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Mobilizing Outcomes from a 5-year Research Program addressing 'Timely Access and Seamless Transitions in Rural Palliative/End-of-Life (P/EOL) care in Canada': A Knowledge Translation Strategy

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Abstract

This paper provides an overview of the knowledge translation (KT) strategies employed in the dissemination of the research outcomes produced by a 5-year Research Program addressing 'Timely Access and Seamless Transitions in Rural Palliative/End-of-Life (P/EOL) (named the ICE program). The nature of this interdisciplinary, national research program, made up of 10 independent research projects, necessitates dynamic and varied KT strategies that are tailored to the specific stakeholder user groups identified. Knowledge translation has therefore been targeted to three identified stakeholder user groups: (1) policy and decision makers; (2) health care professionals, including clinicians and program makers, and; (3) end users, including patients and informal caregivers. The KT strategies that have been employed to date will be discussed specific to each of the three noted stakeholder user groups. Although the research program is now formally complete, the KT work is ongoing.

Keywords: Knowledge translation, stakeholder user groups, rural palliative health care, interdisciplinary research

1.0 Introduction

Based on a 5-year program (2005-2011) of research addressing interdisciplinary capacity enhancement (ICE), 10 separate research projects were conducted by a large, interdisciplinary team of academics and clinical researchers to address 'Timely Access and Seamless Transitions in Rural Palliative/End-of-Life (P/EOL) care in Canada' (herein named the ICE program, after the mandate of the funders - Interdisciplinary Capacity

Enhancement). Funded by the Canadian Institutes of Health Research (CIHR), this research program has produced a wide range of outcomes, from interdisciplinary

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training and capacity building, through to research outcomes which have clear practice applications. This paper provides an overview of the knowledge translation (KT) strategies employed in the dissemination of the research outcomes produced by the ICE program. The nature of this interdisciplinary, national research program necessitates dynamic and varied KT strategies that are tailored to the specific stakeholder user groups identified. Knowledge translation has therefore been targeted to three identified stakeholder user groups: (1) policy and decision makers; (2) health care professionals, including clinicians and program makers, and; (3) end users, including patients and informal caregivers. Understanding user context has been identified as an integral component to the development and delivery of successful KT strategies (Jacobson, Butterill & Georing, 2003) and operates as an organizational framework in this paper. We begin by describing the program of research and the research team, after which the current understanding of KT in both: (a) health care for rural populations, and; (b) palliative/end-of-life care contexts, will be discussed. Next, the KT strategies that have been employed to date will be discussed specific to each of the three noted stakeholder user groups; this discussion recognizes that although the research program is now formally complete, the KT work is ongoing. The paper concludes with a discussion of plausible future KT directions.

1.1 The Research Program and Team

As depicted in Figure 1, the program of research of concern herein included 10 projects in three main areas: *timely access* (4 studies), *seamless transitions* (4 studies) and *interventions* (2 studies). The *interventions* made up the core of the research program, spanning four of the 5-year granting period and informed by many of the studies undertaken in the *timely access* and *seamless transitions* areas. The interventions have also been prioritized and given a large proportion of resources, in terms of time, effort and funding. The overall research program was informed by consultation with palliative care service providers and health care policy makers, coupled with an accrued understanding of salient gaps in rural P/EOL health care research. The overall goal of the research program was to improve the quality of care for rural-based terminally ill persons and their families; this is particularly timely given the fact that the need for P/EOL care is increasing in rural Canada (Kelley, Sletmoen, Williams, Nadin, & Puiras, 2012).

The research team was interdisciplinary, multi-provincial, and included international collaborators. The team was comprised of 30 researchers from 11 disciplines, each of whom had an interest in the entire program of research and a commitment to one or more of the 10 projects that comprised the research program. The investigative team had amassed considerable experience in working with a variety of stakeholders, including NGOs, policymakers and health professionals. As a result, the team was well positioned to produce relevant and timely research where the likelihood of putting evidence into practice was high. The objectives of this team specifically focused on fostering capacity building, in relation to research and knowledge translation excellence in rural P/EOL care research, with an emphasis on a multidisciplinary, international and inter-institutional approach.

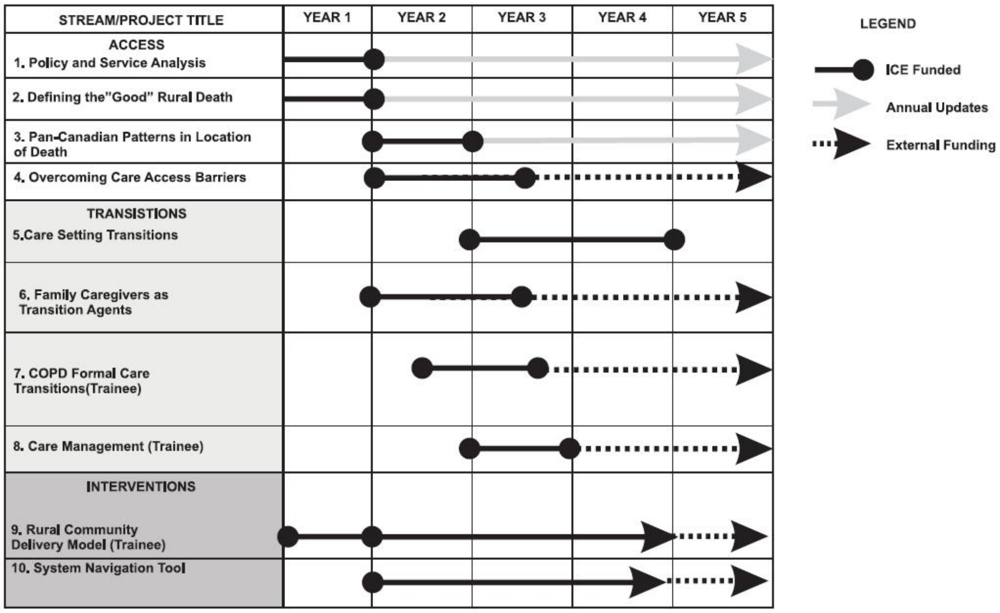

Figure 1. Projects making up the ICE Program of Research

Accordingly, the research "products" or outcomes of the ICE Program have and will continue to be numerous and diverse, ranging from briefing paper documents and peer-reviewed publications, to conference presentations, workshops, and training sessions. All of these outcomes have revolved around the central goal of effective KT. The strategies chosen are, and will continue to be, informed by the most applicable and relevant KT practice, specifically that designed for rural and palliative health care contexts, as will now be discussed.

2.0 Knowledge Translation in Rural & Palliative Health Care

Knowledge translation represents a growing body of literature, described as the "synthesis, dissemination, exchange and ethically-sound application of knowledge to improve…health…, provide more effective health services and products, and strengthen the health care system" (CIHR, 2011).

2.1 KT for Rural Populations

Effective KT programs for rural health care settings often revolve around the same best practices as those designed for non-rural settings, although certain factors characteristic of rural environments must be kept in mind. These include geographic isolation of both health care practitioners and their clients. This is an obvious barrier to effective stakeholder involvement, yet one which is often not adequately factored into the rural KT equation. Due to issues of access to certain technologies, use of the internet can be compromised in rural and remote geographies.

There are many access and quality challenges in delivering rural health services (Boychuk, 2002; Ministerial Advisory Council on Rural Health, 2002; Romanow, 2002)**.** Problems of access include a longstanding shortage of health care professionals, limited access to health care specialists and specialty services, and questionable sustainability of local hospitals (Strasser, Harvey, & Burley, 1994). Associated with access issues are obvious concerns over care quality, given that the vast majority of specialized health care is being provided in urban centres;

consequently, transitional issues from generalized rural to specialized urban geographies are often a major problem. To complicate these challenges, there exist numerous barriers to accessing care for rural residents, including human and system characteristics such as: geographic isolation (MacLean & Kelley, 2001), culture (Krakauer, Crenner, & Fox, 2002), socio-demographic conditions, healthcare services organization and timing of referral (Christakis, 1994), differences in the dying trajectory (Lynn & Adamson, 2003), and legal myths (Meisel, Snyder, & Quill, 2000). These barriers result in service delays, or no P/EOL care services whatsoever (Christakis, 1998). Timely access to care and seamless transitions across services and settings are therefore essential components of quality rural P/EOL care. Moreover, when compared to urban care, rural care can be greatly affected by: distance; weather, and; lack of access or ability to travel by patients, care providers and caregivers (Leipert et al., 2007). Given the diversity and number of challenges to the delivery of rural palliative care, as outlined above, innovative KT strategies must be considered.

Designers of rural KT initiatives must ensure they align their programs with the values of rural stakeholder user groups, the values of which may diverge from those of urban-based investigators and health program administrators. For example, rural health care providers often need access to highly skilled generalists, as compared to their highly specialized urban counterparts (Hays, Evans & Veitch, 2005). As with elsewhere, fostering dialogue among all key stakeholder user groups in rural geographies tends to increase trust and, ultimately, the investment of rural stakeholders in KT initiatives. Stakeholder user groups will tend to contribute more time and energy to KT initiatives if they feel that their investment will be truly influential. This need is showcased in several rural care KT studies (Smylie et al., 2009; Voyageur & Cailliou, 2001).

2.2 KT in Palliative/end-of-life Care Contexts

Rural P/EOL care services have traditionally developed within existing health care structures, although they are at their infancy when compared to other health care systems elsewhere (Robinson et al., 2009; Wilson et al., 2005). For example, much of the clinical services available in rural P/EOL care are provided by generalists, including nurses, physicians and social workers—the majority of which have no specialized palliative training. This care is also often provided within traditional health care institutions, such as hospitals and nursing homes; these settings sometimes have a designated palliative bed or section, but often do not (Sachs, 1997; Seamark & Seamark, 2004).

Like KT in rural contexts, the translation of knowledge in P/EOL care contexts is similarly informed by unique features, barriers and challenges. These are beginning to be recognized, as reflected in the latest Parliamentary Committee on Palliative and Compassionate Care Report (2011), *Not to Be Forgotten: Care of Vulnerable Canadians.* This report identifies the need for integrated P/EOL models that accommodate geographic, regional and cultural diversity, as well as better coordination and dissemination of research and information on P/EOL (Parliamentary Committee on Compassionate and Palliative Care, 2011). Palliative innovations developed in rural Canada are often effective for rural Canada, as is illustrated in the two intervention projects that make up the ICE research program, as discussed below. The research conducted for Project 1 identified a number of innovative approaches in palliative care development in Canada, describing them as circumventions around the traditional health care systems (Undisclosed Authors, 2010). These included the extensive employment of volunteers in rural geographies.

Such innovations are not surprising given that, in Canada, palliative care currently falls outside of the formal health care system, with a peppering of services being provided both within traditional institutions, such as hospitals and hospices, as well as in non-traditional community-based venues, such as volunteer and residential programs and in the private home, as well as via the internet and telephone. To complicate this even more, service delivery varies enormously within and between provinces given provincial jurisdiction over health care (Wilson, Northcott, Truman, Smith, & Anderson, 2001). This lack of a formal service structure presents challenges for KT in P/EOL care contexts.

To meet these challenges, a number of non-traditional rural palliative service informational KT strategies have been implemented, including: teleconferencing, telehomecare and telehealth programs for caregivers and recipients, all which have been hailed as a successful strategy in rural Alberta and British Columbia (Undisclosed Authors, 2010). Internet-based initiatives have also been identified as key approaches in delivering and disseminating health information in rural Canada, such as the website of the Canadian Virtual Hospice: www.virtualhospice.ca (Undisclosed Authors, 2010). Finally, the Pallium Project has been a key program in delivery of rural palliative care (n.d.). This program, funded through a Canadian Health Transfer in 2004, focused on developing education and training models for rural communities and providers over two years via workshops, travel funding, development of support tools, and facilitation of community-level hospice meetings (Undisclosed Authors, 2010). Although the funding transfer ended in 2004, and evaluative data is still being compiled and, to date, the program has informally being marked as a success by the practitioners involved (Undisclosed Authors, 2010).

The complexity of the KT process is further complicated by the temporal nature of the palliative care trajectory. Prognostication at end-of-life is complex; it attempts to estimate death and, in so doing, inform the disease trajectory to determine: financial costs; changing therapies, and; access to care needs (Brickner, Scannell, Marquet, & Ackerson, 2004; Glare & Sinclair, 2008; Skilbeck, Small, & Ahmedzai, 1999). As a result, caregivers must constantly renegotiate care needs and knowledge, including medical terminology, symptoms, and equipment (Ashpole, 2004). This process is additionally complicated by the taboo nature of palliative care, where caregivers and patients may require more time to accept the diagnosis and move from curative to palliative care (Ashpole, 2004). As much as these caregivers and patients require specific KT strategies to overcome these barriers, additional KT strategies are needed to target the other many diverse types of stakeholders, including: clinicians, care recipients, program planners and policy-makers.

As informed by preexisting research on the rural P/EOL care context, as described above, a full spectrum of communication strategies specifically targeting the three identified stakeholder user groups are suggested, including: use of existing community programs, organizations, stakeholder/researcher committees, and; use of organized opportunities where large numbers of recipients are present, such as town hall meetings, lay workshops, conferences targeting specific audiences, etc. (with an overall emphasis on building trust and fostering two-way communication) (Smylie et al., 2009; Timmons et al., 2007). Equally, internet and telephone-based KT options, if available, are suggested as essential, particularly given the geographic isolation and distance between stakeholder user groups. Canada currently offers a telehealth option, which has been identified as a rural health-appropriate circumvention to the traditional health care system in palliative care (Undisclosed Authors, 2010).

3.0 Stakeholder User Group-Specific KT Strategies

The KT strategies developed for this research program are on-going, and will be presented according to the three stakeholder groups identified in this program of research: (1) policy and decision makers; (2) health care professionals, including clinicians and program makers, and; (3) end users, including patients and informal caregivers. Although the KT strategies are discussed according to these three groups, the KT activities undertaken for this program of research are, in reality, complex, overlapping, and do not always differentiate across stakeholder user groups. Research has identified best KT practices for each autonomous group (Lavis, 2006), and has only begun to explore the mechanisms through which KT strategies are affected and informed by the relationships between each of these three key stakeholder groups. To illustrate, how a clinician accesses new information about best practices is different from how he/she accesses information specific to how to best support the physician-client relationship.

In order to support diverse environments, particularly with respect to the rural palliative care service context, as discussed above, diverse strategies have been developed for each of the three stakeholder groups.

3.1 Policy and Decision-Makers

Included in this category are any individuals, organizations, committees or other bodies that utilize raw knowledge or research results to inform further action and development, including policies and programs. This category also includes the use of research to inform additional research and funding opportunities. Given this, the target of these KT strategies were local, regional, provincial and federal governmental and non-governmental bodies (i.e. Canadian Rural Health Research Society), funding organizations (i.e. CIHR), and a wide variety of researchers interested in rural health care. Knowledge translation strategies were therefore developed with the objective of informing policies and programs while offering suggestions for action and future research. The information communicated was tailored to accommodate and address the current climate and relevant options in existing policies and funding strategies, while also being packaged in a format that was of high quality (Lavis, 2006).

Traditional KT strategies have been targeted to this first group of stakeholders. Traditionally, KT has included the publication of research results in peer-reviewed journals, as well as oral and poster presentations at conferences. At the time of this publication, over 45 peer-reviewed journal articles from the ICE program have been published in a variety of discipline-specific and policy-related publications, many of which are accessible via the ICE website (www.palliative.mcmaster.ca). These papers are often preceded by oral or poster presentations at professional/academic conferences; over 55 conference presentations have been given at various scales, from the local health care administration through to provincial, national and international bodies, such as the International Palliative Care Congress. These conference presentations have targeted three audience types: (1) health policy, (2) disease advocacy and palliative care services, and (3) rural health(care). The ICE bookmark (see Figure 2 below) has been widely disseminated at these conferences, allowing recipients to further explore the research program and the outputs produced. These traditional KT strategies have, thereby, attempted to disseminate information to a broad, albeit relevant, audience.

In additional to traditional peer-reviewed publications and conferences presentations, the ICE team undertook additional innovative methods for disseminating research results to palliative and rural health program planners, policy makers and researchers, including the development and implementation of annual ICE program-specific conferences (2005-2011). The penultimate conference was a 2-day broadcast across the world using web-based video-conferencing technology (*Elluminate!*), entitled *Moving Palliative and End-of-Life Care Forward (May 2010).* A wide range of policy makers were involved in this meeting, either in person or via intranet, where ample opportunities were made for members of the audience to ask questions, make comments and/or constructive suggestions (see www.palliative.mcmaster.ca. for more details).

The ICE team was also specifically funded to build capacity in interdisciplinary training for graduate students and new investigators, the result of which was the creation and successful implementation of 54 capacity-building opportunities for faculty trainees, new co-investigators, new collaborators (health authorities, programmers and institutions), research assistants, post-doctoral fellows, and doctoral, masters and undergraduate students. Additional KT activities were undertaken within this wide-ranging interdisciplinary collaborative team to ensure knowledge transfer, exchange and dissemination; these included annual face-to-face ‘trainee’ workshops, which accompanied team/ICE program-specific conferences, and innumerable project-specific face-to-face team meetings and teleconferences—the results and minutes of a selection made available on the ICE website (www.palliative.mcmaster.ca), a site which has experienced ongoing development since the first year of the ICE program.

Finally, special briefs and presentations were prepared for policy and decision-makers, such as provincial health ministries. Policy briefs, which include background information, new evidence and relevant and specific recommendations for action, have proven highly effective KT strategies for decision-makers. The ICE team has developed policy briefs based on research results of each of the ten projects for dissemination to stakeholders; all but two outstanding briefs are currently available on the ICE website (www.palliative.mcmaster.ca).

3.2 Health Care Professionals

This stakeholder group is identified as those who work directly with patients and family members and whom may liaise with program planners and evaluators when accessing or enhancing services used by their clients. In the research program of concern, these individuals often include nurses, social workers, physicians, counselors and program coordinators. Printed education materials have proven effective with health care practitioners in some cases, particularly when coupled with other, more active KT strategies. Active KT strategies may include: train-the-trainer and interactive toolkits, interdisciplinary lunch-and-learns and workshops. These types of knowledge translation strategies are particularly valued and effective when serving dual purposes, such as enhancing practitioner knowledge while simultaneously being used in conversation with patients (Bowden et al., 2005; DiCenso et al., 2002; Edmonston & Williamson, 1998; Leaffer & Gonda, 2000; Orfaly et al., 2005).

Given this, a number of active and passive KT strategies have been developed, including printed education materials, such as a bookmark (see Figure 2), publications for clinician-specific groups, and lay reports of research findings; these are available on the ICE website under the stakeholders and resources pages. These tools are being disseminated through individual ICE team members, as well as through partnering stakeholders and organizations having membership made up of the targeted health care professionals (i.e. the Canadian Hospice Palliative Care Association). Equally, specific articles are planned for dissemination to clinicians via newsletter and newspaper articles in rural health and palliative care forums.

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Figure 2. ICE Bookmark with URL.

This bookmark details contact and other relevant information about the ICE team for specific dissemination to stakeholders. In addition to being disseminated widely at conferences and workshops, it can be downloaded off the ICE website.

One particular ICE project has been specially designed to support rural health care practitioners; consequently, specific KT strategies have been used to target this group. In Project 9, a conceptual model for developing palliative care in rural communities was developed and validated; it articulates how local rural healthcare providers develop palliative care programs according to a number of phases (see paper in this Special Issue). This model has application to policy-makers, practitioners and communities; however, it has primarily been developed for use by communities and practitioners to develop palliative care services for end-users and, consequently, KT strategies have targeted rural health care practitioners. The model has been validated (Kelley, Williams, DeMiglio, & Mettam, 2011), and has proven to work as an intervention. It will be disseminated nationally through rural health care and palliative care networks.

Finally, clinicians and professionals were also included and targeted in many of the policy and program KT initiatives, noted above; this included the production of academic publications and conference presentations. Health care professionals were also well represented in the audiences of the annual TAST conferences, which were held in various places across the country. Inevitably, these traditional

KT products have and continue to inform health clinician curriculum and, consequently, the teaching of clinicians. For example, given that many of the investigative team also teach in nursing schools, they have had the opportunity to integrate the research results into their lectures and various other course materials.

3.3 End Users (Patients, Informal Caregivers)

Included within the end user stakeholder group are patients and informal caregivers, such as friends and family members. As discussed earlier in the introduction, this stakeholder group is particularly difficult to access given their cultural and geographic diversity, coupled with the emotional and taboo nature of the palliative prognosis. Given the success of other health programs aimed at rural health care practitioners and end-users, such as Pallium, telehealth and telehomecare, the ICE website was initiated and developed early in the research program. The website has links to other resources and information, as well as downloadable copies of printed educational materials, both useful for end users. The key KT strategy for end-users is the dissemination of the intervention results of Project 9 (as discussed above) and Project 10 (see associated papers in this Special Issue for more details). Project 10 is a system navigation tool, named the ‘Changes Toolkit’, the purpose of which is to assist families in managing palliative patient and family caregivers' transitions, particularly those across settings (i.e. home to hospital). This tool has applications and relevance to family members, caregivers and clinicians and is currently being developed for an online format. This intervention is timely given the arguments being made for the use of health care system navigators, advocated to guide individuals and families through the intricacies of the health care system. Navigators help with solution identification, decision making in crisis situations, consensus building between the family and care providers, the brokerage, implementation and review of care plans (Parliamentary Committee on Compassionate and Palliative Care, 2011). The ‘Changes Toolkit’ is being planned for national level dissemination for use by end-users, much like the community-capacity building toolkit that was created out of Project 9. Given that both Projects 9 and 10 are practical, applied intervention projects, it is not surprisingly that they are similarly targeted to end-users.

4.0 Discussion & Conclusions

According to Kelley et al. (2012), despite the fact that the need for rural palliative care is growing, “development of rural palliative care programs has been hampered by lack of palliative care education and training for rural health care providers… [and] models to guide the development of rural programs (Kelley et al., 2012, p. 222). The ICE program has targeted this knowledge gap by concentrating on the advancement of rural P/EOL care via research and capacity building, ultimately targeting three stakeholder user groups identified.

Although our studies did not directly involve First Nations communities, there is certainly the possibility of First Nations being informed by the research outcomes via the various KT strategies outlined. Indigenous communities are evenly concentrated between remote/rural and urban areas in Canada, with 54% of the aboriginal population residing in urban areas (Statistics Canada, 2006). This means a comparatively greater proportion of aboriginal populations reside in rural areas than non-indigenous populations, the latter which are 80% concentrated in urban areas (HRSDC, 2011). Indigenous peoples represent a unique and growing community (Statistics Canada, 2001), varying in culture, demographics, and access/use of services (Voyageur et al., 2001). In a comparative qualitative study, KT preferences were remarkably different between Canadian urban Inuit, urban Métis and semi-rural Pikwakanagan First Nation communities, reflecting unique cultural practices and values (Smylie et al., 2009). The authors suggest that this oversight in accounting for individual indigenous preferences in KT has further enhanced rural health inequalities in Canada (Smylie et al., 2009). This research indicates the need to adapt specific and diverse KT strategies for rural populations that are tailored to the diversity of the rural population in Canada while also meeting the diverse needs within and among indigenous communities. Increased exploration about how we can continue to meet the cultural and geographic diversity of our three stakeholder user groups, and particularly marginalized and under-represented communities such as First Nations, is needed.

As we continue to develop and explore the creation of KT strategies inclusive of all three stakeholder user groups, we must continue to consider conventional KT methods, while also employing innovative methods to overcome program barriers and the capture the diversity of both our research results and the stakeholders for whom they were created.

5.0 Acknowledgements

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