Psychosocial Care

SUPPORTING FAMILY PALLIATIVE CAREGIVERS

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TRIAL SUMMARY: Family palliative caregivers receptive to new decision aid

The authors reported on the development of a decision support guide for family palliative caregivers that aims to educate and prepare these individuals for the caregiving trajectory, create space for the consideration of care options, and support decision making over time. A literature search was conducted and data extracted to identify the knowledge, skills and resources available to address the needs expressed by family palliative caregivers. Consequently, the patient decision aid development process was adapted to develop a decision support guide for family palliative caregivers that is flexible, applicable to both male and female caregivers, comprehensive, and delivered in acceptable language. Family palliative caregivers are guided through four steps to assist them with decision making: 1) thinking about their current caregiving situation; 2) thinking about how their caregiving situation might change; 3) exploring caregiving options in their area; and 4) identifying the best options if their caregiving needs change. Three focus groups (n=4; n=6; n=4) were conducted with bereaved family caregivers to provide feedback on the draft decision support guide.

FINDINGS
Participants reported that the guide highly resonated with them and their past caregiving experiences. Recommendations from the focus groups included that the guide be completed with healthcare providers to stimulate conversation about caregiving needs, that it be completed either in steps or in its entirety, and that it be used over time and specifically revisited at points of illness transition. The authors identified that the next steps in the development of the decision support guide should include modifying the guide based on the feedback from the focus groups, aesthetically redesigning the guide in collaboration with a graphic expert, and pilot-testing the decision support guide with current family palliative caregivers.

COMMENTARY: Many Canadians wish to spend their dying days at home. There is also an emphasis in the public health care system on home-based care in an effort to contain costs. Current models of home care are based on the premise that family caregivers espouse a key role in the provision of care that allows those with a life-limiting illness to remain at home.

Family caregivers often feel they have little choice in the process of becoming a caregiver. Their decision to provide home-based care is influenced by a number of factors, including fulfilling a promise to the dying individual to provide care at home, wanting to maintain a sense of normalcy, and previously having negative experiences in an institutional setting. In any case, many family caregivers are not fully aware of what they are taking on and often report feeling ill-prepared for their caregiving role. The emotional and physical demands of caregiving while facing the imminent loss of a family member have profound effects on these individuals. As the patient’s disease progresses and caregiving demands change, family caregiver distress is heightened. Many caregivers are reluctant, however, to ask for help. Caregivers may fear that soliciting help from healthcare professionals will result in transferring the patient to the hospital, thus breaking their promise to the patient to be cared for at home. The decision support guide under development by Robinson and colleagues recognizes that the decision to become a caregiver happens at one point in time and is separate from the ongoing decision to continue providing care at home. The guide provides valuable assistance to plan for and address changing care needs without threatening the caregiver’s role.

The needs of family caregivers will, in part, be determined by how they view their caregiving role. Family caregivers often view themselves as both clients and coworkers in relation to the healthcare system. Caregivers readily identify needs related to knowledge, skills and supports to enable them to provide care. Caregivers also acknowledge that they have self-care needs but often resist considering help to address these needs and focus instead on needs related to being providers of care. Being able to continue to provide care, however, necessitates that caregivers remain healthy themselves, which requires that their self-care needs be met.

One of the strengths of the decision support guide being developed by Robinson et al. is that it is based on the identified needs expressed by family palliative caregivers themselves. Not surprisingly, these needs focus on knowledge, skills, and supports to enable family members to be the caregivers they want to be. The decision support guide enables caregivers to consider their own self-care needs and contemplate care options without undermining their central role. Creating this space as part of the decision making process may facilitate discussion about these needs might change and/or be met over time. Caregivers can be supported to maintain their
own health and thus maintain their ability to provide care at home. Such discussions may also help healthcare providers to better understand and support caregivers’ ongoing decisions related to providing care.

Family caregivers who are able to negotiate the decision for home-based care with the dying individual seem more prepared and better able to cope with providing care at home than caregivers who make uninformed or indifferent decisions. Moreover, family caregivers appreciate when healthcare providers facilitate discussions about decisions related to providing care at home. Robinson et al’s focus groups with bereaved family caregivers recommended that it would be helpful to complete the decision support guide with healthcare providers to stimulate discussion about caregiving needs. Including the patient in these discussions may also be an important consideration. Open discussions between the family caregiver, patient and healthcare provider that are revisited as the patient’s disease progresses and care needs change may promote negotiated decisions and thus better coping throughout the trajectory of care.

Robinson et al’s work addresses some important assumptions that are often made in relation to family caregivers’ desire or ability to provide home-based care. The decision support guide that is being developed is a much-needed tool that can help family palliative caregivers understand that caregiving is a process that changes over time, plan for possible changes in needs for care, and feel supported in their planning. Robinson and colleagues offer a significant and novel contribution to our knowledge of family palliative caregiving, and continued development of the decision support guide will undoubtedly provide a valuable resource to support family caregivers with decisions surrounding the provision of home-based palliative care.

References

Disclosure: Ms. Wurz, Ms. Bernatchez and Ms. Penner report no conflict of interest relevant to these articles.