Managing Patients with Complex Healthcare Needs: Workshop Resource

Hamilton Central Health Links

www.hchealthlink.ca
Introduction

“Needs that individuals have are not complex — they are remarkably simple, but often numerous…transportation to appointments, a refrigerator for storing medications, a telephone to communicate with care providers, nourishing food, a place to call home. Specialty care for people with diabetes, cancer, or asthma, methadone treatment, mental health treatment, and issues with food security and housing stability are not in and of themselves complex challenges; the complexity arises when the tasks of making connections among multiple care providers and linking each intervention to the individual’s overall care plan fall in the lap of the individual alone without effective partnering or support.”(1)

It is likely that during the course of your career as a healthcare provider, you have encountered at least one patient whose numerous healthcare challenges felt overwhelming. While no formal definition exists, you may have been talking to a complex patient, otherwise known as a person with complex healthcare needs (PCHNs). This patient group typically presents multiple, chronic comorbidities. These can be accompanied by socioeconomic and behavioral challenges that further complicate the process of navigating the healthcare system.(2) The purpose of this document is to provide an overview of research literature on PCHN management as well as discuss a strategy developed by the Health Links program to provide health services to this population in Ontario.

Why is there a growing interest in PCHN management?

Healthcare providers, policymakers, and researchers have increasingly expressed interest in PCHNs for four reasons.

1. These patients experience a lower quality of care compared to patients with acute illnesses in terms of both their patient experience and healthcare outcomes.(3)

2. The Ontario healthcare system does not seem to fulfill the needs of PCHNs. For example, PCHN healthcare providers do not typically communicate with one another and thus may administer treatments or medications that are incompatible. Additionally, PCHNs have a very difficult time coordinating their various treatment plans and appointments. One outcome of poor PCHN management is that many go to the emergency room whenever their problems become more severe.(2)

3. The expected number of PCHNs will rapidly increase in the next two decades as the baby boomer population continues to age and develop chronic diseases.(4)

4. Though no formal numbers are available, a growing body of international and Canadian evidence suggests that there’s a significant overlap between the PCHN population and the top 5% of health systems users in Ontario. This 5% accounts for over 65% of Ontario’s combined hospital and nursing home costs, as well as 84% of combined acute care and home-care resources(5,6). Thus, strategies to improve care for PCHNs can result in increased savings for the health system.
Defining complexity

There is no formal definition for complexity in the research literature. Consequently, different jurisdictions and research teams working with PCHNs have developed unique, but similar guidelines to define and screen for complexity in their patient population. In Ontario, complexity in patients is often defined as

- Four or more chronic/high cost conditions including a focus on mental health and addictions conditions.
- At least one problem relating to
  - Economic characteristics (low income, median household income, government transfers as a proportion of income, unemployment).
  - Social determinants (housing, living alone, language, immigration, community and social services etc.)

It is important to acknowledge how fleeting the word complexity truly is. Patients who do not fit this definition or even other models of complexity might be very suitable for specialist PCHN care. Similarly, some patients who fit this definition might not be suitable. In addition, each healthcare provider will tailor their approach to helping complex patients differently depending on the goals of their practice or program. We will explore the issue of patient suitability with greater depth later in this resource.

Defining high health system users

Healthcare providers rarely have the time or resources to gather socioeconomic data on all of their patients. Thus, an approach used by the Ontario Health Links program is identity PCHNs to screen the top 5% (by age group) of health system users – a patient group known to have many of the characteristics of complexity.(6)

While this population does consume a high level of resources, the specific resources and problems for which the resources are used differ greatly between age groups. For example, the most common diagnoses in the <18 age group are preterm birth, cancer, and mental health disorders. In addition, 59% of expenditures can be attributed to the top 5% of system users in the age group. On the most part, <18 high system users only consume large amounts of healthcare resources in the short term. In fact, they are very unlikely to appear among the top 5% in consecutive years.(7) In contrast, the most common diagnoses and reasons for hospital admission in the adult and elderly populations are chronic diseases such as heart failure & chronic obstructive pulmonary disorder, or acute events such as hip fracture and stroke. Across all age groups, the top 5% of health system users have a 15% chance of dying in next 2 years, 45% chance of being in the top 10% of health care users for next 2 years, and 33% chance of dying in 1 year if they have at least 5 ER and 3 hospital admissions in the past year.
Table 1: Distribution of cost thresholds per person across cost categories, by age group

<table>
<thead>
<tr>
<th>Cost category</th>
<th>All</th>
<th>&lt; 18</th>
<th>18–64</th>
<th>≥ 65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top 1%</td>
<td>44 906</td>
<td>8 383</td>
<td>22 070</td>
<td>83 039</td>
</tr>
<tr>
<td>Top 5%</td>
<td>7 961</td>
<td>2 329</td>
<td>5 446</td>
<td>45 203</td>
</tr>
<tr>
<td>Top 10%</td>
<td>3 815</td>
<td>1 281</td>
<td>2 610</td>
<td>22 508</td>
</tr>
<tr>
<td>Median</td>
<td>333</td>
<td>195</td>
<td>298</td>
<td>2 211</td>
</tr>
</tbody>
</table>

The above table illustrates the importance of the >65 adult populations in the Canadian healthcare system. It takes an impressive $45,203 per year of healthcare spending to be in the top 5% of spending in the >65 population. In contrast, a patient under the age of 18 only needs to consume $8,383 to be in the top 5% of their age group. Given that many of the most common diagnoses in the adult and elderly population are chronic diseases, there is likely a strong correlation between high health system use, being over the age of 65, and complexity. As previously mentioned, research suggests that there is a causal relationship in which elderly persons develop chronic conditions that contribute to complexity.

**Screening high-cost users of healthcare**

Over the past year, the Hamilton Central Health Links has developed a seven letter typology to determine what management strategy is most suitable for high system users as seen below. An additional screening strategy we use is looking at patients who have been to hospital more than 5 times in a year. We found that they fall into a few groups, or clusters, that can be helpful to recognize in order to be helpful to these people. Here are the clusters we have noticed in our work so far.

A. No longer our patient
   - The patient died, moved away, entered long-term care, etc.
   - Management: no action is necessary

B. Transition to Palliative Approach Warranted
   - The patient has a generally incurable condition in a person who we would be “surprised if they were alive” in 1 year, but who continues to receive service from the acute care sector, often without wanting it.
   - Management: A ‘frame shift’ conversation and plan are warranted, moving from acute care to a more palliative approach with advanced care planning.

C. Crisis Resolved
   - The patient had a short-term crisis that resulted in frequent hospital use in the past, but has now completely resolved. We expect no further hospitalization for this problem.
   - Management: No need for further planning or management.

D. Ongoing Medical Crisis where frequent hospital use is warranted
The patient has a serious medical problem that does require a lot of active treatment or workup, and no outpatient options or prevention plans seem appropriate at this time.
Not expected to die within a year, and might improve or remain stable long term
Management: Frequent hospital use may be inevitable. Consider developing customized social/medical supports to improve quality of life as well as a customized plan between providers to improve communication and coordination.

E. Repetitive medical/social/psychological crises, frequent hospital use not warranted
The patient presents a pattern of repeating medical, social or psychological crisis is occurring and we don’t expect a spontaneous improvement.
The patient is expected to live more than 1 year.
Management: Developing a deeper understanding of the person, and some co-planning regarding access to care, crisis management, improved social context (housing, income, transport, relationships), or better services could result in more positive outcomes

F. Frequent hospital use due to too many providers without coordinated plan
Many providers involved, no clear diagnosis or treatment strategy, providers generating excess investigations, referrals, interventions and not communicating with each other.
Management: Develop a ‘stop the madness’ conference and plan. The patient’s providers could be fewer or more coordinated in the face of health condition unlikely to improve.

G. Medical problem could benefit from more workup and expertise
The patient’s needs warrant further investigation or expert opinion to improve their diagnostic accuracy or specific treatment.
Management: Accelerate focused specialist care and investigation towards the patient

It is important to note that these “types” are, of course, not written in stone. They are fluid, and people may move from one to the other or may not really fit any one in particular. Given that it is not cost effective for all patients to receive specialized management for PCHNs, research suggests that patients who fit models E through G warrant specialist PCHN care, as we will discuss shortly.(8,9)

Models of PCHN management

Over the past decade, several PCHN management models have emerged, many of which share similar, core characteristics that can help address the problems in patient typologies E through G above. First, the complexity of PCHN histories necessitates the use of stories when describing experiences. Secondly, PCHNs and care providers require a sufficient amount of time – often much longer than the usual 10-20 minute appointments – to process these stories.(10) Some studies suggest that physicians may even need multiple meetings to develop an understanding of their patient’s healthcare challenges.(11) Third, multidisciplinary teams are often necessary to provide PCHNs the full spectrum of services they need. Finally, most models of PCHN care incorporate opportunities for shared decision making in which providers work with their patient to identify which care options best meet the their needs and desires.(12,13) Other characteristics of PCHN management known to improve success include in-person meetings, training programs for providers who work with PCHNs, and the presence of informal caregivers.(4) Among the models of PCHN management, several which integrate these four characteristics are listed below.
Patient Centered Medical Home

The concept of the patient centered medical home has been increasingly promoted internationally as a cost effective way to increase the quality of health services. In this model, the patient’s healthcare is entirely coordinated by a healthcare provider who works with a broader healthcare team. To best serve the patient’s needs, his or her care team is multidisciplinary, and thus may include nurses, patient navigators, specialists, physiotherapists, and social workers among many other roles. (11) Built on the shared decision making model, patients are active participants in their care. For example, they may partake in discussions with all of their healthcare providers to share both personal healthcare information as well as care preferences. (14) Evidence for this model has been mixed, largely due to high heterogeneity in how care has been delivered in different healthcare settings. In a recent systematic review, PCMHs had a small but positive effect on patient experience, moderate effect on the delivery of preventative care, a small to moderate effect on healthcare provider experiences, a reduction in emergency department visits (95% CI of RR, 0.67 to 0.98), no reduction in hospital admissions (95% CI of RR 0.84 to 1.10), and no evidence of cost savings. (15) Evidence for PCMH success in Ontario is limited, though it is clear that some implementations of patient centered models such as family health teams can be more costly compared to private practices (16,17). More evidence on PCMH success in Ontario is expected to be delivered in the upcoming years.

Virtual wards

Over one third of patients admitted to an Ontario hospital are re-admitted within 90 days. In an effort to reduce hospital crowding and cost resulting from repeat patients, the virtual ward model places an emphasis on moving hospital-like care into the community setting. (18) In this program, patients are followed after their discharge by a multidisciplinary team of healthcare professionals. Similar to the hospital setting, these professionals regularly meet to discuss the patient’s care and needs. While there has been some success in the virtual ward model elsewhere, the model has seen limited success in Canada. A recent RCT in Toronto found that the virtual ward model had limited to no success in reducing hospitalizations or costs up at one month, three months, 6 months, and one year after the intervention was delivered. These results should be interpreted with caution. The virtual ward model has seen success elsewhere in the world, and it is likely that its failure in the Ontario setting was due to existing health system fragmentation in provider communication and EHRs among other sources. (8)

Case managers

The use of case managers – sometimes known by other names including system navigators or patient navigators - have been proposed as a way to provide PCHN support without substantial changes to the existing healthcare system. In this model, patients are assigned to a case manager who works with the patient to navigate their health needs and services. To ensure that there is enough time spent on each patient, case managers for PCHNs may have much lower caseloads than care managers for comparably less complex patients. Case managers often work directly with physicians or multidisciplinary teams to ensure that they have a holistic understanding of their patient’s needs. (4) Similar to patient centered medical homes, literature on case managers is highly heterogeneous. Literature on case managers has focused on specific diseases and settings. In particular, the model has seen a great degree of success in managing the care of oncology patients. In addition, recent systematic reviews suggest that this
intervention has a positive effect on patient outcomes, though further research will be necessary to elucidate its cost effectiveness and characteristics in other disease contexts. (19, 20)

PCHN Care in Ontario

There has been widespread interest among Ontarian policy-makers and healthcare providers in improving PCHN care. In December 2015, the provincial cabinet released a discussion paper on the implementation of the Patient Centered Medical Home model. In preparation for the potential changes to the healthcare system, a number of research projects exist in the province to evaluate the implementation of the medical home model. Started in 2013, Health Links is an initiative launched by the Ontario Ministry of Health and Long-Term Care. Its purpose is to improve the care coordination and health care experience of PHCNs – many of whom are among Ontario’s highest health system users - as well as their providers. Built on the philosophy that PHCNs should only need a single point of contact in the healthcare system to receive help on all of their diverse needs, Health Links connects patients to a multidisciplinary team of healthcare providers who take an active role in care coordination. Taking a more holistic approach, the health links care coordination involves examining not only the medical needs of PHCNs but also their financial and social context. Currently, there are 69 health links across Ontario which are geographically grouped based on the local health integration network they reside within. One of the major interventions mandated by the Health Links program is the development of coordinated care plans. These documents, made in collaboration between patients and their circle of care, summarizes the patient’s goals, health status, current supports, and use of services. By analyzing this information, healthcare providers can better understand where there are gaps in care and how they can be successfully addressed. If you would like to learn more about the health links program, please see the Hamilton Niagara Haldimand Brant LHIN presentation on the Health Links Model of Care available as an attached resource, go to http://hchealthlink.ca/resources.

Overview of the care planning process

Identifying and categorizing PCHNs

Using any of the approaches discussed in “Defining and identifying complexity”, categorize your patient. Include patients who match the definition of complexity or high system user typologies E through G for care planning.

Developing a plan of action

Below is a table of recent patients triaged using the patient typology at the McMaster Family Practice. In this context, triaged refers to whether or not the healthcare providers have collaboratively reviewed the patient file of the potential PCHN. Regardless of the patient’s source of complexity, the next step should always be to gather more information on the patient’s medical history, social history (e.g. family, finances, housing), and goals. This can happen by arranging a case conference involving multiple healthcare providers from diverse specialities, a meeting to interview the patient and create a coordinated care plan, or a discussion with the patient’s most responsible physician. More rarely, it may be possible to identify specific issues in the patient’s life that must be addressed such as social determinants of health (SDOH) or improper medication.
**Figure 1: Triage Status for Health Links Patients at McMaster Family Practice**

- **TRIAGED, deemed ACTIVE, 44**
- **TRIAGED deemed INACTIVE, 53**
- Not yet triaged, 53

**Bar Chart**
- Repetitive medical/social/psych crises: 28
- Medical problem unsolved: 8
- Transition to Palliative Approach Warranted: 4
- Fragile family system: 3
- Too many providers without coordinated plan: 1
- Crisis Resolved: 29
- No longer our patient: 11
- Medical Crisis where frequent intervention warranted: 9
- Patient Passed Away: 4

**Figure 2: Actions for “active” patients**

- Reach out to pt to schedule a follow up with PCP, 12
- Case conference w/ 2+ providers, 18
- Phone call by MRP to determine next steps, 2
- Med review, 2
- Discussion of issue related to SDOH, 1
Beginning the care plan interview

At the Hamilton central health links, we developed an interview guide to accompany the PCHN management process. What we found is that PCHNs require in depth interviews and many opportunities to answer open ended questions. Based on the options for active patients (Figure 2 above), the patient care plan (PCP) interview is an outcome that will happen whenever there is a need to gather more of the necessary patient’s social and medical history to develop a care management strategy. It isn’t uncommon for this process to take over forty minutes. We do promise however that you will learn so much about your patient that the time will be worth it. Using the guide, please read each section and ask a mix of open and closed ended questions necessary to solicit answers to all of the listed questions. Following, you will need to apply your understanding of disease management, financial support services, social support services, and community services to build an integrated care plan that best matches the patient’s needs. Accomplishing this task requires practice. Thus, we will be spending the majority of the workshop interviewing patients about the problems they face and working with fellow providers to develop solutions.

Further information and resources

All further content in the care planning process will be discussed during the workshop. You can access additional readings, the source references for all citations within this guide, and other materials at hchealthlink.ca/resources. If you have any questions regarding the content in this guide, please direct them to Aditya Nidumolu (workshop assistant, nidumo@mcmaster.ca) and Dr. Dale Guenter (workshop facilitator, guentd@mcmaster.ca)
Work Cited


