

# **Navigation and Self-Management: Innovative Approaches to Managing Chronic Conditions**

Workshop Proceedings

## **Overview**

Access, integration, co-ordination and continuity of care are continuing challenges for patients with multiple, complex care needs, their families, providers and the health system in general. The intent of this workshop was to create a forum for leaders to look at creative approaches to address these needs by applying the concepts of self-management and navigation.

This workshop was sponsored by the Shared Care Network Development Initiative under the PHSA Primary Health Care Transition Funding in partnership with the Canadian Strategy for Cancer Control.

## **Goal and Objectives**

The goal of the workshop was to discuss and apply concepts that assist people to manage their complex chronic conditions by:

- Increasing common understanding of how self-management and navigation concepts contribute to addressing issues of access, integration, co-ordination and continuity of care.
- Exploring the application of concepts to chronic disease and condition management.
- Identifying tools and processes used in self-management and navigation and their applicability to current work relating to chronic disease management issues.

## **Agenda**

- 0730 - 0830 Breakfast and Registration
- 0830 - 0835 Welcome (John Millar)
- 0835 – 0915 Perspectives on Managing Chronic Conditions (John Millar)
- 0915 – 1030 Self-Management: An Outcome for Managing Chronic Conditions (Patrick McGowan)
- 1030 - 1045 Refreshment Break
- 1045 - 1130 Small Group Discussions
- 1130 – 1200 Respondent Panel (John Millar, Patrick McGowan, Richard Doll)
- 1200 - 1245 Lunch
- 1245 – 1500 Navigation Concepts & Application Panel: Canadian Strategy for Cancer Control, Canadian Breast Cancer Foundation, BC Cancer Agency
- 1500 – 1515 Refreshment Break
- 1515 – 1610 Small Group Discussions
- 1610 – 1630 Closing Remarks (John Millar)

### **A Shared-Care Model for Complex Chronic Disease Care: A Community of Practice**

[Powerpoint slides: A Shared Care Model for Complex Chronic Disease Care](#)

Dr. Millar welcomed the participants who were from all across Canada and thanked the large number of partners including the BC Cancer Agency, The Canadian Strategy on Cancer Control, the Canadian Breast Cancer Initiative, the University of Victoria – Centre on Aging and the BC Ministry of Health and the Health Authorities. The impetus for navigation has come from the world of cancer but can be extended to other chronic conditions such as diabetes, heart disease and mental health. The PHSA (Provincial Health Services Authority) is a unique organization in Canada. In existence for only two years and run by a government appointed board, it spans the province and oversees coordination and delivery of provincial programs and highly specialized health care services.

The Provincial Health Services Authority became involved in the shared-care model and chronic conditions because of the need for better prevention and management of chronic

conditions. The capacity for delivering these highly specialized services is not sustainable. The projection for the next 10 to 20 years is that the prevalence of chronic conditions will continuously grow along with increased health care expenditures (increase of 8% per year). By 2017, given this current rate of growth, government funds will be available only for health care and education. We must do a better job at managing and preventing chronic conditions. The model driving the thinking in BC is the Expanded Chronic Care Model (ECC) originally developed by Wagner in the United States, and the community layer of the ECC Model was added onto this original model.

A single-disease, collaborative approach has been used in diabetes and CHF. This collaborative approach to a single disease has resulted in spectacular improvements but many people have multiple co-morbidities. What UBC has coined 'the high 5' is the small percentage of the patient population who generally have multiple chronic conditions and consume 40% of health care resources. The model worked for single diseases. Would the model work for multiple chronic conditions and the 'high 5'? From this came the idea of building on the success of the single disease approach. The Shared Care Report involves five proof-of-concept sites which will evaluate how well the shared-care model might work.

## Concepts

*Shared care.* Not clearly defined. In a literature search, shared care was defined as an approach to care which uses the skills and knowledge of a range of health professionals who share joint responsibility in relation to an individual's care. It also implies monitoring and exchanging of patient data.

*Navigation.* Negotiate a path through the health care system. In cancer, trained navigators assist patients, similar to case managers in other settings.

*Prevention.* Build it into every stage of the game (e.g., National Health Service in the UK). Primary prevention can still be brought in for patients with multiple co-morbidities as this will decrease the likelihood of further deterioration.

*Community of Practice 'COP':* the network of providers, the patients with their families and support groups. This term is a Microsoft term used in the IT world and we are extending this concept. The Shared-Care Model (SCM) is applicable in primary, secondary and tertiary care. The SCM's common elements are shared responsibility for patient care and a clear differentiation of roles and legal responsibilities between providers. The SCM starts with collaborative training of health care professionals from the outset. One of the key concepts is the communication platform (the SharePoint Communication Tool) which includes such things as care protocols, integrated care pathways, algorithms, clinical data, self-management tools. This communication platform has the potential to be a powerful tool to bring together 'Communities of Practice.' A

challenge to implementing the SCM is power and status differences. Factors for success include an emphasis on shared-care methodologies in training future health practitioners.

Proof of concept sites include: Penticton, Prince George, Quesnel, Victoria and BC province-wide hepatitis, and Fraser Health. The challenge will be to move from primary care to primary "health" care.

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## **Self-Management: An Outcome for Managing Chronic Conditions**

### [Patient Self Management \(Patrick McGowan, BC\)](#)

The second presenter was Patrick McGowan from the University of Victoria Centre on Aging. Dr. McGowan provided a basic review of the differences between acute and chronic health conditions and the increasing incidence and prevalence of chronic health conditions. Using a case example he demonstrated the difficulty of getting people to make even slight behaviour change. He then introduced the concept of patient self-management, comparing and contrasting it with traditional patient education. He then explained the role of patient self-management in the BC Expanded Chronic Care Model. He demonstrated two major self-management strategies to assist people to change behaviour – Mastery Learning and Problem-Solving. Lastly, he provided a summary of the research literature demonstrating the effectiveness of patient self-management programs for persons with chronic health conditions.

Dr. McGowan concluded his presentation with five key points:

1. In managing chronic health conditions, just knowing information is not enough. People need to actively engage in specific behaviors.
2. Having someone "hold one's hand" to guide them through a health crisis is beneficial to many people; however, it is the individual who will need to learn to manage by him/herself the rest of their life.
3. In planning solutions to overcome barriers of achieving patient self-management, we must keep our focus on end goals rather than on processes.
4. In today's age we should be using "best practice" programs and interventions.
5. Strategies and interventions are more effective when they are integrated into the larger infrastructure (e.g., The BC Expanded Chronic Care Model).

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## **"How does patient self-management address issues of access, co-ordination, and continuity of care?" (Discussion 1045-1130)**

To maximize group discussion and innovation, the workshop organizers pre-assigned participants to a specific group. Each table had a discussion facilitator.

## **Discussion Group Responses**

### **Access**

Patient self-management addresses issues of access because the 'empowered patient' takes ownership, takes responsibility, is their own advocate and is an active agent. In being an active agent, the patient will have increased accessibility to services, earlier access and access other health care providers.

Patient self-management addresses issues of access because of the ability of the 'self-manager' to access the health care system at the point where they feel it is necessary.

Patient self-management addresses issues of access because self-management increases the power of the patient, and the patient can access the right service at the right/most appropriate time for them. The patient is better prepared to more effectively use the time with the specialist when they get there. Health problems may be better managed resulting in less need and frequency to see the specialist, thus leading to decreased waiting times.

### **Coordination**

Coordination is addressed because the personal health care plan is built on patient generated goals and is not system driven.

### **Continuity of Care**

Patient self-management addresses issues of continuity of care in that motivation is a huge part of self-management for both providers and patients, and the individual [patient] knows what he wants and needs and will work towards it. To promote patient self-management, health care professionals need simple strategies and techniques. In the current system, there is little continuity.

A 'self-managing' patient will be more likely to follow through, therefore addressing continuity of care. Self-management (including prevention) can generalize to the patients' family and generations, again increasing continuity of care. The problem-solving skills a 'self-managing' patient develops can be used again and again in different situations, thus increasing access, coordination and continuity of care.

Patient self-management addresses issues of continuity of care by allowing the patient to have the whole picture, even owning their personal health records, and thus leading to reduced uncertainty [and better coordination]. The patient will utilize resources more appropriately, efficiently, effectively, therefore freeing up resources for other things.

Patient self-management addresses issues of continuity of care because of its applicability across environments e.g., acute, chronic, rehabilitation, and end-of-life. A 'self-manager' will have the ability to access the health care system at the point where they feel it is necessary.

Continuity of care will be improved as there will be a decrease in duplication of services with 'one-stop' shopping (virtual/real) when the patient goes for help.

### **Additional Comments**

#### *Need to include the communities*

- There are different communities that need to be addressed in self-management: the professional and the patient (may be elderly, may be aboriginal, may be uneducated, and may not be ready for self-management).
- In order for self-management to succeed, all members of the community need several repetitions of the self-management concepts.
- Each community will need to re-assess the self-management concepts as to what worked and what didn't work.
- There is a need to determine how to involve the 'broader community' to become part of the world of the self-managing individual, especially if the 'self-manager' has co-morbidities.

#### *Barriers*

- There are many barriers to implementing self-management with health professionals, providers and patients. These include time, funding, consistency of concepts, and a reframing of the role. Each person needs to take ownership of his/her role.
- Is there evidence that patient self-management does address the issues of access, coordination and continuity of care?

#### *Paradigm Shift*

- There is a need for health policy and a public education plan to prepare the public first and intervene at a much earlier point (i.e., before developing a chronic condition or at an earlier stage of 'at-risk').
- A paradigm shift is needed which promotes a team approach, with personal responsibility by the patient and health providers supporting and encouraging patients.

#### *Change in system and supports needed*

- Additionally, new tools and a coordination of roles (beyond patient self-management) are needed to achieve increased access, coordination and continuity of care.
- The importance of starting where the patient is at (e.g., first diagnosed, marginalized and highly motivated, pro-active).
- A health care system with self-management will require the integration of changing roles, territoriality, cross-disciplinary education (beginning with college and undergraduate education), team-building and competencies.
- Community capacity needs to be built to support self-management.
- Patient self-management will change the way the health care system is used, reducing the burden on the traditional/current health care system. The health care system may still be utilized to the same degree, but in a different way.

## *Funding*

An additional issue is the need for a different funding pattern to implement change e.g., health care provider remuneration as in the UK health system.

### **Navigation: Concepts & Application**

#### **Panel of Experts from the Canadian Strategy for Cancer Control, Canadian Breast Cancer Foundation, & BC Cancer Agency**

The Navigation Panel focussed on concepts and application of Navigation and was chaired by Richard Doll. Presentations were made by eight participants. Follow the links below for copies of the presentations:

- [Patient Navigation, \(Richard Doll, BC\)](#)
- [Cancer Patient Navigation, \(Sandra Cook, Nova Scotia\)](#)
- [Patient Navigation Community Liaison, \(Donna Smith, Nova Scotia\)](#)
- [Empowerment and Team Work-a complex symptoms management care model, \(Anne Plante, Quebec\)](#)
- [Implementation of an infirmiere pivot en oncologie \(IPO\) for Head and Neck cancer in Quebec city area, \(Lise Fillion, Quebec\)](#)
- [Patient Navigation, \(Joanne Stephen, BC\)](#)
- [Strategies for Cancer Control - BC Model, \(Maria Cristina Barroetavena, BC\)](#)
- [Uncovering the Gaps: An inquiry of Breast Care in BC by the Canadian Breast Cancer Foundation, \(Julie McMillan, BC\)](#)

#### **"How can patient navigation be applied to your setting?" (Discussion 1515-1610)**

##### **Discussion Group Responses**

Patient navigation is already being carried out to some extent. Patients are coming into the health care system with complex medical, psychosocial and financial situations. The concern is that health care providers have little time for this activity and it is done 'off the side of the desk.' Thus, they question its effectiveness and quality. As well, there is no follow-up with patients. This is the reality of limited resources.

The types of activities being done to support patient navigation include: navigation tools for health professionals, education for family doctors (e.g. diabetes clinic is educating family doctors), incentives for family doctors (e.g. flow sheets) and salaried physicians. Information lines such as the Cancer Information Line and the BC NurseLine are being utilized. While internet sites and books have been developed, they may be inaccessible for those with limited reading and internet skills. A concern therefore is those patients who do not have the skills to carry out navigation.

Projects in development in the Northern Health region include the coordinator/ navigator providing online services to health care providers as to what is available and what

resources can be called upon for use. In Penticton, they are looking at combining three programs (renal, cardiac and diabetes) and having an overall navigator whose role would be to avoid duplication of effort and the overload of patients.

### **Additional comments**

#### **What would need to be in place?**

This group felt that patient navigation needed to be a dedicated part of the job (be determined in the role/function of a health professional). The health care professional would have to be someone able to think outside the box. Patients would need to be taught self-management skills so that they could be part of the process, with the navigator's role of supporting patients to develop self-management skills. The system will need flexibility. An individualized care plan could still be developed as a "safety net" for those patients who act as 'self-managers.' Health care professionals will require training and support. Clinical information systems will need work.

#### **The navigator role**

Is the navigator necessary? Should it be a designated role or can a health care team assume the role? Is the patient able to be their own navigator, and if so, what supports are needed and wanted? What is the best way to use navigators (e.g., disease specific, geographic areas, at-risk populations, SES, or cultural/ethnic target audiences)?

The role of the navigator was described by a navigator. This person is involved in: dealing with complex systems and across boundaries; clarifying roles for both providers and patients (who does what?); allowing for better use of providers' individual areas of expertise; providing patient kits or tools (information); addressing emotional issues (e.g., fear); repeating and reviewing information; addressing different learning styles; being the one person the patient can return to over the treatment trajectory; hearing the whole journey/experience of the patient; and lessening the stress that comes with system confusion. The role of a navigator can also be to provide temporary social support and then to connect this person to existing supports and resources.

A central issue identified by all groups was whether to have a "navigator" or to include "navigation" in the role of all health care providers and patients. If a navigator is introduced, what target audience should the navigator work with? What responsibilities would fall under the role of the navigator (e.g., quality improvement for health professionals, supporting both health professionals and patients, supporting patients to develop self-management skills). There was some agreement that at certain times (e.g., crisis or acute situations) or in certain cases such as those patients lacking reading, language or internet skills, the services of a navigator may be required.

Navigation should be based on the needs and experiences of the patient, with the patient identifying what is missing for them. The navigator collects the information and takes it

to the health care team for analysis. The navigator can also do quality improvement for the health care team.

Other points include the need for the navigator to be given an initial education and awareness of community resources. As well, an appropriate referral to the navigator is important.

The cost of implementing a navigator in the short term may increase due to salaries and the increased use of the health care system. However, long-term outcomes need to be assessed to determine how patients use resources and whether patients are more educated and receive better care

### **The role of the patient**

Start where the patient is at, and give them the right to choose whether to navigate for themselves or have someone take on the role of navigator. Questions were raised about whether to have a 'navigator' as opposed to having 'navigation.' There is a continuum of care between the navigator and self-management. The navigator can assist in times of crisis or acute stages of a condition, while self-management would be appropriate between crises, and for chronic conditions. A foreseeable difficulty is that if the patient as navigator role is used, there will be an issue of self-referral and eligibility i.e., you may not be able to refer yourself.

### **Navigation education**

Communities (i.e., patients, health care professionals, front-line staff, dedicated staff on a health care team, integrating health professionals as part of the team) need navigation education as well as a re-design of work flow to reduce or eliminate gaps in the system and areas of overlap and duplication. There is a need for levels of trust based on rural, religious and cultural factors. The system must address patient needs in the community (not only medical needs, but also emotional and financial needs by providing support and advocacy).

Challenges cited include roles and possessiveness of health care professionals. Interdisciplinary training and responsibility need introduction in the first 2 or 3 years of health care training. Navigation training needs to be built into the current health system (this includes information on self-management as well as navigation). There needs to be a cultured thought shift from "it's not my fault".

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### **Closing Remarks (Dr. John Millar)**

From today's session, it is evident that there is a lot of interest to proceed in the area of promoting navigation and self-management. We have been introduced to several new concepts and ideas during our panel and group discussions, but we have also discovered

that there are a lot of new questions and areas to be explored. We hope that our session today will provide a stimulus for people to continue this initiative in their own local health communities.

Our next steps as part of the PHSA Shared-Care Initiative will be to meet with our proof-of-concepts sites tomorrow to discuss how the learnings from today about navigation and self-management can be integrated into their project plans. We are excited to be working with these teams to move forward on this important initiative.

Thank you all for coming, and special thank you to Patrick McGowan and the panel presenters.