What Does Participation in Care Planning Mean for Patients with Multiple Chronic Conditions?

Presenter Disclosure

• Presenters: Sydney Haubrich
  Jenny Kelly

• Relationships that may introduce potential bias and/or conflict of interest:
  – No relationships to disclose
Acknowledgements

Funding:
• Alberta Innovates Collaborative Research and Innovation Opportunities (CRIO) – Team Grant

Research Team:
• Doreen Rabi (PI)
• William Ghali (Co-PI)
• Julie Babione
• Jaime Kaufman
• Jessica Van Dyke
Overview

• Share research findings
  – Goal of the project is to create a digital care-planning tool
  – Conducted interviews and focus groups with patients and providers
  – Found that their views of patient involvement differ significantly

• Discuss how findings could shape project outcomes

• Ask for feedback
Background
Prevalence of chronic conditions

- NCDs
- Other causes
Managing chronic conditions
Person-centred care

Image source: vexels.com
Person-centred care plans

- “Patient-Centered Plan-of-Care Tool for Improving Clinical Outcomes”
- Process:
  - POC designed by research team
  - Patients met with doc to complete POC tool
  - Completed form: one copy for patients, one for clinic

“To date, care plans have rarely been patient centered. [...] Most research has focused on the development of plans of care used by a single discipline, such as nurses or physicians, or within a single setting, such as an acute care hospital (ACH) or home healthcare agency.”

Patient involvement in shared decision making

Shared decision making can:

• Improve patient confidence in the treatment
• Reduce patient anxiety

Health-related behaviours and the clinical encounter

Three system-level changes to address patient involvement:
1. Planned visits
2. Regular follow ups
3. Pre-activation

Pre-activation

“Pre-activation describes a process of assisting patients to be more assertive during the medical care visit. This [...] can be accomplished by pre-visit face-to-face discussions, written materials, or computer interactions.”

Pre-activation for chronic condition management

Guidebook helped to:

• Improve patient involvement in self management through experiential knowledge

Perceptions of information in guidebook:

• Patients seek information that is therapeutic and supportive
• Providers wanted the information to improve compliance and utilize their services better

What we want to achieve
Methods
Study participants

Patients (n=18)

• E.g., cancer, diabetes, cardiovascular disease, and migraines

Image source: pacerinnovates.com
Study participants

Providers (n=38)

- E.g., family physicians, social workers, specialists

Image source: vexels.com
Qualitative data analysis

Process:
1. Code transcripts
2. Reconcile codes
3. Group codes into themes
Results
Providers want to involve patients

Building rapport:

“I try to see [the patient] as soon as I can after they are admitted, recognizing we are not here weekends or evenings, and try to establish that rapport. [...] Having discussions with them so that they are actively involved.”

–Provider 9
Providers want to involve patients

Setting goals:

“I approach [care planning] with setting goals and saying, ‘This is your decision. It’s easy for me to sit here in my seat and say [what] you need to do, [...] but you need to tell me what you are able to do and willing to do.’ That comes after building a relationship.”

–Provider 26
Providers want to involve patients

Building rapport; setting goals:

“After about six months, [my care team] realized that I was a very compliant and knowledgeable patient, so they handed [medication decisions] off to me. They said, ‘Go through your results every week. If your results are going down, you know these numbers are good. You decide what to do with your medication.’ And that worked perfectly.”

–Patient 13
Barriers to involving patients

*Not all patients want to be involved:*

“This process [of care planning] takes a couple hours of patient time. We tell them, “We try to use it so our team can provide optimum care for you, and it can help you achieve your goals,” but people are not willing to trade two hours of time to do that. [...] It’s not necessarily a physician barrier in our practice.”

–Provider 22
Barriers to involving patients

Not all patients want to be involved:

“Some patients, through their own personality or through their own particular stage of illness, are not able or are unwilling to be their own advocate. They just want to be treated. They want the physician to be the expert.”

—Patient 2
Barriers to involving patients

*Dynamic clinical environment:*

“And while we absolutely want to involve patients in every decision that is going to be made, nobody plans for what happens when you’re [in the hospital].”

—Provider 6
Barriers to involving patients

*Dynamic clinical environment:*

“I found [my hospital stay] an interesting experience, because doctors would come and doctors would go, but no one would talk and consult or tell me what they were doing. [They were] reading a chart and walking away. And everybody just missed the whole thing.”

—Patient 18
Barriers to involving patients

*Protecting patient:*

“It’s almost like a **paternal approach** to patient care, we look after patients so much that sometimes we don’t necessarily include them in all the information they need to know. We are protecting them.”

–Provider 30
Barriers to involving patients

Protecting patient:

“I find it very frustrating that I’m waiting and waiting and waiting, and have no answer to exactly what it was that is wrong, let alone who I can see; what are the treatments.”

—Patient 21
Barriers to involving patients

*Differences in goals:*

“You want to be able to address those issues [that are important to the patient], because you want them to feel like they’re heard. You want them to feel like we’re trying to achieve their goals. But sometimes, it’s frustrating, because their goals are nowhere near what needs to happen.”

–Provider 9
Barriers to involving patients

Differences in goals:

“I think we all struggle, too, with what we think [the patient’s] problem is, and what the patient thinks their problem is. [...] Sometimes I find I struggle with that. I have an idea about what I think is wrong and that they should be acting on it.”

—Provider 33
Providers want to involve patients

Differences in goals:

“You know, there is no cure [for COPD]. There is no way to bring back that capacity. But if you can maintain it, great. I live a pretty good life. I have been able to travel. [...] I don’t want to fight anymore. I just want to sit back, relax, and hopefully breathe. [...] The only thing I want to do is go fishing.”

—Patient 5
Barriers to involving patients

*Under-investment in care planning:*

“[We have] under-investment in primary care, poor coordination, crappy payment structure, and a **total lack of incentivization** for these care plans. [...] There’s **no payment**. The payment models in Canada, and Alberta specifically, they’re not aligned to manage comprehensive care plans.”

–Provider 10
Barriers to involving patients

*Under-investment in care planning:*

“If you are a doctor, and you have limited time, you have ten minutes for a patient, there is a back up [of people waiting], and you also have a lot of work after the office is closed. We also have to think of that. I think it is more the system that needs to be worked on than a lot of the doctors.”

–Patient 15
Strategies to involve patients

Coordinating care:

“And sometimes in my case that’s, like if the plan if for us to get someone to supportive living, maybe they need to encourage them to make some phone calls themselves, so that they can be involved in the process.”

—Provider 8
Strategies to involve patients

Coordinating care:

“What I found most **difficult** [about my cancer treatment] was that for every appointment, **I had to make the appointment**. Otherwise, I wouldn’t hear from anybody.”

—Patient 15
Strategies to involve patients

Providing educational information:
“I think one of the things that has worked well, with limitations, is the patient passport. It’s really an education binder or document that encompasses their disease journey. Not necessarily their own experience, but expectations of what to see, what could happen, how to prevent it in the future, organizations that they can go seek for counselling needs. I find that helps.”

–Provider 30
Strategies to involve patients

**Receiving educational information:**

“I got a folder with so much information, it was all booklets [...] about cancer, about all possible treatments of cancer, about all these health groups. You are **bombed with so much information**. [...] It was so wrong because, you know, the day after you know you have cancer, how are you going to be able to process that?”

—Patient 15
The future of patient involvement

“The care plan, in my opinion, should be directed by the patient’s goals, and then the care team should work around the patient and their goals to build that comprehensive plan that’s integrated around that patient. This doesn’t exist in Canada yet.”

—Provider 10
The future of patient involvement

"In my mind, the middle ground is that [...] we have this collaborative approach, where the patient feels that they are part of a team all trying to reach the same goal, which is the patient’s health and their quality of life getting better. There’s an open line of communication. There is not a question of it being patient driven or clinician driven, it is team driven."

–Patient 2
Next steps
Tool for patient-provider collaboration

- Create tool to address gaps
- Working with developers
- Goal is to support productive clinical encounters
“Pre-activation”

- Yourself
- Your support system
- Your desire for involvement
- Your values
- Assessments

Image source: vexels.com
Learning style

Image source: vexels.com
Digital literacy

Image source: vexels.com
Health literacy

Image source: vexels.com
Physical activity

Image source: vexels.com
Nutrition

Image source: vexels.com
Social supports

Image source: vexels.com
Possibilities

Image source: vexels.com
References


Contact us

Sydney Haubrich
sydney.haubrich@ucalgary.ca | 403.210.7420

Jenny Kelly
jekelly@ucalgary.ca | 403.210.9264