



A volunteer service focused on the wellbeing of caregivers of people at the end of life

A study

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A research project

- To implement and formatively evaluate a volunteer “Caregiver Guide” service to help family caregivers of people at the end of life **maintain their wellbeing**
 - While providing care (last 3-6 months)
 - Into early bereavement (first 6 months)
 - No hands on care of the patient

Study design: qualitative formative evaluation

Rationale

Caregivers of people at the end of life:

1. Are on call 24/7
2. Neglect their own needs
3. Tend to be treated as caregivers rather than as family in need of support themselves
4. Are losing a loved one
5. Most services abruptly stop when the patient dies

Their health suffers (physical and mental)



Ideal



Reality



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Rationale

Potential solution:

- Highly trained volunteers
 - Professional involvement as required

Caregiver Guide Service

- Guides visit caregivers approximately weekly in person (or by phone, email, texting)
- Guide Coordinator
 - matched caregivers with Guides
 - supported Guides
 - helped problem-solve
 - found community resources
 - available to caregivers by phone
 - linked with clinicians
- Team meetings approximately every 3 weeks

Training of Guides

1. Palliative Care McGill volunteer course
2. 5 sessions on Guiding caregivers
 - Format changed over time
 - Caregiver Guide Handbook (available)
3. Work with a volunteer on a palliative care inpatient unit
4. Team meetings

Training of Guides continued

Topics in the 5 caregiver-focused sessions

1. How the service works
2. Caregiver experience
3. Family functioning
4. Guiding caregiving
5. Guiding caregivers to care for themselves
6. Bereavement, spiritual wellbeing
7. Signs of impending crisis
8. How the local health care system works
9. Legal issues



FINDINGS



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Data collection

From who

- 23 caregivers
- 9 Guides
- Guide Coordinator
- 4 health care professionals

Types of data

- 37 individual interviews
- 4 focus groups
- Reflections (Guides, Coordinator, Robin)
- Participant-observation in team meetings



THE GUIDES' EXPERIENCE



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Guide experience

Benefits


- Help/Contribute to society
- Part of a team
- Learn/grow

Challenges

- First visit
- Boundaries
- Ending the relationship



THE CAREGIVERS' EXPERIENCE



Caring for the caregiver

The
foundation:
a unique
relationship

Guide shares experience

Caregiver can
share things they
wouldn't share with others



Some effects of Guiding

- Empowered to:
 - Ask for help
 - Take care of themselves
- Bolstered their self-esteem
- Improved emotional state
 - ↓ Guilt, stress, anxiety, crying
 - ↑ Calm, ability to handle “my darkest moments”

Broader Outcomes

- Fewer calls to health care providers for the patient
- Patients able to stay home longer
- Guide helps to maintain a sense of self



Renewed service

Leadership team replaces Coordinator

- Experienced Guides
- Robin
- Hope & Cope Volunteer Coordinators

Currently training new Guides

Service re-launch expected in a few weeks

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