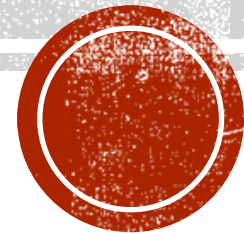


Till Death Do Us Part? - Exploring the experience of involuntary spousal separation in long-term care

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Research Coordinator, Centre for Studies in Aging & Health, Providence Care

Special Thanks To: Erika E. Petersen, Amanda Ross-White,
Dr. Pilar Camargo-Plazas, Dr. Melissa Andrew, Dr. Rylan Egan (Supervisor)



LAND ACKNOWLEDGEMENT



Acknowledgement of Territory

Queen's University is situated on traditional Anishinaabe and Haudenosaunee Territory. To acknowledge this traditional territory is to recognize its longer history, one predating the establishment of the earliest European colonies. It is also to acknowledge this territory's significance for the Indigenous peoples who lived, and continue to live, upon it – people whose practices and spiritualities were tied to the land and continue to develop in relationship to the territory and its other inhabitants today.

The Kingston Indigenous community continues to reflect the area's Anishinaabek and Haudenosaunee roots. There is also a significant Métis community and there are First Peoples from other Nations across Turtle Island present here today.

WEBINAR OBJECTIVES

1. Explore the unique experiences and perspectives of spouses involuntarily separated during LTC admission, across different contexts (i.e., setting, type of separation, cognitive ability) and mental health outcomes.
2. Outline practical recommendations to improve spouses' mental health outcomes, and overall experiences, related to involuntary separation at the individual, organizational, and system level.
3. Highlight the importance of, and approaches to, engaging with older adult residents and their spouses within the organizational and governance decision-making process.

WHO AM I? WHY AM I HERE?

- Defending my PhD next month Healthcare Quality @ Queen's University
- Research Coordinator, Centre for Studies in Aging and Health, Providence Care Hospital
- Queen's University Teaching Adjunct and Teaching Fellow – Healthy Aging & Research Methods
- Other research projects and interests in palliative care, participatory research, seniors with diabetes, intergenerational programs and age friendly communities







Link to Video:

<https://www.youtube.com/watch?v=IFijHMZR2C8>

INTRODUCTION

- The increasingly older adult population in Canada has led to constraints in LTC policies, often resulting in the separation of older adults from their spouses (Glasier & Arbeau, 2019; Mancini, 2019; Statistics Canada, 2018)
- In Canada, LTC residents can be involuntarily separated from their intimate partner (Glasier, 2016, Mancini, 2019).



INTRODUCTION

- Social relationships (i.e., spousal relationships) have a significant impact on the mental health of older adults (Bethell, 2021; Walker & Luszcz, 2009)
- Spousal relationships are particularly important for older adults in LTC, as loneliness and depression are major public health concerns in this setting (Grover et al., 2018)
- Loneliness and depression have a bi-directional, negative influence on LTC residents' health (Aylaz et al., 2012; Barg et al., 2006)



INTRODUCTION

To support separated spouses, additional research is needed to understand the unique experiences of involuntary separated spouses, as well as exploring separation across different contexts (i.e., setting, type of separation, cognitive ability).

Link to Video:

<https://www.youtube.com/watch?v=jwdYFGAiqow>



**RESEARCH
PURPOSE**

The primary aim of this dissertation was to explore spouses' experiences of involuntary separation in Ontario, secondary to LTC admission.

Experience of loneliness and depression due to spousal separation by long-term care residents and their spouses: a qualitative systematic review

Robertson, Madison A.¹; Petersen, Erika E.¹; Ross-White, Amanda^{2,3}; Camargo-Plazas, Pilar^{2,4}; Andrew, Melissa⁵; Egan, Rylan^{1,2}

Author Information[Ⓞ]

JBI Evidence Synthesis (J):10.11124/JBIES-23-00334, April 18, 2024. | DOI: 10.11124/JBIES-23-00334

BUY PAP

Metrics

Abstract

Objective:

The objective of this review was to describe the experiences of loneliness and/or depression for residents and their spouses who are separated by long-term care placement.

Introduction:

Loneliness and depression have a pernicious influence on the overall health and well-being of older adults. Older adults' mental health is significantly affected by social relationships, including those between spouses. However, research pertaining to the experience or effect of spousal separation on long-term care residents and community-dwelling spouses' feelings of loneliness and/or depression is limited.

Inclusion criteria:

This systematic review included studies that recruited community-dwelling spouses and long-term care residents over 50 years of age with living spouses from whom they are separated due to long-term care placement. Studies on the experiences of loneliness and/or depression due to spousal separation with one or both spouses living in long-term care were included in this review.

Methods:

Ovid MEDLINE(R) was used for the initial search. A full search strategy was developed for Ovid MEDLINE(R), CINAHL (EBSCOhost), Embase (Ovid), and PsycINFO (Ovid). The review was conducted using the JBI approach, with 2 independent reviewers performing study selection, critical appraisal, data extraction, assessment of confidence, and data synthesis.

Results:

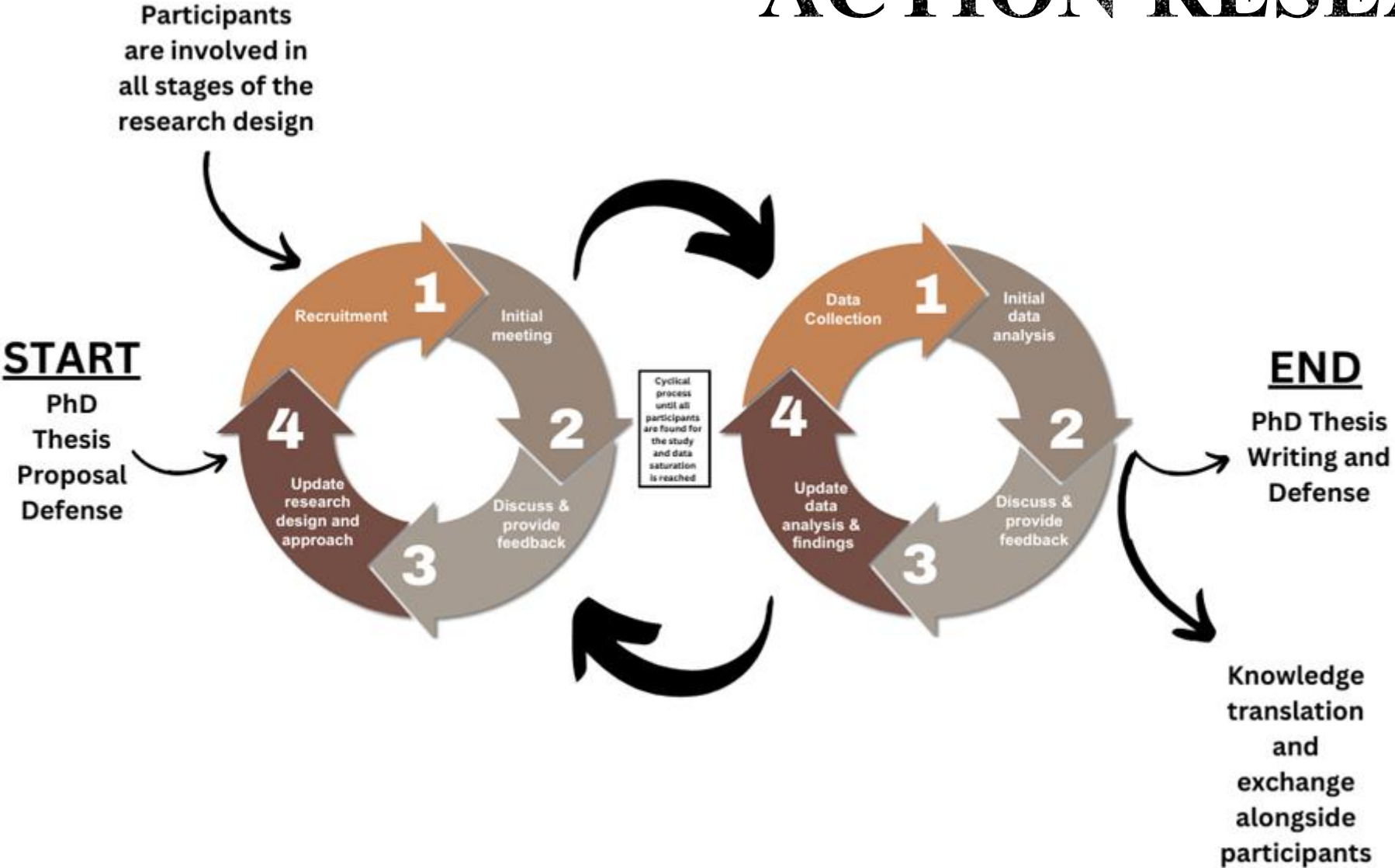
Eleven papers were included in this systematic review. Four synthesized findings were extracted from 10 categories and 42 findings: i) Loneliness and depression result from a lack of physical and social connection for separated long-term care residents and community-dwelling spouses; ii) Community-dwelling spouses feel unprepared and upset with spousal separation due to a lack of psychological support; iii) Behavioral strategies can prevent community-dwelling spouses and long-term care residents from developing loneliness and/or depression; and 4) Community-dwelling spouses have differing abilities to adapt and cope with feelings of loneliness and/or depression.

Conclusion:

This review provides a comprehensive synthesis of the feelings of loneliness and/or depression spouses who are separated due to long-term care admission experience. This review has demonstrated that there is a lack of literature inclusive of the voices and perspectives of all spouses affected by spousal separation in long-term care. The limitations of this review include the small number of included studies and the range of quality of included studies. Recommendations include additional research on the lived experience of spousal separation from the perspectives of long-term care residents and their community-dwelling spouses. Further, additional psychological support is needed for separated spouses guided by the suggestions and experiences of long-term care residents and their community-dwelling spouses.

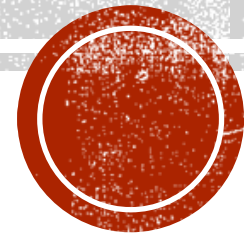
STEP 1: SYSTEMATIC REVIEW

STEP 2: PARTICIPATORY ACTION RESEARCH

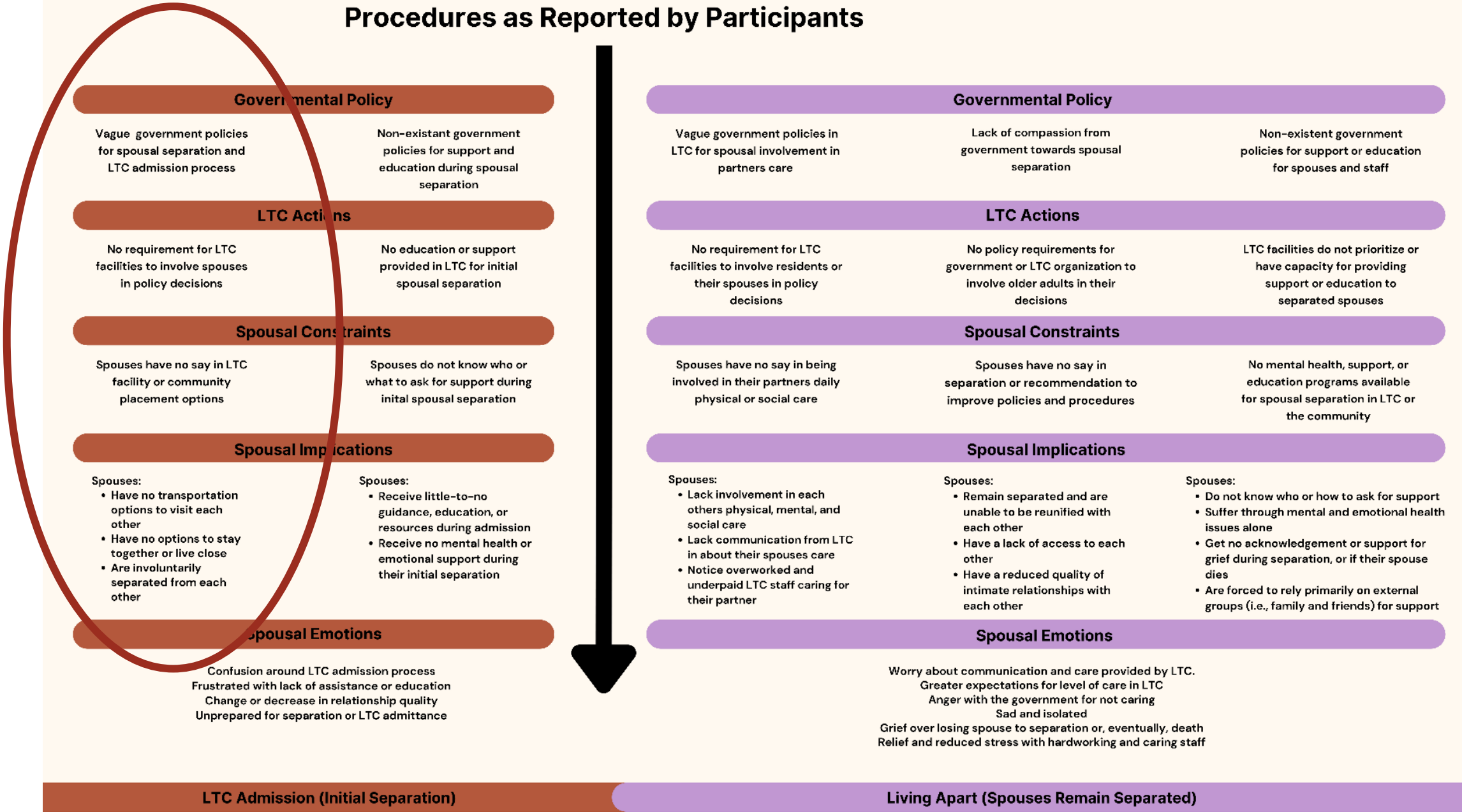


EXPERIENCES OF SPOUSAL SEPARATION

From the voices of spouses



Government LTC Policy and Procedures as Reported by Participants



Study Findings

“I just feel like something was ripped out of [my] life... when the day came for Thomas to move, it was horrible... Wouldn't it be nice? ... Wouldn't it be nice if Thomas was at [my facility] and we could all get together here?” (P9)

“I think personally, that the seniors in Ontario need to know what they could be in for... I still don't think many of the seniors know what they're in for, even tons of people in [independent living].” (P1)

Study Findings

“Now I'm getting physiotherapy on Mondays and Wednesdays, so I hurt afterwards. So... by the time my drive [to visit my spouse] came at one o'clock... I was in so much pain, [my driver] did not want to take me anywhere except to bed. And I just kept saying, I have got to go and see [my spouse]. I have just got to get there.” (P2)

Government LTC Policy and Procedures as Reported by Participants

Governmental Policy

Vague government policies for spousal separation and LTC admission process

Non-existent government policies for support and education during spousal separation

LTC Actions

No requirement for LTC facilities to involve spouses in policy decisions

No education or support provided in LTC for initial spousal separation

Spousal Constraints

Spouses have no say in LTC facility or community placement options

Spouses do not know who or what to ask for support during initial spousal separation

Spousal Implications

- Spouses:
- Have no transportation options to visit each other
 - Have no options to stay together or live close
 - Are involuntarily separated from each other

- Spouses:
- Receive little-to-no guidance, education, or resources during admission
 - Receive no mental health or emotional support during their initial separation

Spousal Emotions

Confusion around LTC admission process
Frustrated with lack of assistance or education
Change or decrease in relationship quality
Unprepared for separation or LTC admittance

Governmental Policy

Vague government policies in LTC for spousal involvement in partners care

Lack of compassion from government towards spousal separation

Non-existent government policies for support or education for spouses and staff

LTC Actions

No requirement for LTC facilities to involve residents or their spouses in policy decisions

No policy requirements for government or LTC organization to involve older adults in their decisions

LTC facilities do not prioritize or have capacity for providing support or education to separated spouses

Spousal Constraints

Spouses have no say in being involved in their partners daily physical or social care

Spouses have no say in separation or recommendation to improve policies and procedures

No mental health, support, or education programs available for spousal separation in LTC or the community

Spousal Implications

- Spouses:
- Lack involvement in each others physical, mental, and social care
 - Lack communication from LTC in about their spouses care
 - Notice overworked and underpaid LTC staff caring for their partner

- Spouses:
- Remain separated and are unable to be reunified with each other
 - Have a lack of access to each other
 - Have a reduced quality of intimate relationships with each other

- Spouses:
- Do not know who or how to ask for support
 - Suffer through mental and emotional health issues alone
 - Get no acknowledgement or support for grief during separation, or if their spouse dies
 - Are forced to rely primarily on external groups (i.e., family and friends) for support

Spousal Emotions

Worry about communication and care provided by LTC.
Greater expectations for level of care in LTC
Anger with the government for not caring
Sad and isolated
Grief over losing spouse to separation or, eventually, death
Relief and reduced stress with hardworking and caring staff

Study Findings

“I wish we would have had more time to let [us] know [about being separated] too but if you don't grab [the open LTC bed] right away you can wait. [LTC staff] said we really wanted her to go in there... they recommended that place.” (P5)

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Study Findings

“Because [LTC organizations and the government] don't understand that spouses or caregivers do a lot of work looking after their loved ones. And if our [spouses] were closer here we could do a lot more [and that] would take some of the strain off the workers because I know they're all short ended.” (P1)

Study Findings

“I'd like to see more flexibility in government policy. Maybe the rules are too hard, maybe they're too rigid, maybe they need to have more flexibility to be able to consider individual situations. My guess is... every situation is going to be new and individual... so given that they're few and far between, where's the flexibility in the administrative process that's going to allow people to stay [together]? Can we allow these [spouses] to get into the same home together, if that's their goal?” (P7)

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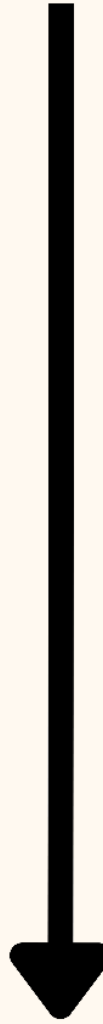
“What I really don't understand [is that] we don't want an extra bed. We don't want an extra room. What is the big deal if a room becomes available here? Transfer one of our spouses [here] and put the person that's next on the list [in their place].”

(P10)

Study Findings

"They're very good here. They're very kind and compassionate, and empathetic... [Malcom, my husband,] settled in well with the staff being kind like they are." (P8)

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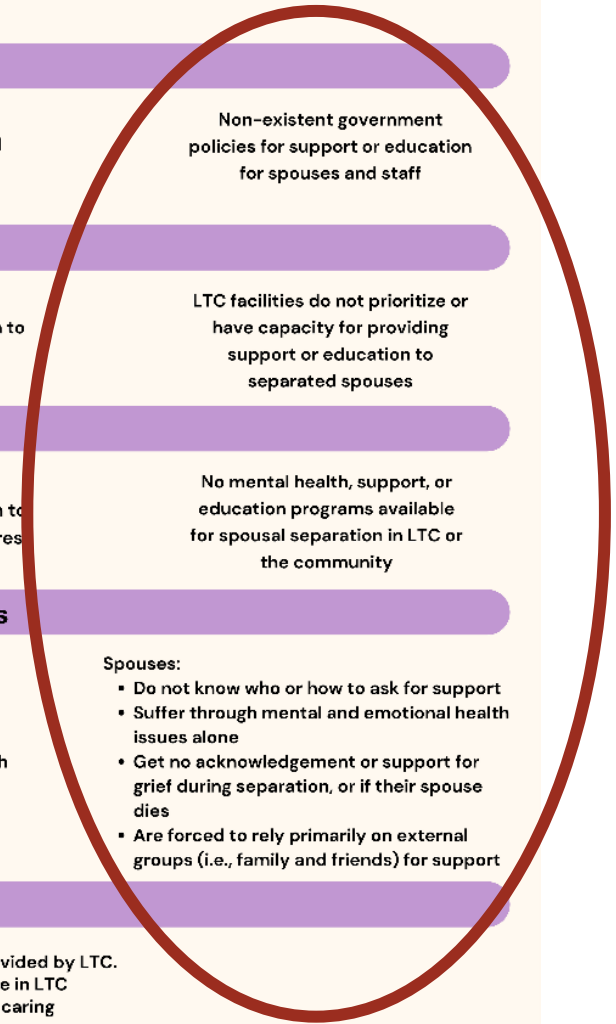
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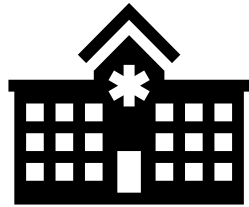
“But I never thought of talking to anybody about mental health issues or emotional issues.” (P 11)

“... and it’s not like [LTC staff] provide a specific program for [mental health]. It's more like an [general] everyday support.” (P7)

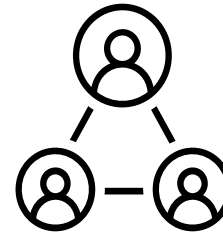
SO, WHAT NOW?



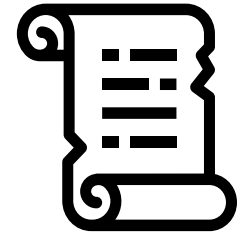
Role of
Healthcare
Practitioners



LTC
Organizations,
Staff, &
Leadership



Inclusion of
Older Adults in
Decisions



Guide Policy,
Procedures and
Care Pathways

POLL

What changes would you need in your organization or practice to address these results provided by spouses?



Recommendations and Solutions for Improvement Suggested by Spouses

LTC ADMISSION AND INITIAL SEPARATION:

- Increased access to transportation at all LTC facilities that is specifically tailored for older adults
- Policies to be more individualized for specific situations i.e., people with or without living spouses
- More facilities with LTC and retirement apartments together
- More shared living spaces available
- More education and information provided at LTC facilities for spouses
- Digital literacy and education for all spouses before and during LTC admission
- Organizations and Government officials should invite separated spouses to speak on their lived experiences of LTC admission and spousal separation
- Additional research and evaluation on spousal separation during LTC admission
- More knowledge translation and dissemination activities to educate the general population, especially older adults who are at higher risk for separation and LTC admission
- Both formal and informal mental health and emotional support for spouses experiencing LTC admission and separation, both in LTC facilities and in the community

WHEN SPOUSES REMAIN SEPARATED:

- introduce more specific LTC policies that target problem areas for spouses (i.e., allow spouses to still have alone time)
- Increase the support and compensation of LTC staff within LTC facilities
- Allowing spouses to be more involved in the care of their partner
- Giving spouses more access and communication with staff when they are not physically present
- More education and information are provided at LTC facilities for spouses
- More transparency and communication to the spouse living in the community and/or independent living on the medical well-being and care of the spouse living in LTC.
- Additional research and evaluation on the impact of spousal separation in collaboration with older adults
- More knowledge dissemination and translation activities to educate the general population about spousal separation (i.e., writing a novel, sharing videos and infographics on social media)
- Both formal and informal mental health and emotional support for spouses dealing with separation in LTC and in the community. Supports should address the range of emotions and experiences described by spouses who have been separated
- More support programs using a variety of delivery methods (i.e., formal counseling, peer support programs)
- The creation of mental health “Champions” in support programs at LTC facilities and in the communities, who provide peer support, education, and guidance to spouses based on their own experiences with separation.

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SPECIFIC RECOMMENDATIONS FOR DEMENTIA AND COGNITIVE HEALTH



Individual Psychotherapy
or Counseling



Self-Care and Relaxation
Training



Caregiver and Family
Support Groups/Therapy



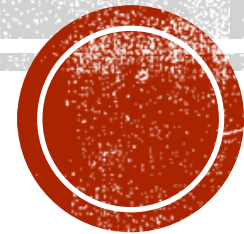
Psychoeducation



Behavioural Skills
Training

POLL

What challenges or facilitators do you envision for implementing these spousal recommendations?



INCLUDING OLDER ADULTS WITH DEMENTIA IN YOUR WORK

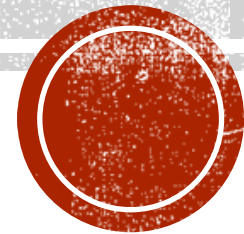
- Older adults with dementia
- Discouraged participation and communication

Overlooked
population

A diagram consisting of a white rounded rectangle with a dark red border containing a bulleted list. Below this rectangle is a solid dark red rounded rectangle containing the text 'Overlooked population'. A thick, dark red curved arrow starts from the bottom right of the red box and points towards the right side of the slide.

POLL

How can you involve the voice and perspectives of older adults with dementia in your work?



Link to Video:

<https://www.youtube.com/watch?v=xyC4iJU6Fp0>

**THANK YOU,
QUESTIONS?**

Connect with me:

Email: 12mar9@queensu.ca

Twitter: @madirob12