Integrated Knowledge Translation in Mental Health: Family Help as an Example

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Abstract

Objective: To describe and provide an example of integrated knowledge translation. **Methods:** We review the elements of integrated knowledge translation and describe the Family Help Program, a distance treatment program for child mental health as an example of integrated knowledge translation. **Results:** Family Help, a distance treatment program for child mental health, was developed with a grant from the Canadian Institutes of Health Research (CIHR). One of the requirements of the grant was involvement of community partners. This partnership resulted in a form of integrated knowledge translation (KT). To be successful, integrated KT requires the engagement of all partners and maintenance of mutual respect. The grant met its objectives and several distance treatments for child mental health were developed and evaluated. Integrated KT was effective in supporting the transfer of this research project into clinical practice and Family Help is now employed in several collaborating health districts. **Conclusion:** Integrated KT in the early phases of research has significant advantages when the purpose is inclusion of key stakeholders' (e.g. decision makers and consumers) knowledge to yield an effective product and facilitate uptake into clinical practice.

Key words: integrated knowledge translation, dissemination, disruptive behaviour disorders, anxiety disorders, Family Help Program

Résumé

Objectif: Donner un exemple de transfert des connaissances intégrées. **Méthodologie:** Nous analysons les éléments du transfert des connaissances que nous illustrons en présentant *Family Help*, programme de soins de santé mentale à distance destinés aux enfants. Ce dernier intègre le transfert des connaissances. **Résultats:** *Family Help* a été mis au point grâce à une subvention des Instituts de recherche en santé du Canada (IRSC). L'implication des partenaires de la communauté était une des exigences de la subvention. Le résultat de ce partenariat a conduit à une certaine forme de transfert intégré des connaissances. Plusieurs traitements à distance de troubles mentaux chez les enfants ont été mis en place et évalués. Le transfert intégré des connaissances a été efficace: il a permis d'appliquer ce projet théorique à la pratique clinique. Le programme *Family Help* est maintenant appliqué dans plusieurs districts de santé. **Conclusion:** Le transfert intégré des connaissances présente des avantages significatifs lorsqu'il recourt aux connaissances des principaux acteurs (décideurs et consommateurs) pour offrir un produit efficace et faciliter l'adoption des pratiques cliniques.

Mots clés: transfert intégré des connaissances, diffusion, troubles sévères du comportement, troubles anxieux, Family Help

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 Submitted: November 6, 2008; Accepted: January 30, 2009

Background

Scientists in mental health often work for years to obtain research grants and conduct methodologically sophisticated research, only to find that their research, which they believe to be eminently useful, is not used or that it takes many years to find its way into practice. The implementation of research findings into clinical practice is often a slow and haphazard practice (Agency for Health Research and Quality, 2001). The Canadian Senate Report on the Status of Mental Health in Canada, entitled Out of the Shadows at Last (Kirby et al., 2006), stated that without effective knowledge translation within mental health services, "ineffective or even harmful treatments may continue, while effective, evidence-based treatments may not be adopted by policy-makers and mental health service providers," p. 263.

Knowledge translation (KT) can be defined in many ways. In a review of the terminology, 29 different terms were used by 33 applied health research funding agencies (Graham et al., 2005). Some of the more common terms applied to this process are knowledge translation, knowledge transfer, knowledge exchange, research utilization, implementation, dissemination, and diffusion. Of all the terms, KT is the one gaining prominence in Canada (Canadian Institutes of Health Research, CIHR). The CIHR defines KT as: "...the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system (http://www.cihr-irsc.gc.ca/ e/26574.html#defining)."

The key element in the CIHR definition is that the primary purpose of KT is to address the gap between what is known from research and the implementation of this knowledge by key stakeholders with the intention of improving health outcomes and efficiencies of the health care system (Graham et al., 2006). The Ontario Provincial Centre for Excellence's "Integrated Evidence and Knowledge Exchange Framework" emphasizes that both the clinical practice evidence for child and adolescent mental health and how the information is exchanged or translated among diverse stakeholders must be founded on equally credible scientific methods (Levesque et al., 2007).

There are two broad categories of KT (http://www.cihr-irsc.gc.ca/e/29418.html): 1) End of grant KT, which can be categorized as diffusion, dissemination or a more intensive application (implementation) of research findings and; 2) Integrated KT which involves activities that are woven into the research process (Lomas, 1993).

End of grant KT includes researcher-push activities to diffuse research results through the traditional academic methods of conference presentations, peer reviewed publications, and website postings as well as more active tailored messages to specific audiences such as workshops for clinicians and policy oriented briefs for administrators (Graham et al., 2006).

Integrated KT is different. It is a way of doing research in which research stakeholders or users of the knowledge generated by the research are engaged throughout the research process (Graham et al., 2005). What sets apart integrated KT from other forms of KT is that it involves engaging stakeholders at the beginning of the project and keeping them intimately involved throughout the project. Stakeholders can include any group but most often include one or more of: the public, patient groups, clinicians or decision makers. Knowledge users may be involved in shaping the research questions, deciding on the methodology, helping with data collection and tools development, interpreting the study findings, crafting the message, disseminating the research results and moving the results into practice.

Integrated KT is a collaborative, participatory, action-oriented way of conducting research that results in the co-creation of knowledge by researchers and knowledge users. The end result of this collaboration in the integration of research findings into clinical practice in a more structured, efficient, expedient and effective manner. Integrated KT is not appropriate for all research. For example, much research is not intended to produce a result that should be directly used in policy making, clinical care or public health (Tetroe, 2007).

Bero et al. (1998) conclude that the most frequent method of KT, the passive dissemination of information (e.g, publications, postal delivery, conferences) are generally ineffective and at best result in small changes in practice. There are a variety of possibly effective strategies for the dissemination of research findings (e.g., educational outreach visits, reminders, combined approaches, such as audit and feedback and reminders), each of these strategies involves some sort of active, intensive effort to alter clinical practice (Bero et al. 1998).

Changing clinical practice represents one challenge for KT; utilizing research evidence to influence government policy in program delivery presents another type of challenge. Few empirical studies have examined research use in the context of the health policy development process (Waddell et al., 2005). The factors important in conveying research to policy makers include personal contact between research and policy maker and timely communication of research findings (Innvaer et al., 2002; Hanney et al., 2003). Waddell et al. (2005) interviewed policy makers regarding the development of policy in the treatment of children and adolescents with conduct disorder. Findings from this study indicate that policy makers do use research evidence, but only as one source of information among many competing influences, such as public opinion, institutional constraints and fiscal restraints. They emphasized the importance of researchers learning about the policy process, establishing research policy partnerships to build relationships of trust and increasing personal contact to bridge the culture gap between the research and policy context (Waddell et al., 2005).

The purpose of this paper is to describe an example of KT activities integrated within a pediatric mental health research project. In the present example, clinical practitioners, health policy makers and consumers were appropriate audiences for the KT infrastructure that was developed to support the ultimate goal of uptake of the Family Help intervention into the provincial mental health system.

Case example: Family Help

The history of Family Help

Family Help is a distance mental health delivery system designed to address the lack of timely access to child mental health services (Lingley-Pottie & McGrath, 2006, 2008a; Lingley-Pottie et al., 2005). Evidence-based interventions are provided to families in their homes at convenient times. Family Help intervenes early to prevent diagnosable disorders (e.g. disruptive behaviour disorders and anxiety) from becoming severe. Families learn skills through written handbooks, demonstration videos and weekly telephone support and problem solving with a paraprofessional coach.

Family Help research was funded primarily by CIHR to develop and evaluate new ways of increasing access and decreasing wait time for pediatric mental health services. The research spanned a seven year period which included the development of the materials and a pilot clinical series for each module which informed the design of the final step, a large randomized clinical trial (RCT) of the modules.

The content of each Family Help module uses interventions that have been shown to be effective in clinical trials (Cunningham, Bremner & Boyle, 1995; Kendall et al., 1997). The novel aspect of Family Help was the delivery system, where evidence-based interventions were modified for delivery at a distance. The Family Help RCTs have been completed (McGrath et al. in preparation). The main outcome papers are in preparation for publication and therefore will not be presented in this paper.

Methods

During the development of this project, it was predicted that this novel, non-traditional (no face-to-face contact, use of paraprofessionals) approach might meet resistance from a variety of stakeholder groups, including health care professionals, decision makers and the community. This could impede timely integration into the health care system after the research was completed. Therefore, an integrated KT strategy was developed during the early research planning, and implemented throughout all research phases. The key stakeholders were identified to ensure their ideas informed the format of the modules and all aspects of the study design. They remained actively involved during trial evaluation phases, assisted with ongoing dissemination strategies and facilitated system integration.

Informing design through integrated KT (See Table 1: Time 1)

A panel of international, interdisciplinary experts and health care professionals were involved in material content development and research program design. Content was also informed by community members of varying age, sex, ethnic, socioeconomic and educational backgrounds. Community members provided feedback about the readability of the content, comprehensiveness of the exercises and applicability of the examples in the handbooks.

Active and regular involvement with colleagues and stakeholders at the political and policy decision making level (e.g., Nova Scotia Department of Health and the local Nova Scotia District Health Authorities) provided insight from their unique perspectives. Their concerns included access to mental health services, risk management and cost-effectiveness. For example, traditional therapy using licensed health care professionals can be costly over time and may not be necessary when problems are mild to moderate in nature. Paraprofessionals have been shown to be as effective as professionals in behavioural therapy (Weisz et al., 1995). Therefore, trained and professionally supervised paraprofessional coaches were selected to deliver Family Help.

Integrated KT during the research (See Table 1: Time 2)

Ongoing feedback from Family Help users, physicians and decision makers during pilot studies was used by the researchers to make improvements. Consistent with general practice in RCTs, a study management team was created to oversee the study logistics, progress and act as the decision making body for the trials. The management team met bi-weekly in person or via teleconference in the early stages, then monthly or as needed in the latter stages of study completion. The management team included the Principal Investigator (psychologist), two Coinvestigators (a decision maker/psychologist and a physician) and the Program Manager (nurse/research co-ordinator).

A second stakeholder group, acting as an advisory committee, was established at the beginning of the research project and remained actively involved throughout the research phases. These stakeholders were identified and intentionally selected from the Mental Health Services in the research sites. Consensus from discussion with committee members determined that regular reporting to these stakeholders during the trial regarding research progress, coach productivity, risk management and costs was important to maintain engagement over time. The Advisory Committee members were champions of the project, providing important linkages to support the successful integration of the Family Help trial in their health district. The committee met monthly for the duration of the pilot and RCTs either in person or via teleconference.

Physicians and other health care professional stakeholders were contacted throughout the study phases to provide ongoing feedback about the research program. Private visits to clinic offices were scheduled regularly. Presentations were arranged with groups in each district periodically throughout the study term. Feedback from this group informed the development of a comprehensive communication process to bridge the gap between physician referral and treatment progress. Regular clinical progress updates were communicated by the researchers to the physicians throughout the Family Help study participation process.

Finally, educators, care providers, community members and the end users of treatment services were included as a stakeholder group by means of regular presentations, by members of the management committee, in the schools and community resource agencies. Public appearances included information booths at local malls, store fronts and community exhibits that promoted family health. Feedback from these stakeholders informed the researchers about the type of information to include in program descriptions, as well as the needs/desires of the stakeholders in terms of program availability.

A newsletter, distributed by mail and/or email, was implemented to disseminate information about the program, referral process, contact information, study updates and testimonials from the users. It was circulated approximately every four months to a variety of local stakeholders (e.g., politicians, decision makers, health professionals, academics, educators and community groups). Public awareness campaigns were developed in conjunction with the local collaborating hospital public relations departments. Formal study launches were highly promoted and included key speakers from the funding agency and health leaders (institutional, district and provincial), drawing media attention. Modes of advertisements included posters placed in a variety of visible locations, such as physician offices, libraries, community organizations in all participating areas; promotional materials were sent to the schools regularly for distribution to parents; family practitioner and public health newsletter ads; radio ads; newspaper ads (local and community newspapers and flyers); television public service announcements and web-site links. Research staff interacted at local conferences via information booths and presentations. Information and contact with staff was accessible through the Family Help website (www.bringinghealthhome.com) that housed the aforementioned newsletters. The goal of the public awareness campaign was to saturate the market with study information to ensure outreach to the general population for the duration of the trials.

The role of integrated KT following completion of the study phase (See Table 1: Time 3)

Continued KT efforts were maintained in the latter stages of research to ensure timely uptake of Family Help services, post-trial completion. The KT focus changed from research recruitment to service promotion and awareness. The goal was to avoid interruption of services by securing funding for Family Help to be integrated as part of usual care.

Presentations about Family Help delivery system, user acceptance and preliminary results were targeted at a provincial and international level. Conferences (e.g., Nova Scotia Child and Youth Action Committee Conference; Biennial Niagara Conference on Evidence-Based Treatments for Childhood and Adolescent Mental Health Problems), known to be well attended by health policy makers, mental health directors and professionals, primary-care family practitioners and health care providers, were attended (i.e., posters and presentations). The Family Help management team presented to local Nova Scotia, District Health Authorities Mental Health Directors and their teams as well as the Nova Scotia Department of Health.

The Advisory Committee met as needed in the later phases to provide advice about avenues that should be pursued for information dissemination to facilitate uptake of the treatment program, post-research. When new funding was allocated, the institutional Public Relations departments arranged official launch announcements. Media attendance increased public awareness of Family Help service expansions, drawing national attention.

Results

The results of this integrated KT strategy lead to wide acceptance of the Family Help distance delivery system by the approximately 350 users (parents and children) who participated in the trials, local NS physicians (referral source) and other health care professionals early in the research phase (Lingley-Pottie & McGrath, 2006, 2007, 2008b). This resulted in swift service uptake in many provincial health districts even before the final outcome results were published. Funding was secured immediately by one District Health Authority for all the Family Help modules and by another District for the Behaviour Module. Soon after, services were expanded to an Ontario health area. Within 2 years, services for all modules were expanded to two additional Nova Scotia District Health Authorities. Interest has subsequently been expressed in other provincial health districts, other Canadian provinces, the United States and Europe.

During the pilot and RCTs, the researchers gained knowledge from the users, family physi-

cians and Family Help coaches that improved program content, logistics and design. For example, the promotional campaign was evaluated by tracking the source and site of the referrals and how users heard about Family Help. Consequently, we were able to focus recruitment strategies and promotional activities.

We believe that the most effective KT strategies were face-to-face engagement with stakeholders as well as active participation in community-based activities. This was evidenced by the influx of referrals received subsequent to such activities. Dissemination of information through the local schools was effective likely because it reached our target population. The success of the employed KT strategies elicited interview invitations from newspaper, radio and television journalists. These invited activities provided increased exposure about the program at no expense to the researchers.

The KT strategy described here created an open, iterative feedback process between stakeholders and researchers. Additional research projects were generated as a means to address any concerns or potential barriers to future uptake. For example, many were skeptical about whether therapeutic alliance could exist in the absence of face-to-face contact. A study designed to explore this issue found that distance therapeutic alliance can exist between the coach and adult or child (Lingley-Pottie & McGrath, 2006, 2007, and 2008b). Feedback from physicians about the Family Help clinical progress letters spawned another study. This project examined physician and parent preferences for a traditional, text-dense, narrative style versus a concise, graphical style clinical letter.

Limitations

One challenge faced by the study team was securing ample funding and time to travel to the remote areas of Nova Scotia to meet with the local physicians, health care professionals and community resource agencies. To overcome this challenge, extensive planning and extended trips designed to cover a large geographical area over a few days enabled the team to optimize the time spent in the field. During winter months telehealth information sessions were organized to overcome the travel barriers.

Time 1: Research design and material development		
STAKEHOLDERS	REASON FOR INCLUSION IN KT PLAN	PROJECT CONTRIBUTIONS
Mental health services directors/ policy makers (NS ¹ Dept of Health; local NS ¹ district health authorities)	Program delivery and uptake	Current access to mental health services; projected cost savings, risk management.
Community members/consumers	Delivery preferences, content readability/applicability	Program delivery methodology, e.g., videos, manuals
Interdisciplinary experts and healthcare professionals	Program content and material development	Program delivery methodology, project design
Time 2: During the active research pha	ase	
STAKEHOLDERS	REASON FOR INCLUSION IN KT PLAN	PROJECT CONTRIBUTIONS
Study management team (non-scientist members)	Continuing engagement as research champions	Study progress; adverse events; logistics
Mental health services directors/policy makers	Program delivery and uptake	Treatment outcome, coach productivity and costs, risk management
Advisory committee (intentionally selected key stakeholders from research sites)	Champions of the research program; adapting the research to the specific geographical sites; linkage to sites	Study progress, logistics, enrolment numbers
Physicians and mental health care professionals	Recruitment, clinical responsibility, uptake	Logistics and success with patients, clinical progress and outcome reports including graphical presentation of individual client progress to treating clinicians; program availability
Community Members, care providers and educators	Awareness of the Family Help program for recruitment and uptake	Availability, program descriptions
Users of Family Help	Program development/enhancement, trouble shooting	Clinical progress, treatment satisfaction
Media	Public awareness, recruitment	Access to research study information
Time 3. Following completion of the st	tudy phase	
STAKEHOLDERS	REASON FOR INCLUSION IN KT PLAN	PROJECT CONTRIBUTIONS
Mental health services directors/policy makers	Provincial uptake and implementation	Study results; cost effectiveness
Advisory committee	Dissemination of results, uptake, linkage to study sites	Clinical progress and outcomes, next steps
Study management team	Dissemination of results, uptake, linkage to study sites	
Media	Public awareness	Funding announcements; service availability and uptake; service acceptability

Table 1. Timeline and content of the Family Help integrated KT Plan

¹NS = Nova Scotia, Canada

Funding allocated for promotional activities was not sufficient to support an active campaign utilizing multiple strategies over a five year time period. For example, although a televised advertisement would reach many families in their home, grant funds could not sustain airtime costs over time. Therefore, at the time of grant application, it is important to ensure that budgets are adequate to support a multitude of effective KT strategies that will reach the target population.

Another limitation encountered was the inability to meet requests for outcome data by decision makers prior to RCT completion. In accordance with RCT requirements, in order to protect the integrity of the RCT the researchers could not complete an interim analysis. Communication of this limitation to the stakeholders early in the research phase can provide an opportunity to develop alternative reporting strategies that will provide sufficient information to facilitate funding decisions and uptake.

Conclusion

Similar to the findings by Bero et al. (1998), this study determined that the most effective KT strategy was face-to-face engagements with stakeholders as well as active participation in community-based activities. Developing an integrated KT plan with a variety of stakeholders and strategies can bridge the gap between research and clinical practice application. Moreover, involving a variety of key stakeholders in the trial plan can lead to an improved product that will meet the needs of all involved. In turn, this can improve success for timely integration with current practices, ultimately improving the delivery of mental health services for children and youth. Including decision makers in the integrated KT plan provides a unique opportunity to inform them of research progress, and allows for sufficient time to develop funding strategies, if appropriate. In addition, this collaboration enables the researcher to become aware of the realities and limitations of the political system, and to gain insight that research evidence is only one of many competing sources of information and influence within the political sphere (Waddell et al., 2005).

Although there are many benefits to using integrated KT, this approach may not be appropriate for every research project. Some researchers are not personally disposed to share control of a project, especially with nonscientists who have a very different world view. Some projects are appropriately shared with only other scientists in the research field. When deciding whether or not to embark upon integrated KT activities, it is important to recognize that it takes time and patience. The scientist who believes that a single meeting where he or she can tell the decision maker what is going to be done and get the needed endorsement is not developing integrated KT. Similarly, the decision maker who believes that the scientist will just do what the decision maker wants will likely be disappointed. Integrated KT requires a commitment of both the scientist(s) and the decision maker(s) to a process that neither alone controls. The results can be very gratifying. Not only can integrated KT expand the horizons of both groups, it can fast track appropriate uptake of scientific knowledge into the clinic.

Acknowledgements/Conflict of Interest

Family Help research has been supported by the Canadian Institutes of Health Research, the Canadian Foundation for Innovation, the Hospital for Sick Children, and Human Resources Development Canada. McGrath is supported by a Canada Research Chair. McGrath is in the process of commercialization of Family Help and may benefit financially if this is successful. The authors have no other conflicts to disclose.

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