OLDER ADULTS' PERSPECTIVES ABOUT PRIMARY CARE: INFORMING NURSE PRACTITIONER LED PRIMARY CARE

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Abstract

This study describes community dwelling older adults' experiences in accessing and using primary care services from a spectrum of primary care model. This study reports the findings from one focus group. Older adults shared their past and current experiences with primary care and their opinions to inform the design of a new nurse practitioner led primary care service. Inductive thematic analysis was used to develop themes and subthemes. The themes were: lack of voice and value in primary care; communicating information; and primary care vision of older adults for older adults. Older adults have specific health concerns that are currently not being addressed in primary health care systems. Understanding the experiences of older adults'utilization of primary care services is an important [illegible] to inform the ongoing development for a prototype nurse practitioner primary health care service embedded within a social service organization in Western Canada.

Keywords: Older adults, Primary Care Providers, Experiences, Primary Health Care

Introduction

Health care has changed dramatically over time due to population aging, multiple comorbidities, technological advances, and public interest in engaging in their own health care (Public Health Agency of Canada, 2015; World Health Organization [WHO], 2015). Older adults are more likely to have multiple chronic illness conditions, atypical presentation of acute illnesses, and complex social needs (i.e. housing, finances, loss of spouse), thus, increasing their likelihood of accessing health care services (Canadian Institute of Health Information, 2011; Health and Social Care Information Centre, 2015). Yet, the present systems of care and health resources are not adequately met older adults complex health needs (Baumbusch, Leblanc, Shaw, &Kjorvin, 2016; Covinsky, Pierluissi, & Johnston, 2011; Dahlke, Baumbusch & Hall, 2017). Moreover, health care consumers are more informed, actively engaged in their health care, and considered quality health care a basic human right (Savage et al, 2016). It is necessary that accessing and using primary care services to meet personalized (or individualized) healthcare be understood from the perspective of older adults. The purpose of this study was to understand the perspectives of older adults' needs related to primary care.

Background

Primary care is defined as health care that is accessible to individuals and families within the community and is the first contact an individual has with the healthcare system (Starfield, 1998). Primary care should include the prevention and treatment of common diseases and injuries, referrals and coordination with other levels of care, health promotion and rehabilitation services. Family physicians, nurse practitioners, pharmacists, and telephone advice lines play an integral role in providing primary care services to older adults (Government of Canada, 2012). Older adults are defined as individuals over the age of 60 (World Health Organization, 2018).

Older adults may face obstacles to active engagement in their care due to low health literacy, transportation immobility and hearing impairment (Kotval & Zeenat, 2017; Pandhi et al, 2011). Individuals with limited health literacy have difficulty accessing health information leading to deficits in self-management of health, use of preventative services, and higher hospitalization rates (Public Health Agency of Canada, 2014). Family members are often required to assist older adults with low health literacy to navigate health needs (McGhan, 2014; Pinquart & Sorensen, 2011). Moreover, people over the age of 75 drive less leading to transportation challenges (O'Neil, 2015), which can lead them to discontinue activities and services that are necessary for their daily living and personal health, thus negatively impacting their quality of life (Kotval & Zeenat, 2017). Meeting older adults'complex health and social needs, while encouraging active engagement in their personal health care is challenging.

We were interested in exploring how to best tailor services that meet older adults' complex health care need in a newly opened and unique primary care model. The new primary care model uses nurse practitioners as the main provider of health services in collaboration with other services co-located within an existing centre for seniors. There is a unique formal collaborative agreement between the senior's centre and a faculty of nursing to engage in research and teaching activities at the site.

To understand older adults' needs and preferences we utilized (or adopted) the process of Human Centered Design (HCD). Human-Centered Design (HCD) has been used to incorporate consumers in the design process using design thinking. Initially conceived in the early 2000s, design thinking is a process for designing and developing innovation that is sensitive to consumer needs and values. The process involves an iterative cycle of refinement that leads to the development of a consumer-informed product specifically design to meet the unique needs of a population (Brown & Wyatt, 2010; Vechakul et al., 2015). The HCD process also relies on knowledge of human emotions, behaviors and thought processes to guide product and service design that work for specific consumer groups (Vechakul et al., 2015; Searl, Borgi, &Chemali, 2010). This study aimed to engage older adults in discussions about their experiences and desires in accessing and utilizing primary care services as the first step in a HCD process.

Methods

Focused ethnography was used to analyze and interpret the experiences that older adults shared with us during the beginning of the HCD process. Older adults who attended a well-established senior center in a large western Canadian city that provided a variety of social service programs and resources for older adults were in our inclusion criteria. Focused ethnography is a useful method to explore a topic in context and a distinct shared experience, characterized by short field visits and an emphasis on communication activities and cultural elements such as routines, ideas, knowledge and actions. (Cruiz & Higginbottom, 2013; Lobiondo-Wood & Haber, 2015; Wall, 2015). Older adults were recruited by advertisements and flyers. Participants were eligible if they attended the center for social services, spoke and understood English, and were capable of providing informed consent - understanding the risks and benefits of the study. Participants self-selected by contacting the research team or by signing up through the center.

Data collection began after ethics was obtained from the university on record (ethics number 73530). Semi-structured interviews of older adults occurred in a focus group using an interview guide after participants had the opportunity to ask questions and had signed a consent form. Sample questions were: Are you currently involved in decision making with your primary care (PC) provider? If you could get anything new or different at your PC providers' office, what would that be? and does the way your PC provider talk/interact with you make you feel in control of your own health? The focus group was audio-recorded and transcribed verbatim. There were eight participants, three males and five females in the focus group reported in this paper. This focus group was part of a larger study, it was used as a student's honours project.

Data was analyzed using inductive thematic analysis (Lobiondo-Wood & Haber, 2013). Three independent researchers reviewed the transcript.Topic coding using the participants' words was used. Next, codes were grouped together into categories. Categories were grouped together to develop themes (Lobiondo-Wood & Haber, 2013).

Rigour was maintained by addressing credibility, confirmability, dependability and transferability. Credibility and confirmability occurred through debriefing among the researchers after the focus group and during analysis (Lobiondo-Wood & Haber, 2013). In ethnography, moving from particular instances to general patterns is accomplished by identifying themes and patterns to develop explanations about the social context. The researchers read the transcripts individually and then met to discuss analysis and reach consensus about categories and themes. This process was used to refine the themes and categories.

Reflexivity was enhanced by using a journal to write down any biases that arose to ensure that these biases did not interfere with the analysis process (Lobiondo-Wood & Haber, 2013). Dependability was ensured by having research procedures documented throughout the study to create a transparent process (Lobiondo-Wood & Haber, 2013). Transferability was maintained by detailing sampling, setting, constraints, data collection techniques, the number of participants, the length of the focus group and the results of the study to allow for the application of this research into other contexts (Lobiondo-Wood & Haber, 2013). Providing rich detail provided insights into the cultural context and health needs of older people that could provide possible transferability to other sites.

Findings

Three themes emerged as a result of data analysis: lack of voice and value in primary care; communicating information; and primary care vision of older adults for the ageing population.

Lack of Voice and Value in Primary Care

Participants' interactions with PC providers (PCP) influenced their perception of primary care. Some times the PCP was the participants' physician, or nurse practitioner, other times the PCP was a physician seen in a walk in clinic. Participants had experienced a variety of PCP services. This include not being listened too and feeling undervalued. During the focus group session, six of the eight participants discussed feelings that they were not being listened to and felt that their perspectives (or opinions) were irrelevant to their PCP.

Not being listened to and Feeling under-valued

Participants believed they did not have the full attention of their PCP, in part due to limited time during appointments. For example, one participant stated, "there's not enough time being given [to] listening to the clients (P2)." Similarly, another participant felt that their PCP "wasn't paying attention to his patients (P3)." Participant three described a time when a resident attended to her primary care. The resident (physician) would leave the room to confer with the PCP every time she had a question and then would return with the answer. Her PCP never came out of his office to talk to her, contributing to her perceptions of not being listened to or being taken seriously by the person she came to see (her PCP) about her health concern.

Participants believed that a thorough assessment was not completed during their interactions with PCPs due to their old age. Two other participants also asserted that PCPs did not care about older adults' health because they were going to "die soon anyway (P3)." They felt that older adults might have been used to practice on because "if they [PCPs] make a mistake they can say whoops, because it wasn't a young person, so it's not as bad (P6)." Participants believed their age was a contributor to the quality of care received from their PCP.

Five of the eight participants felt they did not have enough time during interactions with their PCPs to meet their health care needs, this lack of time contributed to their feelings of not having the full

attention of PCP, but also of being undervalued. Participant interactions with PCPs felt rushed. One participant talked about how they chose to leave a PCP because they were "just getting people in and out (P6)". Participants also explained the challenges they faced with getting an appointment with their PCP and thus being disappointed that at times they did not receive a thorough examination. "I take my car in for a checkup and they give it a 19-point inspection and I didn't even get a three-point inspection…. a lot of physicians really don't have the experience or the time or don't really care [enough] to do a thorough [assessment] or proactive testing that seniors need (P3)." Another participant talked about trying multiple times to see their PCP for a prescription refill and eventually making an appointment three weeks in advance in order to get a prescription refill. One participant provided a different perspective when he explained; "I really appreciate the fact that I never have to wait in his [PCP] office and I never feels rushed (P2)." However, most participants believed that "the practitioner needed more time with clients than is normally being allowed (P2)." Participants viewed this lack of time for assessment and/or discussion with physicians contributed to their feeling of being undervalue and discriminated against their advanced age.

Communication about Information

Five of the eight participants discussed the importance of obtaining correct information and understanding what kind of information they could ask for. Thus, effective communication is perceived as essential component of high quality healthcare.

Type of communication

Good communication, from the participants' perspective, included explanations of diagnoses, medications and lab work. One participant stated, "I want him to tell me how my blood work is and what those pills are for (P4)." Another participant felt that "medication should be explained to patients so that they don't overdose or have an episode [with their medication], it all should be clearly explained, and you don't get this at the clinic (P1)." Participants openly shared their expectations about "good care" and "good communication." One participant described how she "could have hugged" (P4) her physician because "she showed [her] everything that's going on, all the things [she] was taking and everything", something her previous PCP had never done. Participants talked about the importance of a simple explanation and how this information could improve their health care experience. Another participant expressed a wish that "all doctors were like that" (P7). As one participant put it "excellent care in that place was everything was explained to us, explained to [my father] and explained to me (P6)." Another participant explained a positive PCP experience at the new nurse practitioner led clinic: "I've been to the nurse practitioner here ... and I've really been much more comfortable than I have been going to any doctor and I just feel that they're focused on seniors and I don't feel rushed (P5)." It would seem that good communication was associated with good care.

Knowing what to ask

Participants explained they did not always know what questions to ask in order to get the health information they needed. One participant detailed a particularly frustrating interaction when she asked her PCP what her lab numbers meant, but all he explained was that she was fine. Participants wondered about their rights and ability to get information about their results. For example: "He never tells me anything. Am I allowed to ask? He just says you're fine, you are good (P4)." One participant talked

about the fear associated with interacting with a PCP: "we're often frightened to go to the doctor (P6)." This fear was attributable to not knowing if they were going to receive good or bad news, if they would be listened too, or if they would get the care they needed. One participant explained "they never tell the doctor anything and when the doctor asks, they don't respond sufficiently (P2)." These communication problems with PCP were related to not feeling safe sharing information with the PCP.

Primary Care Vision for Older People

Participants discussed primary care services that they would like to see implemented or supported, these included having a healthcare advocate, senior focussed facilities/services that meet the specific needs of older adults such as senior friendly aids and access to mental health care.

Healthcare advocate

Participants explained that a healthcare advocate could help them remember to ask the right questions and remember what was discussed after they left the appointment. One participant stated "I always go with my daughter…because I often forget to ask questions because I'm nervous, but the advocate can help" (P2). While another participant said, "the doctor said now we're going to put you on aspirin and my daughter-in-law and son were sitting there they said she can't take aspirin" (P4). Participants also expressed the importance of having someone with you when you receive bad news, "he says, you have cancer and he starts talking and you don't hear anything [else] he says" (P4).

Senior friendly aides

Participants described the importance of tools as component of their vision for primary care, these tools would help them remember appointments, medications and assist them in getting information in the event of an emergency. "I always relied on my memory and then one day I realized I couldn't, so I started writing down things" (P6). Another participant used "a talking medication device… as a pill reminder" (P1). Another participant described a fall that made her think that "if [they] had a concussion [they] wouldn't have been able to call someone [or get help] so maybe having more availability for these buttons, necklaces that people use would be a good thing "(P3). In addition to on-site access to services, access to information and reminder services outside of the physical space were also mentioned as important.

Senior focused services

Participants talked about the importance of "senior focussed facilities/services" (P2, P3), characterized by pharmacies in the same location for easy access to medications, PCP's that have gerontological knowledge and PCPs willing to explore options with them. This vision for primary care was described as a community-based health center that included nurse practitioners, physicians, specialists, a pharmacy and appropriate transportation to the site. Another participant mentioned that she took "herbal medicines and vitamins" (P3) suggesting that complimentary services in a community-based health center would also be helpful.

Participants talked about services they would like to access to as part of their vision for primary care. One participant asked "When are we going to get foot care back?" (P2). Two participants talked

about wanting "to see more psychologists available to people who have depression because the antidepressants work …[but] nobody's ever addressed that with me" (P3). Another stated "I suffer from depression …. and [after] seeing the psychologist yesterday ... I had a breakthrough. (P5). Home visits by PCP were also mentioned by one participant and every other participant in the focus group agreed that "of course we want [home visits back]" (P2). It was unclear as to whether these requests were related to their current struggles to access these services in their current primary care models of service.

Discussion

Participants in this study identified the importance of having enough time during their appointments with PCPs, having medical information communicated to them in a way they could understand and more services that meet the unique needs of senior population incorporated into primary care settings, for examples, foot care or on site pharmacy services.These ideas are not new, rather they were services they had experienced throughout their lifetime. The findings from this study have informed the HCD process of the clinic resulting in the development of services in the new primary care model. An interesting finding was that the older adults did not ask for any services that they had not previously experienced. Rather they asked for services they had previously been offered in other settings, but were no longer available.We wondered what might have contributed to participants' inability to think outside the box about primary care services. Further research is needed to understand how to engage adults in brainstorming novel ideas about primary care.

Time was mentioned repeatedly as something lacking in most PCP interactions. Other scholars have similarly reported that patients' feel valued when PCPs spend time with them and PCP attitude is particularly important to older adults (Benbenishty & Hannink, 2017). Similar to our findings, easy access and short waiting times, being listening to and giving clear information have been reported as contributing to positive health care experiences (Anderson, Barbara & Feldman, 2007). Respectful listening and questioning can help to engage older adults in their personal health care management and facilitate a better understanding of their overall health and well-being (Anderson et al., 2007; Sheridan et al, 2015).To facilitate listening to older adults' needs, appointments at the new primary care are now at least 30 minutes in length with access to same day appointments.

Although participants wanted information, they lacked confidence about what to ask and PCP's explanations were not always clear and easy to understand. This lack of confidence could be related to health literacy as 88% of older adults have limited health literacy (United Nations Educational, Scientific and Cultural Organization (UNESCO), 2017). Patients identified improved communication, involvement in decision-making and cohesion when nurse practitioners were included as members of health care team (Kilpatrick, Jabbour, Fortin, 2016). Based on the findings from this study, a health literacy seminar was offered to older adults who attend the senior centre where the new NP-led primary care services are located. The seminar was designed to provide older adults with strategies to support effective interactions with PCPs. Other services participants identified were not new, so they were easily instituted at an organizational level in the new primary care model lead by NPs.

Communication can be challenging especially if there are language, or cultural differences and/or patients hiding the fact that they don't understand what the PCP is telling them (Blackstone & Pressman, 2016; Divi, Koss, Schmaltz, Loeb 2007). As a proactive step, the NP-led clinic has recruited providers representing various cultural backgrounds and some older adults come to the clinic specifically to see

these providers who are fluent in their language and/or familiar with their cultural needs. The seniors' centre where the services are located has deep roots in many cultural communities with access to translators and informants to provide clarity on the cultural needs of our diverse older population.

Senior-focused care was discussed by several participants as important. Scholars have identified the need for care to be focused on the aging population (Leuven, 2012; King, Boyd, Dagley& Raphael, 2018). Primary care is important in providing comprehensive care for older adults with co-morbidities requiring focused assessments. Depite the research indicating the need for primary care models to spend more time with older adults and enhance gerontology assessment skills, it remains a rarity (King et al., 2018). The NP-led clinic within this senior's centre represents a new way of organizing and delivery primary care services specifically focussed on the needs of older adults.

Study Limitations and Implications

This study is limited to the experiences of a small group of older adults who attend or receive services at a seniors centre in Western Canada. The inclusion criteria limited the sample to only older adults who spoke English and who were able to come into the seniors center for a focus group. Future research is needed to understand the experiences of older adults in primary care settings, particularly those with lower socio-economic backgrounds, immigrants and older adults with health conditions or disabilities that affect them cognitively and physically.

Conclusion

This study provides a beginning understanding about older adults' perspective of their likes, dislikes and needs based on their experiences with primary care. Participants suggested they wanted longer appointments, clearer communication and made valuable suggestions on how primary care could be more senior focused. Some of these recommendations were immediately incorporated in to the services provided at the new NP-led primary care service. More research is needed to evaluate the effectiveness of these recommendations and implementation for older adults.

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