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Why Patients Must Participate in our Health Care System And Why it is So Difficult

To be Posted on www.patientsassociation.ca
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Population Health 1800-1850

- Longevity at Birth ≈ 36 years (Britain)
- Infant, Child & Maternal Mortality ≈ 25%
- Longevity at 20 years ≈ 70 years
- Everyone @ 40 had at least one Chronic NCD
- Vast majority of deaths due to infectious diseases at all ages

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Birth of Current Health Care Systems

- 1865 – Joseph Lister and modern sterile surgery
  - Anaesthetic plus asepsis makes modern surgery possible
- 1880 - Louis Pasteur (1822-95) & Robert Koch (1843-1910)
  - Anthrax, Tuberculosis etc. caused by identifiable micro-organisms.
    - Vaccines were developed
  - Identify microbes causing infection after surgery
    - Sterile operating rooms and procedures begin
    - Modern laboratories are built everywhere
- 1880 – Prosperous times: New Hospitals are built
  New housing, New sanitation etc.
- 1910 – Flexner Report on medical education
    - In US and Canada
    - Drs Professionalize

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Success of the System

- 1850-1950 Rapid decline of death by infectious diseases: The Mortality Shift
- 1930-1950 Births and deaths seen as acute events which need hospitalization
- 1880-1950 More deaths are now due to non-communicable chronic diseases (NCDs) like heart disease, COPD and cancer

Population Health 1950

- Longevity at birth 1950
  - Canada: 66-Male 71-Female
- Longevity at 20 years is the same
- Minority of deaths due to infectious diseases
- Mortality shift attributed to success of scientific medicine

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Scientific Health Care

- Medicine has made you healthy
- Leave it to the scientific professionals
- Expert based, acute hospital focused
- The scientific health care system grows
- Science will ID cause & cure of diseases
- Body is separated from the person
- Patient has little or no role in system

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Non-Communicable Diseases Shift

- To 19th Century: everyone over 40 had at least one chronic NCD
- 21st Century: everyone over 65 has at least one chronic NCD or other
- 25 years more of illness free life (Why 60 is the new 40)
- Mortality shift and NCD Shift attributed to multiple determinants of health

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Population Health 2008

- Life expectancy at birth 2008:
  - Canada 79-Male 83-Female
- Longevity at 20 years is the same
- Internet calculator says I will die at101
- 90% of deaths due to Chronic NCDs
- Less than 5% deaths due to IDs (WHO)
- 40% of people with chronic NCDs have more than one – good reason for speaking of complex chronic NCDs

NCD mortality

2008 estimates	***males***	***females***
Total NCD deaths (000s)	103.1	105.1
NCD deaths under age 60 (percent of all NCD deaths)	15.5	10.9
Age-standardized death rate per 100 000		
All NCDs	386.5	265.0
Cancers	142.2	106.6
Chronic respiratory diseases	26.9	16.0
Cardiovascular diseases and diabetes	151.6	90.1

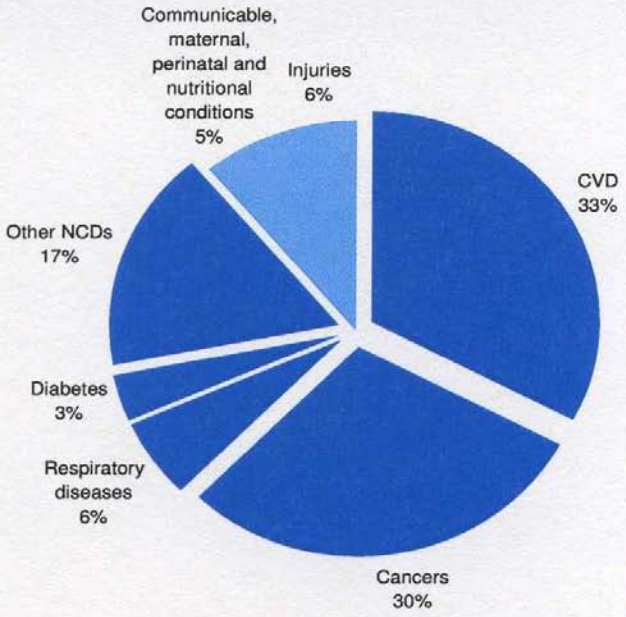
Behavioural risk factors

2008 estimated prevalence (%)	***males***	***females***	***total***
Current daily tobacco smoking	15.4	11.6	13.5
Physical inactivity	34.0	37.4	35.7

Metabolic risk factors

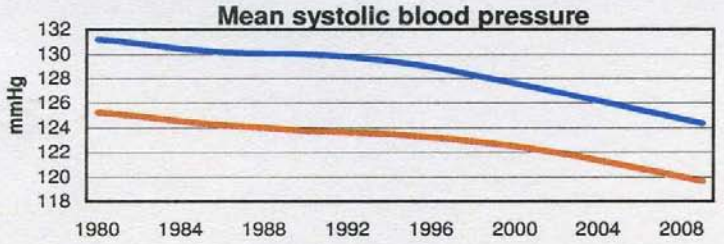
2008 estimated prevalence (%)	***males***	***females***	***total***
Raised blood pressure	35.8	31.6	33.6
Raised blood glucose	...	...	...
Overweight	67.8	58.7	63.2
Obesity	26.0	26.4	26.2
Raised cholesterol	54.8	57.6	56.2

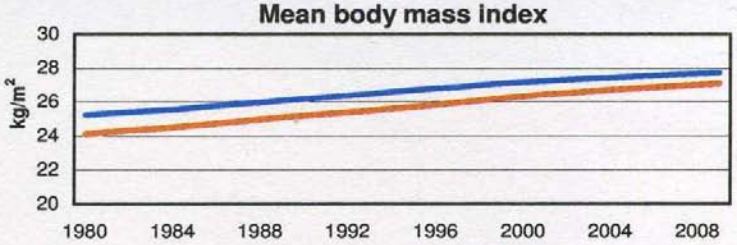
Proportional mortality (% of total deaths, all ages)

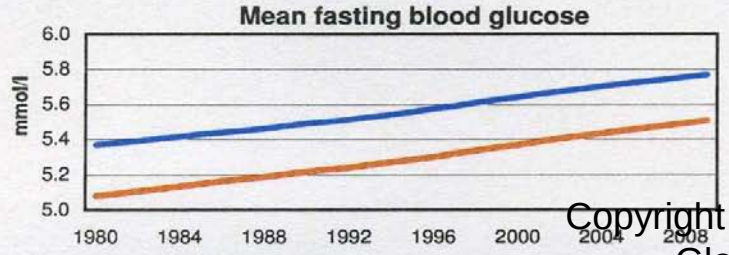


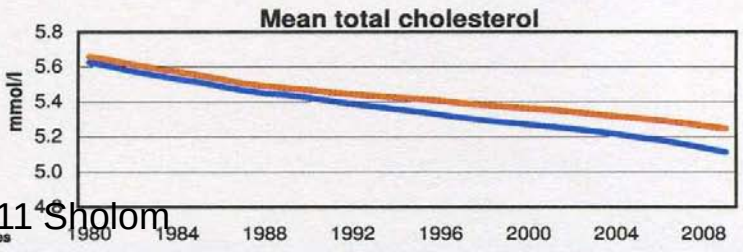
NCDs are estimated to account for 89% of all deaths.

Metabolic risk factor trends









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The Shift from Acute to Complex

Variable	1850	1950	2008
Longevity at Birth Male	35	66	79
Longevity at Birth Female	32	71	83
% Infectious Diseases Deaths	70%+	40%+	5%-
Age of Population with at least 1 NCD	40	?	65
% with Complex NCDs (2 or more)	?	?	40-50%
Reasons for Mortality Shift		Science	Complex

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System Does Not Keep Pace

- Continued emphasis on acute episodes
  - Hospitals continue to grow in size and cost
- Constant expansion of body categorization
  - Increase in specialization
  - More than 100 specialties and subspecialties
  - Increased drive for protocol based care
  - With ever diminishing length of use (More acute)
- Overall little inclusion of patients as people
- Why it's hard for hospitals to be patient centred

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Simple

Following a Recipe

- The recipe is critical to success
- Recipes are tested to assure replicability of later efforts
- No particular expertise; knowing how to cook increases success
- Recipes produce standard products
- Certainty of same results every time
- Optimism re results

Complicated

A Rocket to the Moon

- Formulae are critical and necessary
- Sending one rocket increases assurance that next will be ok
- High level of expertise in many specialized fields + coordination
- Rockets similar in critical ways
- High degree of certainty of outcome
- Optimism re results

Complex

Raising a Second Child

- Formulae have a use. But not alone
- Raising one child gives no assurance of success with the next
- Expertise however multi-disciplined can help but is not sufficient
- Every child is unique in critical ways
- Uncertainty of outcome remains
- Optimism re results

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Complicated Acute Diseases

- Abrupt onset
- Often all causes can be identified and measured
- Diagnosis and prognosis are often accurate
- Specific therapy or treatment is often available
- Protocol-based intervention is usually effective: cure is likely with return to normal health
- Profession is knowledgeable while laity is inexperienced and dependent
- Patient's contribution largely unnecessary

Complex Chronic NCDs

- Gradual onset over time
- Multivariate cause, changing over time
- Diagnosis is uncertain and prognosis obscure
- Specific treatment is available but also requires judgment
- No cure, pervasive uncertainty: support & self care over time is needed to maintain health
- Professionals & patients must share knowledge to maintain or improve health
- Patient's contribution critical

Adapted from: Halstead Holman, MD (Stanford)

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What is a Patient?

Complicated Acute Disease

- A diseased body to be diagnosed and treated
- An autonomous individual with no relevant links to others
- Focus on the disease or organ
- Prescribed treatment
- The person named on the OHIP card

Complex Chronic Condition

- A person with a particular history and personality
- A group of people including the person and those close
- Broad interest in history and lifestyle
- n of 1 trials
- Anyone who has had a significant health care experience themselves or as a companion

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What is a Patient Centred System

- Responds to the morbidity of the population
- Increases capacity to self-assess and self-manage with mutual support
- Continuous care to maintain health
- Avert acute episodes of chronic conditions
  - Self-monitoring signs of acute onset
  - Easier access to mutual & professional support
  - Rapid response to indications

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How to be More Patient Centred in Our Present System?

- Recognize how and when this hospital ignores patient experience
  - Recognize patient anxiety in the ER
  - Recognize professionals who are patient aware
- Make patient experience board material
- Engage patients to redesign services
- Improve links to Primary Care and other parts of the system

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Patients' Association of Canada Mission Statement

As a patient led and patient governed organization, the Patients' Association of Canada promotes the patient voice and the patient perspective in health care in order to improve everyone's health care experience.

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Some of our activities

- At the Clinical Level
  - Patients' Choice Awards (with OMA)
  - User Guide How to Navigate the System
- At the Service Delivery Level
  - Redesigning the day of moving in at Baycrest
  - Training front line ER staff to deal with patient anxiety
- At the Policy Level
  - Supporting board members who want to assume the patient perspective: A Trillium project

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To Join Us

- Look at the web site
  - www.patientsassociation.ca
  - If you find good reason to,
  - Sign up for the newsletter
- To contribute
  - Write to communications@patientsassociation.ca
  - Or donate on our web site