

Commentary by The Change Foundation
FALL 2009

HAVING THEIR SAY & CHOOSING THEIR WAY:

Helping Patients and Caregivers Move from Hospital To 'Home'
A Quality Improvement Project on Patient Transitions



THE CHANGE FOUNDATION

HEALTH CARE DESERVES
OUR FINEST THOUGHT

COMMENTARY

Having Their Say & Choosing Their Way: Helping patients and caregivers move from hospital to 'home' October 2009

This commentary, a companion to the detailed reports documenting the quality improvement project called Having Their Say & Choosing Their Way, focuses on what The Change Foundation learned from the initiative and what has changed on the ground because of it. It includes insights from project participants we interviewed as well as information on improvements at the policy, regulatory, and organizational level to support seamless care for elderly patients as they move from hospital to 'home'.

Everyone involved in the project is committed to providing the best care and experience possible for patients/clients, and to continually learning and improving their processes and practices. We commend the site partners for their commitment to quality improvement, patient input and public scrutiny to drive change. The Change Foundation is proud to have funded this project, in partnership with the Ontario Association of Community Care Access Centres (OACCAC), and we thank the hospital and Community Care Access Centre (CCAC) participants for their leadership.

Having Their Say & Choosing Their Way is a quality improvement project so it focused on opportunities for improvement, not on all the successful transitions that occur each year. The purpose of the research was to understand what would be of value to clients from their own perspective. What was learned through this research can also be used to inform policy and identify opportunities to improve transitions between acute care and CCACs.

The findings reinforce that effective changes often do not require large amounts of new resources but a different way of thinking. New thinking, new process, better outcomes for all. We encourage everyone committed to improving patient experiences to read this commentary and the detailed project reports at www.changefoundation.com.

Patient/Caregiver Views: Hospital to Home

"They're almost like family. She's really caring, she really helps my mom."

"I confused about everything." "You don't really know who to call...and what number to call?"

"They just give it to me brochure. So many you know. So many I have."

"The hospital [CCAC coordinator] was great. They actually emailed and made all the arrangements for home care."

"If you didn't have no Portuguese speaking this program to me wouldn't be working for me."

"It's sort of like a black hole you know. You call the Care Coordinator and she says 'I forwarded the paper'. You call the CCAC, and CCAC says 'We haven't' received the paper.' I'm not sure how the paper flows."

"I feel that my parents are getting the home care that they need with this woman."

"They said in hospital, when you go home the Nurse go home too. Nobody come at night and nobody come in the morning."

Patient/Caregiver Views: Hospital to Long-term care

"Would it have been possible, or should be possible, to do some planning ahead without sort of

committing to an application for a room, to get into the system, you have to say you're willing to take a room on short notice, or pass on it and then maybe lose your place."

"She stayed in hospital too long...and that was what I think killed her mentally."

"[CCAC Coordinator] and [Social Worker] work very close together all along. I had a lot of support."

"Well I don't know what [CCAC's] goal is to tell you the truth .What they can provide again I don't know."

"I asked them if I could have my mother stay with me until the private room at [x home] was ready and they said if I take her out of the system she won't get the private room. She will go to the bottom of the list. So, so long as I keep her at [y home] she's still on the list for the private room at [x home]. So that is a catch 22 that I'm not particularly fond of, you know."

"The main thing is CCAC placement communication directly to the family lead, right? Because that is the main missing link. Because then, a simple question I still don't know is how long are the waiting lists?"

"They should make sure that the CCAC is involved from the beginning in the hospital and so that you keep up that relationship."

INTRODUCTION

TRANSITIONS ARE TELLING. One of the best ways to assess whether a health-care system "works" for those it serves is to look at patient transitions from one provider, service or setting to another. When the different parts and players in the system work well together, the transitions are seamless, sensible, and satisfactory for both patients/clients/caregivers and the health-care providers involved in their care. When they don't, the consequences for patients are real and regrettable—and often avoidable if the root causes are addressed: poor communication and inadequate information systems, faulty design and processes, and confusion about who is responsible for what.

To understand more about what helps and hinders good transitions, The Change Foundation funded *Having Their Say, Choosing Their Way*, in partnership with the Ontario Association of Community Care Access Centres (OACCAC). The project, undertaken with the South East CCAC and Quinte Health Care's Trenton Memorial Hospital and later, with the Toronto Central CCAC and Toronto Western Hospital, examined two distinct patient journeys among the elderly who had been designated as alternate-level-of-care patients: transitions from hospital to home with home-care services, and transitions from hospital to placement in a long-term care home. The project went beyond aggregate statistics and client satisfaction measures to:

- conduct in-depth interviews with patients/clients and their families about their experience;
- observe and map all the steps involved in discharge planning and placement in long-term care facilities.
- identify what was of value to the patient/client/caregiver in the transition process and what contributed to negative experiences for them. (see project reports for value statements validated by the patients/clients/caregivers)

Acting on the project findings, (see selected findings/patient & caregiver views in sidebars), the partners identified a number of opportunities to improve transitions for elderly patients, providers and the system: to make them timelier, to ensure patients receive the right care in the right place at the right time, and to decrease the number of alternate-level-of-care days as well as hospital re-admissions. The project pinpointed many tangible steps that hospitals and CCACs can take — and, in fact, are already taking — to improve patient experiences, derive more value from scarce resources, and deliver better care. “We have made progress in focusing more on the people and tailoring the process to better meet their needs. At the same time, we are establishing stronger connections with other partners across the health-care system,” says Stacey Daub, Senior Director, Client Services, Toronto Central Community Care Access Centre.

SEEING THE PEOPLE, NOT JUST THE PROBLEM

THE POWER OF the *Having Their Say, Choosing Their Way* project is in its ability to see the system through the eyes of patients/clients and their families, to document the patient experience, and use it to guide change. The real-life stories of patients are powerful and compelling, and they can provide more depth and understanding than standard patient satisfaction tools.

“The study reminded us that we are caretakers of peoples’ lives and futures,” says Katherine Stansfield, Vice President, Patient Services, Quinte Health Care. “Each part of the system is responsible for a segment of the process, but it’s a person’s life we’re impacting. We can’t lose sight of that in the midst of stats and aggregate numbers.”

“In quality improvement, the focus is often only on making processes more efficient,” says Toronto Central CCAC’s Daub, but to design a good process, you have to take into account the client experience. We have to really see the people we’re caring for, and understand how they experience that care. Through this process, we learned that different parts of the system see people differently. For example, those of us working in the community may see an older person with mild dementia who is functioning quite well at home with supports. But when that same person falls in the garden and is taken to hospital, the hospital tends to see a frail, disoriented person who should be in a long-term care home. If the CCAC coordinator can stay connected to people when they go into hospital, there’s a better chance that we can get the system to see their capabilities as well as their needs, develop supportive care plans and get people back home.”

OPENING THE DOOR BETWEEN COMMUNITY AND HOSPITAL CARE

THE STUDY REINFORCED the negative impact of a “silo” approach to care, where the responsibility of community care providers stops at the hospital door. The people responsible for coordinating care in the community often have valuable information about the person who has come into hospital. They know about his or her home situation as well as the

Selected findings for Quality Improvement work

There were 247 steps in the hospital-to-home process, using nine databases, 35 forms/tracking sheets/brochures; 11 handoffs/waits for patients

Patients/caregivers need more face-time with staff to navigate a complex, confusing system — in a 20-step process, only two involved time with the patient.

People felt positive about the help they received that got them home from hospital, when they felt cared about, when the 'little things' were looked after, and when they received service in their language of choice.

People going home with home care lack clear and complete information to help them understand what is available to help them when they get home. "I don't know" was a common refrain.

There was sometimes a mismatch between the timing and type of home-care services and what people needed most at home.

There were 160 steps in hospital-to-long-term care process, using nine databases, 36 forms, and 15 handoffs/waits for patients.

There is a need for more proactive community placement information sharing among providers

working across the system, more consistent, patient-friendly communication.

Patients and caregivers felt rushed in reaching life-changing decisions based on 'best guess' information in a process that lacked transparency, clarity, and ownership.

There is little understanding among patients about their relative position on a wait list, how much time they have to wait, and what moves people higher on the waiting list for an available bed; rules governing hospital discharge confusing.

Care options — including supportive housing, home care, — not systematically offered. Once labeled "ALC", patient info heavily oriented to long-term care choices.

Patients often unclear about central coordinating role of CCACs.

Patients and caregivers involved in moving from hospital to long-term care commonly spoke highly of the acute care provided, the staff helpfulness in certain locations, and reported that health often improved after going to long-term care. The design of the hospital to LTCH transition, however, yielded deficiencies identified by patients and caregivers.

supports and services available in the community, but their knowledge often goes unused. Instead, hospital discharge workers are trying to help people make decisions about their care when, as Stansfield says, "they may only have known the person for five minutes and have very little information about them."

The organizations involved in the study — and others — have already taken steps to integrate care and link community and hospital services. For example:

- CCAC case managers (called care coordinators in Toronto and elsewhere) in the South East and Toronto Central now work much more closely with their respective hospitals Quinte Health Care and Toronto Western Hospital to plan discharges.
- The South East CCAC has increased staff in the hospital. A CCAC case manager is now "embedded" in the emergency department at the Belleville Hospital and other hospitals and is part of the team, responsible for discharge planning so one consistent person is coordinating people's care throughout the process. Case managers are in the hospital at certain times every day, allowing families to know when that service is available and making it easier to arrange a meeting.
- The CCAC and Quinte Health Care are examining the discharge process from hospital for all client populations.

- The South East CCAC meets with all hospital partners at least quarterly at the executive level and monthly at the operational management level.
- The South East CCAC has also introduced and resourced a review to ensure “client value” is part of all processes.
- Toronto Western Hospital and the Toronto Central CCAC now meet monthly to identify and discuss key transition issues.
- As of September 2009, a CCAC care coordinator has been based in the emergency department at Toronto Western Hospital.
- The Toronto Central CCAC is assigning care coordinators who are responsible for a smaller number of clients with complex needs rather than carrying a generic caseload. This wrap-around support model for high-risk populations—seniors, children and adults with medically complex needs—provides much more intensive support and follows the client across the continuum. Those clients will be helped through the transition from hospital to home by a care coordinator who they already know and who has been supporting them at home—instead of by a hospital staff member who doesn’t know them or their stories. The care coordinator will visit the client on the first day or two back home, accompany them to the first follow-up doctor’s appointment and provide ongoing support.

“This project has definitely helped forge a stronger and more collaborative relationship between the South East CCAC and QHC, with a client-centred approach to our collaborative efforts,” says Stacey Roques, South East CCAC Senior Director, Client Services. “*Having Their Say* has helped set the foundation for many other initiatives, ensuring that the client experience is at the core of what we do.”

STREAMLINING PROCESSES

THE PROJECT CONFIRMED that the processes involved in discharging someone from hospital to long-term care or home care are time-consuming and cumbersome. “Of the 200 minutes of total staff time involved in transitioning someone into home care, only 20 minutes of this time is spent with the patient,” explains Jeff Doleweerd of Doleweerd Consulting, which conducted the studies. “A lot of time is being spent completing paperwork and processing information into a variety of forms, databases and applications. This is not valuable to patients, is frustrating to staff, and represents a tremendous opportunity to redesign the process and reinvest this time in patient care.”

As part of its response to the study, Toronto Western Hospital has streamlined its discharge practices and policies. “We saw huge opportunities to improve efficiency and effectiveness,” says Kathy Sabo, Vice President, Toronto Western Hospital. “We now have a standard definition for alternate level of care across all our organizations. We’ve updated our discharge policy and developed a toolkit with case studies to guide discharge planning. We are implementing a standard letter to all families which explains that, when their family members finish acute care, they will receive supports to go home or to an appropriate level of care.”

At Toronto Western Hospital, the goal is to start planning for discharge as soon as someone arrives. “We really want to push things to happen faster,” says Sabo. We want CCAC care coordinators integrated with our teams so we can improve both patient flow and the care experience. In our view, the CCAC care coordinator is the best person to have the conversation with clients and families about the transition to the next level of care because they have more information on the options in the community.”

The OACCAC is strongly supporting efforts to streamline processes; they are working with CCACs to implement a common Client Health and Related Information System (CHRIS) to develop common assessment tools and automate a significant amount of the paperwork. This allows case managers or care coordinators to spend more time with clients and speed up the start of their treatment plan. Hospitals and emergency departments will also have access to a list of CCAC clients so they can notify the CCAC when a client arrives at emergency and/or is admitted. The CCAC also receives automatic referrals from hospitals when patients being admitted meet certain criteria, such as over age 75 with a chronic condition.

“In many cases, the person may not need to be hospitalized,” explains OACCAC CEO Margaret Mottershead. “If a CCAC case manager can see and assess the person in the emergency department, it may be possible to provide the services they need at home.”

CCACs are also collaborating with other care providers within their LHINs — including hospitals, community support agencies and mental health and addiction services.

“The public policy goal is to reinforce that as providers of care we are all — together — accountable for the health of our population, and for helping them move through the system and get the care they need, when they need it,” says Mottershead. “As the only entity with the legal authority to place people from acute care to their next destination — whether that’s the person’s home, supportive housing, a day program or a long-term care home — we must have the capacity to follow clients wherever they are in the system, and to match services and resources to their needs.”

IMPROVING COMMUNICATION AND INFORMATION

DAUB CAUTIONS THAT STREAMLINING THE FORMS, databases and systems may make the process more efficient but it will not be enough to improve the patient experience if hospitals and CCACs don’t address the need for accurate information and open communication.

Communication is key to helping clients and families “choose their way”.

Doleweerd agrees: “It’s vital that the person responsible for discharge planning — whether it’s the CCAC case manager or a hospital social worker or nurse — be able to give clients and their families real-time accurate information about their care options and wait times. People going home from hospital with home care said that what’s important is to know who is going show up at their door on Monday to provide care, what time they will arrive and the type of care they will provide. Front-line staff should have access to information technology that tells them exactly what services are available for the client.”

Doleweerd acknowledges that with the wide range of services and service providers in every community it’s a challenge to be able to provide complete, accurate information.

Mottershead says that CCACs realize that people are looking for a comprehensive response to all their needs: “As part of CCACs’ role in system navigation, we go beyond the traditional basket of services that home care provides to ask people about other areas in which they may need help. For example, whether they can manage meal preparation and — if not — link them to Meals on Wheels programs.”

“Over the past two years, we’ve gained a clearer understanding of the impact that client satisfaction has on overall health outcomes, and we’re shifting our focus more to the client’s experience throughout the care journey. Care isn’t just health care, it’s caring for the patient

or client before, during and after treatment, and through the transitions from one setting to another. We need to take a more holistic approach, to comprehensively assess and address all their needs: physical, mental, social and spiritual. We also have to develop a strong relationship with family members who provide ongoing care and are a key resource in helping people feel better and stay well.”

The system is already changing to improve communication and to give Ontarians easier access to accurate information. For example, each CCAC now has a person answering their phone line 12 hours a day, seven days a week so when people call for information, they receive it right away. And to make it easier for families to find information about services — preferably before someone is in crisis — CCAC websites have been redesigned to put client needs at the centre of the information, to make the websites easier to navigate and to clearly explain the CCAC role in the health-care system. Questions are framed from the client perspective, and the website prompts people to help them find what they need.

Part of the integrated website — www.310ccac.ca — features a search tool that will connect clients to information or government, private, or fee-based services in any community across the province. The sites include information on all services available to people in their communities, such as Meals on Wheels and activation programs. It can also help people find their closest drug store and the locations of family health teams. There is also one phone number — 310-CCAC — that people can call to reach their local CCAC.

INTRODUCING NEW PROGRAMS & REVISITING POLICIES TO SPEED THE CHANGE

WHILE THE STUDY WAS UNDERWAY, the Mississauga Halton LHIN and CCAC introduced *Home First*, a program designed to bring people home from acute care with appropriate supports either while they were waiting for a long-term care placement or to allow them time to make a decision about long-term care. As a result of the program, the region saw its applications for long-term care home placements drop from 50 to four a month.

The Toronto Central CCAC started a similar program, called Waiting at Home, and reports that the program has been highly successful. In the last year, 40% of clients who were waiting at home for a placement ended up not needing long-term care. According to Daub, even those who did end up in a long-term care home felt more positive about the transition because they had time to make a choice, and prepare for the move. The Home First Program is being rolled out in all Toronto hospitals this fall. The goal is to decrease the number of ALC patients being transitioned to LTC and the number of patients who are newly designated eligible for Long Term Care while they are still in hospital. There have been many instances where patients are designated eligible for LTC because they are still in the acute case of their recovery and when they are later assessed found to be capable of getting the right care and support with community-based resources. The Program is based on the following principles: if a patient is admitted to hospital from home all efforts must be made to discharge the patient back to their home; the LTC process is designed for decisions to be made at home and not in hospital; all discussions regarding LTC or other community options should occur outside of acute care; “home” will always be considered as the first option.

These initiatives demonstrate that, in many cases, people just need the right level and mix of supports at home.

“Giving people more control and choice adds value to the care experience,” says Daub. “In many cases, we can provide options in the community that cost no more than long-term care, and have good or even better outcomes. To get these, we just have to think and work differently.”

The studies identified many specific changes to improve transitions and the care experience for patients/clients — and as noted above, many are already underway.

However, all sites acknowledge that changes would be easier and faster with supportive programs, policies and legislation. For example, some of the requirements of the Long-Term Care Act make it more difficult for people to “choose their way”, and the current CCAC service purchasing model can sometimes make it hard for a care coordinator to immediately tell clients who will be providing their care. With the large number of community agencies providing home care services, it can be a challenge for CCAC to ensure that a client receives coordinated services from just one or two agencies.

Mottershead believes that recent policy changes, such as allowing CCACs to run clinics and to offer other professional services, such as respiratory therapists and pharmacists, will improve care in the community, help avoid adverse medication events and reduce the need for clients to go to hospital in the first place. The Health Care Connect initiative, led by CCACs, is helping unattached patients find a primary care provider and should lead to better health and fewer hospital visits.

CCACs are also working together with the Ministry of Health and Long-Term Care and the Collaborative for Health Sector Strategy at the Rotman School of Management at the University of Toronto to develop a new strategy to strengthen home care and to test innovative changes to policy and client service delivery. As part of the strategy, the partners are collaborating on the Integrated Client Care Project, a multi-year initiative to develop and evaluate an integrated care model designed to improve client outcomes by focusing on three main principles: specialization, integration and coordination. In this new model of care, providers will work together across sectors to provide value for clients over the full episode of care.

Says Adalsteinn Brown, Assistant Deputy Minister, Health System Strategy Division, Ministry of Health and Long-Term Care and Chair of the Integrated Client Care Project Steering Committee, “The project will focus on client-centred approaches to organizing care where the opportunity to improve client outcomes take precedence.”

LISTENING TO PATIENTS/CAREGIVERS

THE MOST COMPELLING ASPECT of the *Having Their Say, Choosing Their Way* project for the organizations involved was hearing the voices of the clients and caregivers. While everyone knew that there were problems with the transitions from acute care, the stories made the problems real and urgent. CCACs are committed to providing a positive client experience and, as far as possible within their resources, will continue to listen to and work with patients/clients to develop individualized plans for care.

The key question about every step in the process, says Doleweerd, is: “Does it add value for the client? By optimizing the patient experience, you will improve the process and make the system more efficient.”

TAKE-AWAYS & CONCLUDING COMMENTS

THE CHANGE FOUNDATION draws the following conclusions from the project:

1. Quality Improvement Techniques Can Improve the Process and Outcomes of the Provision of Health Care. Formal quality improvement techniques are relatively new to Ontario health care but are becoming more widespread. Providers are able to use these techniques to examine the processes of health care within their organizations, but the analysis of the transition between two providers or two locations is less common. This project demonstrates how quality improvement techniques can bridge that transition and improve patient care.
2. Preplanning for enhanced supports at home and if necessary a long-term care placement is essential. Bringing in more support to someone's home or deciding to move to a long-term care facility can be a difficult decision for patients and their families. Having to consider these decisions while dealing with a hospital admission compounds the stress for all involved. The individuals in the project who found themselves in this position identified the need for clear, accurate information from all their providers and the need for time to make the right decision for them. A hospital bed is not the right place for this discussion. This project demonstrates the need for earlier identification of community needs and earlier discussions with providers and patients and families about a continuum of options. It also identifies the need to develop more alternatives to either home with support or long-term care.
3. Consistent, patient-friendly communication and information makes a difference. In circumstances where patients and families had good information from the CCAC and/or hospital staff, the transition out of the hospital was better.
4. Information management systems that cross provider boundaries are essential. This project identified that patient transitions were delayed by time spent waiting—waiting for faxes and forms, for instance. These delays can be reduced by health information systems that all providers use to share information, update patient status, and communicate with one another in a timely manner.
5. Analyzing processes of care from the patient perspective yields results. Quality improvement techniques stress the importance of understanding the views of the “customer.” This project demonstrates what patient-based opinion can add of value to the care process.
6. Leadership makes a difference. Both the CCAC and hospital providers in the project did not have to participate. But they did—and then they began to act on what they learned, changing to improve the quality of care for the people in the communities they serve.

Health care is large and complex. Systems and processes should be designed to be both administratively efficient **and** centred on the people needing care. The Change Foundation is proud to have worked with our hospital and CCAC partners on this project to highlight opportunities for improvement—many of which do not require large amounts of new resources but a change in thinking. New thinking, new process, better outcomes.

The Change Foundation will continue to turn its mind and resources to improving the quality of care in the community and would welcome further collaborations with community partners. Keep abreast of our upcoming projects by subscribing to The Change Foundation e-newsletter, *Top of Mind*, or visiting www.changefoundation.com.

The Change Foundation would like to thank the Toronto Central CCAC, Toronto Western Hospital, the South East CCAC and Quinte Health Care's Trenton Memorial for their willingness to participate in this quality improvement project and to share their findings. In particular, we would like to thank Stacey Daub, Kathy Sabo, Katherine Stansfield and Stacey Roques from the project sites as well as Doleweerd Consulting Inc consultants Jeff Doleweerd and Tim Berezny. We also acknowledge our project partner OACCAC and its CEO Margaret Mottershead and Lisa Droppo, Chief, Programs.