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The Face of Complex Chronic Disease: Using Patient Experience to Inform Policy and Practice

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Study Team and Objectives

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Objectives

- Understand the needs and experiences of people who have complex chronic disease

- Improve care for this population

Bridgepoint Health- our “research lab”

Research Question

"What are the Characteristics, Needs and Experiences of Individuals with Complex Chronic Disease?"

Bridgepoint Health:

A Post-Acute Stopover for People with Complex Chronic Disease (CCD) and their Families

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Bridgepoint Patients have Complex Chronic Disease

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Complex Rehabilitation

-Hip and Joint Replacement

-Multiple Fractures

-Functional loss from Stroke

Complex Continuing Care

-Advanced Diabetes

-Progressive neurological and degenerative conditions

-HIV/AIDS

-Severe Stroke

Patients in these programs also have (some combination of):

Multi-morbidities

Multiple medications

Heavy care needs

Mental health challenges (e.g., depression and stress)

Financial stress

Social isolation

Why is it important to conduct this research?

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#1: Growing numbers of individuals are living longer with multiple health, social and mental health challenges (complex chronic disease).

#2: These individuals commonly get excluded from research; therefore we have a poor understanding of their needs and experiences.

#3: The cost is high
→ for the person (poor quality of life, disruption from work and family) and
→ for the health care system- consumes upwards of 80% of health care budgets across the world ($80 billion dollars/years in Canada).

#4 Historically, no clear mandate for complex continuing care and complex rehabilitation in our health system (aside from post-acute)

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Complexity Framework

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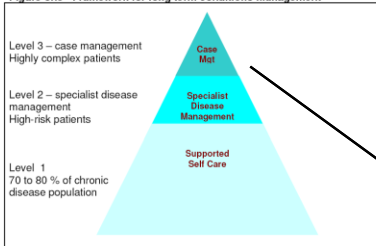

HEALTH AND SOCIAL EXPERIENCES
e.g., healthcare utilization, quality of life, self-management, healthcare system navigation, etc.

MEDICAL/PHYSICAL HEALTH
e.g., multimorbidity, polypharmacy, physical functioning, chronic symptoms, clinical practice guidelines, etc.

DEMOGRAPHICS
e.g., age, gender, ethnicity, education, etc.

SOCIAL CAPITAL
e.g., social support, caregiver strain, socioeconomic status, relationships, etc.

MENTAL HEALTH
e.g., depression, substance use, cognitive capacity, psychological wellbeing, etc.

SOCIO-POLITICAL AND PHYSICAL ENVIRONMENT

Methods and Procedures

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1 YEAR +

Conceptual Framework Development

- Evidence base, expert consultation (Dr. M. Sullivan @ McGill, Dr. P. Ritvo @ York), and BP staff

Interview Guide Development

- Item development based on conceptual framework & consultation
- Survey tool developed to capture bio-psycho-social factors
- Pilot testing - research assistants, "mock patients", and patients

Recruitment

- 4 Research Assistants, 3 Student Interns, 5 volunteers
- Patient Care Managers to identify potential participants

Methods and Procedures

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1 YEAR +

Data Collection

Consent

Interview scheduling, logistics, and multiple visits

Digital recordings

Data Entry

Quantitative – Data entry, data cleaning, data verification

Qualitative – Transcription and verification of transcripts

Data Analysis

Thematic coding of qualitative data using NVIVO9 software

Quantitative descriptive analyses using SPSS & SAS

Representativeness of the Sample

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Demographics	BP Study Sample (n = 116)	All Patients in Hospital During Data Collection Period (n = 865)
Age (mean and range)	63 *19-96*	71 *18-97 years*
Gender	58% female	56% female
Marital Status	27% married or living common law	25% married or living common law
Primary Language	79% English	93% English
Education	43% high school or less	No data available

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3 Key Findings

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- **High prevalence of mental health challenges**
  - Depression, stress, anxiety
- **High variability in health profiles**
  - Broad mix of health problems, symptoms and illness histories
- **Different model of care required**
  - Comprehensive data collection
  - Supported transitions
  - Provider “tool-kit” (capacity to respond to physical, social and mental health needs)
  - Dignity and respect for patient

#1 High Prevalence of Mental Health Challenges

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- **48%** of the participants displayed **significant depressive symptomology**

- There was a significant difference* in the depression scores between people with a spouse/partner ($M = 5.7$) and those without a spouse/partner ($M = 8.6$). The mean score for individuals without a spouse/partner meets the cutoff for depression.

- No differences in depression levels between genders, education levels, age groups, or number of health conditions

*$t(102) = -2.13$, $p = 0.0359$

Redefining Rehabilitation

"I think people think it's an easy solution. Medicate someone to the point of not feeling and the problem is solved. And I think many people could do with talk therapy, and it should be part of a complex, comprehensive rehab program. Because when you're in a car accident and your body gets broken, you become broken as well."

- *Bridgepoint Patient*

#2 High Variability in Health Profiles

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- Patient histories revealed a combination of early life illness, trauma, stress, poor coping, etc for approximately **one-third** of participants
- Mean number of health conditions per person: 5
  - 25% had 7-12 conditions
- There was a significant difference* in the number of health conditions among people with partial/complete post-secondary education ($M = 5.7$) and those with high school or less education ($M = 4.4$). Individuals who were more highly educated had more conditions on average.
- No differences in number of health problems between genders, age groups, ethnicity or presence of a life partner

*$t(101) = -3.14$, $p = 0.0022$.

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#2 High Variability in Health Profiles

Severity of Illness

- Symptom and function measure (score 0-10). Mean illness severity score: 5.9. Positively correlated with depression scores ($r = 0.44$, $p < 0.0001$)

Symptoms	Functional Challenges
Pain 78%	*Mobility* 83%
Weakness 71%	*Activities of Daily Living* 60%
Emotional Upset 70%	*Equipment/devices* 43%
Illness Related Symptoms 46% (nausea, vomiting, etc)	*Paying attention* 43%
Sensory challenges 27%	*Carrying on a conversation* 28%

#2 High Variability in Health Profiles

Self-Rated Health

- Approximately **half** of participants reported declining or fluctuating health

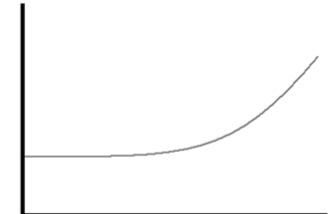
- 7% of participants reported that their health had stayed the same

- Almost **half** of participants reported improvements in health

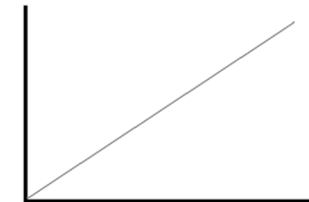
PARTICIPANT REPORTED HEALTH TRAJECTORIES (n=103)

25.4 %
Periods of improving and then worsening

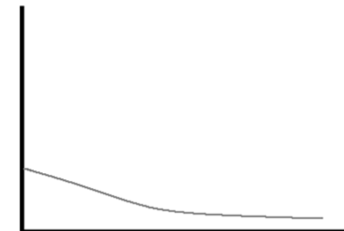
25.4 %
Taking a long time to improve, but improving



21.8%
Improving slowly or steadily



19.1%
Generally worsening



7.3%
Staying the same

#2 High Variability in Health Profiles

Emerging Qualitative Typologies

- **Life as Expected**
  - Typically older people who have many illnesses as a product of age
- **Life Interrupted**
  - Typically young and mid-life population (sudden unexpected event), may eventually resume former lives
- **Life Complicated**
  - Trajectory into poor health; risky behaviors
- **Life Altered**
  - Typically degenerative, downward physical trajectory, likely to have to redefine/renegotiate life course
- **Life Medicalized**
  - Complexity of managing conditions, but strong social support

#3 Different Model of Care Required

Targeted/ Comprehensive Assessment Needed

- Integrate information collected to avoid overlap
- Include the history of the patient with help from family caregiver (if available)
- Information collected/given in smaller (easy to digest) increments

"The first, second, third day, you are here, you'll probably meet 8 different people. And you should see the overlapping questions. Why can't you correlate everything you've got to ask to one person?"

#3 Different Model of Care Required

Supported Transitions Needed

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- Approximately **<u>1 in 3</u>** participants had concerns about leaving Bridgepoint including:
  - Making home adaptations
  - Future location of care (e.g., long-term care facility)
  - Accessing care and lack of follow-up
  - Pressure on family
  - Ability to manage
  - Loss of social life

***Interviewer**: Because I know when we talked last week, you were unsettled about all this.*

***Respondent**: I was upset. I didn't want to go to an old aged home. I mean who would? I don't feel like I belong there. I don't feel that that's the place I belong.*

***Interviewer**: Remind me how old you are.*

***Respondent**: 56.*

#3 Different Model of Care Required

Bio-Psycho-Social Care Plan and Improved Provider Capacity and Quality

- Physical, social and mental health support
- System navigation (particularly for most at risk/vulnerable)
- Optimal staff to patient ratios
- Faster response times
- Clear communication
- Care consistency (between providers and units)

#3 Different Model of Care Required

Respect and Dignity for Patients

- Looking beyond the ailment to the person
- Considering the patient as an active contributor to the care experience
- Providing tailored care (what is important to the patient?)- small things matter

Question for consideration:

"What conditions in the workplace are working toward or against addressing these things?"

What is Health?

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The famous French physician and philosopher of disease, Georges Canguilhem in his 1943 book ***The Normal and the Pathological*** :

“Health is the ability to adapt to one's environment. Health is not a fixed entity. It varies for every individual, depending on their circumstances. Health is defined not by the doctor, but by the person, according to his or her functional needs. The role of the doctor is to help the individual adapt to their unique prevailing conditions. This should be the meaning of “personalised medicine”.

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Conclusion and Implications

A bio-psycho-social approach required for all phases of the care experience

1) Assessment
2) Care Package
3) Transitions

Implications for Policy and Services

- Questions our current definitions of health and rehabilitation (acute/biomedical orientation)

- Raises the following question: *"What accountability, governance and funding structures are required to build and sustain a model of care for individuals with complex chronic disease?"*

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