Policy and Practice Note / Note de politique et practique

Stakeholder Meeting: Integrated Knowledge Translation Approach to Address the Caregiver Support Gap*

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RÉSUMÉ

Les aidants familiaux sont une partie intégrante et de plus en plus débordée du système de soins de santé. Il y a un écart entre ce que les données de recherche démontrent être bénéfique pour les soignants et ce qui est réellement fourni. À l'aide d'une approche basée sur l'application intégrée des connaissances (AC), une réunion des intervenants a inclus des chercheurs, des aidants familiaux, des associations de soignants, des cliniciens, des administrateurs de soins de santé et des décideurs. Les objectifs de la réunion étaient d'examiner les données issues des recherches en cours et de tenir un dialogue entre les intervenants multiples sur les lacunes, les facilitateurs et les obstacles à la fourniture d'un soutien aux aidants naturels. Cent vingt-trois individus ont participé à cette réunion. Trois populations cibles des aidants familiaux ont été identifiées pour discussion: soignants d'aînés atteints de démence, soignants en fin de vie et soignants d'aînés ayant des besoins de santé complexes. Les résultats de cette réunion sont et seront utilisés pour éclairer le développement des efforts visant à mettre en œuvre à la fois des recherches et des politiques afin de fournir un soutien aux aidants familiaux en se basant sur les preuves.

ABSTRACT

Family caregivers are an integral and increasingly overburdened part of the health care system. There is a gap between what research evidence shows is beneficial to caregivers and what is actually provided. Using an integrated knowledge translation approach, a stakeholder meeting was held among researchers, family caregivers, caregiver associations, clinicians, health care administrators, and policy makers. The objectives of the meeting were to review current research evidence and conduct multi-stakeholder dialogue on the potential gaps, facilitators, and barriers to the provision of caregiver supports. A two-day meeting was attended by 123 individuals. Three target populations of family caregivers were identified for discussion: caregivers of seniors with dementia, caregivers in end-of-life care, and caregivers of frail seniors with complex health needs. The results of this meeting can and are being used to inform the development of implementation research endeavours and policies targeted at providing evidence-informed caregiver supports.

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The World Health Organization (WHO) defines family caregivers as those who provide unpaid care (WHO and Alzheimer's Disease International, 2012). Family caregivers are an integral and increasingly overburdened part of the health care system. Caregiving can be associated with physical, emotional, and financial costs (Stajduhar et al., 2010). There is a gap between what research evidence shows is beneficial to caregivers and what is actually provided. Using an integrated knowledge translation approach guided by the knowledge to action cycle (Graham et al., 2006), a stakeholder meeting was held among researchers, family caregivers, caregiver associations, clinicians, health care administrators, and policy makers. The knowledge to action cycle includes a central evidence funnel surrounded by an evidence-informed cycle that focuses on adapting, implementing, evaluating, and sustaining knowledge into practice (Graham et al., 2006). The overall meeting goal was to inform future implementation research efforts by reviewing current research evidence combined with multi-stakeholder dialogue on the potential gaps, facilitators, and barriers to the provision of evidence-informed caregiver supports. The findings of this meeting could inform the development and implementation of evidence-based practice and policy aimed at improving supports for family caregivers.

Participants

A two-day meeting was attended by 123 individuals (24 caregivers [18 female; six male]; 11 policy makers; 23 health administrators/managers; 24 researchers/academics; 29 health care professionals; 12 from community organizations). The Alzheimer Society of Alberta and the Northwest Territories (ASANT) and the Alberta Caregivers Association recruited participants to attend the meeting from within their family caregiver communities. Administrators, employees, and board members from these two associations also participated. Additionally, researchers, clinicians, health care administrators, and policy makers associated with a number of key national institutions attended, along with international research experts and stakeholders (e.g. WHO, Stanford University). Three target populations of family caregivers were identified for discussion: caregivers of seniors with dementia, caregivers in end-of-life care, and caregivers of frail seniors with complex health needs. Meeting participants self-identified which of the three discussion groups they wished to participate in, and, when individuals identified more than one group, the meeting organizers allocated participants in an effort to balance discussion group size and expertise.

Agenda

The agenda for day 1 of the meeting included an evidence-based review of published literature, plenary sessions, and interactive discussions. Focusing on the evidence-funnel within the knowledge-to-action cycle (Graham et al., 2006), the meeting began with summary presentations of research evidence specific to the target populations. In order to prepare the evidence summary, a literature search was conducted by JM of Ovid Medline, EMBASE, PubMed, and CINAHL from inception to October 2013 focused on English-language articles and identifying systematic reviews or randomized controlled trials of caregiver interventions or outcomes. Key search terms varied by the targeted caregiver population but included "caregiver", "carer", "support, "interventions", "dementia", "terminal care", "end-of-life care", "palliative care", "frailty", and "frail older adult" when relevant. Additionally, the references of key articles were searched to identify relevant articles. The search identified 314 citations that were reviewed by JM (191 related to online supports for caregivers of persons with dementia; 67 related to caregivers of persons in the terminal phase of illness; 56 focused on supports for caregivers of frail seniors with complex health needs); 42 articles were included in the final review (11 related to online supports for caregivers of persons with dementia; 21 related to caregivers of persons in the terminal phase of illness; 10 focused on supports for caregivers of frail seniors with complex health needs) (see Table 1).

Plenary sessions were also delivered by recognized national and international researchers on topics relevant

Table 1: Results of literature review on caregiver supports

Summary of Key Citations and Findings for Online Supports for Caregivers of Persons with Dementia

Author, Year, Journal	**Study Design**	**Key Findings**
Godwin, K. (2013) *American Journal of Alzheimer's Disease & Other Dementias*	Systematic review Randomized controlled trials between 1990–2012 Computer or web-based interventions for unpaid caregivers of persons with dementia	Variability in the content, delivery, and outcome measures Increased caregiver confidence in decision-making, self-efficacy, perceptions of the positive aspects of caregiving Reductions in stress, strain, anxiety, and depression
Powell, J. (2008) *Journal of Telemed Telecare*	Systematic review Information and communications technology 15 articles included	Inconsistent outcome measures Some interventions may have had modest effects on improving carer stress and depression
Marziali, E. (2006) *The Gerontologist*	Randomized controlled trial 10-session internet-based videoconference support group or control	Statistically significant baseline to follow-up change in stress score in intervention group
Beauchamp, N. (2005) *The Gerontologist*	Randomized controlled trial 299 employed family caregivers "Caregiver's friend: dealing with dementia" Web-based support group or control	Improvement in caregiver self-efficacy, intention to get support, and caregiver gain Reductions in stress, strain, anxiety, and depression in caregivers
Brennan, P. (1995) *Nursing Research*	Randomized controlled trial "Computer Link" (computer access to electronic encyclopedia, decision support, and tool for communicating with other caregivers) or control	Caregivers accessed website on average, twice per week Increased confidence in decision-making No significant difference in decision-making skill or in social isolation
Casper, G. (1995) *Medinfo*	Randomized controlled trial "Computer Link" or control Same study population as Brennan '95, Bass '98	Statistically significant improvement in decision-making confidence No significant change in decision-making skill
Bass, D. M. (1998) *Journal of Aging and Health*	Randomized controlled trial "Computer Link" Same study population as Brennan, Casper 1995	No significant between-group differences in strain For spousal caregivers, the intervention resulted in a statistically significant reduction in relationship strain
Eisdorfer, C. (2003) *The Gerontologist*	Randomized controlled trial 3-armed trial of structured ecosystem therapy (SET), SET plus computer telephone integrated system (CTIS) or minimal support control	Caregivers in the combined SET plus CTIS had a significant reduction in depressive symptoms at 6 months SET alone did not have a significant effect on depressive symptoms in caregivers
Mahoney, D. (2003) *The Gerontologist*	Randomized controlled trial Telephone- computer system (stress monitoring, counselling, voicemail to disease experts, and a distraction call for the care recipient)	Statistically significant intervention effect for caregivers with lower mastery at baseline for the three outcome measures (bother, anxiety, and depression)

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Table 1: Continued

Summary of Key Citations and Findings for Online Supports for Caregivers of Persons with Dementia		
Author, Year, Journal	**Study Design**	**Key Findings**
Gitlin, L. (2003) *Psychology and Aging*	Summation of follow-up data across all Resources for Enhancing Alzheimer's Caregivers' Health (REACH) sites	Statistically significant pooled estimate for decrease in burden for women in the intervention groups Significant improvement in burden and depression for caregivers with high school or less education in the intervention groups
Finkel, S. A. (2007) *Journal of Geriatric Psychiatry*	Randomized controlled trial Screen phone with ability to send and receive phone and text messages, and support group sessions delivered over the phone or control	Participants with higher baseline depression experienced significantly greater reductions in depressive symptoms than did participants in the control group

Summary of Key Citations and Findings for Caregivers of Persons in the Terminal Phase of Illness		
Author, Journal, Year	**Study Design**	**Key Findings**
Candy, B. (2011) *Cochrane Database of Systematic Reviews*	Systematic review 11 randomized controlled trials 1,836 caregivers of patients with terminal disease Practical or emotional support, coping skills	Direct caregiver support reduces psychological distress Direct caregiver support may improve coping skills and quality of life (results not statistically significant) Provision of care to care recipient resulted in non-significant decrease in caregiver psychological distress
Stajduhar, K. (2010) *Palliative Medicine*	Review of family caregiving for individuals with terminal conditions Home-based (excluding formal care) 123 articles (1998–2008) with quantitative results	Caregiver needs: psychological, financial, and occupational Caregiver outcomes dependent on appraisals and coping strategies Reactions are more important than patient characteristics in caregiver outcomes such as depression and anxiety
Bee, P. (2008) *Journal of Clinical Nursing*	Systematic review (n = 26 studies) Practical information needs of informal caregivers providing home-based palliative care to people with advanced cancer	Knowledge gaps: incontinence care, diet, access to specialist services and equipment, patient comfort, medications, and symptom management Period after discharge especially turbulent as caregivers undertake new direct-care tasks Caregivers want to increase their nursing competencies and want more information on medication, symptom control, and more written material
Kim, Y. (2012) *Current Opinion in Supportive Palliative Care*	Literature review 27 articles published between 2010 and 2011 dealing with cancer caregivers' needs	Female and spousal caregivers reported poorer quality of life than others Patients' symptoms and personal care needs were primary stressors to caregivers

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Table 1: Continued

Summary of Key Citations and Findings for Caregivers of Persons in the Terminal Phase of Illness

Author, Journal, Year	Study Design	Key Findings
Harding, R. (2003) *Palliative Medicine*	Systematic review of interventions for carers of patients using home cancer and palliative care services	Hospice care: decreased anxiety, increased satisfaction Spouses who attended a stress and activity management group had significantly higher knowledge scores, were more active, coped better with medical situations, and were more satisfied with the care provided
Williams, A. (2011) *Palliative & Supportive Care*	Systematic review Descriptive studies to determine changes in caregiver needs during different stages of the caregiving process	Increase in burden, depression, anxiety, and distress among caregivers as the patient's condition worsened Age, gender, and spouse versus non-spouse were inconsistent outcome predictors
Gomes, B. (2013) *BMC Palliative Care*	Systematic review – 210 studies from 33 countries Preferences for place of care at the end of life or place of death 34, 000 patients, 19,000 caregivers, and almost 30,000 general public members	Moderate evidence that most people prefer a home death (75% of studies; 9 out of 14 of these were high quality) Home preference estimates ranged from 31–87% for patients, 25–64% for caregivers, and 49–70% for the public
Critchley, P. (1999) *Journal of Palliative Care*	Systematic review Comparative studies of palliative care	Caregivers reported that patients who died at home preferred this, and half of patients who died in hospice or hospital would have preferred home death
Deitrick, G. (2006) *Journal of Pain and Palliative Care Pharmacotherapy*	Systematic evaluation and critique of 15 websites	No interventional or outcome data
Allen, R. (2008) *Journal of Palliative Medicine*	Randomized controlled trial Home visits with the family to construct a personal legacy (scrapbook or audiotaped stories) versus control (3 supportive telephone calls)	Reduced caregiving stress in intervention group in comparison to increased stress in control caregivers Improvement in patient's self-reported dyspnea and pain Increase care recipient social engagement
Walsh, K. (2007) *British Journal of Psychiatry*	Randomized-controlled trial 6 weekly visits by a trained advisor who provided advice, information, and emotional support n = 271 informal caregivers who scored high on a screening tool for psychological distress	Psychological distress was lower in the intervention group across all time points (not statistically significant) No between-group differences in carer strain, quality of life, satisfaction with care, or bereavement outcome 1/5 of caregivers in the intervention came too late 1/3 felt that more sessions would have been helpful

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Table 1: Continued

Summary of Key Citations and Findings for Caregivers of Persons in the Terminal Phase of Illness

Author, Journal, Year	**Study Design**	**Key Findings**
Northouse, L. (2007) *Cancer*	Randomized controlled trial 5 family sessions targeting communication, hope, coping, uncertainty, and symptom management or control standard care 235 prostate-cancer-spouse dyads	Participants reported less uncertainty and better communication with spouses compared to controls Improved quality of life, self-efficacy, communication, less negative appraisal of caregiving, uncertainty, hopelessness, and symptom distress in intervention group
Carter, P. (2006) *Cancer Nursing*	CAregiver Sleep Intervention (CASI) *n* = 30 family caregivers of a person with advanced cancer who reported difficulty with sleep	All study participants showed improvements in self-reported sleep quality Intervention group had greater improvements in Sleep Quality Index scores than did control at each time point
Kissane, D. (2006) *American Journal of Psychiatry*	Randomized-controlled trial Family-focused grief therapy versus control *n* = 81 families of patients dying from cancer	Non-significant decrease in distress in intervention participants than in control participants No between-group differences in depression or social adjustment
McMillan, S. (2006) *Cancer*	Three-group randomized-controlled trial Hospice plus coping skill training Hospice plus emotional support Usual hospice care	Coping skills intervention led to significantly greater improvement in caregiver quality of life, lessened burden of patient symptoms, and improvement in caregiving task burden No change in caregiving mastery or coping in any group Substantial attrition rates across all 3 treatment groups
Hudson, P. (2005) *Journal of Pain and Symptom Management*	Randomized controlled trial Two home visits by a nurse, a phone call, a guidebook, and audiotape of self-care strategies Control = standard home-based palliative care *n* = 106 caregivers of patients dying with cancer	More positive caregiving experience No effects on preparedness to care, self-efficacy, competence, or anxiety Decrease in the reward for the standard therapy group and an increase in reward for intervention group
Northouse, L. (2005) *Psycho-oncology*	Randomized-controlled trial FOCUS: *F*amily involvement, *O*ptimistic attitude, *C*oping effectiveness, *U*ncertainty reduction, and *S*ymptom management *n* = 134 breast cancer patients and their caregivers	More positive appraisal of caregiving in intervention arm At 3 months; the effects were not sustained at 6 months No between-group differences in caregiver uncertainty, hopelessness, coping, or quality of life
Keefe, F. (2005) *Journal of Pain and Symptom Management*	Randomized-controlled trial Partner-guided pain management intervention or usual care control *n* = 78 advanced cancer patients and caregivers	Significant increases in caregiver's self-efficacy for helping the patient control pain and other symptoms

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Table 1: Continued

Summary of Key Citations and Findings for Caregivers of Persons in the Terminal Phase of Illness

Author, Journal, Year	**Study Design**	**Key Findings**
Addington-Hall, J. (1992) *BMJ*	Randomized-controlled trial Coordination group (services tailored to their individual needs) or usual care *n* = 554 cancer patients, life-expectancy < 1 year	Coordination group carers were significantly less likely to feel angry when they thought of the patient's death No between-group differences in anxiety, depression or sleeplessness, self-reported health, or physical symptoms
Kane, R. (1984) *The Lancet*	Randomized controlled trial Hospice versus conventional care *n* = 247 terminally ill cancer patients	Hospice patients' family caregivers were more satisfied and had less anxiety than did controls
Weitzner, M. (1999) *Quality of Life Research*	Randomized non-controlled study to evaluate the reliability and validity of the Caregiver Quality of Life Index – Cancer	Test-retest reliability was 0.95 ($p < .0001$) Internal consistency was 0.91

Summary of Key Citations and Findings for Caregivers of the Frail Senior with Complex Needs

Author, Journal, Year	**Study Design**	**Key Findings**
You, E. (2012) *BMC Health Services Research*	Systematic review Case management (assessment, planning, facilitation, and advocacy for options and services to meet an individual's needs)	Improvement in lessened burden and stress in some studies 1 study reported higher satisfaction 1 study reported improved well-being
Lopez-Hartmann, M. (2012) *International Journal of Integrated Care*	Systematic review Support services for informal caregivers of community-dwelling frail elderly 4 systematic reviews 10 primary studies	Positive effect of respite on caregiver burden, depression Negative effect respite on caregiver quality of life Positive effect of individual and group support on caregiver depression Positive effect of group support on depression, coping; positive effect of phone and computer support on caregiver depression, burden, and anxiety
Bauer, M. (2009) *Journal of Clinical Nursing*	Literature review Hospital discharge practices of frail older people and family carer's experiences	Communication between staff and family is often poor Caregivers feel they receive inadequate information, and feel pressured to have the patient discharged Comprehensive discharge protocol and discharge liaison has been shown to have positive outcomes for patients
Mason, A. (2007) *Journal of American Geriatrics Society*	Systematic review Effectiveness and cost-effectiveness of community-based respite care for frail older people and their caregivers	Adult daycare neither benefited nor harmed the care recipients with no effect on institutionalization Home care prolonged life at home Lessened caregiver depression and burden in frequent (2–3 times per week) users of adult daycare Significant reductions in caregiver stress but no effect on entry into long-term care from respite Meta-analysis found significant effect on burden with respite care

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Table 1: Continued

Summary of Key Citations and Findings for Caregivers of the Frail Senior with Complex Needs

Author, Journal, Year	Study Design	Key Findings
Yin, T. (2002) *Nursing Research*	Meta-analysis Effectiveness of group and individual interventions on decreasing burden on caregivers of the frail elderly	Moderate positive treatment effect of group and individual interventions on caregiver burden
Melis, R. (2009) *Age and Ageing*	Randomized controlled trial Dutch Geriatric Intervention Program (6 in-home nursing visits for frail older patients) or usual care	Non-significant decreases in caregiver burden Higher baseline burden in co-habiting caregivers Decreased burden in co-habiting caregivers
Smith, T. (2006) *The Gerontologist*	Randomized trial Telephone support group (TSG) program for spouses and adult child caregivers of frail older adults *n* = 97 (36 spouses and 61 children)	TSG was more effective in reducing burden and depression, and increasing social support, knowledge, and use of community resources in adult child caregivers No significant differences in outcomes for spouses
Toseland, R. (2004) *American Journal of Orthopsychiatry*	Randomized-controlled trial Health Education Program (HEP) (coping strategies, education and support) versus usual care *n* =105 caregiver-care recipient dyads	Severe depression significantly decreased for HEP participants, and increased for usual care controls Increased perceived effectiveness in HEP participants, decreased perceived effectiveness in controls
Baumgarten, M. (2002) *Journal of Aging and Health*	Randomized-controlled trial Immediate admission to an adult daycare center or 3 months waitlist control	Frequent attendees were older, more cognitively and functionally impaired, more likely to have a spouse caregiver and less likely to have no caregiver Caregivers of high attendees were more likely to be women, older, and to have higher burden scores Caregiver had more time to pursue his/her own activities 26% felt relationship with the care client had improved
Labrecque, M. (1992) *American Journal of Orthopsychiatry*	Single-blind randomized-controlled trial Support group for spouses caring for frail, elderly veterans Support, education and discussion, problem-solving and stress reduction	Caregiver's perceptions of spouse's health deteriorated in the control group, improved in the support group Support group experienced less burden than control No significant intervention effect on anxiety Inconsistent effects on depression outcomes Stress related to caregiving decreased over time in both groups

to our three targeted caregiver populations, including research related to online supports for caregivers of seniors with dementia, end-of-life care, and caring for frail seniors with complex health needs. Findings, from three semi-structured focus groups with a total of 23 family caregivers and which were conducted prior to the meeting by research team members in collaboration with ASANT and the Alberta Caregivers Association, were then presented to further explore evidence-to-practice gaps. Methodological details and results of these focus groups have been previously published (Brémault-Phillips et al., 2016). However, standardized coding techniques were utilized to identify themes. Specifically, the focus groups identified issues related to caregivers' knowledge, skills, and access to resources. Finally, utilizing a modified World Café technique, meeting participants were divided into three groups to discuss potential facilitators and barriers to providing evidence-informed caregiver supports to the three targeted caregiver populations. The World Café approach was modified by having team member facilitators and scribes present at each table, rather than having a participant remain behind to brief the next round of participants. Further, the discussion rounds decreased in length as the Café continued. However, all discussion rounds provided participants sufficient time to connect ideas, and to contribute new content. The table facilitators recorded major themes identified by participants on poster boards for all participants to see and comment on further, while the table scribes took more detailed notes that were subsequently used to expand on these major themes within this article.

Working from the foundation of information sharing of day one, the second day of the meeting involved a smaller group of individuals interested in further exploring implementation research strategies and interventions that would address the identified gaps and barriers in the three targeted caregiver populations. Although this consisted primarily of researchers and academics, other engaged stakeholders such as caregivers (four in total), health care providers, and members from ASANT and the Alberta Caregivers Association also attended day two. One specific focus of day two was to explore potential research collaborations with the WHO in terms of online modules that they were developing for caregivers of persons with dementia. Ethics approval to conduct the meeting and related activities was received from the University of Alberta Research Ethics Board.

Evaluation

Participants were asked to evaluate the meeting. Among the 50 participants who provided written feedback from day one, 92 per cent agreed that the event provided an excellent learning opportunity, 98 per cent agreed that the featured presenters were excellent, and 88 per cent agreed that the event provided a good opportunity for networking. All participants felt that the event was free of commercial bias, and 96 per cent agreed that it was well-organized and worth their time to attend.

Recommendations from Stakeholder Meeting: Identified Gaps, Facilitators, and Barriers

Caregivers of Seniors with Dementia

Given the demands placed on family caregivers of persons with dementia, access to support services from the convenience of home is potentially attractive. The growing availability of the internet makes internet-based caregiver supports a potentially viable cost-effective option. Multi-component internet-based caregiver interventions have been shown in several small studies to decrease caregiver perceptions of burden; decrease caregiver stress, anxiety, and depression; and increase caregiver self-efficacy and confidence in decision-making (Bass, McClendon, Brennan, & McCarthy, 1998; Beauchamp, Irvine, Seeley, & Johnson, 2005; Casper, Calvitti, Brennan, & Overholt, 1995; Eisdorfer et al., 2003; Godwin, Mills, Anderson, & Kunik, 2013; Mahoney, Tarlow, & Jones 2003; Marziali, & Donahue, 2006; Powell, Chiu, & Eysenback, 2008). Based on this, both ASANT and the WHO were interested in supporting caregivers of persons with dementia using online resources and, hence, the reason for focusing on internet supports at this meeting.

Internet interventions provide an opportunity for interventions that can be tailored to individuals and their changing needs. Therefore, development and implementation of an online support tool for caregivers of persons with dementia was explored at day two of the meeting. Specifically, the tool could incorporate interactive caregiver self-efficacy and self-management modules, developed with support of the WHO (http://www.who.int/mental_health/mhgap/evidence/dementia/en/), into a local web-based resource such as ASANT (www.asantcafe.ca).

Some of the key facilitators that participants identified for an online caregiver support tool included the potential to have questions answered at any time, to build a sense of community, and to validate individuals who are isolated due to geography and/or stigma. This tool could meet the needs of both primary caregivers and other family caregivers. The evolution of technology makes this an increasingly popular form of support and is a way to consolidate information. Potential barriers that were identified included challenges related to accessibility and usability across diverse groups of end users, and developing a tool that is adaptable to changing technology and evidence. Other issues included (a) ensuring website credibility and maintenance; (b) involving caregivers (end users) in development and evaluation; (c) considering user privacy issues; (d) providing both health care professional and caregiver perspectives; (e) considering information needs across the disease continuum; (f) making optimal use of existing resources; and (g) aligning with the formal health care system.

Caregivers in End-of-Life Care

Participants identified that interventions to improve outcomes for caregivers of persons in the terminal phase of illness are challenging. The literature suggests this is because of the limited period associated with advanced disease and the attempts family caregivers make to try to prepare for the eventual death of their family member or friend, while also helping the dying person (Harding, List, Epiphaniou, & Jones, 2012). However, systematic reviews of studies with this population suggest that caregiver appraisals, coping strategies, and resources have the most impact on positive outcomes (Bee, Barnes, & Luker, 2008; Harding et al., 2012). For example, interventions such as emotional support and advice on coping directed to caregivers result in decreased distress, improved coping ability, and increased caregiver quality of life (Bee et al., 2008; Harding et al., 2012). Evidence provided from randomized-controlled trials suggests that caregiver coping skills interventions lead to decreased burden and increased quality of life in the caregiver, and that psychosocial interventions result in a more positive caregiving experience (Candy, Jones, Drake, Leurent, & King, 2011; McMillan et al., 2006).

Potential facilitators identified during the meeting for supporting caregivers of persons at the end of life included the development of provincial frameworks for end–of-life care and additional research. Gaps and barriers include the challenges of identifying the population and support needed by caregivers providing end-of-life care, the diversity of this population, and available resources. Identifying the population is a challenge as caregivers of persons at the end of life include those dealing with a variety of advanced diseases, who may or may not access palliative care services, and who are bereaved. Some caregivers have not considered the eventual death of their family or friend, and others do not view death as a natural process, making it difficult to discuss end-of-life issues. It was felt assessments need to identify caregivers at highest risk, as well as the diversity of needs and supports required among caregivers.

Participants identified that current services and resources to support family caregivers of persons in the terminal phase of illness have differing goals. For example, some services reduce the amount of caregiving, while others focus on improving caregiving skills, coping, and problem solving. As well, resources are more limited in rural areas. Participants indicated that the current focus is on providing resources and information to family caregivers and that more attention is needed in building relationships with and supporting caregivers themselves, rather than on supporting caregivers to provide care. It was also suggested that resources need to be flexible, practical, and simple because of the intensity and time demands of caregiving. As well, resources and supports need to focus on the whole illness experience.

Caregivers of Frail Seniors with Complex Health Needs

For this meeting, frail seniors with complex health needs were broadly defined as older adults with multiple medical, functional, and/or psychosocial issues. Studies involving caregivers of frail seniors with complex health needs have demonstrated several benefits of both caregiver and care recipient interventions. Systematic reviews have demonstrated evidence for case management, comprehensive discharge planning, and respite care (Bauer, Fitzgerald, Haesler, & Manfrin, 2009; Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; Mason et al., 2007; Yin, Zhou, & Bashford, 2002; You, Dunt, Doyle, & Hsueh, 2012). Randomized controlled trials provide evidence for in-home geriatric intervention programs, telephone support groups, health education programs, and adult daycare (Baumgarten, Lebel, Laprise, Leclerc, & Quinn, 2002; Melis et al., 2009; Smith & Toseland, 2006; Toseland, McCallion, Smith, & Banks, 2004).

Meeting discussions identified many potential caregiving barriers. Since family members may not identify themselves as caregivers, requests for respite support or assistance that might alleviate stresses of caregiving can be delayed. This can leave caregivers consumed by caregiving tasks and with little time to manage their own needs. Family caregivers can feel isolated as their role and that of the person being cared for changes. Family dynamics and language barriers can complicate matters further, particularly when expectations related to care differ among family members. Family caregivers who do not reside in the same home or community can experience somewhat different challenges related to travel and receiving information second-hand. Privacy policies, accountability, and legalities related to sharing information within the health care system can be additional barriers.

Participants identified that the health care system tends to be complex, fragmented, constantly changing, and challenging to navigate. This can be a particular issue for persons with complex health needs who frequently interact with various components within the system. Duplication of resources, long wait times, poor communication, and use of technologies that lack integration can all impede the flow of information, cause redundancies, and delay access to services. Health care providers caring for individuals with complex needs are often under-resourced and ill-equipped to provide support to caregivers. This can leave the caregiver feeling unsupported, and needing to advocate, liaise with, and train health care providers in an attempt to fill system gaps. Economic issues due to care-related expenses or lost wages further add to the burden of caregiving. Earlier identifications of caregivers, education, and skills training of health care providers, and system changes aimed at providing appropriate evidence-informed caregiver supports could potentially address some of the gaps and barriers. These identified barriers are not necessarily unique to those caring for frail persons with complex health needs, but can be amplified by the complexity of the care needs of this population.

Participants also identified numerous facilitators. Although more resources are undoubtedly needed, caregivers have access to health care and community-based resources, and are supported through generally well-intended health care providers and agencies. There seems to be increasing awareness within society and government around the critical role that family caregivers play, and a growing awareness of the need to develop more formalized caregiver supports.

Next Steps

This meeting brought together key stakeholders, which is an important initial step in enabling collaborative relationships to develop among stakeholders. During this meeting, the current research evidence was reviewed, care gaps identified, and potential facilitators and barriers to evidence uptake explored. The results of this meeting can and are being used to inform future implementation research endeavours targeted at providing evidence-informed caregiver supports within practice. The findings of this meeting could also be used to inform policies aimed at better supporting family caregivers. To date, the results have been used to inform the development of a resource tool kit for interested stakeholders and to inform a funded grant examining the efficacy of online support tools for caregivers of persons with dementia.

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