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Cover Page Footnote

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What older adults want from their health care providers

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Abstract

Changing demographic trends and population needs have increased demand for chronic complex care and contributed to rising health care costs. The study sought to identify unmet health care needs of older adults and opportunities for service improvement in a high need suburban neighborhood of a prairie province. The insights provided by older adults informed the service design for a new model of integrated care in community settings. Narrative inquiry methodology was used to understand care experiences through stories. Stories of older adults' health care journeys were elicited with semi-structured interviews. A paradigmatic approach to analysis was applied with holistic coding, mapping of story elements followed by comparison and theming across participants' stories. Older adults perceived that relationship and informational continuity fostered effective communication and supported coordination of care. Timely access to care was valued and flexibility in types of medical encounters was suggested as an option to improve provider responsiveness. Access to information about community resources was limited and older adults required support with navigation. Structural (e.g. availability of services and transportation), financial and personal barriers exist for older adults to access and use community health services. Health care transitions were inadequately supported by comprehensive discharge planning, timely communication and follow up post discharge. New models of care need to embrace person-centred and goal directed approaches to the delivery of care to improve patient experience. Older adults offer valuable perspectives as community partners and co-designers of systems change in efforts to re-engineer health services.

Keywords

Patient experience, patient engagement, integrated healthcare

Introduction

Two formidable challenges for Canadian health care systems in the 21st century include an aging population and rising prevalence of people living with multiple chronic conditions.¹⁻³ These changing demographic trends and population health needs increase demand for complex care and social services and contribute to rising health care costs.⁴ Despite recognition of the growing need for chronic complex care among the aging population, the existing biomedical models focus on the provision of acute episodes of care by specialists. Additionally, poor access to intermediate levels of care, (e.g. home hospital, community paramedicine, rapid response teams and stroke rehabilitation outreach), has adversely affected patient flow from acute care to community and increased need for Alternate Levels of Care (ALC) beds.^{5,6} These forces have resulted in high acute service utilization by patients with complex care needs, and prompted closer examination of health care delivery pathways.⁷

Nationally, health system transformation and reengineering of health care delivery have become a priority.^{8,9} The health system's focus has been driven by

research that suggests that integrated care delivery systems offer a flexible approach to provision of comprehensive, coordinated care across the care continuum^{10,11} and hold promise for improving health, satisfaction, and service utilization outcomes of older adults.¹²⁻¹⁴ A renewed focus on primary health care, with expansion of interprofessional collaborative primary care teams, has also been identified as an important strategy to achieve national and local health goals.^{8,15,16}

The study was conducted in a medium-sized Canadian city where taxation-based, publicly-funded services (Medicare) are delivered by a provincial health care system, operating in parallel with fee-for-service physician models.¹⁷ Additional health care services, including home care, long term care, prescription medications, outpatient physiotherapy and rehabilitation services, are funded through a mix of public and private insurance coverage, and out-of-pocket payments. Consistent with the national focus, the local integrated care model was developed to align health system functions and processes, and aims to produce a seamless care experience. Model development and implementation was ceded to a team comprised of project leads, project manager, quality improvement

specialist, design consultants, and clinicians. An advisory group, comprised of clients and families, worked closely with the team to ensure that community perspectives and needs were considered.

The integrated care (IC) model is based on primary care principles of client centred, community designed, and team delivered care. It features an interdisciplinary team which is co-located in a community health centre with a shared electronic health record. Services will be expanded to include ambulatory and intermediate care in addition to home care.

There are World Health Organization (WHO) guidelines for integration of care but it is unlikely that a single best practice model will meet all system and population needs.¹⁸ Furthermore, despite growing promise of integrated care models, little is known about patient experiences in integrated care settings.¹⁹⁻²¹ This is consistent with an emphasis on IC model success defined by quality measures such as clinical effectiveness, cost effectiveness and patient satisfaction.²² While measuring quality is important, there is a need to identify critical domains, within integrated care models, that contribute to a meaningful patient care experience.²³

A central model design objective was to improve patient experience. Hence, the aim of this qualitative study was to better understand the health service needs of older adults in a suburban neighborhood by eliciting narratives of their care experiences across the care continuum. This provided insight about unmet health care needs and identified opportunities to improve services to better respond to the complex care needs.

Methods

Narrative inquiry is a way to understand and study experience.^{24,25} In the context of this study, stories were elicited about the health care journeys of older adults, as a way of understanding their care experience. A critical lens was applied to acknowledge that the patient's voice has historically been silenced and one project goal was to support patient engagement in shared decision making about health system priorities.²⁶⁻²⁹

Eligible participants included older adults (aged 50 years or older) who had a health care experience, (e.g. hospitalization, family physician, physiotherapy, pharmacy, home care), in the past 12 months. The intent was to sample a broad range of experiences among older adults with diverse sociodemographic characteristics and health care needs. Using purposive sampling, we recruited 42 participants from multiple sites. Sites included four community residences and a mall located in the same suburban neighborhood as the community health centre. These residences included public and private retirement communities with varied levels of support, including

assisted living. Client and family advisors were also invited to participate. The study was issued an exemption by the university's research ethics board, as it was considered quality improvement. Despite the exemption, the study conduct was still expected to adhere to research ethics principles, and use the instruments that we outlined in our application.

Data collection

Semi-structured interviews were the main data gathering strategy employed during the study. An interview guide was developed that identified the main topic areas to be covered. The initial open-ended question revolved around, "what is it like to be a patient in this community". This was followed by a series of questions to understand factors contributing to positive and negative health care experiences. Probes were used to further explore an issue or gain clarification.

Most interviews were conducted in person at a mutually agreed location. However, there were two telephone interviews, and one participant exchanged information through a series of emails. In most cases, the interviews were conducted with a single individual, although a support person was sometimes present. The first author conducted all interviews from December to the end of January 2018. Interviews were digitally recorded and transcribed. The average duration of interviews was 38 minutes (range 7 to 114 minutes). Transcripts as well as notes were imported into NVivo 11 Pro, a software used for textual data analysis.

Data analysis

Using a paradigmatic type of analysis, individual interviews were considered as stories.³⁰ Storied data were analyzed for common threads, patterns and themes to illuminate the story's meaning. Each interview was read in its entirety to situate each participant's experiences within the broad context of their lives. Consideration was given to who they were in relation to their past (e.g. occupations, social roles), and how their multiple identities converged on the stories that they chose to tell. The types and frequency of contacts with health care services were explored, as well as the participant's current health and functional status and the significance of support from others. Where participants expressed emotions in relation to utilization of services, this was also noted.

The health experience wheel³¹ provided ideas about how to visually summarize the data collected in stories into discrete phases that could be compared. The health experience wheel is a tool for representing information about a patient's care journey.³¹ Usually the care journey is divided into phases (e.g. diagnosis, treatment), and represented as segments of the wheel. Positive and negative experiences are shown with emoticons and

excerpts that summarize the interactions and convey information in a compelling way.

In an iterative process, each interview was summarized with a single ‘map’. The process allowed each story to remain intact while creating a platform for comparing stories across participants. Each map summarized information about who was involved, what happened and where, how they felt (green indicated positive experiences), and suggestions for change. (Figure 1) The story elements were refined through comparisons and named often using the participant’s own words. Exemplary excerpts were provided to support the interpretations that were presented.

Peer debriefing with project team members facilitated critical dialogue and reflexivity. This process provided the opportunity to challenge assumptions about things that were observed or heard, interrogate thought processes and explore multiple and alternative explanations for the data. The client advisory group also provided feedback about the team’s interpretations and whether they were consistent with the clients’ own experiences. Initially, individual transcripts were provided to some participants to allow them to critically reflect on what they had shared. Some authors have questioned the benefits of this practice of transcript review and advise that both advantages and disadvantages should be considered when adopting this practice.^{32,33} This approach was used but, subsequently abandoned as participants found it overwhelming, and difficult to read, while others did not respond.

Results

Participant characteristics are summarized in Table 1. More than two thirds of participants were female (N=29), and 66% were 75 years or older. All participants were

living independently although some participants received help with selected self-care tasks such as bathing and instrumental activities of daily living.

Table 1. Descriptive characteristics of the sample

Variable	N (%)
Age (years)	
50-64	6 (14.3)
65-74	8 (19)
75-84	18 (42.9)
≥85	10 (23.8)
Gender	
Female	29 (69)
Living arrangements	
Live in independent units	42 (100)
Need assistance with IADL*	11 (26)
Family support	34(81)

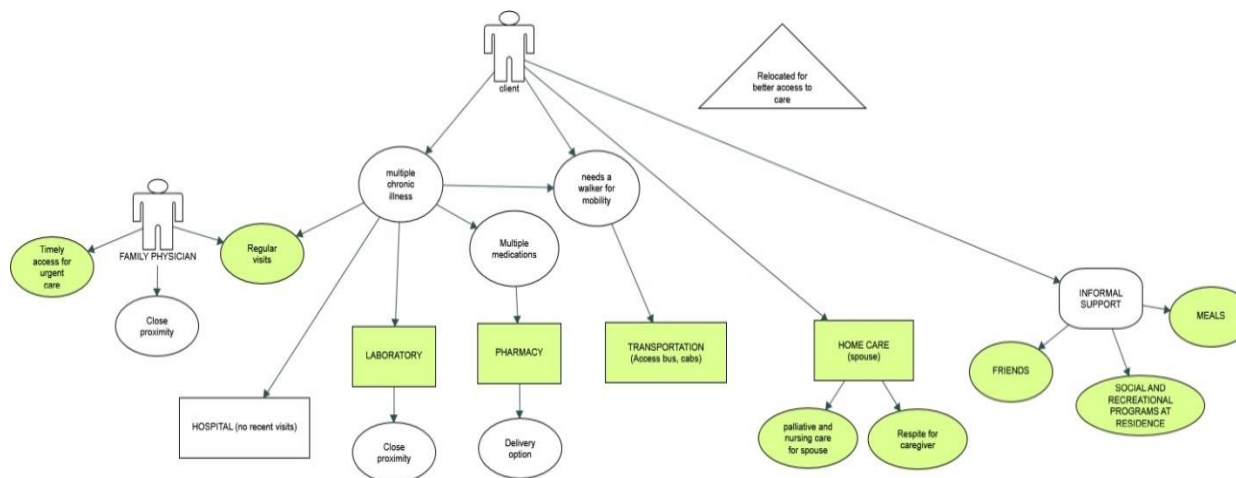
*IADL =Instrumental activities of daily living (e.g. meal preparation, housework, transportation)

Several commonalities were noted across the participants’ stories of their care experiences. They are reported as four themes including, 1) access to information and services, 2) communication between patients and care providers and among care providers, 3) support from family and staff at residences, and 4) smooth transitions between acute and community services. Pseudonyms have replaced participants’ names and identifying information has been removed to preserve confidentiality.

Theme 1: Access to information and services

Participants commonly had contact with multiple services including family physicians, laboratory, pharmacy, and

Figure 1. Example of a map



home care. They identified that proximity of services was important for access. They described structural (e.g. number, organization and configuration of services), financial and personal factors that shaped the experience of care.

1.1 We don't know what's out there

Older adults' knowledge of community resources varied, as did knowledge of technology available to access information. For example, many participants had never heard of the 811-health information line (24 hour health information and support line). A participant explained how she had incidentally learned about key community resources. She remarked,

I had never heard of Client Patient Access Services (CPAS) until [name] came into our lives and what a wonderful thing that is to be a part of! But we didn't know, and many others still don't know ... there should be a registry of all these things listed. If I am unable to drive for a while, we may need the services of the Access Bus. I know of its existence, even though I don't at the moment know how to enroll to be able to use it. But I do know how to find out, and that is so comforting. Are there more things I should know about and don't? (Jane, caregiver)

1.2 It is difficult to get a doctor now

Participants also perceived limited availability of family physicians to meet the growing demand for services. This was thought to be more difficult for persons who were new to the area. Dave said, "I think it is very difficult to get a doctor now. If you don't have a doctor and you are new to a city, it is difficult."

Even though it was perceived that there were more specialists, lengthy wait times were a barrier to timely access. This seemed to vary depending on the area of specialization. One participant explained his futile attempts to see a cardiologist to get medical clearance for his dental surgery.

Before I can get the teeth out, to have new teeth in, they put me to sleep and take the teeth out and put the new ones in. The teeth are made and sitting at the dentist's office. I paid over three thousand for them and now I can't proceed with the work. You try and get an appointment with the cardiologist. It is impossible. It is a hard problem in [province]. (Floyd)

1.3 Flexibility in types of encounters

Although some participants received urgent care at medical centres, they preferred to see their regular provider than 'a stranger'. Some participants thought that access to services could be improved by offering more flexible types of encounters with family physicians. In addition to in-person interactions, some participants wanted to call or email their doctors when they had a concern. Karlene explained,

"And a system where we can go to see our doctor without having a long wait for an appointment. Even information back from my doctor would be wonderful. Even if I could phone, email or something so that she can know that I have a concern."

1.4 Sometimes I can't afford the stuff I need

For some participants, the cost of services was a barrier to access and utilization. This often related to community therapies that were not covered under the provincial insurance package. Karlene, who lived in subsidized housing, expressed her concern about access to outpatient physiotherapy when she was referred by her doctor. She said, "The other doctor gave me a physiotherapist list. I remember I checked for a physiotherapist and it was going to cost \$100 just for the first appointment. I said no."

Another participant described her struggle to see a podiatrist due to financial barriers.

The podiatry rate is like \$60 for half an hour; the same with physio. It is pretty expensive. So yeah, I feel sorry for the diabetics who need foot care and can't afford it, you know because there are a lot of diabetics seeing the public podiatrists. So yeah it will hurt a lot of people at the lowest end of society. (Laura)

In some retirement residences, foot care services were offered through partnerships with private providers at a cost. Some participants made sacrifices to obtain the services when recommended by care providers. Beth explained, "Yes, it is hard, but I have been getting it for four years. So we have to pay for it. I need it for my diabetes."

1.5 Personal factors (Acceptability of services)

Personal factors, (reflecting acceptability of the services), had an impact on participants' utilization and experience. Services that provided outreach to homebound older adults were valued.

Laboratory services. There were mixed experiences with the neighborhood laboratory depending on whether participants knew about the service app. The app allowed participants to check in online and gauge expected wait time for services. This meant that they could plan when they wanted to go to minimize wait times. Participants who were unaware of the app and could not exercise their preferred option to make an appointment were among the most disgruntled. A participant who received assistance from her daughter with transportation and scheduling shared her experience. Mary said, "She [her daughter] can see the wait times. We went the other day and I went right in."

Pharmacy services. Administration of medications was an important activity for participants. Most participants were

taking several medications for managing multiple chronic conditions. Participants reported that pharmacies offered bubble packed medications and flexible delivery options that included home delivery. This was especially appreciated during the winter, when it was less desirable to go outside.

I get it [medications] from the [pharmacy]. I get the bubble pack for the whole month. So yesterday morning, Shoppers called me that they had the pack ready and they deliver between 2 and 5. So I said fine I will meet them downstairs. I go downstairs, and they tell me the amount and I get my medication. (Sarah)

Home care services. Participants received a variety of home care services such as respite for caregivers, palliative care, nursing and self-care such as baths. Some participants who were referred for home care services were reluctant to accept help although functional decline made it increasingly difficult to perform tasks such as household chores. The reasons offered were privacy, wanting to take care of oneself, and not wanting to be a burden. Gene reflected on her conversation with her doctor regarding the progress of her recovery after surgery.

And I said to him [her doctor] I am so tired. I would mop the kitchen floor and I have to sit down. I vacuum the rug and I have to sit down. He said that will go on for quite a while. You will get very tired with this operation. I guess I have to live with that. I don't want anybody doing my work if I can just go on my own speed I can do it.

Outreach services. Outreach services allowed providers to observe how clients functioned in their homes and make practical recommendations. Janet explained how helpful it was to have the occupational therapist visit her home.

We have experienced wonderful help with his medical needs. It was so "special" to have the physiotherapist come here and make recommendations based on the limitations of our available space and the furniture we have. She recommended that he sit in a more upright chair than the recliner he "lived" in, which has greatly helped his shoulder pain. This could not have been done had she not come here and seen where he lives and what he does. (Janet)

Theme 2: Communication

Relational aspects of care were important to older adults in this study. Older adults wanted their care to be delivered by providers who knew them, listened to them, spent adequate time and offered the opportunity to be involved in decisions about care and treatment options.

2.1 I wish that you would listen to me

Participants reinforced the importance of effective communication between the patient and provider as well as among providers across the care continuum. Allan explained, "My doctor doesn't rush and that is one thing that I like about him. I often wonder how he gets through the day because he has several other people to deal with." Another participant emphasized the importance of patient involvement and the opportunity for shared decision making in formulating the care plan. Lena shared her frustration that her doctor did not consider her preferences and needs.

The doctor that I have, she and I didn't get off on a good footing...I would like to talk to her. She is always pushing meds on me. I want to say what is another natural way that I can work on this? I know there are times when you need meds. I need meds for my thyroid now as it is giving out. But in some situations, I want to find a natural way to work at my health issue if I can rather than take medicines all the time. She doesn't seem to have time for that. You know to talk about that. It is just a hurry all the time. (Lena)

2.2 Why don't you talk to each other?

Older adults experienced care as fragmented and disease-focused. This evoked feelings of isolation and reduction to individual parts of a whole person. Sharon shared her journey with multiple cancer diagnoses and complications from her treatments.

It is like an octopus because that's what I deal with in my physical being right now. To my vagina, to my breast to the other side where the breast is removed, the lymphoedema and my mouth that flares up from the chemo. I have to deal with many professionals [names]... Every time I got someone else. That's not ok. I am one person. It is not ok that health care has divided the human body into 62 parts and makes the person go all around. You are either a doctor and you know what you are talking about or you don't (Sharon).

In contrast, Beth was referred to a rehabilitation program to help with recovery from a recent stroke. She was very pleased with the integrated approach and that she would receive support from multiple providers who were co-located including physiotherapist, occupational therapist and a dietitian. Transportation was also arranged to facilitate her attendance and participation. She commented,

It has been wonderful, I have been very lucky. I will be starting a stroke program twice a week for five hours per day. They will teach me how to walk without dragging my leg and some exercises for my eyes. My family doctor referred me and then the stroke doctor took over from there... Yes she (physiotherapist) will be working

with me. Also, a taxi will come and pick me up and take me to the hospital. That has all been arranged already. Everything is at [name] and I will be seen by these four doctors every time I go. Like I said, for me it has been excellent. Then for the foot care procedures I have to go through... there is a whole bunch of stuff in here” [points to her binder with the information].

Participants had mixed experiences with shared information in medical records. A participant was frustrated that different providers would ask her similar questions about her medical history. Over the years, she had multiple care episodes and had resorted to compiling the information into a personal dossier that she carried with her. Laura explained, “I don’t know how up to date the records are in the hospital, or if they are easily accessible. But like I said every time I see another one I take my history because they ask anyway. They always ask so...it helps me to remember everything.”

2.3 I like to see the same person

Relational continuity was important to older adults in this study. Participants often had long standing relationships with primary care providers. When transportation was not an obstacle, some participants sacrificed convenience for continuity and remained with their doctor even when one of the parties had relocated. Some participants also preferred consistency in home care personnel as it fostered trust.

Home care nurses came in and removed the drainage and next day they came back and removed the staples. I think the only issue that I have with the home care nurses that were there every day... it was a different nurse every time. You don’t get accustomed to one person and I don’t know if it is trust. If it were the same person, a little bit of a relationship could be established, and it would be more encouraging for the patient. (Brian)

Theme 3: Support to cope with chronic diseases and functional decline

Participants described the importance of support from various informal and formal sources to continue to age in place including family, friends as well as staff in community dwellings. This was integral to facilitating self-management among older adults who were fearful of losing their independence. Danny who required oxygen, had poor vision and required assistive devices for mobility appreciated his sister’s support. He said, “My sister does lots for me. She buys me groceries and all my medications. She gets what I need personally. She also takes me to the doctor. I got a niece and she is pretty good too and comes to see me sometimes.”

Older adults enjoyed the social support at community dwellings and there was universal agreement that

recreational programs were adequate. Opportunities for physical activity were an integral part of programming, and all offered the opportunity for at least one daily meal at supper. Arrangements varied across residences with some including all meals, while others a set number of meals were included in the rent. This allowed older adults to adapt to changing health care needs and remain in the community.

Oh yeah. The people are nice and we have programs, occasional speakers and so on. There is always something happening downstairs. Coffee is always downstairs. There is coffee corner from 9 to 4 o’clock, if you want coffee. I really don’t drink coffee, I go downstairs and I put a little coffee in the cup and the rest hot water. Just to be with the people. (Silvia)

Theme 4: Health care transitions

Some participants described their recent hospital experiences. Discharge from hospital was a concern when community support was inadequate. A participant discussed his concern when his frail elderly spouse who was in assisted living was discharged after day surgery. He said,

They now call that day surgery and they want them out right away... She wanted to stay there at least overnight to make sure that there was no bleeding and pain killers were working. I stayed with her ... I was afraid that something would happen during the night. She might get up and fall. (Brian)

Another participant was concerned about timely communication about discharge to be able to arrange transportation to go home.

They had on the board there that I would be going home [date]. I was geared towards that. Then my niece phoned and talked to the head nurse if there has been any change. And she says it might be today, tomorrow or Monday. My niece wanted to know when I was going home. She told her to phone around 3 and I will be able to tell you. My niece is a nurse and she knew this nurse would be going home at 3. So she phones at 2:30 and she gave her an answer. If she had phoned at 3 then she would not have been there. Why didn’t she tell her right off the start and say you want to know and I have to look into this? (Olene)

Discussion

This study highlights several unmet health needs and opportunities to improve service design and care experiences of older adults in the community. Participants almost invariably had multiple chronic conditions and complex care needs. This is consistent with the comorbidity profile of older adults in Canada.³⁴ Most

participants reported regular contact with a family physician but also intermittently received specialist care.³⁴ They experienced the health care system as fragmented and disease focused.^{35,36} Older adults who had encountered integrated care services, (usually in chronic disease management programs), found that care was better coordinated and convenient for them. This supports the system's focus on establishing an integrated model with team-based care to improve coordination and health of older adults with multiple chronic conditions and complex care needs. Integrated care models such as System of Integrated Care for Older Persons (SIPA) and Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) have been evaluated and found to decrease utilization of hospital-based services, institutionalization and functional decline among the frail elderly.^{13,37}

Older adults in this study expected efficient sharing of health information among health services across the care continuum. The team has recognized the need to improve sharing of information among providers and across systems to improve coordination of care. An integral component of the new model of care is the creation of a shared electronic medical record, that is single source of information about an individual's plan of care. This would reduce the burden on older adults to recall lengthy and complex medical histories. It also would decrease risk of overprescribing and repetition of lab work and other tests.

Effective communication is an essential function in patient-provider interactions across the continuum of care. Older adults wanted to be listened to and to have their preferences considered in the plan for care.⁴ Other studies have shown that older adults value the quality of the interpersonal interactions with their health care providers.³⁸⁻⁴⁰ The new model of care orients the clinical team to apply person-centred approaches to care. It includes support for older adults to define goals, and engage in shared decision making to the extent desired, and also includes measures of client centredness as performance metrics of model success.

Older adults expressed frustration at both the length of time waiting for an appointment to see specialists and the duration of consultation with providers. Similar findings have been observed in other studies.^{38,41,42} Shorter wait times were desirable to allay concerns about functional decline or deterioration due to delayed intervention. The new model will accommodate longer appointments to address complex care needs and offer some specialized services to improve timely access to care.

Consistent with various models that predict health care utilization, several access barriers including structural (e.g. availability of services, transportation), financial and personal (e.g. acceptability) were identified among older

adults in this study.^{43,44} The project has committed additional human resources (e.g. community therapies and physician) to address some of the gaps. Partnerships with municipal services and community-based organizations, (e.g. public transit, Council of Aging, Alzheimer's Society), are being explored to mitigate the impact other factors (e.g. transportation and peer support).

As older adults experience functional decline and lose the ability to drive, dependence on others or public transportation increases. Transportation is a potential barrier to access among older adults in this community.⁴⁵⁻⁴⁷ Seasonality also poses a challenge for older adults who may fear falling even with assistive devices, and limit excursions away from their residence. Service design will consider the impact of seasonal changes when facilitating outreach services to older adults.

Older adults in this study had limited knowledge of community resources and services that were available to support healthy aging. This is compounded by lack of a comprehensive repository of current community resources, as well as limited access to web-based information. Although the digital divide among age cohorts is decreasing, use of information technology among Canada's oldest adults (age 75 years or older) remains low.⁴⁸ A recent study among older adults in a rural community in Saskatchewan also reported that the preferred method of health information dissemination is through word of mouth.⁴⁹ There are likely differences between older adults in urban and rural contexts that influence preferences, including key determinants, such as experience with technology and perceived computer self-efficacy.⁵⁰ While there is a need to disseminate information using multiple channels, capacity and preferences should be considered. This has implications for care providers' who should assess their patients' health information needs, access to current information about resources, and provide support for navigation when required.

Strengths and Limitations

A narrative inquiry approach allowed participants to freely express their opinions, and determine what was most meaningful to them in their experience. This contributed a missing but valuable perspective to inform conversations about what good care looks like from their perspective and important components to be considered for the model of care for the community.

The study engaged a diverse sample of participants who reside in retirement communities and are potential recipients of the new services. Barriers to engagement for more fragile and harder to reach individuals were also addressed by reaching out to the most populous multi-unit retirement residences.⁵¹

Study participants included persons who were living independently. Persons who are residing in assisted living facilities have more functional decline and require more support and resources. Thus, their perceptions and health care experiences may be different from those expressed in this study.⁵²

Conclusions

Older adults in this study identified several health system attributes that could be optimized to improve health care experiences. The gaps identified such as need for relational and informational continuity as well as shared decision making have been incorporated into the design elements and care processes. Community needs assessment has also supported the business case for additional staff including nurses, geriatricians, occupational and physical therapy, and social workers. The appropriate staff complement will increase capacity for service provision to meet the demand and increase access to services. Partnerships with community-based organizations have been strengthened and allowed for better alignment of programs and services, expanded reach and coordination. Client and family involvement in the design process has allowed for better understanding and response to community needs.

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