Patient engagement in healthcare and decision-making

Heart & Stroke Clinical Update
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Jennifer Price, RN PhD
APN Cardiology &
Chief Nursing Executive
Disclosures

No Disclosures
The expression “nothing about us without us” was first coined by disability rights activists to convey the idea that no policy should be reached without full participation of representatives of all stakeholders. More recently, it has been adopted by patient communities seeking broader involvement with the healthcare system. Although the drive for patient involvement has come from patients, the medical community has much to gain.
Why Patient Engagement?

For patients with chronic disease or conditions that require self-management support, the content and methods of communication with patients and families are of critical importance.
Learning Objectives

Upon completion of this session, participants will be equipped to:

1. Summarize the concepts and benefits of patient engagement in research.
2. Explain and apply a patient centered approach to clinical decision making
3. Integrate the needs of patients including gender equity, ethnicity, Indigenous heritage, and geographical challenges.
Patients as Partners in Care

Explain and apply a patient centered approach to clinical decision making
Patients as Partners in Care

Patient-centred care (PCC)/Shared decision making (SDM)

SDM – 1982

Clinicians share best available evidence
Support patients to consider options
Achieve informed preferences

PCC – 1988 The Picker Institute

Called attention to the need for clinicians, staff and health care system to shift focus from diseases and back to the patient and family

Important to have a better understanding of the experience of illness and to address patient needs in an increasingly complex/fragmented health care system
Patients as Partners in Care

Eight characteristics of care as most important indicators of quality

Patient perspective

Respect for preferences, values and expressed needs
Coordinated and integrated care
Clear, high-quality information and education for patient and family
Physical comfort, including pain management
Emotional support, alleviation of fear and anxiety
Involvement of family and friends
Continuity – including through transitions
Access to care
Patients as Partners in Care

Practically – PCC is about the engagement of patients

To successfully meet the previous eight dimensions of quality patients need to be enlisted and engaged in designing, implementing and evaluating care systems.
Patients as Partners in Care

Fateful healthcare decisions
Crossroad of medical options
Diverging paths have different and important consequences with lasting implications

SDM
Clinician and patient
Healthcare team
Family friends
Patients as Partners in Care

How does SDM work practically?

Clinicians offer options, share risks and benefits
Patient expresses preferences and values
A Multidimensional Framework For Patient And Family Engagement In Health And Health Care

<table>
<thead>
<tr>
<th>Levels of</th>
<th>Continuum of and shared leadership</th>
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<tr>
<td>Direct</td>
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<tr>
<td></td>
<td>Patients' information about diagnosis</td>
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<td></td>
<td>Organization surveys patients about their care experiences</td>
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<td>Policy making</td>
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<td>Public agency conducts focus groups with patients to ask opinions about a health care issue</td>
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Factors influencing engagement:
- Patient (beliefs about patient role, health education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)

SOURCE Authors’ analysis. NOTE Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.
Patients as Partners in Care

Choice Talk

Ensure patients know that reasonable options exist
A planning step

Option Talk

Providing more detailed information about the options

Decision Talk

Supporting the work of considering preferences and deciding what is best
Patients as Partners in Care

Stanford Chronic Disease Self-Management Program

Take PART
P – Prepare
A – Ask
R – Repeat
T – Take Action
Patients as Partners in Care

Benefits of PCC

- Enhanced adherence to treatment plans
- Improved health outcomes
- Increased patients’ satisfaction with healthcare services
Self-management support in a women-only cardiac rehabilitation: Are we empowering our patients?

Many women indicated that they take charge of their health: *I have to look after myself. You know in a sense I have to take care of my own health.*

Other women are more comfortable letting the health care providers make decisions. *I have no choice….if they say “do this” I do it …I know they are professionals.*
A Pilot Trial of a Coaching Intervention Designed to Increase Women’s Attendance at Cardiac Rehabilitation Intake

The evidence obtained from this pilot trial suggest that a telephone coaching intervention designed to enhance self-management is feasible and may improve attendance at CR intake for women following hospital discharge with a cardiac event.
Engaging the seldom-heard

Integrate the needs of patients including gender equity, ethnicity, Indigenous heritage, and geographical challenges.
Engaging the seldom-heard

These groups are often referred to by as “hard-to-reach”, which unfairly communicates that there is something about them that makes their engagement difficult.
Engaging the seldom-heard

We use the phrase “seldom-heard” to describe people who often experience barriers to public participation and engagement, and/or whose perspective and ideas are often under-represented in decision-making.

We say “seldom-heard” because we believe that the use of appropriate approaches, techniques and tools can and should ensure full participation for anyone
Engaging the seldom-heard

Seldom-heard people are often historically-marginalized groups (e.g. racial and ethnic minorities, Indigenous peoples, the LGBTQ2+ community), people experiencing homelessness, living with a disability, or addiction, or "silent majorities" (women, newcomers, the working poor, or young families), who, depending on the context, who face barriers to meaningful involvement in decision-making by and with government.
Engaging the seldom-heard

Ensure those impacted have a say

“Nothing about us without us”
Engaging the seldom-heard

Engagement Principles

Build trusted relationships
Engage early and allow time
Improve accessibility and consistency of engagement
Promote effective, transparent engagement
Engaging the seldom-heard

Benefits of more inclusive engagement include:

- increased understanding
- integration of vision of diverse people and communities
- increased support
- increased knowledge and capacity
- greater equity
Engaging Patients in Research

1. Summarize the concepts and benefits of patient engagement in research.
2. Discuss challenges
3. Framework for solutions
Engaging Patients in Research

United Kingdom

INVOLVE

established 1996

part of the National Institute for Health Research in the UK
to support active public involvement in the NHS

United States

Patient Centered Outcomes Research Institute (PCORI)

established 2010 as part of the Patient Protection and Affordable Care Act

non-profit, non-governmental organization

estimated budget of $650 million/year
Engaging Patients in Research

Canada

The Canadian Institutes for Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR)

- established 2011
- allocated $60+ million

Support for People and Patient-Oriented Research and Trials (SUPPORT)

- provincial and territorial units
Engaging Patients in Research

ENGAGING PATIENTS IN HEALTH RESEARCH: The Ontario Experience

CMAJ 2018;190(Suppl 1):S1-S56
Engaging Patients in Research

Patient Engagement – Benefits

Patients have a personal experience of disease

Enhance

- study design
- practicality
- recruitment
- data interpretation
- dissemination
Engaging Patients in Research

Patient Engagement is a Continuum
Engaging Patients in Research

LEVELS of PATIENT and RESEARCHER ENGAGEMENT in HEALTH RESEARCH

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<th>HOW CAN THIS BE DONE</th>
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<td>Through orientation and information sessions, and media campaigns in an open atmosphere for sharing</td>
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<tr>
<td>Through qualitative, quantitative, or mixed methods research</td>
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<td>Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels</td>
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<tr>
<td>Patients as members of standing working groups and research advisory committees</td>
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<tr>
<td>Patients as co-investigators and research partners, and as members of research steering committees</td>
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<td>Through patient or community steering committees and patients as principle investigators</td>
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Time, Knowledge, and Funds Needed

Vandall-Walker, 2017

Shaded area indicates the levels that the AbSPORU Patient Engagement Platform focuses on.
Engaging Patients in Research

Core Areas for Engagement

Governance and Decision-Making

- involve in key governance structures
- commit to engage patients in decision-making
- peer review
- priority setting
Engaging Patients in Research

Challenges to engaging patients

Enabling contribution
  Access
  Communication

Relationships
  Clinical
  Collegial

Tokenism

Ability to contribute
Engaging Patients in Research

Framework for solution

- Facilitate
- Identify
- Respect
- Support
- Train
Comments:
- Example from your work to improve referral and access for women to cardiac rehabilitation programs would be valuable.
- If possible to tie in sex and gender differences in heart disease would be ideal.
- Integrating the needs of our patients while assuring gender equality in cardiovascular health.
- Audience response technology will be available for this session (both for in person attendees and webinar), so you will have an opportunity to poll/test the audience if you wish to utilize.

Lisa