Supporting family caregivers: The development and use of a decision guide

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Family Caregiving

The bulk of palliative and life limiting illness care is given by family members. Our system is dependent upon them.
What have we learned from family palliative caregivers?

• Taking up the job is automatic and taken-for-granted
• Family caregivers do not know what they are getting into
• Sometimes they are afraid to ask for help

Sometimes there is a promise

Promises were challenged by:

- a lack of preparedness for caregiving
- difficulty accessing professional support and information
- frustration with the inadequate help received.

Consequences

• Pushed beyond capacity relationally, physically, emotionally → compromised ability to provide care at home
• Broken promise → unbearable guilt, betrayal, and failure
What do family palliative caregivers need?

When asked explicitly about their personal needs as a palliative caregiver, identified needs focused on:

- The need to be skilled and know more
- The need to navigate competing wishes, needs, demands, priorities
- The need for an “extra pair of hands”

Robinson, Pesut, & Bottorff, 2012
The Dilemma of Supporting Family Caregivers
What could we do?

We asked the question: given what we and others have learned about family palliative caregivers, what would an effective intervention need to do?

- **Educate & prepare** – if they do not know what they are getting into, do not know what is ahead, and do not know the resources that are available, could we help?

- **Create space for options** – if home is viewed as the best place to die, but commitment to following this path may have serious unintended negative consequences, how can we support consideration of options?

- **Support decision making** over time as things change.
Translating Knowledge into Practice

- Review of the evidence including research, grey literature, and patient/family support tools/resources
- Data extraction to explicitly identify the knowledge, skills and resources that address family palliative caregiver needs as well as track the ‘level of evidence.’
- Adaptation of the patient decision aid development process
Development of the Guide

- Guiding principles:
  - **Flexible** – useful over time and illness progression in communities with differing availability to resources (e.g. rural communities)
  - **Applicable** for both male and female caregivers
  - **Comprehensive** but not too high burden
  - Plain, acceptable **language**
Early versions

Tool Development

Assumption: Caregiving is an ongoing process and decisions are ongoing. Tool supports ongoing reflection about how things are going, what is needed, and how to carry on.

Aims and Objectives of Tool

Primary aim: Aim of the intervention/tool is to support desired outcomes — e.g., support/enhance QOL, building self-efficacy, e.g., caregiving, around problem-solving and decision-making.

- To support caregivers in reflecting on their own experiences throughout the caregiving process
- To help caregivers identify what they perceive are their caregiving to assist with decision making
- To help caregivers determine which aspects of caregiving become burdensome or problematic
- To facilitate shared decision making and dialogue
- To help caregivers anticipate and prepare for issues that arise throughout caregiving trajectory
- To support ongoing reflection about how things are going and how to carry on
- To build caregiver self-efficacy and increase problem-solving skills
- To support caregiver health and wellbeing during caregiving
Guidance from caregivers

- Focus groups (3) with bereaved family palliative caregivers (12 women, 3 men).
Focus Group Responses

The guide brought forth strong memories of past caregiving – it resonated with the participants.

• **Advice:** Don’t shy away from clear language about palliative care and end-of-life

• **Recommend:** Complete with a health care provider and use to stimulate conversation (connection with intent)

• **Recommend:** Could be completed in steps or as a whole

• **Recommend:** Should be used over time – introduced and revisited at points of illness transition (e.g., when cancer has spread). “It is a work in progress” (Focus Group 1)
Caregiving at home for someone with life-limiting illness

A family caregiver guide
What Happened Next

• Piloted with current family palliative caregivers and evaluated via cognitive interviewing
Findings

- Cognitive interviews conducted with 5 current family palliative caregivers for someone with advanced cancer
- Findings were consistently positive.
  - No major revisions required; minor revisions needed
  - Well organized; “Clear, self-explanatory and complete.”
  - “Very useful; a great resource.”
  - Participants indicated that the guide invited them to reflect (viewed positively) and they anticipated it would facilitate discussions regarding EOL issues and caregiving options.
Minor Revisions and Re-Design

• Let’s briefly look at the Guide (new and improved)
This decision guide is for me, if:

- My family member is living with a life-limiting illness
- I would like to plan for possible changes in needs for caregiving for my family member.

Providing care for a family member is a process that often changes, sometimes quite suddenly. You may provide more care over time — alone, or with help from others. Careful planning allows you to care for your family member at home for as long as possible if you choose to do so. This guide will help you with this plan.

You will be guided through four steps to help you with your decision planning:

1. Think about my caregiving situation now.
2. Think about how my caregiving situation might need to change.
3. Explore caregiving options in my area.
4. What are my best options if the needs for caregiving change?
Think about my caregiving situation *now*.

<table>
<thead>
<tr>
<th>How am I managing with...</th>
<th>I DO NOT NEED HELP</th>
<th>I COULD USE SOME HELP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home maintenance:</td>
<td></td>
<td></td>
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<tr>
<td>• Inside</td>
<td>○</td>
<td>○</td>
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<tr>
<td>• Outside</td>
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<td>○</td>
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<tr>
<td>Car maintenance</td>
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<td>○</td>
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<td>Grocery shopping</td>
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<td>Cooking</td>
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<td>○</td>
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<tr>
<td>Taking care of pets</td>
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<tr>
<td>Home changes for safety and convenience (e.g., wheelchair ramps, grab bars in the bathroom etc.)</td>
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<tr>
<td>Getting special equipment (e.g., walker, hospital bed, commode, wheelchair)</td>
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<td>○</td>
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<tr>
<td>Personal care of your loved one:</td>
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<td></td>
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<tr>
<td>• Bathing</td>
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<td>• Toileting</td>
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<tr>
<td>• Dressing</td>
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<td>• Transferring in and out of bed</td>
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<td>○</td>
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<tr>
<td>• Managing incontinence of bowel and/or bladder</td>
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<td>• Wound care</td>
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Now what? .....Implementation and Evaluation

- Our current study: putting the Guide into practice in urban and rural communities, seeing how it works, determining if it is helpful, identifying needed revisions, analyzing implementation successes and barriers
- 25+ family caregivers participated
- Many were supported by Hospice Palliative Care Volunteers
What did we learn?

• Consensus that the guide is useful from the caregiver and provider perspective

• Not useful for: last stage of illness, end-of-life, caregivers who do not like to look forward (1)

• Many (if not most) received the guide too late, i.e., they were experienced caregivers who had “figured out” how to do it

• But – even those caregivers found it useful. “It always raises questions.” “Caregiver stress comes from lack of knowledge, the Guide helps you work through it.”

• Can be used in many different ways – e.g., in pieces, all at once, alone, with support

• MUST be augmented with information about local resources
<table>
<thead>
<tr>
<th>Category</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparedness for caregiving</td>
<td>12 stayed the same or improved their score; 3 showed a decline (felt less prepared)</td>
</tr>
<tr>
<td>Caregiver competence</td>
<td>9 stayed the same or improved their score; 6 showed a decline (felt less competent)</td>
</tr>
<tr>
<td>Rewards of caregiving</td>
<td>10 stayed the same or improved their score; 5 showed a decline (felt fewer rewards)</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>12 felt their burden deceased or stayed the same; 3 reported feeling their level of burden increased</td>
</tr>
</tbody>
</table>
Suggestions for improvement

• Broad information about local resources – an insert?
• Information about timing of decision making – e.g., funeral planning before death
• More information about Advance Care Planning
• Specific suggestions about what to do and how to do it (examples)
• Some recognition of the emotional nature of the work and the decision making

• **Dilemma**: covering enough but not making it too big. One participant said: “This guide could be four times bigger.”
• But the guide is not meant to cover all aspects of caregiving. It is meant to support decision making.
What’s next?
Questions
Thank you.
Acknowledgements

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Selected references


