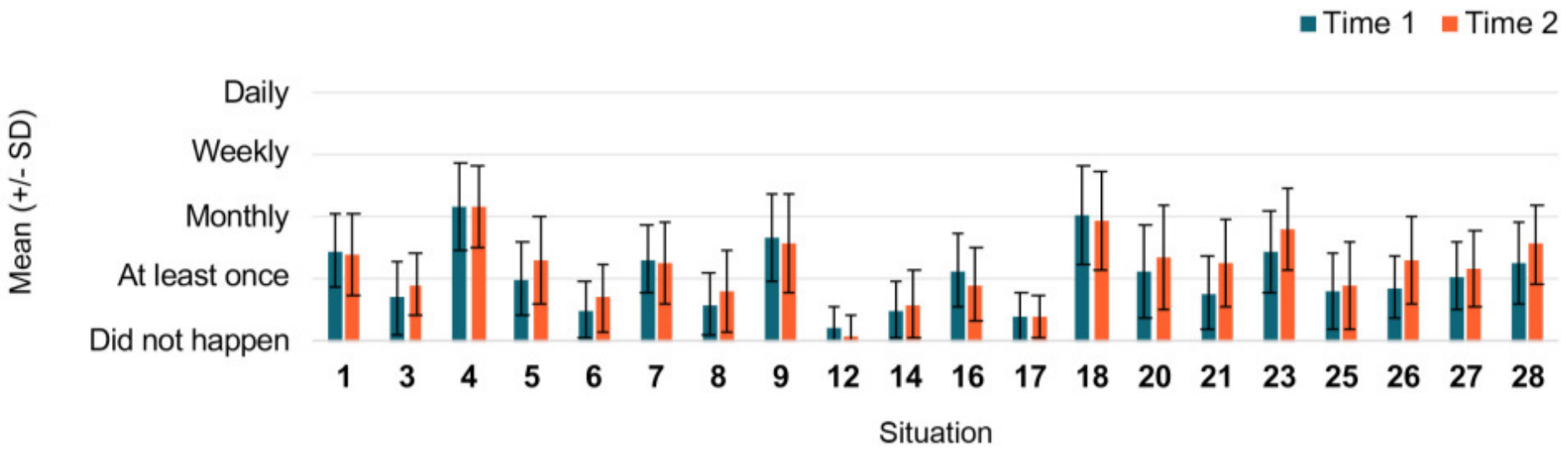
Impact of the DIT on levels of moral distress?

0 = NO Moral Distress → 10 = Level of moral distress that feels like it's too much to handle

Awosoga, et al., (2018). Development and validation of the Moral Distress in Dementia Care Survey instrument. Journal of Advanced Nursing, 74(11), 2685–2700.

Moral distress in the workplace

a) *Indicate how often you have found yourself in each situation over the last year*



1 Having to follow a family's wishes for care even if it doesn't seem the best for the resident with dementia

3 Having to give care to the resident with dementia that I believe goes against the family's wishes

4 Telling the resident with dementia things that are not true so he/she won't get upset

5 Seeing residents with dementia get medication to control their behavior, even though I disagree with it

6 Carrying out doctor's orders that I don't think are the best for the resident with dementia

7 Seeing medications being withheld from a resident with dementia because that's what the family wants, but I believe the resident needs it

8 Avoiding giving care to a resident with dementia because I am afraid the resident might hurt me

9 Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time

12 Not reporting what I believe is neglect or abuse of a resident with dementia because I'm afraid of causing trouble

14 Going along with care for a resident with dementia that I don't agree with because of pressure from my coworkers

16 Seeing residents with dementia living with pain because it is not treated appropriately

17 Having to give care to a resident with dementia that I believe goes against what is in their personal directive

18 Seeing the care suffer for residents with dementia because there are not enough staff to do the work

20 Having to rush the care of residents with dementia due to lack of time - even though I know it might upset them

21 Being unable to ensure that the resident with dementia is in the right facility to receive the right level of care

23 Seeing the care suffer for residents with dementia because of high staff turnover

25 Having to provide care to aggressive residents with dementia without the supports I need to feel safe

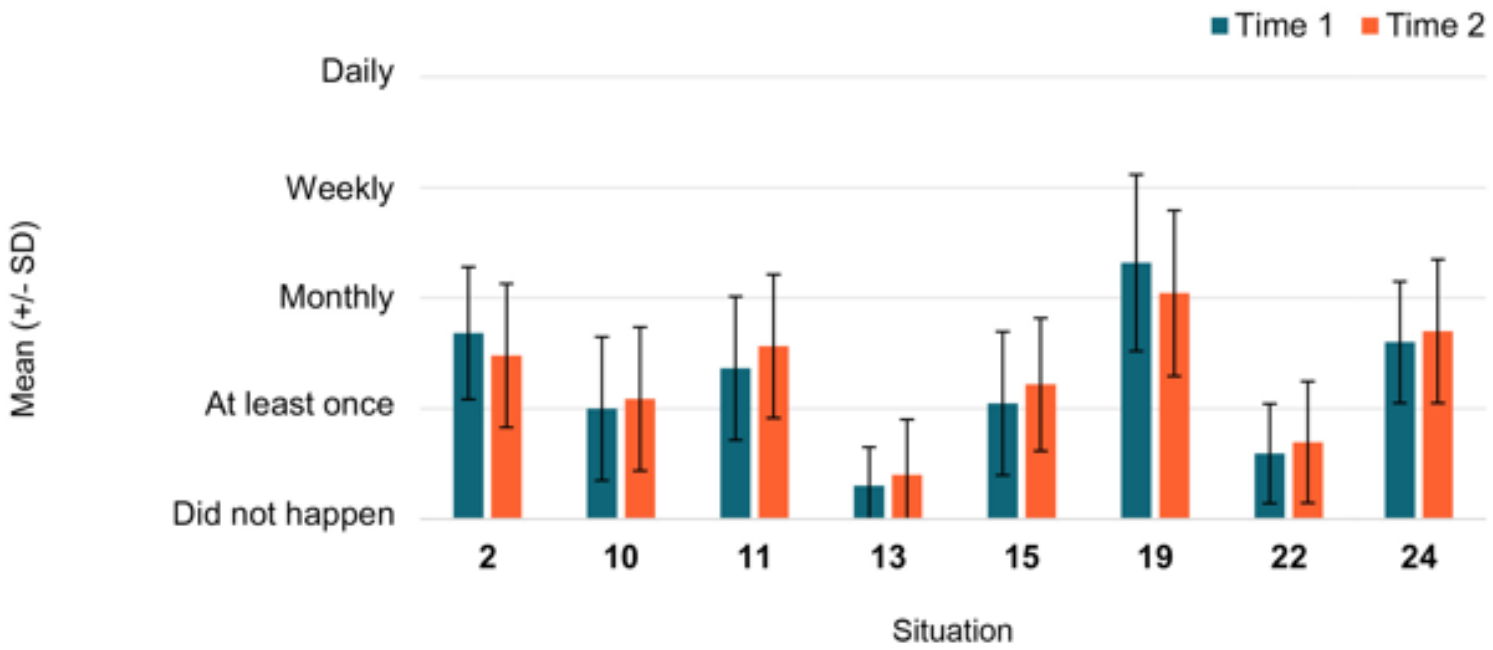
26 Having to work without the supports I need to prevent residents with dementia from hurting other residents

27 Seeing the care suffer for residents with dementia because physicians do not visit often enough

28 Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies

Moral distress in the workplace

a) *Indicate how often you have found yourself in each situation over the last year*



Situations

2 Seeing care that does not show respect to residents with dementia

10 Seeing a resident with dementia receive poor care because there is no consistent care plan

11 Seeing poor care for a resident with dementia because of poor communication between staff members

13 Not reporting problems with the care of residents with dementia because I feel no one listens anyhow

15 Having my ideas about best care for residents with dementia ignored by management or other staff

19 Seeing a low quality of life for residents with dementia because there are not enough activities

22 Having to provide care that I think is against the wishes of the resident with dementia

24 Seeing the care suffer for residents with dementia because staff lack the knowledge and skills they need to provide dementia care.

Impact of using the DIT

"Sometimes coming out with a label [moral distress] can validate peoples experiences because some can't sleep because they are thinking about these decisions they have to make at work… this wouldn't have been discussed without the DIT"
[P301, Managerial/Administrative]

"It really helped us try to change our view to be less clinical and more resident-focused on what they needed to survive the isolation, I guess. We stopped looking at it more like, we need them to be in isolation, and more like, what do they need to be able to be in isolation?"
[P303, Managerial/Administrative]

"Who they [residents] are as a person is the most important thing, and it's the first thing in the care plan…For me, it's like this huge change. That's a huge cultural change. That to me is impressive"
[P307, Frontline]

Best Practices

- Models of care within LTC settings should prioritize person-centered care (PCC) principals and values
- Model and encourage LTC staff to approach day-to-day tasks and problem solving through the lens of PCC
- Take a flexible, and adaptive approach guided by LTCH stakeholders, when implementing PCC interventions like the Dementia Isolation Toolkit

Knowledge mobilization

DIT Dementia Isolation Toolkit

www.dementiaisolationtoolkit.com

Toolkit

All components of the toolkit are available for free, online through the website. A subset are available in French.

Huddle Tool Guide

Facilitate the implementation of the DIT

Training videos

Translated into seven different languages

Isolation Worksheet E-PDF

Isolation Decision Worksheet- E-fillable PDF

Fill out the isolation decision worksheet online with our E-fillable PDF version. Note: an example filled-out version is included in the PDF.

Person-Centred Care Worksheet E-PDF

Person-Centred Care Worksheet- E-fillable PDF

Fill out the person-centred care worksheet online with our E-fillable PDF version. Note: an example filled-out version is included in the PDF.

Isolation Care Plan Summary E-PDF

Isolation Care Plan Summary- E-fillable PDF

Fill out the isolation care plan worksheet online with our E-fillable PDF version.

Isolation Communication Signs PDF

Isolation Communication Signs

Download these signs to remind residents of isolation practices like personal protective equipment, hand-washing, and how to safely leave their rooms

Huddle Tool E-PDF

Huddle Tool Guide

This huddle tool provides a guide to bringing team members together to discuss the impact of infection control measures simply and efficiently.

COVID-19 Dementia Symptom Poster

COVID-19 Dementia Symptom Poster

This poster reminds those who see COVID-19 symptoms other than fever to consider getting a COVID test.

Publications and resources

Click on the links below to view our team's published work for Dementia Isolation Toolkit.

Academic publications

Prevalence, causes, and consequences of moral distress in healthcare providers caring for people living with dementia in long-term care during a pandemic

Haslam-Larmer L, Grigorovich A, Quirt H, Engel K, Stewart S, Rodrigues K, Kontos P, Astell A, McMurray J, Levy A, Bingham KS, Iaboni A. Dementia. 2023 Jan;22(1):5-27.

Educational publications

Facing difficult decisions in a pandemic

The Dementia Isolation Toolkit. Long Term Care Today. Spring/Summer 2021 p 30-31.

Media reports

Doctors concerned about rise in dangerous medications in long-term care homes during pandemic

Kaleigh Alkenbr, CTV News Health. December 3 2020.

Other resources

Podcast: Dr. Andrea Iaboni and a new toolkit for LTC to help care of residents during an outbreak

Thank you

Dementia Isolation Toolkit

www.dementiaisolationtoolkit.com

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