Patients Canada

What Happens When Patients Get Engaged and

Become Partners?

Make your experience count

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Agenda

1. Why patients were not engaged
2. What has changed
3. Why Patient must become partners
4. Patients Partnerships Today
5. How Patients Canada Helps

A brief history of our health system

Before 1850

- Longevity = 35-40 years
- Leading causes of death – infectious diseases
- Cholera, tuberculosis, small pox, typhoid fever, etc.

Major Innovations 1850-1880

- 1850 – Use of Ether as Anaesthetic
- 1867 – Joseph Lister & carbolic acid
- 1880-81 Robert Koch and Louis Pasteur discover cause and vaccine for anthrax and other infectious diseases

The 20th century health care system begins

Rapid decline of % of death by acute infectious diseases – success!

- Hospitals grow
- Doctors specialize
- Laboratory success including the discovery of insulin
- Penicillin begins to save lives in WWII (1940-45)
- New surgeries are performed
- Medical science promises silver bullets
- Cures all around!

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Quality in the 20th century healthcare system

- Patients as bodies for treatment
- Accurate diagnosis
- Timely protocol driven treatment
- Complete patient compliance
- Well-defined outcomes

Canadian medicare

Saskatchewan

- 1947 Saskatchewan Hospital Insurance Program
- 1962 Saskatchewan Hospital & Doctor care

Canada

- 1957 A National Hospital Insurance Program
- 1966 Medicare Hospital & Doctor care
- 1984 Canada Health Act: Medically necessary
  - Covers hospital care and Doctors fees
  - Does not cover drugs
  - Does not cover much non-medical treatment

Disease shifts: acute > chronic

Canada today (mostly 2012)

- 89% of deaths due to chronic diseases
  - Cancer, heart disease, lung disease, diabetes (WHO Atlas)
- <3% deaths due to acute infectious diseases
- 49% of the population is on long term medication
- Almost everyone over 65 has at least 1 chronic condition
- 2005 76% of people 65+ had taken medication within 2 days
- More than 20% with chronic conditions have 2+
- Canada has second highest per capita expenditure on prescription drugs in the world (over $900 per capita)

*Stats from 2012

Comparison between Medical Diseases

Infectious diseases (19th century)

- Simple or complicated
- Have clear diagnoses
- Can be "conquered" with vaccines and respond well to established procedures without much patient participation
- Care in Hospital and with specialist

Chronic conditions (21st century)

- Complex
- Many causes
- Need patient & family participation
- Care in the community

WHO Definition of Universal Health Coverage

Universal coverage (UC), or universal health coverage (UHC), is defined as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

This definition of UC embodies three related objectives:

equity in access to health services - those who need the services should get them, not only those who can pay for them;

that the quality of health services is good enough to improve the health of those receiving services; and

financial-risk protection - ensuring that the cost of using care does not put people at risk of financial hardship.

Universal coverage brings the hope of better health and protection from poverty for hundreds of millions of people - especially those in the most vulnerable situations

Patients without Universal Health Care in Canada

- **Less Access to Prevention, Promotion, Primary Care, Medication,**
  - Rural and remote populations;
  - People with multi-morbidity;
  - Individuals with addictions and/or mental health issues;
  - The very poor;
  - Recent immigrants and people whose first language is not English;
  - People with cultural differences
  - People in the LGBTQ community
  - Those with hearing or vision loss or mobility issues;
  - Aboriginal communities
  - Family Caregivers
  - The frail elderly;
  - Women in all these groups have more difficulty than men

- **Many do not have family doctors**
- **Do not have access to appropriate care for chronic conditions**

Robert Salois Report in Québec

In 2013

3.4 .Million - Total emergency visits

1.1. Million - by Ambulance (non-ambulatory visits)

18.4 hours -Average wait for non-trauma patients in ER

Some common consequences:

Incontinence – on a gurney without bathroom trips

Confusion- Lights on for 18 -24 hours

Mobility - Poor balance after 8=18 hours on a gurney

Weakness – No regular food service in the emergency room

Bed sores – No regular movement of patient on gurney

Return to Emergency Department within 30 days of discharge

Expenditure in Health Care in Ontario (2013 Budget)

2103 Total Expenditure on Healthcare	$48,900,000,000
Expenditure on top 5% of Users	$28,800,000,000

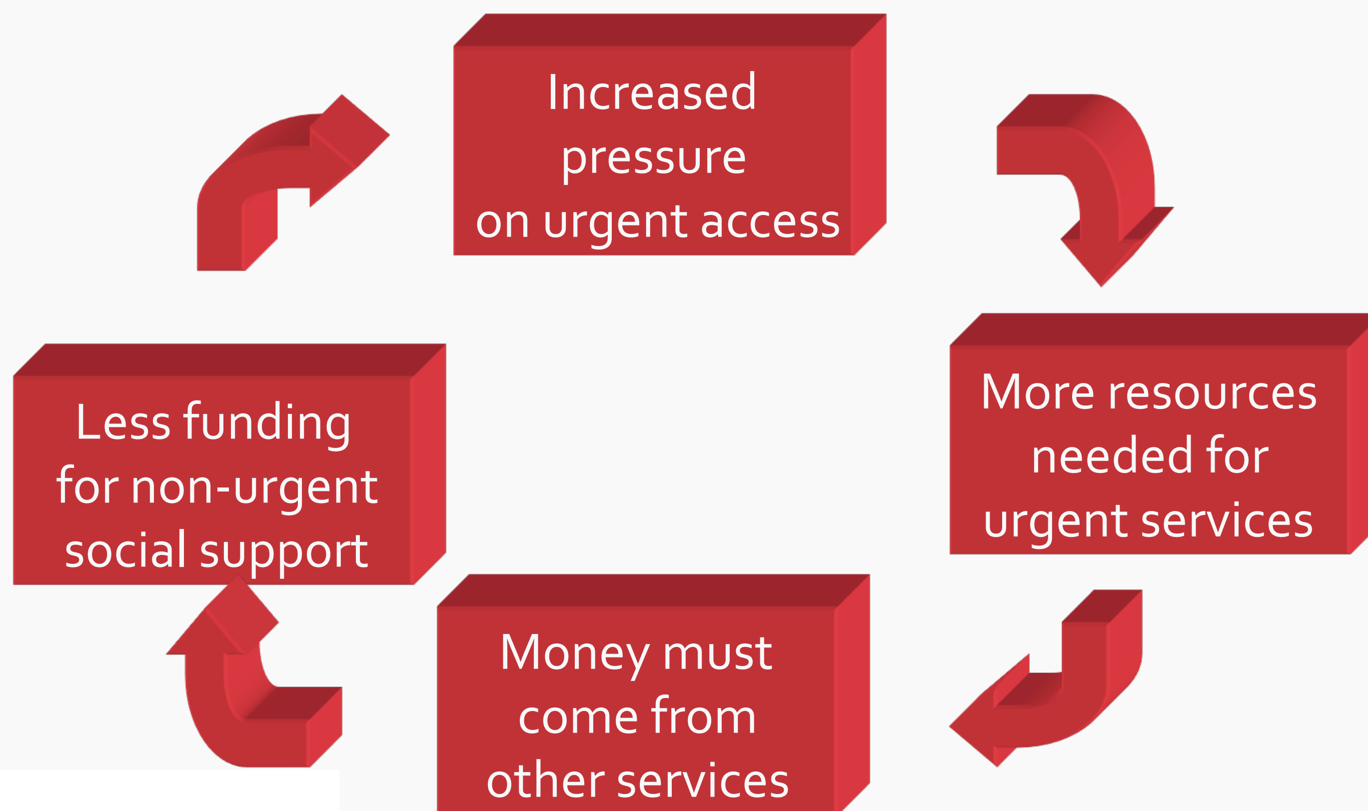
The top 5% of users are largely those we have called third class patients.

Ontario spends a good portion of $28,800,000,000 on revolving care for

- Rural and remote populations;
- People with multi-morbidity;
- Individuals with addictions and/or mental health issues;
- The very poor;
- The frail elderly;
- Recent immigrants and people whose first language is not English;
- People with cultural differences
- People in the LGBTQ community
- Those with hearing or vision loss or mobility issues;
- Aboriginal communities
- Women

The frail and older patients in all these groups most often arrive at the emergency room on stretchers and return frequently

The Vicious Cycle



Quality for Complex Chronic Care

- Access to care before situation becomes acute
- Continuity of care with the same provider and team
  - Understanding of expressed needs of patients
  - Ongoing multi-platform communication
  - Assistance with transitions of care
- Partnership with patient (and family) to design shared care plan
- Resources in the community for ongoing support
- Low use of emergency department

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Examples of Patient Partnerships Across Canada

- Canadian Foundation for Health Improvement
  - More than 20 projects to bring patients into planning and development roles including St. Mary's Hospital in Montreal.
- University of Montreal Professional Patients Program led by Vincent Dumez
- Patients Canada Trillium Project to Review Hospital Engagement
  - Thunder Bay: Patients on Executive Team
  - Holland Bloorview Kids Rehab: Paid Patient organizers
  - Kingston General: Hospital Patient Advisory Council
- British Columbia: Patient Voices
- Alberta: Multiple guidelines to partner with patients
- Canadian Institutes for Health Research Patient Engagement Strategy
  - No research without patient partners throughout
  - Strategy for Patient Oriented Research
  - Patients Canada as a partner
- Nova Scotia: Active patient partners in strong development

Three Kinds of Patient Partners

Patient 1.

- My condition is all I care about
- This makes it difficult for the patient to get a full picture

Patient 2.

- My hospital can do no wrong
- Excessive loyalty blinds patients who have "gone native"

Patient 3.

- I want to give back because of the good care I received and I want no one else to suffer the bad experiences I had.
- A good candidate for patient leadership

The PatsCan Procedure for System Change

- Gather patient narratives about their healthcare experiences
- Bring narratives to PatsCan Advisory panel for discussion
- Discuss and elaborate narratives
- Debate, debate, reduce, edit and reframe.
- Identify Expressed Needs
- Develop Easily measurable patient targets
- Broadcast them across the system

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Type 2 Diabetic

- Grandfather of 5, looks pasty and tired
- Wife checks blood sugar .. 16 (too high)
- Calls family doctor – cannot get through
- Leaves note at Dr's office - no response
- Wife checks blood sugar .. 23(way too high)
- Calls family doctor's office; Dr says call ambulance
- Entry through emergency room
- No space for wife during triage
- Is there for all visiting hours, brings no food
- Patient stabilized, but diminished & returns home after 4 weeks
- Return trip by car instead of private ambulance ($500)
- Frequent hospital visits as home invalid for 18 months till death
- Many similar stories

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PatsCan Advisory Panel Discussion

- Some Expressed Needs

- Someone to hear and respond to concerns on line or by phone
- Patients can make same day urgent appointments
- A third seat in the triage Position
- Hospital food rules allow home imports
- Open visiting
- Transport to and from hospital
- Home is retrofitted for compromised patents
- Support for family caregivers
- A library to share (modular) mobility aids

Patients Canada Creates Key Performance Targets

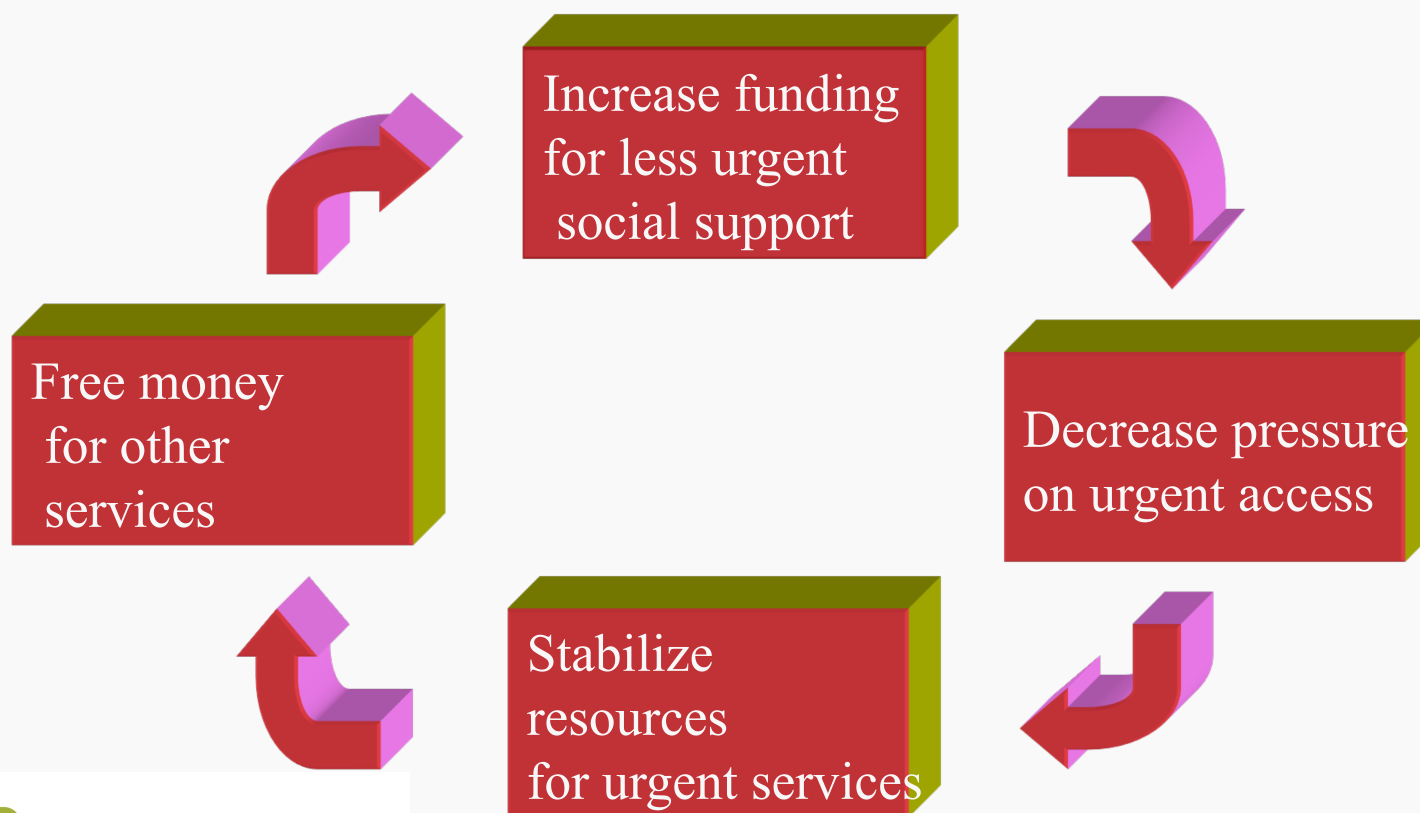
Easily measurable interventions improve patient & family experience

- There is a third chair in the triage position for family member
- There is clear way to contact primary care team if needed
- There is support for suitable transportation to & from health care
- Parking costs for regular visitors for health services are reduced
- It is possible to make appointments on line
- It is possible to renew prescriptions on line
- It is possible to access test results on line
- It is possible to easily access and correct one's medical record

Where Key Performance Targets (KPTs) are Adopted

1. Accreditation Canada has developed patient centred accreditation for 2016 with the help of many Canadian patient groups.
2. Patients Canada contributed to the development of primary care performance indicators at Health Quality Ontario
3. Some of our KPTs are in place in patient centred institutions. There are three chairs in the triage position in Kingston General.
4. CIHR is funding us to develop and distribute KPTs as a part of a five year project.

A Virtuous Cycle



Patients Canada

- We help develop patient leaders based on
  - A deep appreciation of patient experiences
  - A rich understanding of the system and where it is
  - Interactions with others in the system
- We review plans for patient partnerships
- We assess current patient partnerships
- We help with the application of KPTS
- We evaluate outcomes of patient partnerships
- We prepare organizations for future accreditation

Join us! Donate! Thank you

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