



CASE STUDIES

Patient engagement



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The 7th annual conference of the MUHC-ISAI, taking place October 2 and 3, 2014, in Montreal, will explore different facets of patient engagement in order to more thoroughly understand what it is, why it matters and how it is done. The conference will hear about initiatives underway in Canada and abroad to include patients in the design of health services and to empower patients to effectively manage chronic conditions.

In preparation for the meeting, we offer you an in-depth look at three projects undertaken by clinicians, staff and patients at the MUHC. They illustrate the need for action, the results that can be achieved and the challenges that must be overcome to make patient engagement an integral part of our healthcare system.

Challenge

The My Tool Box chronic disease self-management program

A network of expertise has developed in Quebec around a program that works through volunteers to improve people's ability to manage chronic disease

The best health technologies and most dedicated teams of professionals can only do so much for chronic conditions. Patients are the main players in managing their own disease, and empowering them to do so is a central challenge in health care today. Education is one key aspect. Excellent programs have been developed to teach people about treatments and strategies that help disease management. Equipping people with the skills and tools they need for self-care, however, requires a change in mindset — they need to see themselves as part of the solution.

This challenge was recognized in 2006 by the patients' committee and staff at the McGill University Health Centre's (MUHC) Montreal Neurological Hospital (the "Neuro"). With a small innovation grant, they set out to pilot a self-management program for MUHC patients living with one or more chronic diseases. "Self-management fills the space between knowing something and being able to put it into practice," explains Mario Di Carlo, a patient at the post-polio clinic who was recruited early on in the project. "It helps people understand

they need to get involved, and empowers them to do so." That's the key, according to Cheryl-Anne Simoneau, who has been living with chronic myeloid leukemia since 2000 and also answered the original call to participate. "How do you make people understand the ball is in their court? Regardless of what you've been diagnosed with, you still have a certain amount of control. If you don't empower patients, they can't be partners."

The program

The Neuro decided to adopt a proven self-management program developed at Stanford University that in six weekly workshops addresses what a person must do to live well with one or more chronic conditions. Its goal is to strengthen self-efficacy in order to improve clinical outcomes. Available to license, and already adapted to the Canadian healthcare context by a team led by Dr. Patrick McGowan at the University of Victoria in British Columbia (BC), the program is designed to be volunteer-run and uses a train-the-trainer model: course participants can take further

A My Tool Box workshop in session



training to be certified as workshop leaders and teachers. Mr. Di Carlo and Ms. Simoneau took part in the very first group, were impressed with the results and began long-lasting relationships with the program.

To run the pilot and later direct the program, the MUHC hired Dr. Deborah Radcliffe-Branch, an educational psychologist and Assistant Professor in McGill University's Faculty of Medicine. She had over 20 years experience implementing and evaluating patient education programs and was familiar with the Stanford program's decade-old implementation in BC. She set out to identify patient volunteers with the right leadership qualities and brought in Dr. McGowan from BC to teach the first group of leaders, including Mr. Di Carlo and Ms. Simoneau. "We purchased a license from Stanford for \$1000 that allowed us to hold as many as 30 workshops a year," says Dr. Radcliffe-Branch. The MUHC's self-management program thereafter known as My Tool Box was formally open for business.

My Tool Box is promoted to patients throughout MUHC hospitals, in the community and through word of mouth. Participants sign up for six free weekly two-and-a-half-hour workshops involving 10 to 12 people with a range of clinical conditions or their caregivers. Sessions are led by a team of two volunteer leaders.

The My Tool Box office promotes the program, takes registrations, organizes sessions, provides materials, helps to select and vet prospective leaders, and arranges and pays for their training.

Distinguishing between disease management and self-management

Unlike programs offered by health professionals that focus on managing a particular disease, self-management starts with a personal action plan that specifies changes the person wants to make to improve life. The focus is on reducing the negative impact of disease. "The personal action plan is at the centre of the workshop," explains Mr. Di Carlo. "Each week, people review what worked and what didn't, and what they plan to do next." Classes are highly participative, and can often boost patients' confidence about ways to manage their health and maintain fulfilling lives.

The program focuses on developing competencies in problem solving, decision making, communicating, managing emotions, evaluating treatment results and coping strategies. Self-efficacy is enhanced and people gain confidence in their ability to put skills to work. Updated every five years, the Stanford manual, *Living a Healthy Life with Chronic Conditions*, is used by leaders to guide sessions.

Results

Program uptake

Dr. Radcliffe-Branch has attracted a pool of talented patient volunteers dedicated to making the program available to ever more patients.

If you don't empower patients, they can't be partners.

Mr. DiCarlo and Ms. Simoneau pursued further training to be certified as Master Trainers (responsible for training leaders).

Since 2007, the MUHC's My Tool Box program has completed 153 six-week workshops in English and French, and trained and certified 63 leaders, 30 Master Trainers, and two T-Trainers. Participants can be referred to the program by a health professional, but word-of-mouth referrals are also common. More than 1,900 people living with an average of 3.3 chronic conditions (pain after surgery, chronic musculoskeletal pain,

Positive Program Results

The Chronic Disease Self-Management Program was developed by the Stanford Patient Education Research Center, whose programs, around since the 1980s, are currently in use in 24 countries.¹ The first randomized controlled trial of the Stanford program was completed in 1996 and included results for 1000 people followed over three years. It demonstrated significant improvements in patients' ability to manage their chronic disease(s) and use healthcare resources effectively, with a cost-effectiveness ratio of 1:10. Results showed statistically significant improvements in physical exercise, emotional issues, communication with physicians, control of anxiety, fatigue, incapacity and limitations in social functioning, along with decreases in unplanned hospital admissions and physician visits.² Results have been validated through successful implementation that produced similar results in different countries and populations, including Canada.³



My Tool Box volunteer leaders at an annual reunion

diabetes complications, chronic obstructive pulmonary disease, multiple sclerosis, arthritis, cancer, depression, etc.) have participated in the MUHC's My Tool Box program. Participants meet at the My Tool Box office or in a community venue. They receive the course manual, a workbook and a CD,, which provides a set of easy-to-follow exercises.

Outcomes

In terms of measuring results, the Stanford program includes questionnaires that all have high alpha reliability coefficients. Dr. Radcliffe-Branch uses a selection of nine questionnaires to evaluate the program on an ongoing basis, assessing participants' general health, quality of life and

My Tool Box has reduced participants' emergency room visits from 0.68 to 0.48 per year and cut by half the number of hospital days, from 1.67 to 0.82.

usage of health services at the program's start, and six months after completion.

My Tool Box has brought statistically significant improvements in patients' ability to manage disease symptoms, physical abilities, exercise and communication with doctors. Statistically

significant decreases are evident in pain severity, illness intrusiveness, depression, fatigue and distress. My Tool Box has reduced participants' emergency room visits from 0.68 to 0.48 per year and cut by half the number of hospital days, from 1.67 to 0.82. Dr. Radcliffe-Branch estimates a decrease in healthcare costs of \$3,900 for each patient enrolled in the program.

Adoption in Québec

The MUHC's My Tool Box has become a centre of expertise in chronic disease self-management across Quebec. "In the early days of My Tool Box, Patrick McGowan would come to Montreal to train our leaders and trainers," says Dr. Radcliffe-Branch. "Now we're independent, with two T-Trainers, Mario Di Carlo and Louisa Nicole, who can train leaders and Master Trainers in both French and English."

My Tool Box produced the first French translation of the Stanford materials, including the participant book and training manuals. "When Stanford issues program updates every five years," explains Dr. Radcliffe-Branch, "Dr. McGowan's team in BC completes the Canadian adaptation. The Tool Box team at the MUHC then plays an important role in assuring the translation and adapting material slightly to address certain features of Quebec's health system."

The MUHC's My Tool Box has provided training, materials and support for self-management programs that have been provided to the Abitibi-Témiscamingue Health and Social Services Agency or ASSS (2010), the ASSS Lanaudière (2012), the Family Medicine Unit and Health and Social Services Centre (CSSS) in Chicoutimi (2013), and Bruyère Continuing Care (Ottawa, 2010). An especially close relationship has evolved between the My Tool Box program and the Abitibi-Témiscamingue ASSS.

In 2009, the Abitibi Témiscamingue Health and Social Service Agency's Director of Public Health, Dr. Réal Lacombe, and Health Promotion Advisor Céline Hubert visited the MUHC to see first-hand how My Tool Box worked. They were impressed and asked Dr. Radcliffe-Branch to provide a training session in Abitibi-Témiscamingue. Mr. Di Carlo and Ms. Nicole trained a group of volunteer leaders, enabling them to begin offer-

ing the program. Two of these leaders came to My Tool Box to receive Master Training certification so they could teach additional leaders at home. Today, the Abitibi-Témiscamingue program is able to perpetuate itself. “The MUHC team is very important to us and others in Quebec,” asserts Ms. Hubert. “They are the pioneers in this province. They work in French and English, and provide guidance and advice when we need it.”

Since 2010, 70 workshops have been held in Abitibi-Témiscamingue, with 628 participants, 80% of whom completed at least four of the six sessions. The region now has two Master Trainers, 40 volunteer leaders and five coordinators, one in each CSSS. Ms. Hubert, who is a patient, nurse and advisor at the ASSS, has become a close collaborator with My Tool Box’s Mr. Di Carlo in producing French-language materials.

Expanding participation

“My Tool Box reached a tipping point about a year ago and we rarely have to advertise any more,” says Dr. Radcliffe-Branch. “Volunteers continue to supply posters to hospital clinics. Health professionals and patient word of mouth keep up the flow of participants. And we know they are not finding this type of support elsewhere: less than 20% of patients registered for My Tool Box courses have visited a CLSC (local community health centre) in the past year.”

Ms. Simoneau thinks doctors should play a more active role talking about My Tool Box. “It helps motivate patients. My Tool Box should be integrated into the patient care pathway and emphasized as essential. The program enables patients to advocate for themselves and improve their quality of life.”

In Abitibi, Ms. Hubert says some CSSS have been wildly successful in attracting participants and volunteer leaders, while others have had more difficulty. “The coordinator’s role is very important in sustaining volunteer energy,” she notes, and adds they are learning from high-performing centres.

Maintaining volunteer energy

Witnessing patients regain enjoyment in life keeps volunteers devoted to the program. Mr. Di Carlo recalls one chronic pain sufferer who arrived at

Who’s who in the Stanford program

- **Participants:** People living with one or more chronic diseases and those caring for a loved one with one or more chronic disease.
- **Volunteer leader/facilitator:** A person who has taken the workshop as a participant, undergone a selection process and completed training with a Master Trainer.
- **Master Trainer:** To become a Master Trainer, the volunteer leader/facilitator must have led at least two workshops and completed a four-and-a-half-day certification course (offered by the My Tool Box team in Montreal, facilitated by two T-Trainers).
- **T-Trainer:** Master Trainers take a four-and-a-half-day apprenticeship under supervision of a Stanford-approved T-Trainer and train at least one group of Master Trainers independently to receive T-Trainer certification from Stanford.

the workshop looking to escape a rut. Her action plan was to start playing the piano again, something she had once enjoyed but had to give up because of pain. “By the end of the six weeks, she was not only playing again, but had started getting together with people and enjoying life. Her

Witnessing patients regain enjoyment in life keeps volunteers devoted to the program.

whole perspective changed and her health began to improve,” recalls Mr. Di Carlo. “People arrive with a certain mindset about their condition. By the end of the six weeks, you see a real transformation that positively impacts their health and, often, their treatment options.”

The program is self-perpetuating as volunteer leaders emerge from participating in the program. “The group leaders get to know participants through the six weeks and can make recommendations about suitable leaders to myself and the coordinator,” explains Dr. Radcliffe-Branch. “We then screen and interview potential candidates and if the person is interested and deemed suitable, we offer to provide them the training required for certification as a leader. They’re not strangers anymore.”

Dr. Radcliffe-Branch believes there is more than enough enthusiasm in the volunteer community to grow the program further, but recog-

nizes that adequate funding is key to sustaining that energy. “My Tool Box is appealing to volunteers as an evidence-based program overseen by a professional, with standardized material, in which volunteers become trained

In Abitibi-Témiscamingue, Ms. Hubert says Public Health saw the program as secondary prevention, which justified taking on the preparation, management and financing of the pilot project from 2010 to 2013. This year, the program was incorporated into the service agreement between the Abitibi-Témiscamingue ASSS and the five CSSS on its territory, which are now obliged to hold a certain number of workshops per year. The ASSS provides additional funding to the CSSS for the program: as of 2014, its budget now includes an annual \$30,000 that goes to each CSSS to cover a two-day per week coordinator and the cost of running workshops. The ASSS buys the program’s yearly license from Stanford for \$1000 and coordinates the program at the regional level, playing a pivotal part in training, motivating and equipping CSSS coordinators and volunteer leaders. Ms. Hubert organizes a meeting each year to present the annual report and strengthen ties between volunteers from different locales.

In 2011, New York State counted 361 program sites, and websites are used to direct people toward programs in their neighbourhood.

and valued as ‘expert patients’ who then ‘pay it forward.’ They have the opportunity to foster empowerment and actually see the transformations in people from the start to the end of the program.”

Funding self-management support

In the US, the Stanford program is supported by government. The US Administration on Aging, in collaboration with the Centers for Disease Control and Prevention (CDC), provides funding to 45 states for the establishment of disease self-management networks.⁴

In 2011, New York State counted 361 program sites, and websites are used to direct people toward programs in their neighbourhood.⁵

In Canada, the Stanford program has been implemented in eight provinces and one territory. Funding can take various forms. Self-Management BC is a Ministry of Health Patients as Partners Initiative administered by the University of Victoria, which implements and evaluates the program in the province’s health regions. In Yukon, it is a permanent government-run program. In Ontario, the program is well established and its funding is shared, in some cases, between the Local Health Integration Networks (LHINS) and the Ministry of Health and Long-term Care, with occasional additional private-sector funding.

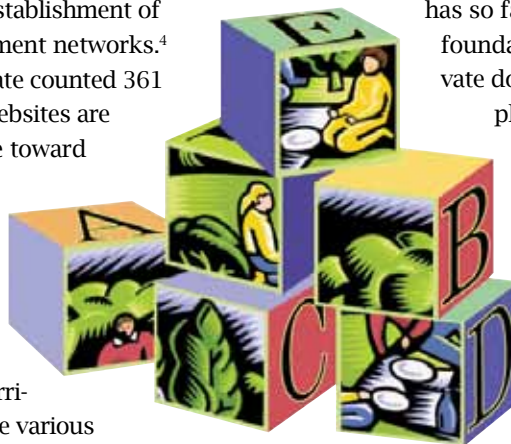
At the MUHC, funding for My Tool Box has so far come from hospital and foundation sources along with private donations and some funds from pharmaceutical companies. A

request for funding from Montreal’s Health and Social Service Agency (ASSSM) was denied earlier this year.

While the My Tool Box program attracts patients from across Montreal, no other hospital or health services centre has yet

initiated the program. The

question of who is best placed to “own” the program in the Montreal area is still up for debate. Some think ASSSM ownership would help the program expand its availability to the community at large. Others see a benefit to being based in the hospital, which reaches people with multiple chronic conditions who can really benefit from the program. “Ideally,” concludes Dr. Radcliffe-Branch, “each health centre would make this program available.” ■



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Challenge

Transforming care at the bedside

MUHC program empowers front-line staff, patients and families to improve quality, safety and performance

Quality improvement in the hospital setting is an ongoing challenge. Major organizational changes receive a lot of attention, with multi departmental committees and large investments. Less visible are the small changes at unit level to improve work processes and environments that affect staff and patient experience of care.

Front-line health workers have the clearest understanding of how things could be improved but often lack the skills and mechanisms to propose and effect change. Current and former patients can make an important contribution to identifying problem areas as they experience the effects of good and poor design most immediately. Simple changes can often result in measurable improvements. While collaboration between staff and patients in continual quality improvement of hospital care sounds good, there is little guidance available on how to bring it about in real-world hospital settings.

The program

Transforming Care at the Bedside (TCAB) is a program developed by the Institute for Healthcare Improvement in the US, which engages nurses to lead process improvement efforts aimed at patient outcomes and the work environment. It focuses on teaching front-line staff how to do rapid cycle improvement processes using the Plan-Do-Study-Act (PDSA) model and enables each unit to identify and accomplish measurable improvement projects. Currently used in over 200 American hospitals, TCAB has demonstrated very clear improvements in patient safety, quality of care and quality of work life.

Ms. Patricia O'Connor, then Associate Director of Nursing (Neurosciences) of the MUHC and later Director of Nursing at the MUHC, encountered the TCAB program at the ThedaCare health

centre in the US (Appleton, Wisconsin), as part of her work on the U.S. Commonwealth Fund Harkness Fellowship program (2008-09). ThedaCare's TCAB innovations were part of a far-reaching transformation at the organization. "Change was no longer solely the responsibility of formal leadership," recalls Ms. O'Connor, "every single employee in the organization was being trained and empowered to bring about improvements." She heard nurses say that for the first time in their careers they actually had time to practise nursing in the way for which they were educated instead of wasting time in non-value-added activities.

Shortly after her return, Ms. O'Connor became the MUHC Director of Nursing and was successful in obtaining funds from the Canadian Foundation for Healthcare Improvement (CFHI) to pilot TCAB at the MUHC. "I was able to show the hospital administration and other stakeholders what TCAB could do and how that would align with organizational goals to improve effectiveness, efficiency and patient flow," says Ms. O'Connor. In August 2010, the program was launched on five units in three MUHC hospitals. The MUHC added an innovation by introducing patients as partners on the TCAB teams in order to understand what improvements were needed from their perspective. A number of patient representatives volunteered to join the different TCAB teams. "No TCAB organization had yet directly embedded patients in the training and redesign work," says Ms. O'Connor.

Three main objectives guided TCAB work at the MUHC: understanding care through the eyes of patients and families and improving the patient experience of care; inviting patients and families to work with staff to redesign care processes that respond to their real needs; and increasing nurse time spent in direct care.

“We knew we didn’t have very good information about the patient experience of care,” says Ms. O’Connor, who made a point of building measurement into the heart of the project. At the very start, she worked with the Quality, Patient

of the MUHC joined in subsequently. A TCAB team composed of frontline caregivers from different disciplines, managers, assistant managers, patient representatives and a TCAB facilitator was created on each unit. Patient representatives were recruited from the hospital’s patient committees, whose members are either former patients or former patients’ family members.

The MUHC’s TCAB program is delivered in four learning modules of about 10 weeks each. Workshops, combined with hands-on learning one day per week with the teams, focus on developing skills in four areas:

1. Rapid cycle improvement processes using PDSA;
2. Improvement of the physical environment using Toyota LEAN 5S methods (sort, set, shine, standardize, sustain) and waste walks;
3. Three specific strategies to improve the quality of care and patient experience, e.g. whiteboards at the bedside, assessment of needs questions and comfort rounds; and
4. Process mapping to improve admission and discharge processes.

“In addition to the US TCAB model,” says Ms. O’Connor, “we stole shamelessly from the UK’s National Health Service (NHS) Releasing Time to Care program, which is more structured and includes protected release time for staff to learn new skills.” In addition, each unit chose a quality indicator such as medication errors, falls or reducing hospital-acquired infections that needed improvement, and tested new practices to find ones with the best outcomes. This helped teams take ownership of the improvement effort, set specific goals, design measurements and evaluate results. Dr. Alain Biron, Assistant to the Director, Quality, Patient Safety and Performance at the MUHC, worked with TCAB teams to ensure that the proposed changes led to improvements that could be measured. “Measurement was embedded even at the stage of identifying what the teams wanted to change,” he says, “and TCAB facilitators were available to help units design and take those measurements.”

Evaluation tools

At the end of each improvement project, TCAB teams from each unit presented their specific

Patient representatives identified needs that staff never would have recognized.

Safety and Performance department to introduce the HCAHPS (Hospital Consumer Assessment of Healthcare Provider and Systems) patient experience of care survey. Information about nursing use of time was also lacking; she obtained software from the Institute for Healthcare Improvement (IHI) that enabled nurses equipped with personal digital assistants (PDAs) to track the time spent on different activities and establish baseline data.

Uptake

The first units to participate in TCAB in 2010 were internal medicine, neurosurgery, gynecologic oncology, psychiatry and a multiservice general surgical unit. Further units at all hospital sites

TCAB in action at the MUHC

SEBASTIEN DORVAL-CAGNON/GLOBAL NEWS



results to the other teams, senior management and funders. They also received feedback on the impact their projects had on broader project goals such as patient experience, nurse responsiveness, team effectiveness and work satisfaction. Front-line RNs, patient attendants and unit clerks, along with patient members of the team, presented what they had done to improve care on their unit and showed their “before and after” results. “That’s what impressed senior leaders within the hospital more than anything,” asserts Ms. O’Connor. “It was a very fundamental shift in accountability where front-line staff became the owners of the improvement capability.”

Dr. Biron was charged with finding and developing appropriate measurement tools to assess specific practices and their cumulative impact on the three main project objectives. “The HCAHPS patient experience survey used throughout the US gave us a much more concrete measurement than the patient satisfaction surveys traditionally used in Quebec. For the first time at the MUHC, we were comparing ourselves with others in terms of patient experience,” says Dr. Biron. “And we found that we weren’t actually doing so well. When we were doing patient satisfaction surveys, everyone was quite happy with the results and scores were quite high. But when we changed the question from “Are you satisfied with the information you received?” to “Did we give you written information upon discharge?” as a yes or no question, results changed.”

Patients played a central role at different levels, participating in TCAB leadership as well as on each of the unit teams. The patients brought fresh eyes and kept teams focused on the patient experience. On the units, TCAB patient representatives would talk to inpatients and get their feedback on proposed improvements. They also conducted post-discharge interviews, along with a research assistant, in patients’ homes. “Patients were probably more open with us than they might have been with one of the nurses,” says Brenda MacGibbon, a patient representative who joined the TCAB team on the gynecologic oncology unit. “While some staff were hesitant at first about opening up the closed universe of their unit to ‘outsiders,’” says Dr. Biron, “they came to value the different perspective that patients contributed to discussions.”



Results

Initially implemented on five units, the TCAB initiative has now been spread to 19 units across the six hospitals of the MUHC. Between 2010 and 2014, approximately 45% of clinical staff (1,400 persons) were exposed to the learning. TCAB results have been studied from a number of different angles. First, the impact of each unit improvement project is assessed to gauge how effective the process was at addressing the problem identified by the team.

On the psychiatric unit, for example, serial admission interviews by the physician, social worker, occupational therapist and nurse were replaced by a team interview with the patient. This cut admission time down from over four hours to just one hour, which avoided repetition and long waits for patients and families, saved considerable health professional time and improved

Overall, TCAB improvement efforts increased the percentage of time nurses spent on direct and value-added care activities.

communication between the team members. This improvement was recognized by Accreditation Canada as a Leading Practice in 2014. Patient satisfaction doubled.

TCAB efforts to improve the physical environment took on a different focus in each unit: nursing stations, medication rooms, family visiting rooms, treatment rooms, supply rooms, staff lounges and patient dining areas were all redesigned through a collaborative process involving

staff and patient TCAB participants. Clocks were installed in all patient rooms. The clean-up of storage rooms resulted in returning an average \$3000 worth of equipment per unit to Biomedical Engineering. Designated spaces were created for equipment, which reduced average time nurses spent looking for equipment from 220 second to 26 seconds — a savings of two full-time-

reach. Staff members were trained to ask three basic questions on each shift to find out the patient's priority for the day: What is your greatest concern right now? What information do you need that would be the most helpful? What do you need from me right now that would help you? On the hemodialysis unit, these questions led to an increase, from February to April 2012, in the proportion of patients who received their blood results from 40% to 100%.

TCAB introduced new methods of assessing quality at the MUHC and these have been integrated into the organization.

equivalent nurses per year. Staff and patients benefited from remodelled spaces that were better adapted to their specific purpose. A room turn-over project, using visual cues such as coloured magnets to indicate room readiness after discharge of a patient, improved communication between team members and housekeeping and significantly shortened the time to prepare the room for the next patient.

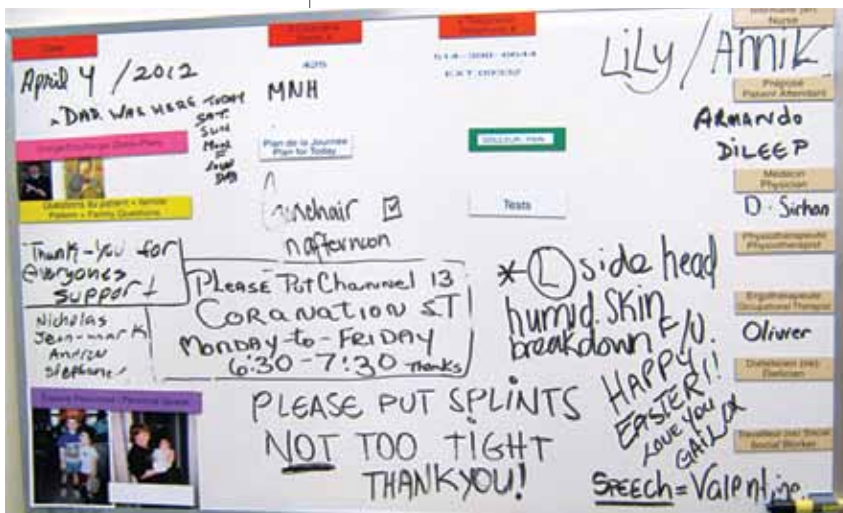
Patient contributions

Throughout these projects, patient representatives identified needs that staff never would have recognized. The family room on the gynecologic oncology unit was actually a source of pride to nurses and staff. It took the patient reps to point out that patients with cancer really did not want to look at walls covered with cancer posters and pamphlets while they were visiting with family. As well, there were sharps containers in the room, which was also used to prepare patients for surgery. "Today the walls are painted and art hangs where the pamphlets used to be," says Ms. MacGibbon. "Surgical preparation has been moved to a room previously used for storage that we cleared out across the hall."

Patient experience of care was improved in different ways. All units provided whiteboards by each patient bed to enable patients and their families to communicate with the care team and provide support and encouragement to each other. Comfort rounds every one to two hours were introduced, focused on managing pain, preventing pressure ulcers (by turning the patient), helping the patient to the bathroom (preventing falls) and ensuring that all items are within

Overall, TCAB improvement efforts increased the percentage of time nurses spent on direct and value-added care activities and improved HCAHPS results on nurse responsiveness (e.g. immediate response after pressing the call button) and communication with nurses. Staff reactions to TCAB and patient involvement in redesigning care have been consistently very positive, as has the nurses' union. Patient representatives were highly engaged and felt valued. Ms. MacGibbon noticed how young patients involved in TCAB became increasingly committed to volunteer work at the hospital following the experience.

Whiteboards



Potential for expansion

TCAB was supported by external funding from multiple sources (the CFHL, the Canadian Institutes for Health Research [CIHR], the Newton Foundation, the Quebec Ministry of Health and Social Services, the Roasters Foundation and MUHC hospital foundations). The main expense was in obtaining protected release time to enable front-line staff to participate in TCAB training

one day per week. It became apparent in the first year that staff could not undertake TCAB work alongside their regular duties. These funds also supported skilled facilitators who worked with the teams. The development and adaptation of new measurement methods were covered by grants initially, but are now integrated into MUHC Quality, Patient Safety and Performance expenditures.

A culture change

2014 represents the final year of the scheduled roll-out of TCAB at the MUHC, with operating rooms and ambulatory care units being included for the first time. Plans for further spread have not been determined. Staff members have acquired skills to lead improvement efforts at the local/unit level and to measure their impact. This learning has led to increased accountability of frontline staff in taking ownership of problems in care delivery. In other words, a culture change has occurred. Units that were not officially participating sought out TCAB facilitators or members of participating units for coaching, especially in ways of improving the physical environment. “Around 2012,” remarks Ms. O’Connor, “we started hearing a number of departments in the hospital say ‘We need to TCAB this’: it has become a verb.”

TCAB introduced new methods of assessing quality at the MUHC and these have been integrated into the organization. “HCAHPS is now part of the MUHC’s Quality and Performance dashboard for the entire organization and we’re comparing ourselves against US benchmarks,” says Dr. Biron. US results are the only ones available publicly at this time, though Canadian comparisons will soon be possible following the Canadian Institute for Health Information’s decision this year to adopt the survey in Canada. All provinces save Quebec will now be introducing HCAHPS in their institutions. The MUHC TCAB team actually contributed to expanding HCAHPS, by beta testing a new pediatric version in collaboration with Boston Children’s Hospital, Harvard University and the US Agency for Healthcare Research and Quality.

“We’ve built organizational capacity for quality improvement,” says Ms. O’Connor. In 2013-14, Infection Control partnered with Nursing and Housekeeping, to use TCAB methods to tackle



Equipment parking lot

Clostridium difficile (*C. difficile*) and vancomycin-resistant *enterococci* (VRE) rates that were the second worst in the province. “Efforts to reduce the MUHC’s very high infection rates had not been successful in producing significant results,” says Ms. O’Connor. “We targeted the six worst units and brought staff through the rapid-cycle improvement and the 5S processes and added in training in hand hygiene, precautions and environmental cleanliness.” For the first time, housekeeping was given protected release time to participate in training along with nurses, patient care attendants and unit coordinators. In eight months, these six units achieved an impressive 30% reduction in rates of *C. difficile*.

TCAB demonstrated to staff, leadership and the patient community that there were important benefits to working in partnership to improve the patient experience of care. The MUHC is now embarking on further organization-wide initiatives to embed patient engagement into its various structures. Ms. O’Connor will use the lessons from her leadership, as Director of Nursing, of the TCAB project to work in a newly created position to sustain and spread patient engagement throughout the organization. Patients will now be integrated, using standardized mechanisms for recruitment and involvement, into all quality improvement initiatives at every level.

“TCAB accomplished a lot of mythbusting about who was supposed to make changes and how,” Ms. O’Connor reflects. “It proved we have enormous untapped talent at the front lines just waiting for that opportunity to learn new skills in order to improve patient care.” ■

Challenge

Living well with COPD

A solid foundation for interdisciplinary patient-centred disease management

“As a physician,” says Dr. Jean Bourbeau, “you hear about where the needs are, from both patients and healthcare professionals, and you see the gaps that need to be filled.” Effective support and management of individuals with chronic obstructive pulmonary disease (COPD) demands a comprehensive and patient-centred approach.

Fifteen years ago, when he arrived at the MUHC’s Montreal Chest Institute from Québec City, Dr. Bourbeau saw a clear need to have physicians, health professionals and patients working off the same page to manage COPD. “That meant getting the team working together and with the patient to improve disease management.” He looked to experience in diabetes, chronic heart failure and asthma that seemed to point the way.

Interdisciplinary care models were in their infancy, and Dr. Bourbeau felt that the first step in coordinating care was to develop evidence-based material that could guide the efforts of a range of professionals to provide best care and patient education. He collaborated with a respiratory care nurse, Ms. Diane Nault; with a grant from the pharmaceutical company Boehringer-Ingelheim, they worked with focus groups and expert advisors to develop the original Living Well with COPD material and structure a self-management education program.



COPD affects between 4% and 13% of Canadians over age 35 (between 1.5 million and 3 million people).¹ The disease (also known as emphysema and/or chronic bronchitis) causes the airways to become inflamed and narrow. COPD is progressive and leads to symptoms of breathlessness, cough and frequent respiratory infections. Acute exacerbations are frightening episodes (as fatal as a heart attack), during which breathing is severely compromised. According to most recent Statistics Canada figures, COPD is the fourth leading cause of death in Canada and the leading cause of hospital admissions. The total cost of COPD hospitalizations alone is estimated to be over \$2 billion a year in Canada. And one hospital admission often leads to another: 18% of COPD patients who were hospitalized for COPD are readmitted, often more than once, within the year. Emergency room (ER) visits following discharge are higher among COPD patients than for any other chronic condition.²

Complex management

Managing COPD relies heavily on patient knowledge, skills and motivation to take medications properly and implement strategies on a day-to-day basis to minimize symptoms and use health resources effectively. It also depends on physicians, nurses, respiratory therapists and other health professionals working from a common knowledge base and using a team approach to deliver consistent educational messages to

equip patients for self-management.

A number of strategies and medications can help people control symptoms of the disease. Medical therapies include bronchodilators to help open the airways and reduce shortness of breath, anti-inflammatories (either inhaled or taken orally) to reduce inflammation in the bronchi, antibiotics to treat respiratory infections and home oxygen for chronic respiratory failure. Healthcare professionals require expertise to carefully select the best options for each individual in a constantly evolving therapeutic landscape. Patients need to develop skills around when and how they should be administered, as well as master breathing techniques, exercise routines and anxiety-reduction and energy-conserving strategies.

The program

“The original pilot of *Living Well with COPD* in the late 1990s showed promising results, but before encouraging its adoption we wanted to test it further and build solid evidence that it was doing what we expected,” says Dr. Bourbeau. With a research grant from the Fonds de Recherche en Santé du Québec (FRSQ) and additional funding from Boehringer-Ingelheim, Dr. Bourbeau conducted a clinical trial in seven hospitals in three cities across Quebec that randomized over 200 patients to receive either usual care or the Living Well with COPD program. The educational intervention consisted of one hour per week of teaching at home for seven to eight weeks, followed by weekly telephone calls for 8 weeks, then monthly calls. Nurses or respiratory therapists acted as case managers, working in collaboration with the treating physician, and were available to patients by telephone throughout the study period. Care providers all worked from the Living Well with COPD materials.

Proven effectiveness

The results of this study, published in the *Archives of Internal Medicine* in 2003 showed that hospital admissions for exacerbations of COPD were reduced by 39.8% in the Living Well with COPD group as compared to usual care, ER visits by 41.0%, and unscheduled physician visits by 58.9%.³ “It was a landmark study internationally and

the first major study to establish the benefits of disease management,” says Dr. Bourbeau. Further studies confirmed these benefits, established the program’s cost-effectiveness and identified components, notably the written action plan, that contribute strongly to positive results.^{4,5,6} Since 2003, there have been over 20 publications on Living Well with COPD⁷, and the program has been adapted and implemented in Quebec, Canada, the US and countries in Asia, the Middle East, Australia and Europe.

Continued support from Boehringer-Ingelheim, Pfizer and other pharmaceutical companies (GSK, AstraZeneca, Novartis) over the years has allowed for the development of additional materials and the creation of a website, livingwellwithcopd.com to make them widely available in English and French to health professionals and patients. The materials are updated regularly under the direction of Dr. Bourbeau and evaluation of the program is ongoing. There are more than 10 research projects currently underway supported by the Canadian Institutes for Health Research (CIHR) and the respiratory health network of the Fonds de recherche du Québec-Santé (FRQS) and unrestricted grants from the pharmaceutical industry.

COPD is an important area of drug development research at Boehringer Ingelheim and the company has seen a number of different respiratory medications approved in the past decade. Suzanne Kimmerle, Healthcare Affairs Manager at Boehringer-Ingelheim, believes the key to Living Well with COPD’s success is that “It has evolved continually as we discover better ways to manage COPD. It is updated regularly to incorporate advances, whether in drug therapy, pulmonary rehabilitation or exercise regimens.” It also incorporates feedback from program users.

How it’s used

Health professionals create a user account on the website to access full-length versions of materials, all free of charge, which they can then print for use in education sessions and to hand out to patients. They can also work directly from the website to teach patients, and patients can access the material independently as well. Registration enables the Living Well with COPD team to track where the program is being used and to keep users



Living well with COPD

Materials available on the Living well with COPD website:

Pamphlets and brochures

- Patients plan of action
- Get moving... breathe easier
- Summary of the program

Modules

- Being healthy with COPD
- Integrating long-term oxygen therapy into your life
- Integrating an exercise program into your life
- Integrating a plan of action into your life
- Managing your stress and anxiety
- Managing your breathing and saving your energy
- Preventing symptoms and taking your medication
- Keeping a healthy and fulfilling lifestyle

“Our priority is to assure that patients hear the same message from the beginning to the end of their trajectory: during doctor visits, with their nurse educator, in learning centres and when receiving care from respiratory therapists.” — Patricia Côté, QACN

informed about updates as they are produced.

The resources include training for health professionals in disease management, pamphlets, flip charts and posters to use in patient coaching, and comprehensive materials for patients. However, health professionals need to know how to navigate the site and find material that’s most appropriate for a given patient and situation. “You can’t just give someone a pamphlet, call that education and expect behaviour change,” says Ms. Kimmerle. Dr. Bourbeau stresses this point. “The Living Well with COPD program is not about just bits of material; it’s a how-to guide for inter-professional collaboration.”

The program offers educational content for patients and a reference framework for health professionals,” says Isabelle Ouellet, clinical nurse coordinator for the Centre-West region and at the Montreal Chest Institute. “Living Well with COPD enables me to base my interventions around proven materials and approaches and serves as a guide when providing individual or group patient education.”

Living Well with COPD is effective at increasing

not just patients’ knowledge but also their motivation to manage their condition. Ms. Jocelyne Goddard, a patient at the Montreal Chest Institute, points out that “it’s one thing to learn how to do an exercise, but quite another to integrate it into your daily routine. Once you do, you see the benefits.” Ongoing contact with the care team helps keep her motivated and education helps her manage symptoms. “Knowing how different exercises and medications work makes me much more confident that I can act before a crisis occurs,” she says.

In fall 2014, Dr. Bourbeau will be launching an expanded patient portion of the site, supported by the Québec Asthma and COPD Network (QACN), the respiratory health network of the FRQS and the CIHR, as well as industry partners (Almirall, Astraeneca, Boehringer-Ingelheim, GSK and Novartis). Living Well with COPD recently became a not-for-profit corporation to assure its sustainability and the team has expanded to include full-time staff and consultants from different fields, from behavioural science to information technology, working to keep the program up-to-date with the latest evidence.

Uptake

The QACN stands as an innovative mechanism to spread disease-specific best practices on a provincial scale. It is unique in providing continuing education to a wide range of health professionals. “We offer a three-day training program geared for all those caring for people with COPD,” says Ms. Patricia Côté, Executive Director of the Network, “and one full day deals with patient education, using the Living Well with COPD materials.” The training program is accredited by the orders of nurses, respiratory therapists and kinesiologists. Funding for network activities comes from both the Ministry of Health and Social Services and pharmaceutical companies.

“Our priority,” asserts Ms. Côté, “is to assure that patients hear the same message from the beginning to the end of their trajectory: during doctor visits, with their nurse educator, in learning centres and when receiving care from respiratory therapists. The QACN promotes use of the Living Well with COPD program so that people don’t spend their time reinventing the wheel. It’s



an indispensable tool.” The educational flip chart is a favourite: on one side are the key educational messages the professional wants to relay, while on the other are images that help the patient understand the messages. Home care providers carry the materials around with them to share with their COPD patients, according to Ms. Côté. The Network recently recruited regional delegates to serve as spokespeople and help disseminate the Living Well with COPD program and additional modules.

Potential for expansion

“The QACN has been instrumental in seeing the program adopted across the province,” says Dr. Bourbeau, who sits on the Network’s scientific committee and is President of its Board this year. “The QACN a very good example of how professional societies and non-profit organizations, with industry and government support, can collaborate to promote better approaches to care.”

Ms. Côté is very optimistic about the Ministry of Health and Social Services’ recent emphasis on chronic disease self-management. Its current strategic plan strongly encourages healthcare organizations in Quebec to take action on self-management of chronic disease.

Other provincial governments are also emphasizing self-management and integration of care in hopes of reducing the very high hospital admission and readmission rates for these patients. In April 2014, the Canadian Foundation for Healthcare Improvement (CFHI) launched a pan-Canadian collaborative, supported by Boehringer-Ingelheim. Its aim is to help healthcare organizations implement supports for COPD patients and their families to facilitate self-management and reduce the need for acute services. For patients with advanced COPD, the INSPIRED (Implementing a Novel and Supportive Program of Individualized care for patients and families living with RESpiratory Disease) program, developed by Dr. Graeme Rocker at Capital Health in Nova Scotia, provides a hospital-to-home, coordinated and proactive approach to care. The CFHI collaborative will enable this approach to be implemented in other hospitals.

The QACN a very good example of how professional societies and non-profit organizations, with industry and government support, can collaborate to promote better approaches to care.

“INSPIRED, which is the first pan-Canadian collaborative program with 19 sites across the country, seeks to significantly increase the current level of care for COPD. Both INSPIRED and Living Well with COPD aim to bring patients the highest possible quality of life while managing their disease,” says Martina Flammer, Vice President Medical and Regulatory Affairs, Boehringer Ingelheim (Canada) Ltd.

Dr. Bourbeau will be collaborating with Dr. Graeme Rocker in Nova Scotia to examine how the INSPIRED program can best encourage use of Living Well with COPD and provide a collaborative framework for interprofessional care across the trajectory.

As the health system has become increasingly integrated and coordinated, Living Well with COPD has been incorporated into the training and work of community health centres, home care workers and specialized pulmonary rehabilitation centres.” All those pieces have come together in the evolution over the past 15 years,” Dr. Bourbeau remarks. He is still working hard to promote its use in all the places people with COPD receive care, including ERs and medical wards, and is undertaking a project with the Montreal Health and Social Services Agency (ASSS) to adapt the program for primary care.

Dr. Bourbeau sees three main challenges in the coming years. The first is collaboration to enhance and spread proven practices and programs. “The second challenge,” says Dr. Bourbeau, “is to implement levers, through government, service agreements and accreditation requirements, to encourage health professionals to focus on disease self-management. The third challenge is to sustain research and evaluation of the programs we are implementing. This is the only way we will improve quality and cost-effectiveness in our healthcare system.” ■

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