

Patient Goal-setting in Kidney Care

Report on Focus Groups

January 2020

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Background

Collaborative goal-setting between health professionals and patients is a key element of managing chronic disease. [BC patient experience survey results](#) over the past decade have consistently found that patient goal-setting has significant potential to enhance overall patient experience in chronic kidney disease (CKD) care. However, little is known about what is needed to improve goal-setting from the perspectives of patients and family caregivers living with CKD, as well as renal health professionals.

From July – September 2019, we conducted a series of focus groups in BC renal programs to identify common areas for patient goal-setting improvement across modalities. This report summarizes the focus group findings, and will inform a workshop scheduled for February 2020 that aims to identify actions to improve goal-setting in various CKD care settings in tangible ways.

Methods

Data Collection

- Period: July to September 2019
- Source: Seven focus groups across BC renal programs that included patient, family and renal health professional participants; 53 participants in total
 - At each focus group: Two multiple choice questions (as per the patient experience survey) were asked to anonymously verify the experience of goal-setting among patient participants
 - Two of the focus groups were held in partnership with Island Health as part of a regional patient experience workshop
- All focus group discussions were audio-recorded and transcribed.

Analytical Approach

The transcripts were categorized into common themes related to perceptions about the benefits of patient goal-setting in CKD and what is needed to improve goal-setting with adults living with CKD.



Results and Interpretation

Participant demographic

Table 1 summarizes the demographics of the focus group participants.

Table 1 Focus Group Participant Demographics

Focus Group Participants	
Patient	20
Family Caregiver	4
Clinician	26
Manager	3
	TOTAL 53
Patients & Family Caregivers	24
Age (years)	
20-39	1
40-59	10
60-79	11
80 or older	2
Gender	
Female	15
Male	9
Indigenous	1
Visible minority	4
Person with disability	5
Clinicians & Managers	29
Role	
Dietitian	3
Director/ Manager	2
Nephrologist	5
Nursing staff	16
Pharmacy technician	1
Social Worker	2
Experience in CKD care (years)	
< 5	3
5-10	4
11-15	9
>15	13
Gender	
Female	26
Male	3

Responses to multiple choice questions

Participant responses to two multiple choice questions that also appeared in the last [provincial patient experience survey](#) (see Appendix) found their perceived experience around goal-setting to be less desirable than reflected in the 2016 survey results.

Benefits for patient goal-setting

Patients, family members and renal health professionals all recognize that setting goals with patients is useful and valuable when it is done well. It is a concept that everyone could relate to within and beyond the clinical care setting, i.e. in daily life.

The key benefits drawn from the discussions include:

- Patient- and family-specific
 - A greater sense of control and hope
 - Motivated and empowered patients
 - Better understanding of kidney health and care
 - Better health and quality of life
 - Enhanced experience of care
- Health professional-specific
 - Better understanding of their patients
- Mutual benefits
 - Better patient and health professional relationship
 - More effective tailoring of CKD care
 - Improved overall patient experience and outcomes

Requirements for improving patient goal-setting

The need to improve collaborative goal-setting with patients focuses around four major themes:

Promote awareness and understanding of goal-setting

- There is a general lack of awareness among participants, especially among patient participants, with “goal-setting.” However, conversations of what goal-setting entails do appear to happen to various extents.
- Goal-setting includes the setting of both medical (e.g. transplant, heart health, medications) and non-medical (e.g. diet, exercise) goals. Both types of goals may be important to the patient and inter-related.

- Goal-setting is an iterative and evolving process that changes as various factors around the patient changes (e.g. patient’s understanding of her/his health and care). The process should include periodic review of the goals.
- Collaborative goal-setting reflects person-centred care in honoring patient preference, activating the patient in her/ his own care, and providing sufficient information for patients to make informed decisions about her/his own health.
- Renal health professional participants highlighted needs for further training and education in goal-setting conversations with patients.

I think we’re opening a whole new, not a kettle of fish here, but you guys are opening my eyes. I mean, my number one goal is to stay alive... I want to see my grandkids for another ten years ... but I don’t know how long I have. I mean, I’ve been through a lot. I don’t know how... to actually approach patients and ask them, “What is your goal?” I mean, it’s a good thought. What do you want? What can we do for you?

- Patient participant

I wonder if, for me as a nurse, I’m thinking that I’m doing some goal-setting when I ask someone... which modality they want, which therapy they want to be on... we provide them some information on it. We communicate with them around what is your choice? What are the impacting factors on your life? And then what would suit your life best? So in my head, I’m thinking that might be a bit of goal-setting with the individual...It might be around your transplant process—“My goal is to get a transplant; my goal is to get a live donor transplant.” What are the steps that need to be taken to get there? For people that have pain, what have we done before? So these might be informal discussions that might be happening, but we haven’t labelled them as goal-setting before.

- Renal health professional participant

Build adaptable process and safe space to guide effective communication

- Participants suggested that facilitative tools and resources for patients, family caregivers and health professionals should be aimed at guiding goal-setting conversations and process. Preference for patient documentation seems to vary among patients.
- Some renal health professional participants suggested standardized guidance on the approach (i.e. process, desirable mindset and attitudes) for collaborative goal-setting would be helpful.
- Personalization and flexibility are key in a collaborative goal-setting process. This may include knowing the patient and understanding what matters most to her/ him, providing information according to the patient's understanding and readiness, and tailoring care to her/his preference where possible. Participants considered various preferences by age group, culture and religion belief.
- Meaningful conversations around goal-setting among patients, family caregivers and health professionals take time, and require a safe physical and mental space that may be lacking in some CKD care settings. Identifying the optimal time for having these conversations can also be a challenge.

We're wired different. I have to write it down, and so I have a goal. I've got it written at home... I write it every day, something I want to achieve every day. It's a small thing maybe. So I'm just saying that mentally everybody thinks different. Some patients, like they know... "I don't have to write it down or anything." Or they say, "Well, somebody else is keeping track of that, so I don't need to." I think everybody has a different way... when they think about goal-setting.

- *Patient participant*

The feedback I've had is they find it very valuable to have that private time where they don't feel like the doctor's rushing through, and that they can bring up something privately. Maybe they don't even want to say their social issue in the group. That's okay. They can talk to you later, because I have something I actually need to talk to you about. We'll just do that.

- *Renal health professional participant*

Harness mutually beneficial partnerships among patients, family caregivers and health professionals

- Effective engagement of the patient in her/his own care enables goal-setting, and in turn yields more collaborative goal-setting.
- Family members are key partners throughout the patient journey in the goal-setting process. Furthermore, they are also impacted by the health care decisions being made.
- Trust in the relationship and effective communication between the patient and health professionals are foundational for collaborative goal-setting to take place.
- Collaborative goal-setting involves the patient and health professionals listening and learning each other's expectations for the patient's health conditions, and aligning expectations to what matters most to the patient.

Of course, you have this sense when it's happening to you, and not to sound negative, but there is this weird thing about trust. Before we would sort of embark on this, and then knowing "No, this is the real deal. You've got to do these meds. This is going to be hard on the body." So letting go and trusting in the process, and then allowing our own personal lifestyle goals to amalgamate with the professional goals that were being recommended by the health care system, as well. It's a coming together of the two.

- *Family caregiver participant*

If I was goal-setting with somebody I was working with, I would hope to ask them what was important to them and then try to figure out how we can support them living in that way that they choose to live. And recognizing that there is a difference between medical team goals and patient goals sometimes. And so sometimes there might be negotiation, do a little bit of both, to help people get to their goals, right. But I think it is important, if we're saying we're doing goal-setting for what is important to the patients, then we need to know what's important to them and have the time to talk about that, so we can help establish how we are going to attain that end goal.

- *Renal health professional participant*

Strengthen continual support along the patient journey

- Many patient participants shared the difficult emotions (e.g. depression, grief, fear) and physical limitations (e.g. tiredness, exhaustion) associated with their health conditions. Psychosocial and peer support are suggested to manage those so as to enable effective goal-setting to take place.
- Multidisciplinary health professional team support for the patient is appreciated as individual health professionals offer different perspectives and their roles complement each other in supporting the whole patient in the goal-setting process.
- Some patient and renal health professional participants suggested having a consistent primary clinical contact person for inquiry and navigation in kidney health and care.
- Goal-setting discussions should carry through the continuum of care for the patient. This means strengthening communications across transitions and medical disciplines (e.g. specialist and primary care)

I'm hearing that there needs to be a piece of honouring when we're looking at goal-setting, the grief and loss around goals having to have shifted and that acknowledgment ... It's not just about setting goals that are realistic or... it is partly that. But it's also a step additionally about honouring how goals that we had for ourselves at one point have had to shift.

- *Patient participant*

I think it's also really important because as the health care team, we're all going to come from different places of talking about goals or language around goal-setting based on our discipline... And so I think it's important that we're talking as a team about how we're looking at short-term, long-term goals with our patients or who on the team might be the best or most appropriate one to be helping with certain goals too. But that we're all participating ...because our lenses are different.

- *Renal health professional participant*

Conclusions

Optimizing goal-setting in patients living with CKD may require a shift in culture to enable more effective and collaborative communication among patients, family caregivers and health professionals throughout the patient journey. As a provincial renal network, the next steps to move forward in this aspect of CKD care may include:

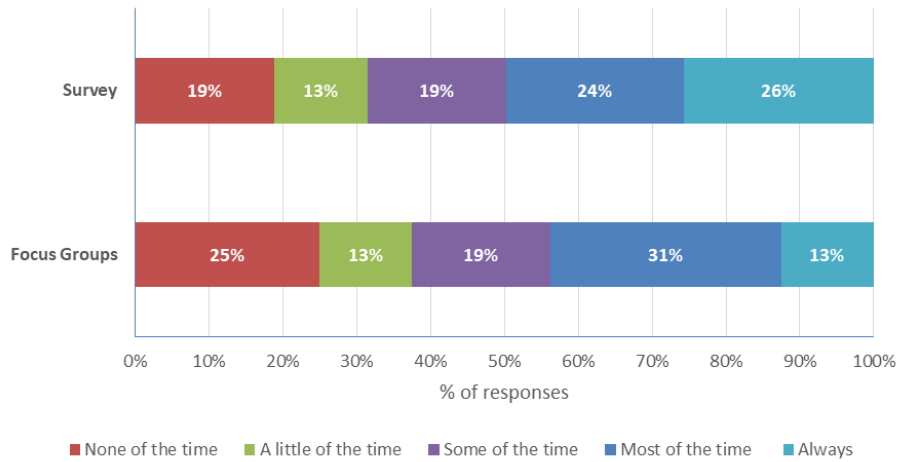
1. Curate existing tools and resources to support patient goal-setting and discern how best to use them in the context of a set of guiding principles (i.e. "spirit") in various CKD care settings
2. Strategize a common way forward, i.e. direction and a framework, for raising awareness, incorporating the tools and resources, and enabling professional education and training in routine CKD care
3. Pilot Step 2 in small scale within local settings, evaluate, and share lessons learned among renal programs

The first two steps will be discussed at the "What Matters to You" Action Planning Workshop.

Appendix

Survey Question Results

Over the past 6 months, when I received care for my chronic conditions, I was asked to talk about my goals in caring for my conditions...



Over the past 6 months, when I received care for my chronic conditions, I was helped to set specific goals in caring for my conditions...

