Telegerontology: A novel approach to optimize health and safety and to “age in place” among people with dementia in Newfoundland and Labrador

Update on pilot project remote communication via skype and app development/use for NLCAHR

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Funding Partners

- Alzheimer Society
- NLCAHR
- Government of Newfoundland and Labrador
- NLMA
- E-Health Unit MUN
- Dr. Maxwell House (Lawson Foundation)

Alzheimer Society CANADA

Newfoundland & Labrador Centre for APPLIED HEALTH RESEARCH
www.nlcahr.mun.ca

Newfoundland Labrador

NEWFOUNDLAND AND LABRADOR MEDICAL ASSOCIATION

Hypothesis

- Goal of this project although not powered to determine causation is to show remotely delivered expertise via Skype will result in less caregiver stress and fewer hospital visits.

Objectives

1. Develop and test methods of remote assessment, communication and management in the home. (Skype, standardized video and telephone etc.)
2. Determine to what extent telegerontology supports the primary caregiver and the family physician to maintain the patient safely at home.
3. Gather pilot data which includes caregiver stress, obstructive patient behaviours, ER visits, falls and institutionalization to prepare for a larger trial and national funding.

Method

Domain	Outcome Tool	On inclusion	Bi-weekly	6 month intervals	End of study
Patient Safety	Falls or near falls recorded in personal diary and confirmed by telephone call		✓	✓	✓
Patient Vitality	Caregiver –reported Frailty Index	✓		✓	✓
	TUG	✓			✓
	Biochemical Marker (albumin)	✓			✓
	MMSE	✓			✓
	Body weight	✓		✓	
Caregiver stress	Questionnaire	✓		✓	✓
Health care utilization	Time to institutionalization/death (using MCP)				✓
	Number of health care contacts recorded in personal diary and confirmed by telephone		✓	✓	✓
	Primary physician MCP billing				✓
	Telegerontology team contacts			✓	✓
	ER visits, Hospital Admissions (MCP)				✓
Satisfaction	Physician satisfaction with care Caregiver satisfaction with care				✓

Home Visit

- VIDEO
- MMSE,MOCA
- FAST
- Kettle Test
- Wash Your Face
- TUG
- FIM
- Caregiver Stress Scale/Home support history

Doctor Visit

- Chart Review :Hx/Px, Labs/xrays,consults,diagnoses
- Diagnosis/Functional med assortment
- F/u Comprehensive assessment letter with suggestions to optimize care

TIME LINE

Task	Jan-Aug 2014	June-July 2014	Aug/Sep 2014 - Feb/Mar 2015	Dec-Jun 2014-2015	May-Jun 2015	June-Nov 2015	July-Aug 2015	Jan 2015	May 2016	July 2016	Nov 2016	May 2017	Jan-June 2017
Group 1 Recruitment	X												
Group 2 Recruitment				X									
Group 1 Physician and Caregiver Pre-Interviews		X											
Group 1 Intervention			X										
Group 2 Physician and Caregiver Pre-Interviews					X								
Group 2 Intervention						X							
Group 1 6 month follow-up							X						
Group 2 6 month follow up									X				
Group 1 12 month follow up								X					
Group 2 12 month follow up											X		
Group 1 18 month follow up										X			
Group 1 Physician & Caregiver Post Interviews										X			
Group 2 18 Month follow up												X	
Group 2 Physician & Caregiver Post-Interviews												X	
Analysis and Write up													X

Observations Caregiver/ Support Side

1. Education is critical to understand the dementia trajectory to help the caregiver /s prepare for the future.
2. Skype seems to enhance communication and gives the same communication as if the patient/caregiver is there in your office.
3. Patients like the connectedness that Skype provides
4. To date system navigation, and validation of approaches used to handle dementia behaviors seem to be key interventional features.
5. Knowing the circle of care dynamic is critical (fragile to stoic steadfast)
6. Home environments enhance ease of care and rural ingenuity is alive and well.
7. Supports in the community are woefully inadequate
8. Health care system communication is complex and emergency home care poorly integrated in the community (3 cases in crisis)
9. Avg weekly intervention Skype time less than 1 hour with 5 active participants.
10. Family stress in dementia care even worse than I anticipated

Special Projects

Chelsea Harris and Cecily Stockley both first year medical students did the analysis of the initial caregiver interview tapes and the physician interview tapes. Chelsea using qualitative technique developed themes of caregiver profiles and Cecily looked at the support systems and literature published in this area.They plan to do the second cohort of families as a continuation of this next year.

A Literature Review on the role of the Primary Care Physician in Dementia Care

Phase I Independent Projects

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Introduction

This literature review was completed for *the Newfoundland and Labrador Telegerontology project*; a project aimed at determining if remotely delivered gerontology team consultation over two years will result in fewer falls at home, fewer hospital visits, and a more prolonged time to institutionalization among people with moderate dementia as opposed to usual care. The purpose of this review was so summarize best practices of primary care physician (PCP) care.

Background

Dementia: a major-neurocognitive disorder[1]

- Prevalence in Canada:
  - 1994: 252,000[2]
  - 2011: 747,000[3]
  - ~ 2031: 1.4 million[3]
- Cost of dementia:
  - 2011: $33 billion[3]
  - ~ 2040: $293 billion[3]
- Institutionalization of a dementia patient is a critical event for which risk should be mitigated; minimizing risks will lead to the most positive outcomes for the patient[4,5,6,7,8].

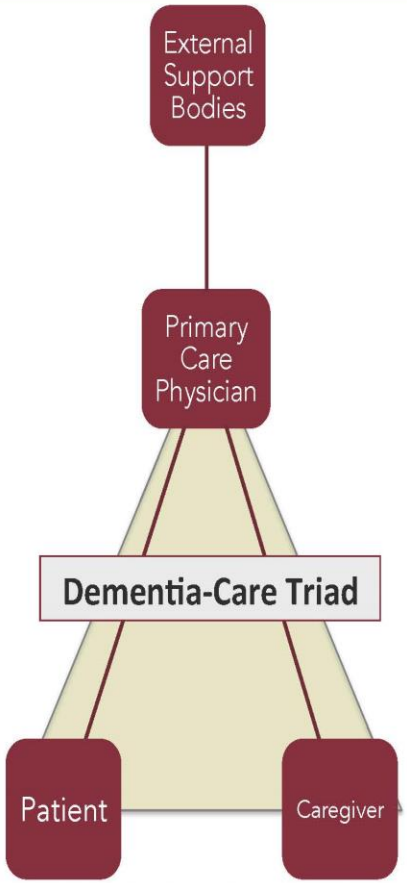

Figure 1: the role of the PCP in dementia care.

Recommendations from the literature:

Forming Relationship with Caregiver

- *Define the Caregiver's Risk of psychological stress* – stress can lead to depression in caregiver, decreased effectiveness of patient care, and increased risk of institutionalization[9,10]. Risk factors include: older age; a higher level of education; living apart from patient; being someone other than spouse[4,8].
- *Use tools to monitor caregiver stress*. Example: the web-based Impact of Alzheimer's Disease on Caregiver Questionnaire (IADCQ)[9].
- *Form a trusting relationship with caregiver* so that effective interventions can occur [6,11,12].

Patient Monitoring

- *Involvement in diagnosis, treatment, management and follow-up.*[6,12,14,15]
- *Early diagnosis is key.*[13,14,16] Survey patients for risk factors (age (65+), genetic history, type II diabetes, head injury, strokes, & high cholesterol levels).[16]
- *Recommend 1° prevention practices to all patients* (diet, exercise, protecting head from injury).[16]
- Mitigate risk for institutionalization by: Managing co-morbidities; Visiting the home and monitoring for safety with interprofessional team (OT, social worker); Being accessible to patient and caregiver[6,15]

Active Partner of the Dementia-Care Triad

- A partnership between the PCP, caregiver, and patient with a goal *to improve quality of life for both the caregiver and patient*[7,13,17]
- Include caregiver and patient in treatment plan and educate on disease prognosis and progression[13,17]
- Be available to both patient and caregiver[17]
- Respectfully contribute what time and resources the PCP can manage[17]

External Support Bodies:

- Liaison and referral role between the triad and interdisciplinary groups (OT, social worker, Alzheimer Society, community homecare)[16, 18]
- Early implementation of home care is a *protective factor* against early institutionalization[7]
- In a 2014 study, Canadian physicians felt that community resources were difficult to access.[15] Interprofessional collaboration must be used to overcome this barrier.[15,18]

Conclusion: using the CanMEDS competencies to care for dementia patients

Risk for institutionalization of dementia patients can be minimized, and quality of life for the caregiver and patient maximized when the interconnected CanMEDS roles are utilized.

- The caregiver and PCP form a trusting relationship; this is achieved through communication, collaboration and health advocacy
- The patient is diagnosed early and monitored carefully; the roles of scholar and medical expert are important here.
- The patient, caregiver, and PCP are all active partners of the dementia-care triad; the roles of collaborator, communicator and manager are especially essential for the triad to be successful.
- The PCP facilitates the connection between the dementia-care triad and relevant support groups; as a professional and collaborator, these connections can be made.

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FACULTY OF MEDICINE

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Optimizing caregiver support: A novel Telehealth approach among people with dementia in Newfoundland & Labrador

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Background

Dementia is a major health issue in Newfoundland and Labrador[1]. Best practice guidelines suggest to keep people with dementia in their home for as long as possible, however most are admitted to long-term care as the disease progresses. Identifying and alleviating caregiver stress through Telehealth (i.e. virtual communication) could potentially reduce the risk of institutionalization and improve dementia care[2].

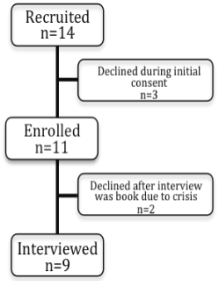
Methods

Data collected from semi-structured, open-ended question interviews with dementia caregivers were transcribed and analyzed using NVivo software. Researchers conceptualized underlying patterns and separated data into themes of stressors and supports.

Images collected during caregiver interviews

Results

Factors that impacted the caregivers were grouped into two categories (Figure 1), factors that increased caregiver stress and limited their ability to care for the patient in the home (stressors) and factors that helped facilitate caring in the home (supports).



Analysis showed that stressors were more frequently mentioned during the caregiver interview when compared to supports. Many of the stressors are modifiable factors that can be addressed via Telehealth.

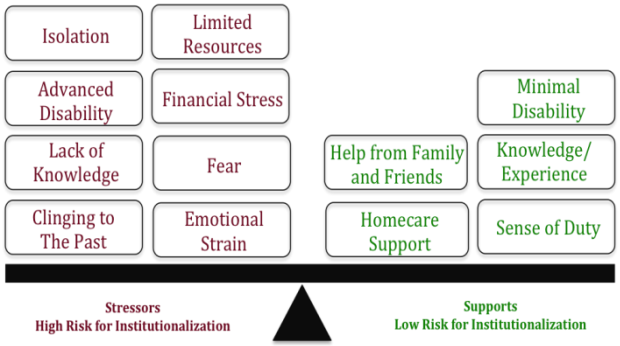


Figure 1

Discussion

Researchers feel that relieving stress and putting appropriate supports in place can prolong the time in which dementia patients can remain in the home with their caregiver. Using a simple analogy of the commonly known game, Jenga®, the blocks represent different caregiver supports such as knowledge, family support, financial stability, access to homecare, and medical support.

The sturdy, c ower has all of the supports in place. There is m risk that the c will face a challenge that will cause them to completely crumble and resort to institutional care.

Caregivers in this group are experiencing stressors but are managing day to at moderate risk of institutionalization.

This group of caregivers are balancing on one or two supports and experience extreme stress. They have minimal supports in place and any form of challenge will cause crisis

Moving forward with this study, researchers can address the caregivers in the high and moderate risk groups and attempt to alleviate their modifiable stressors by implementing various

Conclusions

While completing this project I exercised several of the CanMED roles. By identifying critical needs of the caregivers and developing a model to alleviate stress I was a health advocate. I applied my skills as a communicator when participating in structured interviews, and advanced my skills as a scholar by completing qualitative analysis using NVivo software.

I would like to acknowledge my supervisor Dr. Butler for his contribution to this project I would also like to acknowledge Dr. Michel Ploughman, Ann Hollet, and all other memb of the eHealth unit.

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2. O'Connor M, Arizmendi, B., Kaszniak, A. (2014). Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment. *Journal of aging studies*, 30: 87–93

PHASE ONE SPECIAL PROJECT

MEMORIAL UNIVERSITY

IT Lessons to Date

1. App development which ones
2. Design issues and the user interface(how to talk to computer geeks)
3. Android or Mac
4. Local vs remote app development ….lessons learned
5. Ongoing development and “back end”
6. Caregiver training