

On the Rock, in a Hard Place: Challenges in Working with Advocacy and Care Provider Groups

Tempête sur le Rocher : les défis de la
collaboration avec les groupes de défense des
droits des patients et les prestataires de soins



by MARIA MATHEWS, PHD

*Division of Community Health and Humanities
Memorial University of Newfoundland
St. John's, NL*

SHARON BUEHLER, PHD

*Division of Community Health and Humanities
Memorial University of Newfoundland
St. John's, NL*

ROY WEST, PHD

*Division of Community Health and Humanities
Memorial University of Newfoundland
St. John's, NL*

Abstract

Researchers from Memorial University of Newfoundland collaborated with a patient advocacy organization and the provincial cancer care provider on a study showing substantial variation in out-of-pocket costs for patients travelling to access cancer treatment. While the partnered research phase of the study proceeded smoothly, the successful dissemination of the findings – and the resulting government and media interest – created pressure for the provincial cancer care provider. This agency distanced itself from the study and ended its role in what has proved to be an otherwise successful partnership.

Résumé

Des chercheurs de la *Memorial University of Newfoundland* ont collaboré avec un organisme de défense des droits des patients et le fournisseur provincial de soins aux personnes atteintes de cancer à une étude illustrant les différences significatives dans les frais déboursés par les patients qui doivent se déplacer pour obtenir un traitement contre le cancer. Bien que l'étape de la recherche en partenariat se soit déroulée sans heurt, la diffusion des résultats et l'intérêt que ces derniers ont suscité au gouvernement et dans les médias ont constitué une source de pression pour le fournisseur provincial de soins aux patients cancéreux. Ce fournisseur a donc décidé de mettre fin à sa participation à l'étude, et ce, malgré le succès du partenariat sur les autres plans.

IN THE FALL OF 2001, THE CANADIAN CANCER SOCIETY – NEWFOUNDLAND and Labrador Division (CCS), a non-governmental patient advocacy organization, approached us to request a study of out-of-pocket costs for patients who travel to access cancer treatment. Anecdotal evidence suggests that these costs influence the decisions cancer patients make about their care (Maynard 2001). The CCS had previously embarked on advocacy efforts on this issue, but the provincial Department of Health and Community Services had cited the need for more research.

The Canadian Institutes for Health Research (CIHR), the Newfoundland and Labrador Centre for Applied Health Research and the Canadian Breast Cancer Foundation – Atlantic Division funded the study, with data collection beginning in fall 2002. We surveyed 484 cancer patients, interviewed 21 cancer care providers and gathered information about medical travel subsidy programs across Canada.

We found substantial variation in out-of-pocket costs for patients travelling to access cancer care. One in three rural patients (those living more than one hour away from a cancer clinic) paid more than \$200 for travel and lodging during a single trip to an oncologist, with 9% incurring costs of more than \$1,000 per trip. A significantly

larger proportion of rural residents had higher costs than their urban counterparts and said that expenses for travel, drugs, child care and travel time were important considerations in their care decisions (Mathews and Basky 2004). Patients' cost-cutting strategies (including rationing medications, lengthening follow-up times, or choosing inpatient palliative care) may compromise quality of care. We recommended that the restrictive eligibility criteria of the provincial Medical Travel Assistance Program (the subsidy that reimburses patients for medical care-related travel costs) be reviewed, and that cancer care be provided in smaller communities wherever possible.

The primary audiences for our study were the CCS, the Newfoundland Cancer Treatment and Research Foundation (NCTRF, the provincial cancer care provider) and the Department of Health and Community Services. We also wanted to communicate our findings to study participants, politicians, the public, cancer advocates and care providers in Canada and other researchers.

The KT Initiative

Our knowledge translation (KT) partners were the CCS and the NCTRF. The Department of Health and Community Services declined direct involvement in the study, but asked to be kept informed through ongoing interactions with the CCS and the NCTRF.

As researchers, our goal in engaging in KT activities was to provide rigorous, relevant, evidence-based recommendations that would improve the accessibility and quality of cancer care in the province. The goal of our partners, however, was to advocate for patients with high out-of-pocket costs, and especially to lobby for change to the provincial Medical Travel Assistance Program. These goals required careful definition of the roles of all partners throughout both the research and dissemination phases of the study.

The KT plan for the study included linkage and exchange activities and a multi-pronged dissemination strategy. The goal of our linkage and exchange activities was to identify relevant research questions, inform our partners of our progress, be responsive to changes in the decision-making environment, provide opportunities for our partners to contribute to the interpretation of findings and the development of recommendations and to discuss the roles of all partners throughout the project.

To this end, we held a series of meetings with CCS and NCTRF staff to gain a better understanding of the research problem, the provincial cancer care system and the partners' information needs. We also provided regular updates through email, telephone conversations and in-person presentations. Both partners provided supporting documents and feedback on our research proposals, liaised with government contacts to inform them that the study was underway and updated us on developments relevant to the study. The NCTRF assisted in recruiting study participants. Near the end

of the research phase, we shared preliminary results and recommendations with the CCS and the NCTRF. An NCTRF administrator, with whom we had been closely collaborating, reviewed a near-final draft of the results and recommendations.

During the dissemination phase of the study, the CCS assumed responsibility for organizing the campaign to increase public awareness of the study findings and to lobby politicians and government officials. The NCTRF agreed to disseminate study findings to other cancer care agencies and to organize seminars with its own staff to identify changes in clinical practice. We were responsible for presenting the data (in summary documents and presentations), participating in interviews with the media and meeting secondary dissemination goals, such as debriefing participants, sharing findings with researchers and identifying collaborators for future projects.

In spring 2004, we (the researchers and CCS, in accordance with the roles described above) held a press conference to publicize the study findings; wrote a summary article for the CCS annual report (which was included as a supplement in community newspapers across the province); pursued media coverage; presented study results in non-technical language to community groups and Department of Health and Community Services officials; sent a two-page summary (written in non-technical language and highlighting actionable messages) to all members of the Newfoundland and Labrador House of Assembly and Department of Health and Community Services officials; and held face-to-face meetings with politicians as well as Department of Health and Community Services officials. The summary report was available on request and was posted on the website of the Division of Community Health (Memorial University of Newfoundland).

Results of the KT Experience

NCTRF initially shared the research findings with other care providers, but distanced itself from the study when the provincial government requested information about its support programs and delivery of care. In its response to government and in letters to local newspapers, NCTRF dismissed the study results and the partnership activities, and suggested that it had already addressed the issue of out-of-pocket costs. One letter to the editor noted that “Dr. Matthews’ [sic] recommendations are neither new nor novel” and “it is important that researchers explore the current situation so that recommendations can be more meaningful and valuable” (Paulse 2004). NCTRF abandoned its plans to disseminate the study results to its staff.

In January 2006, in response to our research and the CCS’s advocacy efforts, the NL Department of Health and Community Services changed the eligibility criteria for the Medical Transportation and Assistance Program. These changes allow more patients to claim travel subsidies when travelling outside their health region for medical care. A \$500 deductible was also removed for residents of Labrador. The CCS is

also planning to build a cancer lodge in direct response to the study's findings. The lodge will provide accommodation at subsidized rates for cancer patients who must travel to and stay in St. John's to have treatment. Our results were also used to support the introduction of tele-oncology programs (the evaluation of which includes an assessment of out-of-pocket travel costs). The nationwide CCS network has brought together collaborators and researchers in other provinces, and we are currently developing studies to examine other issues affecting access to cancer care in Canada.

Lessons Learned

This experience taught us valuable lessons about KT in practice. Decision-making and knowledge translation occur in a complex, dynamic environment where the partners' interest in, and perspective towards, the research findings, the researchers, and other

Decision-making and knowledge translation occur in a complex, dynamic environment where the partners' interest in, and perspective towards, the research findings, the researchers, and other partners continually evolve.

partners continually evolve. The desire to use evidence in decision-making competes with other organizational and personal motivations, not the least of which are self-preservation and self-promotion. Health system restructuring was looming in the fall of 2004, when it was widely expected that a new regional health authority would assume responsibility for cancer services from the NCTRF (and the NCTRF would no longer

exist as a separate health board). Such an uncertain political climate would naturally motivate any administrator to demonstrate the value of his or her organization, as well as administrative and political skills, to government decision-makers.

The relationship between the CCS and the NCTRF had been difficult prior to this study: both organizations wanted to position themselves as the leader in cancer advocacy issues in the province. The pressure brought upon the NCTRF by the CCS's advocacy activities only heightened this tension. Although organizations may be interested in realizing similar goals, there may be, nonetheless, an unwillingness to sacrifice other interests to do so.

Our experience also highlights the potential vulnerability that KT can create for researchers, particularly junior academics. KT demands a substantial amount of time

that could otherwise be used in activities that are more highly rewarded by promotion and tenure committees. Moreover, no researcher, particularly those early in their careers, can afford to have his or her professional credibility publicly questioned.

Conclusions and Implications

Despite these challenges, we were able to develop and sustain a positive, mutually beneficial relationship with the CCS. A key element to this achievement has been the appreciation of each other's needs and cultures. The clear division and understanding of roles during the research and dissemination phases of the study allowed researchers to focus on academic activities and the CCS to strengthen its position as an advocate for cancer care. This linkage was further formalized when the principal investigator (MM) was appointed to the CCS board of directors, providing an ongoing forum for us to learn about CCS's research needs, and for the CCS to learn about the potential use of research in its activities.

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Correspondence may be directed to: Maria Mathews, PhD, Assistant Professor, Health Policy/Health Care Delivery, Division of Community Health & Humanities, Health Sciences Centre, Memorial University of Newfoundland, St. John's, NL A1B 3V6; Tel: (709) 777-7845; Fax: (709) 777-7382; Email: mmathews@mun.ca.

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