Our Journey Towards Patient Self-Management: The Patient Experience

Presented by:
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Objectives

• To share our experiences in the development of patient self management tools

• To present clinical insights to its application in the development of patient educational material

• To identify key challenges and enablers

• To share personal stories from patient and their caregivers
TSH CKD Clinic at a Glance

![Bar Chart]

- **Stage 1**: 12 patients
- **Stage 2**: 109 patients
- **Stage 3**: 1,227 patients
- **Stage 4**: 1,077 patients
- **Stage 5**: 407 patients
What is Self Management and how does it fit within our program/organization’s direction?

Why do Self Management?
Why?

- The increasing prevalence of chronic illness, and kidney disease, in particular, makes it necessary to adopt new approaches towards their management (Wagner, 1998; World Health Organization, 2002).

- Patients are expected to manage complex treatment regimens at home, one recommended approach is to place an emphasis on self-management (Accreditation Canada, 2009; Ryan, 2009; Wilkinson & Whitehead, 2009).
Why?

- Patients who are able to self-manage their symptoms maintain an optimal level of health. (Alt & Schatell, 2008; Hall et al., 2004).
Understanding Self-Management...

**Self-Management (SM) defined**- “the ability of the patient to deal with all that a chronic illness entails, including symptoms, treatment, physical, and social consequences and lifestyle changes.”

**Why is Self-Management Important?**

The evidence suggests that SM support:

- Reduces hospitalizations & ED use
- Reduces overall costs

Minore et al., (2009).
Self Management Support

“The systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem solving support”

Adams, Greiner, Corrigan (2004)

Definition used at International conference on patient self management
The Scarborough Hospital Chronic Disease Prevention and Management Framework

**Vision**
Chronic disease prevention and management at TSH demonstrates our strength and excellence at integrated and connected care for our patients and global community throughout the progress of disease.

**Guiding Principles**
- Person-centred
- Holistic
- Culturally appropriate
- Integrated and connected
- Collaborative across sectors
- Evidence-based approach
- Innovative and creative
- Knowledge-driven
- Team-based
- Outcomes-based

**Dimensions**
- Patient-centred
- Integrated
- Equitable

**Program Elements**
- Service Delivery
- Design-Provider Decision Support - Information Systems
- Self Management - Healthy Policies - Supportive Environments - Community Action

**Outcomes**
- Engaged activated communities
- Linked partnerships
- Increased quality of life years
- Decreased burden of disease
- Prepared proactive teams

**Improve Community Health**
LEAN WORKSHOP

NEPHROLOGY FOCI

• Mitigating Risk
• Increasing the Standards of Practice
• Maintain Consistency in Operations (Clinical)

OPERATIONAL PLAN

• Literature review of Self-Management and application to CKD
• Review, Revise & Produce Self-Management Resources
• All staff to attend Choices & Changes Workshop

The Scarborough Hospital
Patient Self Management

• Valuable method that enables and empowers patients to undertake tasks that keep them well and help them cope and manage their chronic conditions.

• Our PSG in collaboration with the CE LHIN Self Management Program made a commitment to incorporate patient self management into our care delivery model.

• Enables supportive interventions by care providers to increase patients skill and confidence.
Background

- MOU between CCAC and TSH included:
  - Delivery of two 6 hour Choices and Changes workshops by our Choices and Changes faculty trainers to 16-30 hemodialysis staff
  - Provision of ongoing support for the Choices and Changes graduates through follow up sessions and 1:1 interviews with graduates
  - Total of 26 hemodialysis nurses trained
  - 15 nurses participated in facilitating self management in the hemodialysis patient population
• 28 patients received care from the 15 Choices and Changes graduates (nurses selected two patients each to work with)

• Four audits of patient charts were done between June and September 2012

• Chart audits included worksheet completed, patient goal identified, techniques used by nurses, assessment of patient’s confidence and conviction and specific follow up plan.

• Patient survey provided to the 28 patients at the end of August
## Chart Audits June – September 2012

<table>
<thead>
<tr>
<th>Month</th>
<th>Worksheet completed</th>
<th>Patient goal identified</th>
<th>Open-ended inquiry used</th>
<th>Reflective listening used</th>
<th>Empathy used</th>
<th>Assess conviction</th>
<th>Assess confidence</th>
<th>Were both conviction and confidence used</th>
<th>Changes in conviction level</th>
<th>Changes in confidence level</th>
<th>Specific plan for follow up</th>
<th>Comments</th>
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Summary of Patient Survey

- 6 patients of the 28 patients filled out the patient survey at the end of August 2012.
- 1 patient was able to identify their “healthy behaviour goal.”
- 4 patients were comfortable communicating with their nurse. 2 responded “N/A.”
- 4 patients rated their experience with their nurse towards their goals as Very Good or Excellent. 2 responded “N/A.”
- 4 patients rated their nurse’s ability to motivate them towards their healthy behaviour goal as Very Good or Excellent. 2 responded “N/A.”
- 3 patients rated their confidence level to achieve their goal as “7.” 1 patient rated “8,” 1 patient rated “9,” 1 patient rate “10.”
- 5 patients rated their confidence level that they have the knowledge to deal with problems or challenges that may prevent them from achieving their goal between “7” and “9.” 1 rated a “3.”
Key findings

• Staff indicated lack of time to interact with patients

• Interaction was seen as added work

• Staff’s lack of motivation

• Separate documentation forms needed

• Nurses’ schedule: rotating shift work = fewer opportunities to interact
Areas for Improvement:

- **Documentation**
  - Simplify paperwork and ensure sheets are in patients charts.
  - Suggest moments during the nurses’ routine when they should have time to document (e.g. while weighing them).
  - Gear future workshops towards the particular unit the nurses work, rather than generalize.
  - Can patients be motivated to provide information rather than wait for the nurse?
  - Can the social workers hand out the patient questionnaire to get a better response rate?
Why is Self-Management important to CKD
Management of CKD patients includes

- Preserving kidney function
- Blood pressure and fluid volume
- Cardiovascular risk factors
- Anaemia
- Psychosocial issues
- Mineral and bone disease
- Nutrition and metabolism
- Health prevention / immunization
- Self management / support
- Transplant work-up
- Ensuring timely placement of dialysis access (peritoneal dialysis catheter or vascular access for haemodialysis)

(Mohlzahn & Butera, 2006)
We're a little concerned about your potassium levels.
Your tests reveal that you are retaining fluids!
Development of a patient educational video

- Initial focus on modality choices & vascular access
- Didactical design and approach to patient education and teaching
- Vetted through our patients via a focus group
Patient video interviews

- The questions used for the patient interviews were directed at specific themes:
  - Peer support
  - Psycho-social support (e.g. coping with CD)
Outcomes of focus group

- Our group identified key themes from the focus group which were:
  - *Early peer support*
  - *More information and clarification on modality choices*
  - *Lack of guidance in accessing e-educational resources to enable patient self management*
What was heard and learned

- Patients knew what they needed and wanted
- The perceptions and understandings of care providers are very different than that of the patients
- Assumptions as to what patients want should not be made
- Engagement of patients is essential!!!
Key Themes for video

- I can’t believe this is happening to me
- How I got my life back
- How I made my decision
- Day to day life
- Peer support
- Patients words of encouragement
Lessons Learned

– Psycho-social aspects of care delivery are often overlooked,
– Patient engagement is essential
– Early engagement with peer support and SW
– Need to create educational resources/curricula to support self-management activities
Preparing for Dialysis

VIDEO CLIP

Introduction

How I got my life back

Peer support

Patients’ words of encouragement
WELCOME TO THE CKD PROGRAM
Chronic Disease Management: Your Guide to Wellness

• Welcome package
  – *Standardize curricula for the introduction and education of CKD patients*
    • Developed by the CKD Inter-professional team
  – *Components include: introduction to kidney disease, medication review, lab results, nutrition and basic diabetes management.*
  – *Partnership with Ryerson: Formative evaluation study to assess the current module, consistent with patient preference and incorporation of self-management ideology*
  – *Foundational work for patient teaching curricula related to CDM*
Great partnerships — share common goals.
# Patient Educational Material/Checklist

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<thead>
<tr>
<th>Subject Material</th>
<th>Date Discussed</th>
<th>Reading Material/ Demonstration provided (if applicable)</th>
<th>Patient Signature</th>
<th>Nurse Signature</th>
<th>Comment</th>
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<td>Causes of kidney failure</td>
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<td>Review of lab work</td>
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<td>Hemodialysis</td>
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<td>• When to prepare access for dialysis</td>
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<td>Creatinine is a waste product that is used to measure how your kidneys are working.</td>
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<td>Kidney Function (eGFR)</td>
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<td>When kidney function is around 20%, dialysis options will be assessed. Depending on your choice, arrangements will be made to start access preparation.</td>
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<td>Hemoglobin (Hgb) is used to carry oxygen throughout the body in red blood cells. When your Hgb is low, you may:</td>
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<td>Phosphate (0.8 – 1.45)</td>
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<td>Phosphate is a mineral that is important in building strong bones and is used to store</td>
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<td>Graph</td>
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<td>Phosp (mmol/L)</td>
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Chronic Disease Management: Your Guide to Wellness

- Patient responsibilities are highlighted and active participation is encouraged

- Self management tools include: patient lab report cards, BP, potassium, phosphorus tracker and HbA1c tracker (if applicable), goal setting and education checklist signed off by both patient and healthcare member.
Commenced April 15th,
- *binders were handed out to most initial patients who were seeing the nurse and dietitian*

**Challenges**
- *language,, overwhelmed patients or not ready/wanting to receive this information.*

**Opportunities**
- *Use Conviction and Confidence Model  to assess patient readiness*
- *Assessment of current module enable team to assess whether self-management concepts are truly employed*

**Next Steps**
- *2^nd Module : Modalities*
ORN Targets

By 2015:

• 100% of patients seen in a pre-dialysis clinic for at least one year will have been assessed for appropriate body access before starting dialysis

• 40% of all new dialysis patients will be on an independent dialysis option within 6 months of initiating dialysis

• 100% of dialysis patients seen in a pre-dialysis clinic for at least one year will have been assessed for independent modalities before starting dialysis
Strategies to Increase PD Starts from CKD

• Per ORN strategies – 100% of patients will be assessed for suitability for HD

• All acute starts and transfers into program will be required to return to the CKD program for modality teach and assessment and transition to HD modality

• ICD in-patient visits

• Targets discussion at division rounds

• Collaboration with CKD/Home Dialysis
Patient Experience

THE REST OF YOUR LIFE...

AVERAGE

MEMORABLE
What this means for TSH

- Be a leader in leading-edge, high-quality chronic disease management
- Improve the system and supports to enhance the patient experience and have positive impact on health outcomes in the CE LHIN
- Build a strong foundation to live our Values, achieve our Mission and realize our Vision
Q&A
References


Thank You