Understanding Bundled Care: COPD and CHF Patient Perspectives

Authors

Gayathri Embuldeniya
Nusrat Nessa
Amanda Everall
Zahraa Saab
Sara Guilcher
Kevin Walker
Walter P Wodchis

February 2019

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

We conducted interviews with patients from three Integrated Funding Model (IFM) programs operating in three different LHINS: South West (A), Central (B), and Hamilton Niagara Haldimand Brant (C), to understand their experiences of bundled care programs and the extent to which an integrated care approach fulfilled their needs.

Research Questions

We examined the following: a) What did patients value about integrated care programs? b) How did patients' desire and ability to be involved in their own care inform their experience of programs? and c) What were patient needs during the program and when transitioning out of it?

Methods

We interviewed 20 patients with COPD and CHF from August to December 2018. We included participants who had enrolled in the program from November 2017 to March 2018. We contacted 33 participants who had indicated willingness to participate in an interview about their experience with the IFM program. Their willingness was captured on a question added to a survey administered to all participants enrolled in an IFM program in February and March 2018. We conducted one-on-one telephone interviews with participants that lasted approximately 45 minutes. Due to low recruitment, we subsequently approached patients by mail, who were enrolled in programs A and C from November 2017 through January 2018 and who had also completed the survey to ask about their interest in participating in an interview. Of the 20 individuals that participated in interviews, 9 were from Program A, 4 were from Program B [a reflection, in part, of fewer patients enrolled in the program itself], and 7 were from Program C. Seven were male and 13 were female, and the majority were seventy years or older (see Table 1). We also included a partner caregiver (of participant A8) who spoke on behalf of the patient.

Table 1: The IFM participants (n=20)

Participant	Condition	Sex	Age
A1	COPD	F	65-74
A2	COPD	M	75+
A3	COPD	F	>65
A4	COPD	F	65-74
A5	COPD	F	65-74
A6	COPD	F	75+
A7	CHF	M	75+
A8	COPD	M	65-74
A9	CHF	F	75+
B1	COPD	M	75+
B2	COPD	F	65-74
B3	CHF	F	75+
B4	COPD	M	65-74
C1	CHF	F	75+
C2	COPD	F	75+
C3	COPD	F	65-74
C4	CHF	M	N/A
C5	COPD	F	75+
C6	COPD	M	65-74
C7	COPD	F	75+

Interviews were recorded, transcribed, anonymized, and analyzed using thematic analysis, with key themes iteratively identified and organized using NVivo 11.

In addition to acquiring an understanding of the services and resources received as part of the programs, we were interested in participants' overall health context as it pre-dated the bundled care initiative, and how their health progressed during and after the program to gain a deeper understanding of needs met and unmet. As such, we asked questions about the impact of COPD or CHF on participants' everyday lives, as well as their experience of the program itself—from the adequacy and appropriateness of services provided to perceptions of patient centeredness. We also asked about the program's role in fostering connectivity and continuity of care as patients transitioned out of it. While small sample sizes for individual programs limited our ability to comprehensively delineate distinctions between programs, the key themes reported below appeared to be largely shared across programs. Program identifiers (A,B,C) and participant identification numbers (1,2,3, etc.) are provided to identify specific programs.

Results

Overall, patients valued the care, reassurance, and connectivity that they experienced during their integrated care journey. They appreciated having programs and providers that recognized and responded to their individual needs. At the same time, patients' perspectives of the success of the programs were informed by their understanding of the programs themselves, and their desire and ability to be engaged in their own care.

The integrated care journey

Participants valued the knowledge and self-management skills they acquired and the individually tailored material resources they were provided. It was important for them to get along with their home care providers, and they appreciated the genuine care their providers displayed. The person coordinating their care – typically an integrated care coordinator – was particularly valued. Patients liked having access to a 24-hour telehealth number and appreciated the connectivity within the program that allowed all relevant providers to have access to their information.

Enrollment

Patients enrolled in the programs offered at participating acute hospital sites across the three LHINS for a variety of (often overlapping) reasons, from simply the desire to get better and receive much needed support at home (A1, A4, A5, B4, C5), to an altruistic desire to help others like them by volunteering in the pilot (A7, C3, C6). The majority had never received homecare services before, and the few who had noted that they did not have to (and would not) give it up in order to enrol in the program (C2, C5).

From hospital to home

As in-patients, participants appreciated having personalized attention (B4, C3), knowledgeable doctors who informed them about their condition (C4), instructed them on the correct use of puffers (B4), and showed genuine concern (A2). They complained about unchanged bedding and inattentive food service (A9, C6, C7), and uncommunicative and discourteous doctors and nurses (A9, B4, C6).

Once they returned home, patients were provided with an individualized care plan detailing the healthcare providers who would be visiting their home. In addition to a 24-hour telehealth number and educational material, patients were also provided with much appreciated resources catering to their needs. For instance, patients could receive a bath chair, a shower stool, shower safety bars, a blood pressure machine, an OxyWatch, a weighing scale, oxygen, oxygen monitoring devices, or equipment to ease COPD symptoms (A5, A6, A7, B2, C2, C3, C4).

During this time, participants valued being able to get along with their visiting health care providers; noting their kindness and care, and looked forward to their visits (A1, A6, B3, C1). The majority found the services provided, the frequency of visits, and the duration of the program appropriate. Programs were thought of as a form of reassurance and encouragement (A2), and a form of “back-up” support:

> I felt that I had people concerned, and there was a back-up for me. So I wasn’t alone. And you know, I could ask them things and they wouldn’t be taken aback by anything. They just gave you

> the support. I think the support was the most important. Just people to talk to and they took an interest. (Program B, 3)

Those who did not value the homecare visits attributed this to clashing personalities with the homecare providers (A8, C7).

> …so his only crank… You know, there's different personalities and stuff. And he says, when he'd have one PSW that was coming, after she left, he's, "Oh, I don't like her." Yeah, okay, well sorry, buddy, suck it up. So you know. But that's his personality issues. […] there was one PSW that he really liked, that he got along well with. And this gentleman was… And again, so here we go, now that was our only gentleman that we had. But [second PSW] was so personable and so good. And like [second PSW] could joke with [patient] in a way that [patient] didn't get mad at him. Like he could find the humour in what [second PSW] was saying and such. So there was just a good rapport between the two of them. It was good. (A8)

Coordination

Healthcare providers with care coordination responsibilities (who were sometimes referred to as the "boss" or "team leader" by patients (A4, C5, C7) played an important role in introducing the program, providing an overview of services, and fostering a sense of continuity from hospital to home, and even in the aftermath of the program. Patients described them as "excellent" (B1, C6), "caring" (C1), "very well spoken" (A2), and "a sweetie" (A6), with one claiming that his positive experience with the program coordinator was the only reason he had consented to be interviewed, noting "usually I don't do this kind of stuff" (C6). Another patient sent a birthday card to her nurse coordinator, who visited her for tea and cookies even after the program was over (A9).

Some patients noticed that information about their condition and care was being shared by all relevant healthcare providers, so that they didn't have to keep repeating themselves (A3, B3), and that even their family doctors were informed about their progress (B3, B4, C1, C3). At the same time, others were not aware of any connectivity between the hospital and homecare (as discussed below), or received contradictory advice about how to administer their medication and puffers, leading one patient to describe it as "a little bit upsy-downsy […] thank God it was over." (C6)

Transitions

Transitions from the hospital to home largely took place smoothly, with patients appreciating physicians who took their needs into consideration when scheduling discharge. As such, while one patient appreciated being allowed to stay in hospital a day longer than necessary because of her anxiety in the aftermath of a friend's death (C3), another felt she was being rushed out of the hospital because of providers' desire to "clear the hospital out" in time for Christmas, and providers' assumptions that she would prefer spending Christmas at home (A9). Patients who experienced continuity of care provided at the end of the program greatly appreciated it. Patients at two programs spoke of being transitioned to telehealth services at the end of the program, where they were given a tablet or tracking sheet to log in vitals, and continued access to the 24-hour telehealth number (A1, A5, A8, B3, B1). The regular phone calls they received from healthcare providers as they transitioned from programs were reassuring:

> … if my vitals aren't good, they would phone me and they'd talk to me. And it's nice when

> somebody says to you, “Well, maybe you should…” Because sometimes when you get upset, you don’t think of what you should do. […] If she says, “Well, okay, take your oxygen, get yourself calmed down. And if you’re not feeling better maybe you better call the doctor.” And I might say, “Well, I’ll call the doctor tomorrow.” It’s just nice to know that somebody’s checking on you. It makes me feel better. Especially when you live alone. (Program A, 5)

Patients who were readmitted to the hospital once the program concluded appreciated that program coordinators checked up on them and spoke to them about how they could continue to offer help (A1, A3, C1).

Perceived Impacts

As seen above, programs imparted education and self management skills (discussed further under patient engagement below), and fostered a sense of security, reassurance, and well being. Patients spoke highly of the education they received (A3, B2, B3, B4, C6) and the self-management techniques they acquired (A1, A3, A4, A5, A6, A8, A9, B2, B3, C1). Programs were also a source of social and emotional support; providers’ concern made patients feel cared for (A1, A5, B3, C5) and gave them “somebody to talk to during the day” (C6). Patients appreciated having someone checking up on them (A5, C2, C3), giving them a “mental life” (C1) and reassuring them that they were doing well (A2). Merely knowing that the program was there (B1) and they had a telehealth number they could call if needed, provided some patients with peace of mind (A1, A8).

Despite the gaps and unmet needs voiced below, in the grand scheme of things, participants reported that programs fulfilled their need for care and support soon after hospital discharge. Participants spoke of programs as something that would benefit anybody (A2); as an initiative that was “absolutely fabulous” and something every hospital and city should have (C2).

> Oh my gosh, you guys have been… And I'm putting you…I'm grouping you all together. Honestly, you guys. But you've been a godsend, really. Really, you guys got me through those most horrific times. And it was so reassuring to know a PSW was coming. It was so… Oh my gosh, like I want…I would love this, yes, for other people. I hope the government sees benefit in this. Like oh my! (Program A, 8)

Patient Engagement

Patients had a range of different approaches to their own healthcare, at the poles of which were those who actively advocated for themselves, and those who preferred a more compliant approach, with neither advocacy nor compliance precluding the other. These approaches were themselves conditioned by patients' values, life histories, socioeconomic contexts, health needs, and culturally familiar ways of negotiating healthcare. At the same time, participants' understanding of the objectives and scope of programs also informed the ways and extent to which they could be involved. Participants' understanding of programs, in tandem with their approach to engaging in healthcare, also informed their experience of the programs.

Understanding the program

Few patients appeared to have a comprehensive understanding of what the program comprised; where it began and ended, its objectives, and what could be expected of healthcare services and professionals involved. Many were informed about the program and asked about their interest in enrolling in it towards the end of their hospital stay. As such the "program" was understood as commencing upon discharge rather than as the continuation of care by a single team that bridged acute and post-acute care sectors. As one participant noted, “I don't know that the hospital communicated with this [program/ home care] at all. I just took this as being a totally separate entity (C2). Patients therefore could experience their acute and post-acute care as distinctly separate entities:

> I don't think the hospital people did [know about comorbidities]. They were more interested in why you’re there…what brought you there, and getting that cured. Now, when it came to your people [at-home providers], we talked a little more in-depth about my arthritis and my AFib, and that type of thing. But no, the hospital… No, they didn’t take into consideration my arthritis or anything, no. […] the hospital people, […] they’re concentrated in getting you in there, getting you fixed, and getting you out of there as quick as possible. And they’re not overly concerned about what your other problems are, unless it falters and you're back in the hospital again. (Program A, 2)

A more sophisticated understanding of the program, as articulated by this patient, was an exception:

> …when I was getting close to being discharged, a representative from the program came and talked to me about it and told me what was involved… that they were trying it out to see if that’s a good way to help people manage at home instead of sort of being rushed to the hospital. […] I guess in a way because they were a team. So everybody got a copy of whatever was happening to me. (Program B, 3)

Such an understanding enabled this participant to know what she could expect during the program as well as when she transitioned out of it. This allowed her to assess whether she needed services offered, ultimately refusing certain services after careful consideration of her needs and abilities.

Participants' ability to be engaged in their own healthcare – alongside their desire to do so – was therefore informed in part by their understanding of the program itself.

The active patient

Patients who had experience being involved in their own healthcare and advocating for themselves felt at ease letting their healthcare providers know about their needs and preferences as the program progressed. They were confident in their decision to enrol in the program, this decision reflexively informed by their healthcare needs, values, or living circumstances. Such patients might enrol because they "needed the education" (B4), because having someone check on them at home provided a sense of security (A4), or because they were "only too willing to try anything" to help them cope with their condition (A5). The program therefore represented a way of "do[ing] everything you can to help yourself" (A2). One participant cited a specific program feature—the 24-hour telehealth number—as a key attraction (B3), while others spoke about the program as a source of support during a time of need.

One participant for instance, whose key sources of support were telephone conversations with a geographically distant daughter and a helpful upstairs neighbour, found herself overwhelmed by her health concerns, and gratefully accepted the program when offered:

> I really thought I was going to die. I could hardly breathe. And I remember sitting on the floor just crying and my nose was bleeding and I was just a mess. And [program coordinator] came in

> to see me and asked me if I would like to be involved with the COPD [program]. I said, "Oh, yes, I would!" (Program C, 5)

The sole caregiver included was a staunch advocate for her less involved partner, and insisted that he enrol in the program:

> He didn't have a choice because I'm the boss. [I said] That's it. It is a good idea. And so no, sorry about your luck, buddy, it's all for you, so here we go. (Program A, 8)

These patients often displayed a keen sense of how their bodies responded to illness, and saw themselves as active negotiators of the healthcare system. A patient who had been involved as a patient representative at her local hospital, and who had long been active in a COPD peer support group that had become a second family, cheerfully spoke about her family doctor's retirement, and her intention to break in the new one: "I've got to bring her around to my way of thinking. It's my body. I know what's going on. Pay attention to me when I tell you something hurts" (C3) She claimed the same authority within the program, and was satisfied with her providers' ability to listen to her:

> Like I know what's happening, and everything like that, right. And they would pay attention to what I had to say. And then they would ask me different questions. […] And we got along fine. […] Like I was really satisfied with what was happening and what I got from it all. You know, like nobody left me out. You know, nobody kept me in the dark. This is me. Talk to me, you know? Like don't go over there and whisper behind my back because you're talking about my condition. Talk to me about it. (Program C, 3)

Similarly, when another patient found that the number of visits she was receiving too frequent, repetitive, intrusive, and not reflective of her improved health, she made her concerns known to the program coordinator:

> I was getting stronger and I was starting to eat. I was starting to feel better. And […] I'm one that doesn't like a lot of people at me. Like leave me alone. Like I want to get through this by myself. I'm not one that will cry for help. […] And then when two of a kind… […] one was still with me. I had a knock at the door, and it was another one to do the same thing. And I said, well, I already have a girl here doing the vitals. […] I talked to the overall nurse that was over all of the people that were coming in. Hey, come on, do I have to have them morning and afternoon? "Well, no, not if you don't want them." And I said, well, I would prefer not to have them. I said daily is okay but not morning and afternoon. I said I can't get anything done. (Program A, 9)

However, patients who were able to advocate for themselves were also more likely to become frustrated when their needs were at odds with what was provided by the program. One patient, for instance, spoke highly of the health care providers who visited his home:

> I made sure that before they were allowed to leave I got all my answers. And yes, I got them in plain English so we understood it, and if I didn't understand, "OK, get back and talk to me in English here." And then, they'd break it down. If I'm not sure, I'll ask once, twice. I'll keep asking until I'm sure. And the education they gave both my wife and I was just out of this world. We know exactly how to deal with it. (Program B, 4)

At the same time, he thought that the exercises he was prescribed were inappropriate and not tailored to his needs.

> … they're appropriate for certain people. No, they weren't for me. […] I was too busy trying to do other things, and the exercises that we were doing were, for lack of a better way of putting it, they were kind of asinine. They were more like the type they tried to get me to do when I had my stroke and when I had the bypass. You know, try to strengthen up the muscles and that. I have COPD, you know. I've got better things to do than come down here and spend 2 hours and getting nothing out of it. So to me that's just… I'd just turn around and say, "You know, I've had enough. I'm not coming back." (Program B, 4)

This patient also felt empowered to voice his concerns regarding the redundancy of the home visits he was receiving, once his health improved. Once all his questions had been answered, he saw these visits as providers merely "coming in to socialize":

> Just because somebody sitting in an office says, "Oh, you've got to do that"? Get real. […] Their talents are better used for somebody that needs them. And me, I didn't need them. That's why I said, OK, enough. (Program B, 4)

The passive patient

The compliant patient, in contrast, was content – to varying degrees—to be led by healthcare providers, confident that they had his or her best interests at heart. A trusting disposition informed the way they related to the program, beginning with enrollment. As such, a few patients passively consented to enrolling in the program itself. One patient, for instance, explained her participation in the program as a foregone conclusion once it was suggested to her in the hospital:

> “Well, I just say yes to everything. […] If they suggest things are a good idea, I just say yeah, okay. […] whenever they tell you to do something, you do it.” (Program A, 6)

Another went along with program enrollment, seemingly not realizing that she had a choice in the matter:

> … He didn’t ask me if I was interested. So he just said, you know, “We don't want you to have to come back. And so we’re going to help you.” And I said, “Well, that would be lovely.” And so he’s very, very nice. And yeah, so it was like I had another hand to hold, sort to speak. (Program C, 7)

These patients tended to privilege medical authority, understanding the role of a good patient as one who was closely guided by healthcare professionals. As one patient said, “…people that’s professional, of course I’m going to listen to them” (A1). Another kept the program manual provided—Living Well with Heart Failure—on her table and diligently read it almost every day:

> I try to do what I’m told […] when I first came out of the hospital, they gave me a sheet of paper where I was to weigh myself, make sure I take my fluid pill, and my weight. So I made extra sheets and I enter it in that book every day.” They [health care providers] just did everything they thought I needed and told me everything they thought I needed to know and kept me informed. (Program C, 1)

Despite her deference to medical authority, this patient appreciated being kept informed about her condition and receiving information about her care in plain language. In contrast, another similarly disposed patient found herself no more enlightened about her condition at the end of the program:

> I'm just a person who… I'm in your hands, you take care of me. […] The only thing I would like to have known is what are you doing and what's wrong with me? […] I didn't know what I had for the treatment they were giving me. […] I think I really never understood. I never really found out. […] And to me, COPD is not an answer. Because COPD could be bronchitis. COPD covers so many things that it could have been anything. […] I just took whatever they did because they're treating me for whatever they see. […] To this day, I still don't know. (Program C, 2)

This patient took this lack of information in stride. Her sense of security that those who were caring for her knew what they were doing was compounded by her sense of dependency and vulnerability as a smoker trying to fight a lifelong addiction.

Others struggled to answer questions about the suitability of services provided, visit frequency, and program duration, as it was the first time questioning these program features had occurred to them. There was a long, bewildered pause after a patient was asked if she felt that her preferences had been taken into account during the program, before she said "they have to do what they have to do, and I have to listen to them. They're here to help me" (A1). Another noted that the thought of questioning visit frequency or program duration has never occurred to her:

> I don't think about those things. When it's over, it's over. When they come, they come. And I don't even think about it. And I guess it's fine because I never… You know, whenever they came,

> they came. And when they said it was finished with, it was finished with. […] I wouldn't have ever thought about [providing input into care] that way. I mean I just did what they told me. (Program A, 6)

Accounting for patient needs

Patients' needs unsurprisingly evolved during the program and as patients transitioned out of the program. Needs were unmet often when they were not explicitly articulated by patients, and unanticipated by healthcare providers and program design.

Patient needs during program

Most participants spoke about their unmet needs not through explicit critique of programs and patient centeredness (for there was much that was appreciated about programs, as seen above), but rather through the implicit identification of discrepancies between their needs, or their assumptions about program services and what was ultimately provided.

Some patients were already familiar with the information provided and self-management techniques taught (B2, C5, C6), and therefore found it repetitive, and the attention provided unnecessary (A2, C5). Others were overwhelmed with the number of visits and the array of visitors (A4, A9). When a patient who was provided with a social worker was asked what she did for her, she replied:

> Nothing. She just sat there talking to me and asked me how I felt and all this and that there, and if I had any problems. You know, mostly talking. [Interviewer: Was it useful to have her?] I didn't think so. No, not really. She didn't tell me nothing that I didn't already know. (Program C, 5)

It was therefore not necessarily evident to all patients that they could inform program structure and delivery, from providing input into what services they felt were most needed, and guiding visit frequency. Some patients could not recall healthcare professionals actively asking about their wishes (A2, C4). One such patient who simply “went along with what they were suggesting,” found himself wondering if the frequency of visits was warranted, not realising that he could provide feedback and potentially tweak his care plan:

> … my condition didn’t change all that much to warrant people being out here every day. I mean I didn’t mind. I didn’t mind them coming. I enjoyed their visit. But… being repetitive and my non-changing of my health, I would say that… I wouldn't say it’s a waste of resources, but I maybe didn’t need as many visits. (Program A, 2)

Patients could also have different understandings of the scope of specific program services, only to be surprised about what they actually entailed. Having been explicitly asked about her home care needs, for instance, one patient actively guided her own care, asking specifically for nursing visits and a bath chair, while also agreeing to physiotherapist visits. She was therefore visited by a physiotherapist who provided her with information about managing her COPD which she found redundant, given her long involvement in a COPD self-management group:

> … And he [physiotherapist] says, “Why am I telling you this? You already know all of this stuff.” […] But you know, I didn’t know what it was and I signed up for it, if you know what I mean. […] Physiotherapy I thought was exercising or something. […it ended up being] just talking about this. Which I already knew, right? […] what the heck, you know, maybe with him coming, it

> made him more aware of what… Because he had to refer to the book a couple of times. So if I educated him a bit… [laughs]. (Program C, 3)

Patients’ misunderstanding of the objectives and scope of services provided could therefore be compounded by providers’ lack of understanding of patients’ previous health experiences and what was important to patients themselves. This could render the education provided by the program, for instance, redundant at worst or a tangentially helpful reminder of pre-existing knowledge at best (A2).

Because some patients were not aware of the scope of the program – the range of services potentially available, for instance—they did not always articulate their needs to their providers, even as their providers did not actively elicit these needs. As such, it did not occur to a participant to ask program providers for help addressing her greatest concerns – her difficulty paying for ambulances to the hospital and taxis back home when discharged during the middle of the night, and a neighbour whose bullying behaviour made her feel unsafe (A1). Another patient did not realise she could discuss her struggle with a smoking addiction with program providers. “I never even considered it,” she said (C2). Yet another had been “sort of making do with what’s in the house,” having been unable to go to a grocery store for three weeks due to being slow and easily tired. She did not feel able to voice these concerns to program providers because of her uncertainty if the cause was COPD or old age (C2).

Patient needs at transition

Patients could be transitioned first to telehealth services, and eventually to other existing services (self-management or exercise classes, for instance) at the end of the program. Those who experienced a transition that resulted in services that did not meet their needs, and those for whom the program simply ended, lamented the lack of personalized continued care.

As such, a participant suggested that structures of coordination that existed during transition did not account for his needs. He spoke of patiently putting up with having to answer “a truckload of questions everyday” after having transitioned to tele homecare. However, his patience was tested when an abnormally high blood pressure reading was reported to his family doctor, triggering a call for him to visit his doctor. Having become familiar with how his blood pressure responded to first readings and different blood pressure meters over the years, and knowing that his being “uptight about something or other,” had contributed to the reading, he perceived this intervention as depersonalized and unnecessary:

> Overkill. Overkill, to me anyway. Fine, you’ve been looking at different things. But you have no idea of my history. You have no idea of me. And until such time as you know my history or me, don’t prejudge. And by looking at stuff that comes in once a day, prejudging. It’s not good. […] But like I said, some mornings you just wake up crotchety and your blood pressure goes [sky high]. So I don’t worry about it. But for them to jump the gun and tell my doctor for me to go in, [SIGH] back off. […] No. Personally, I find it intrusive. (Program B, 4)

The desire for transitions that were sensitive to individual patient needs extended to program structure and visit frequency, as patients transitioned out of the program. A participant from program B wished “the exercise program continue[d] for a longer period of time” (B1), while the program C participant who had long struggled with a nicotine addiction wished there had been some form of continued care that was responsive to her unique needs. Providers had visited her at home twice a week at the beginning, tapering down to once a week, until “all of a sudden, it was done.”

> …I would have liked to have seen them come once every 3 weeks […] And not a phone call either. You know, coming in. Because when they come into your home, they can smell smoke. OK? You can't get away from it. […] It sounds funny, but it's like a child being caught with candy. […] I think they came twice a week at the beginning and then […] they tapered it down to once a week. And then, all of a sudden, it was done. I was disappointed. […] I really would have [liked to have continued for longer…]. To make me behave. (Program C, 2)

While one participant above (B4) critiqued the type of exercises he had been prescribed, another participant in the same program recommended a more client-centered approach to care, as a way of fostering greater provider responsiveness to patient needs. Providers at her exercise program would first provide instruction, then "sit at their desks" while program participants undertook their routine largely ignored, she complained:

> Very easy job for whoever is working there. When you first come, they show you the exercises. You have to do this and this and this. […] And really after that you're on your own. […] I thought they should be with the people, you know, instead of me doing all the things by myself. I could do it at home. I don't have to go there. […] I mean I could have done it wrong but nobody was there to say, "Oh, you did it right," or "You did it wrong." […] be more attentive to the customer, to the clients. You know, watch them. Or come by every once in a while, see how they're doing things, and see if they're doing it right or not. […] For all I know, maybe I did it wrong, you know. (Program B, 2)

The few patients who needed but did not have continued support in some form felt most deserted. This was particularly so if they developed complications after the program ended, when they needed support most:

> … right now, when I really need it, there's nothing, you know. […] I ask how come they just give you this as a teaser or whatever you want to call it and then cut it off? You know, you get used to something nice and then bingo, you're on your own again and fall in […] the same old shit. [The program] was good. But it was not enough. Like I said, it's a teaser. They hang this in front of your nose and let it smell you a little bit and then take it away. (Program C, 4)

This patient had only his wife to depend on for support, and it was she who suggesting weaning off his medication to help with his bad dreams and anxiety attacks.

It was also important for programs to be accessible in multiple ways. As such, one participant spoke of not being able to join a rehabilitation program despite his doctor's support and his desire to do so, because of stringent pathway prerequisites (B1). Others found it difficult to travel to rehabilitation and self-management programs that were inconveniently located, making them dependent on others for transport (B2, C7).

Conclusion

Participants appreciated having access to integrated care programs, valuing the care, connectivity, and reassurance they provided. They valued the personalization and individualization of care when present, missing it when absent. Many recalled instances of health care providers actively responding to their individual needs and listening to their concerns. However, patients' needs and desires were not always known, acknowledged, or privileged, and it is here that there is scope for improvement.

Patient needs were unmet in instances when they were unarticulated by patients, and unanticipated by healthcare providers and program design. Gaps in the patient-centeredness of programs often occurred at a juncture where the lack of understanding of both patients and providers collided. Providers were sometimes unaware of the most pressing needs of patients—concerns that may not be limited to healthcare alone even as they may have important implications for patients' health and overall wellbeing. At the same time, patients who harboured commonly shared assumptions about what constituted relevant medical knowledge, self-censored information pertaining to broader concerns. Others may have embodied preconceptions of the privileged position of medical authority, content to perform the role of a dutifully compliant patient, unaware that they had the option of articulating their opinions let alone questioning program design. Yet others had only a fuzzy idea of what the program entailed, what all their options were in terms of service availability and visit frequency, and therefore how they could help co-design their pathway in a way that best suited their needs.

How then can program providers foster understanding as a step towards greater patient-centeredness? An analysis of patients' experience of the three integrated care programs suggest that providers need to a) actively elicit patient concerns and needs beyond a strictly biomedical paradigm, b) elicit patients' previous health experiences in relation to the condition of interest to assess patients' existing understanding of the condition and familiarity with self-management skills, c) ensure patients have a good understanding of the program itself, from its objectives, duration, range of services on offer, to what can be expected as patients transition out of it, so that patients are better equipped to guide their own pathway, d) acknowledge that patients may have a range of assumptions and wishes about how they should and can be involved in their healthcare; listen to those who wish to advocate for themselves, and respect those who do not while ensuring they are aware that they have the option of shaping their own care, should they wish to do so, e) help inform program design by making programs more sensitive to the diversity of patient needs, while ensuring meaningful transitions and continuity of care.