Complex-vulnerable patients in primary care:

Highlights of a ten-year program of research on disability and primary care

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OMH-LTC

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Acknowledgements

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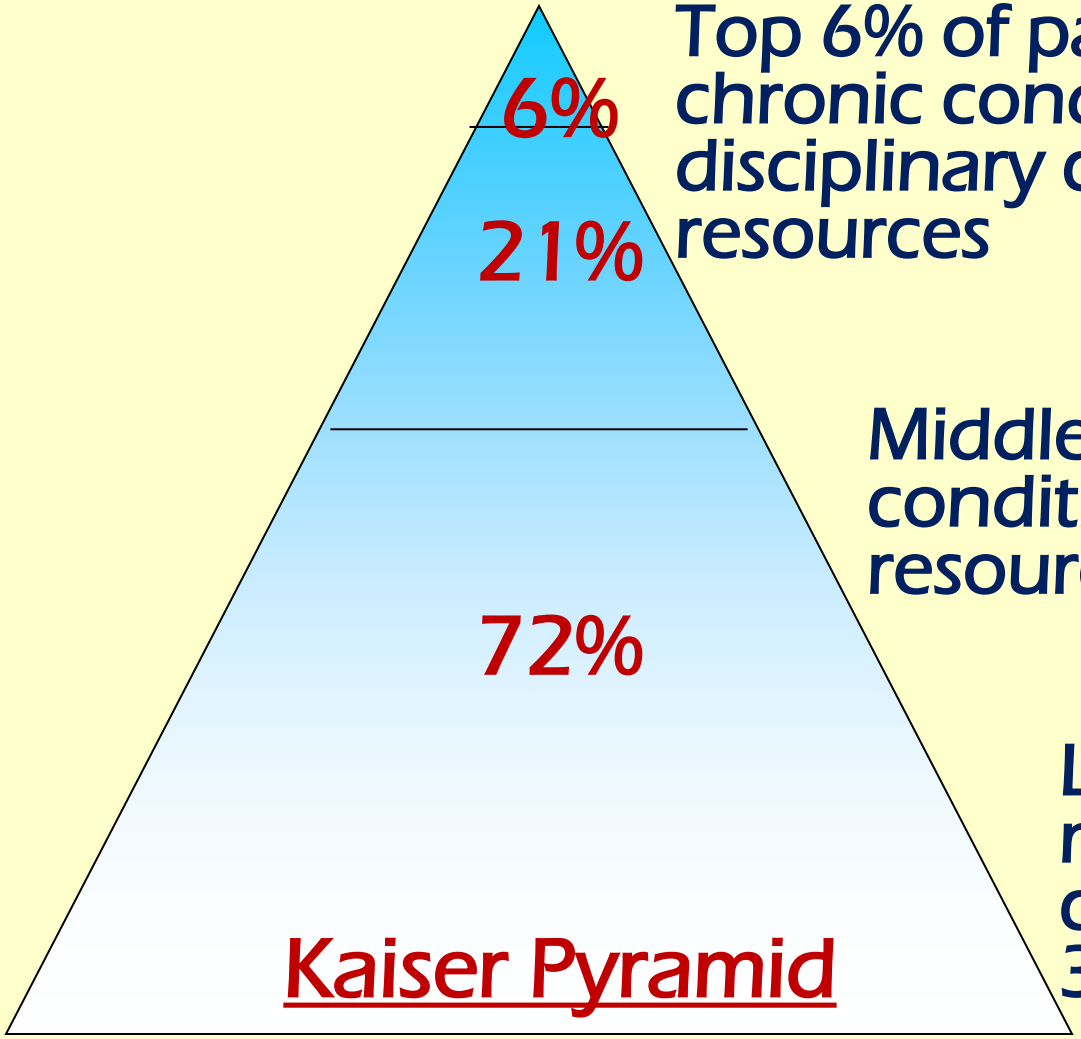
Who do we mean by disabled patients in primary care?

- Adults 18-65
- Self-declare as "disabled"
- Disability a non-normative experience
- Physical, sensory, cognitive disabilities
  - Eg. multiple sclerosis, spinal cord injury, deafness, acquired brain injury, developmental disability, cerebral palsy, blindness, inflammatory arthritis
- May be eligible for multiple disability benefits; depends on family physician to assist with access to system of care and benefits

Disabled patients in primary care



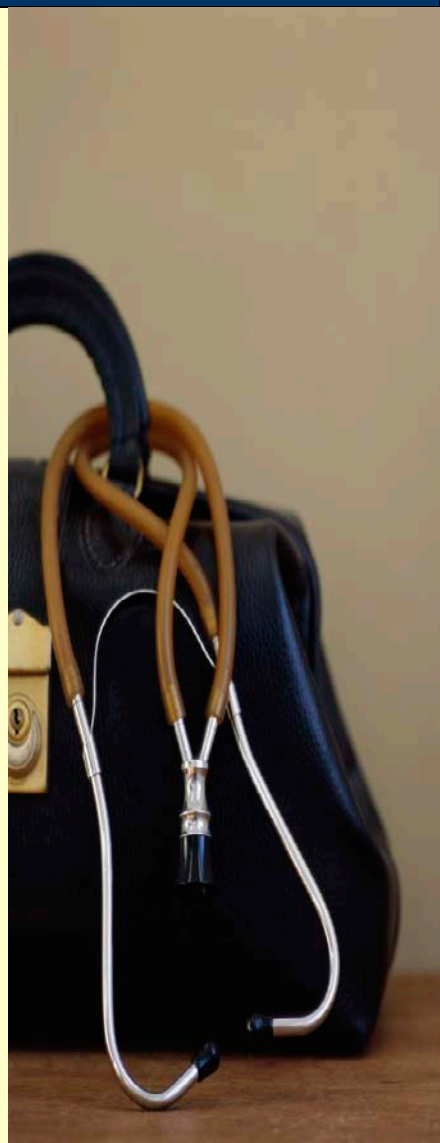
Top 6% of patients have multiple chronic conditions; need inter-disciplinary care; consume 33% resources

Middle 21% - have 1 chronic condition; consume 31% resources

Lower 72% - have mostly acute conditions; consume 36% resources

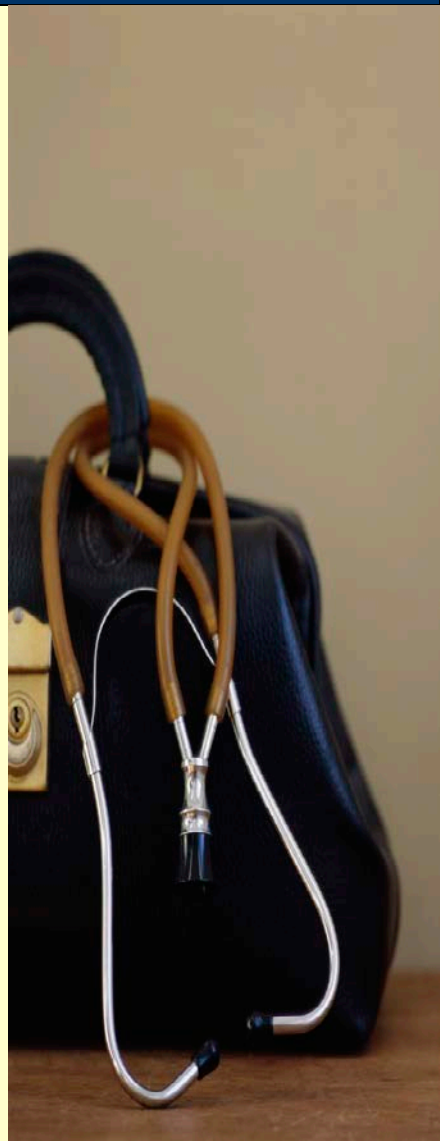
A program of research 2001-2011

- *18 studies*
- *33 key findings*
- *9 funding sources (including OMH-LTC)*
- *40 co-investigators*
- *8 corporate partners*
- *4 countries*
- *See publications list attached:*
  18 grants, 2 books, 5 chapters,
  12 articles



A program of research 2001-2011

1. *Utilization of health services by people with disabilities*
2. *Unmet needs of people with disabilities in primary care*
3. *Access and quality of primary care for people with disabilities*
4. *Models of service for primary care of people with disabilities*
5. *Translating research knowledge about disability for family physicians*



1. Utilization of health services by people with disabilities

1. Disability is a better predictor of utilization than self-reported health, number of chronic conditions, age or gender.
2. Disabled adults (18-65) visit their family doctors 3x more often than non-disabled – ~ 6 visits /yr.
3. Disabled seniors are 60% more likely to visit their doctor than their non-disabled contemporaries.
4. Disabled women (ie., those with multiple chronic conditions) are higher users of primary care than non-disabled women or than men;
5. People with long-standing disabilities usually see multiple service providers, and evolve a complex rubric for seeking entry to the health care system.

1. Utilization of health services by people with disabilities

SUMMARY

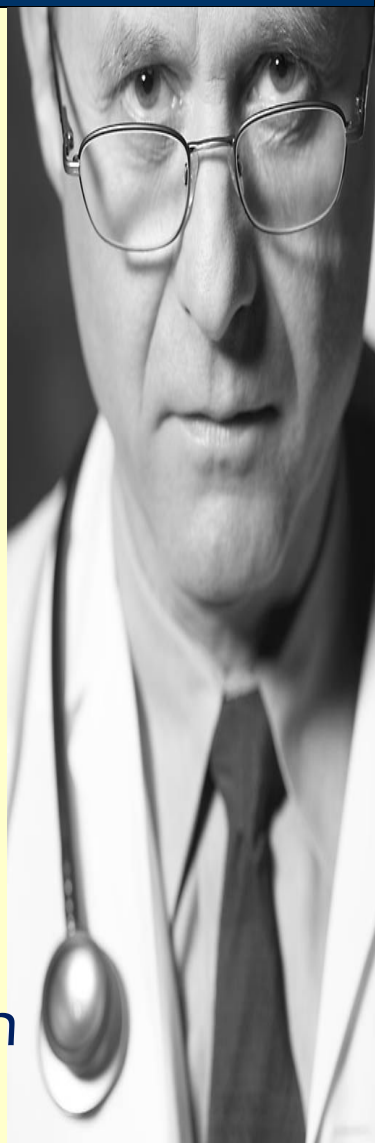
- High users
- Complex history, presentation
- Multiple providers
- Sophisticated consumers

2. Unmet needs of people with disabilities in primary care

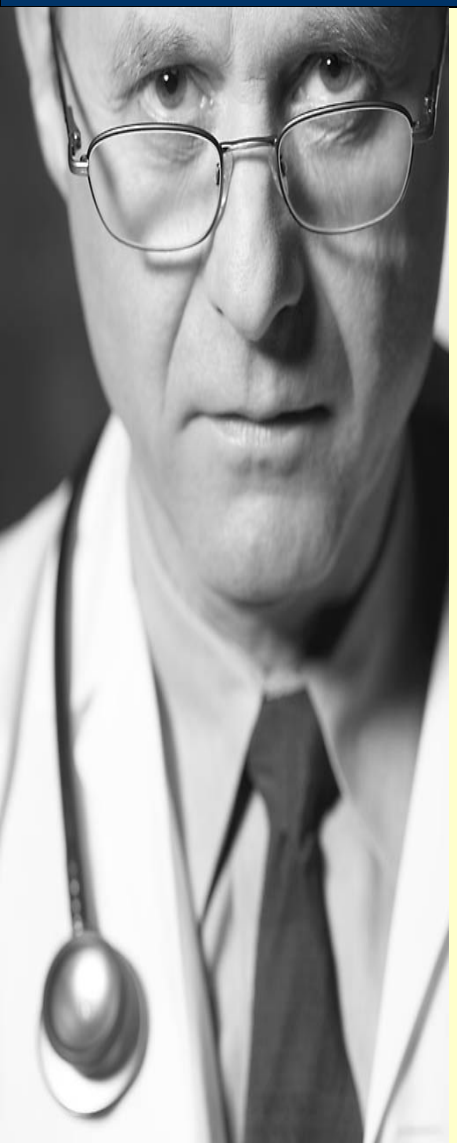
6. Disabled adults report 3x as many unmet health care needs.

7. There were significantly more unmet needs among:
   - the youngest and oldest age groups,
   - those with more chronic conditions and poorer health

8. Reasons for reporting unmet needs are similar to non-disabled Canadians, with the exceptions of:
   - COST – extraordinary costs associated with accessing service, and
   - TIME – unlike non-disabled, time not a factor in impeding access, unmet needs



2. Unmet needs of people with disabilities in primary care

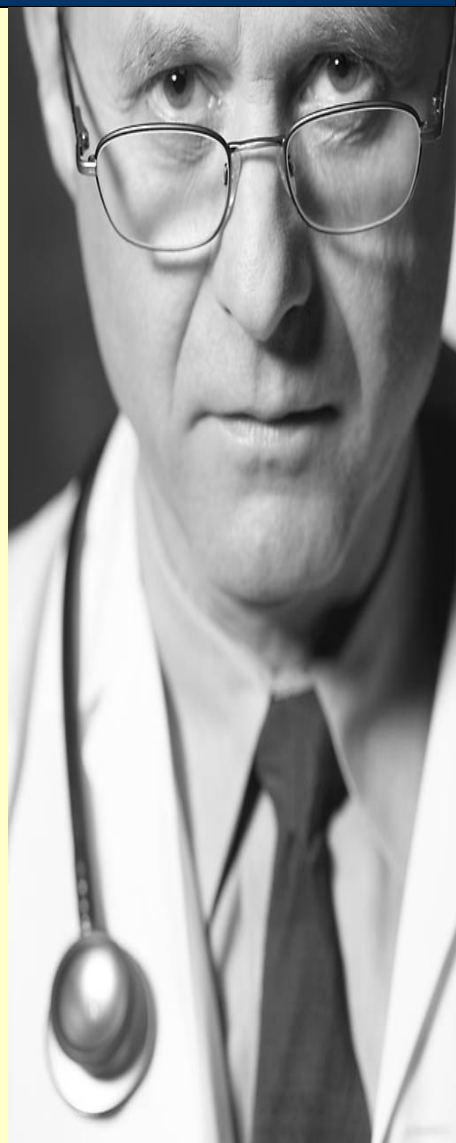


9. Patients encountered four types of barriers in attempting to access primary care:
   - Physical barriers, such as stairs, narrow doorways
   - Attitudinal barriers, unwillingness to accommodate
   - Expertise barriers, inadequate knowledge of disability
   - Systemic barriers, policies that systematically exclude
10. Barriers were encountered at many points in the system:
   - trying to get a doctor
   - trying to get an appointment
   - to get into the building, the office, the exam room,
   - trying to get needed accommodations
   - to receive a reasonable standard of care.

2. Unmet needs of people with disabilities in primary care

SUMMARY

- Excess unmet needs, despite being among most needy
- Extraordinary costs a barrier
- Multiple barriers



3. Access & quality of primary care for people with disabilities

11. 72% was the average score for accessibility in family practices in south-eastern Ontario, with only 15% having adjustable exam tables.
12. Those with good accessibility were also most likely to make accommodations for disabled patients, such as telephone consults, extended hours, home visits.

3. Access & quality of primary care for people with disabilities

13. Physicians noted that their disabled patients are notably different from non-disabled – take longer, more complex, more coordination.
14. Physicians noted that they interacted differently with disabled and non-disabled patients. Differences that impede access include:
    - Patients who need assistance required to bring their own attendant;
    - Physicians less likely to examine patients if there were impediments, such as dressing/undressing, communication;
    - Physicians paid less attention to sexual and reproductive issues among disabled patients;
    - Routine, age-appropriate preventive care was often missed.

3. Access & quality of primary care for people with disabilities

15. Since 1997, there have been published guidelines for accessibility of doctors' offices, but no regulations (Jones & Tamari, *CMAJ*, 1997)
16. Physicians' offices have not previously been required to comply with public sector accessibility standards.
17. The Accessibility for Ontarians with Disabilities Act (2005) will require that by 2025, doctors' offices meet standards of accessibility and customer service.

3. Access & quality of primary care for people with disabilities

SUMMARY

- Disabled patients have different needs in primary care than non-disabled contemporaries
- Inequities currently exist in access to high standard primary care for disabled adults
- Guidelines and assistance with compliance with accessibility standards are required
- Accessibility will become mandatory as AODA standards become law

4. Models of primary care for people with disabilities

18. The literature identified 6 models for integrating rehabilitation in primary care:
    - outreach, clinic, shared care, self management, case management, community-based rehabilitation.
19. Patient, practice and system-level criteria were developed for evaluating models of integrated multidisciplinary primary health care.
20. Factors affecting integration of multidisciplinary providers include: team concept, inter-professional trust, structured communication, community governance, leadership issues, compensation methods, population-health approach.

4. Models of primary care for people with disabilities

20. Shared care model was most attractive to physicians, who valued the learning opportunity and the specialist perspective
21. Community development model (consumer-based, community-based rehabilitation) was preferred by patients – advocacy, skill learning
22. Case management model most demanding in terms of integration of allied health providers.

4. Models of primary care for people with disabilities

23. Practices where physicians were paid by salary (vs. capitation or FFS) were significantly more accessible and accommodating;
24. Salary practices were more compliant with clinical guidelines for selected conditions: urinary tract infection, preventive care, BP and diabetes.
25. Salary practices were more likely to offer weekend and evening service, and multidisciplinary team.

4. Models of primary care for people with disabilities

26. Chronic disease management programs are effective ways to provide multi-disciplinary service to people with disabilities.
27. Solid policy infrastructure is essential to the success of CDM models in primary care.
28. Community Health Centres in Ontario place emphasis on meeting the primary care needs of disabled patients.
29. Family health teams offer a natural fit for inter-professional primary health care, focussing on the needs of disabled patients.

4. Models of primary care for people with disabilities

SUMMARY

- Multiple models exist for interdisciplinary care to patients with disabilities
- CHC and FHT models in Ontario seem the best fit
- There is no one right way; rather a need for an adequate range of options for physicians and for patients

5. Disseminating knowledge about disability to primary care providers

30. Family physicians manage their time very purposefully, and are notoriously difficult for researchers to reach with new information.
31. "Actionable Nuggets" provide evidence-based, action-oriented information about special populations to family physicians in a user-friendly format.
32. Family practices need simple, well-designed, highly specialized tools to assist them to enhance access and quality of care for people with disabilities
33. Physicians are receptive to this information is presented appropriately

SUMMARY

- Low volume of disabled patients – high needs, high resource use
- Specific disability-related needs (health and social) – as well as standard primary care
- Unable to access many aspects (information, physical barriers, attitudes, systemic barriers)
- Need multiple providers, coordinated through primary care
- Various models for integrating disability services in primary care
- Targeted knowledge translation needed

Direct policy implications

- Funding envelope through ORRAN
- OT's /rehab in FHT's / service ratios
- Adjustable exam beds and lifts in FHT's
- Self assessment of accessibility for FHT's
- Human rights case on access to primary care
- Support for CHC /FHT models

Knowledge Translation

- Actionable Nuggets for spinal cord injury
- Currently being disseminated by CMA
- Nuggets in various stages of development for:
  - Veterans' health
  - Frail elderly
  - Chronic pain
  - Post-curative breast cancer

Future research

- AODA training for MD's/ family practices
  - Customer service
  - Built environment
  - Employment
- Complex-vulnerable lists – how well do they promote access for people with disabilities
- Patient nuggets – assisting patients to make better use of medical time

DISCUSSION

U.S. Surgeon General R.H. Carmona:

"The reality is that for too long we have provided lesser care to people with disabilities. Today, we must re-double our efforts so that people with disabilities achieve full access to disease prevention and health promotion services." *(2005)*

Thank you ...

... for this opportunity to share the highlights of 10 years of research on disability & primary care.

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