Supporting Dementia Family Caregivers in Rural Canadian Communities: The Reitman Centre Working CARERS Program

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How did the Cornwall Community Hospital get involved?

• The City of Cornwall met the research criteria regarding being a rural community
• The Reitman Centre research team originally contacted the EMBRACE initiative team
• The EMBRACE initiative is designed to improve the interactions of family caregivers with various health care providers throughout the addiction recovery and/or mental health journey.
• Unfortunately, the EMBRACE initiative did not meet the specific criteria's for this particular research but they knew of the Caregiver Information Sessions being offered through the Geriatric Day Hospital.
The Reitman Centre
CARERS Program

A Therapeutic Skills Training Program

Coaching, Advocacy, Respite, Education, Relationship, Simulation
Reitman Centre CARERS Program

• 10-week small group psychotherapy
• Co-facilitated by two mental health clinicians
• 3 theoretical “pillars”:
  ▪ Tailored dementia education
  ▪ Problem Solving Techniques
  ▪ Simulation

~ Emotional experiences acknowledged and processed ~
The case of working caregivers

It’s just all consuming and so you ride the frustration, you ride the anger.

You’re on a slow, downward spiral where you think you are doing okay and then you find that, “Holy cow, I can’t concentrate the way I used to be able to.”

All of a sudden you’re mulling over the same thing; you’re looking at the same paper for 45 minutes.

I haven’t gone for a walk in more than 2 years. I feel stuck and I have become more stressed, argumentative and negative.

Even though I’m physically at work, I find myself preoccupied with what’s happening at home. I worry about my mother.

I don’t have any other life. I go to work and I come home.

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The Reitman Centre Working CARERS Program

*Special focus on work-caregiving interface*

- **8-week** small group psychotherapy
- Facilitated by one or two mental health clinicians
- Same theoretical principles as the CARERS Program
Research Questions

• What are the facilitators and barriers to dementia caregiving in rural communities?
• How can an evidence-based intervention such as the Working CARERS Program be adapted in rural settings?
Research Methodology

Appreciative Inquiry

Participatory Action Research (PAR)

Chevalier, J.M. and Buckles, D.J. (2013)
Participatory Action Research: Theory and Methods for Engaged Inquiry, Routledge UK
List of Cornwall Community Stakeholders

- Alzheimer Society of Cornwall & District
- Champlain Local Health Integration Network
- Cornwall Community Hospital Geriatric Mental Health Services

... and family caregivers.
Research Stages

- Interviews/Focus groups with caregivers & stakeholders
- Content and format adaptation of the Working CARERS Program
- Delivery of adapted Working CARERS Program in rural communities
- Document, Share, Discuss, Recommend
- Post-Program focus groups with caregivers & stakeholders
- Act
- Act
What transpired and who participated

- 4 full cycles of PAR occurred between 2015-2017
- 31 caregivers from MB, NS and ON were interviewed
- 16 community stakeholders were engaged in the PAR cycles
- 6 local group leaders and 4 simulated patients were trained in the CARERS methods
- 4 cycles of Working CARERS Program were delivered:
  - One using videoconferencing technology
  - Three in-person format
- A total of 20 caregivers participated in the above groups
- 15 caregivers participated in post-program focus groups
Emerging themes from caregiver interviews done in similar communities in Nova Scotia & Manitoba

- What it means to live in a rural community
- Reflecting on personal factors that currently support/act as barriers in the dual role
- Outcomes of dual role
  - Health, social isolation, emotional strain
- Making dual-role work:
  - Workplace “fitting” into my life
  - Fine tuning work conditions
  - Making a “wish-list” re: personal needs
Emerging themes from stakeholders focus groups done in similar communities in NS & MB

• Clients experiencing challenges re: accessing formal supports;
• Need respite care, home-based care, and community care for both people with dementia and their caregivers;
• Need tailored interventions, education and support for adult children caregivers in particular.
Working CARERS in videoconferencing format

Tech Preparation

Group Dynamics & Cohesion

Tailored training

Live simulation on videoconferencing
What they learned - practically

• Pros:
  - Videoconferencing format eliminated time-zone and geographical barriers, improving program accessibility
  - Use of technology and the concept of participating in a group psychotherapy intervention via secured videoconferencing is novel to most participants

• Con:
  - Internet connectivity may not be reliable in some rural areas
What they learned – clinically

Effectiveness of clinical components were preserved:

Problem Solving framework

Communication approaches

Acknowledge rural reality
What they learned - systemically

Enablers

- Local Champions
- Community readiness
- Established structure
- Sustainability beyond research
- Political climate
Immediate next steps

• PAR cycle in Cornwall Ontario in progress

• Sharing study findings: highlight key elements for successful adaptation and implementation strategies to scale the Working CARERS Program model

• Seek valuable insights in a dialogue with invited organizational representatives and dementia family caregivers

• Identify priority activities to advance the uptake, sustainability and future evaluation of the adapted Working CARERS Program
Always keep them in mind in our work...
Acknowledgement

All caregivers and stakeholders who participated in the Working CARERS Program and the associated research

Thank you!