

Experiences of patients with a disability in receiving primary health care

Using experience-based design for quality improvement

Sakina Walji MD CCFP MPH June C. Carroll MD CCFP FCFP Cleo Haber MSW RSW

Abstract

Objective To use patient-guided tours to gain insight into the experiences of patients with disabilities receiving primary care, with the goal of suggesting improvements.

Design A qualitative experience-based design study, using patient-guided tours.

Setting Multidisciplinary academic urban primary care practice.

Participants Patients with disabilities identified by their health care providers.

Methods Patients walked through the clinic as they would on a “typical visit” describing their feelings and experiences. The investigator used a semistructured interview guide to prompt the patient. The tour was audiorecorded and transcribed. Thematic content analysis was used.

Main findings Participants included 18 patients with various disabilities (physical disability, sensory disability, chronic illness, mental illness, learning disability, developmental disability). Strong positive relationships, particularly with the team and administrative staff, profoundly affected perceived access and experience of care. Multidirectional, clear, and respectful communication independently improved patients’ experiences dramatically. Participants said that many access, coordination, and physical barriers were eased by team relationships and communication. Physical space and building issues were troublesome for those with physical and mental disabilities alike. Each participant’s disability itself played a role in their experience but was not described as prominently as their relationship, communication, and spatial challenges. Participants described the patient-guided tour method as valuable to elicit experiences and feelings.

Conclusion Some health care teams are unaware of how relationships and communication affect every aspect of health care for people with disabilities. Highlighting these findings with providers and organizations might prompt a more patient-centred model of care. Our experience-based design consisting of patient-guided tours was effective in assessing how those with disabilities experienced care.

Editor’s key points

- ▶ Studies have demonstrated that those with disabilities are less able to access care from primary care providers when they require it. Some health care teams are unaware of how relationships and communication affect every aspect of health care for people with disabilities. The authors of this study used a developing phenomenologic qualitative method (experience-based design), consisting of patient-guided tours, to gain insight into how patients with disabilities experience receiving primary health care.
- ▶ The patient-guided tours were effective in assessing how those with disabilities experienced care.
- ▶ Access and overall experience of care were greatly improved by strong positive relationships between patients and clinic staff. People with disabilities benefited from clear and respectful communication among staff as well as between staff and patients.

Points de repère du rédacteur

► Des études ont démontré que les personnes ayant une incapacité accèdent moins facilement aux soins de professionnels des soins primaires quand elles en ont besoin. Certaines équipes de soins de santé ne sont pas conscientes de la façon dont les relations et la communication influent sur chaque aspect des soins de santé pour les personnes ayant une incapacité. Les auteures de cette étude ont utilisé une méthode phénoménologique qualitative en développement (conception fondée sur les expériences) qui consistait à faire des visites guidées par les patients, pour mieux comprendre l'expérience que vivent les personnes ayant une incapacité lorsqu'elles doivent recevoir des soins de santé primaires.

► Les visites guidées par les patients ont été efficaces pour évaluer la façon dont les personnes ayant une incapacité vivent l'expérience des soins.

► L'accès aux soins et l'expérience des soins en général étaient grandement améliorés en présence de solides relations positives entre les patients et le personnel de la clinique. Les personnes ayant une incapacité bénéficiaient du fait que la communication soit claire et respectueuse tant les membres du personnel qu'entre le personnel et les patients.

Recevoir des soins primaires : l'expérience de patients ayant une incapacité

Recours à une conception fondée sur les expériences pour améliorer la qualité

Sakina Walji MD CCFP MPH June C. Carroll MD CCFP FCFP Cleo Haber MSW RSW

Résumé

Objectif Utiliser des visites guidées par les patients pour mieux comprendre les expériences que vivent les personnes ayant une incapacité lorsqu'ils doivent recevoir des soins primaires, et ce, dans le but de suggérer des améliorations.

Type d'étude Une étude qualitative fondée sur les expériences au moyen de visites guidées par les patients.

Contexte Une clinique universitaire et multidisciplinaire de soins primaires en milieu urbain.

Participants Des patients ayant une incapacité, identifiés par leurs fournisseurs de soins de santé.

Méthodes Les patients se déplaçaient dans la clinique comme ils le feraient lors d'une «visite typique» et décrivaient leurs sentiments et leurs expériences. L'investigatrice utilisait un guide d'entrevues semi-structurées pour solliciter les commentaires du patient. La visite faisait l'objet d'un enregistrement sonore qui était ensuite transcrit. Une analyse de contenu thématique a été effectuée.

Principales constatations Les participants étaient au nombre de 18 et avaient divers types d'incapacités (incapacité physique ou sensorielle, maladie chronique ou mentale, troubles d'apprentissage, déficience développementale). De solides relations positives, en particulier avec l'équipe et le personnel administratif, influaient grandement sur leur perception de l'accès aux soins et l'expérience vécue. Une communication multidirectionnelle, claire et respectueuse améliorait dramatiquement, à elle seule, l'expérience des patients. Les participants ont indiqué que de nombreux obstacles sur les plans de l'accès, de la coordination et des capacités physiques étaient atténués par les relations et la communication avec l'équipe. Les problèmes liés à l'espace physique et à l'édifice étaient ennuyeux tant pour ceux qui avaient des incapacités physiques que pour ceux qui souffraient de problèmes mentaux. L'incapacité même de chaque participant jouait un rôle dans leur expérience, mais n'était pas décrite avec autant d'insistance que leurs difficultés en matière de relations, de communication et d'espace. Les participants ont trouvé utile la méthode des visites guidées par le patient pour faire ressortir leurs expériences et leurs sentiments.

Conclusion Certaines équipes de soins de santé ne sont pas conscientes de la façon dont les relations et la communication influent sur chaque aspect des soins de santé pour les personnes ayant une incapacité. Notre conception fondée sur les expériences, qui consiste en visites guidées par les patients, a été efficace pour évaluer comment les personnes ayant une incapacité font l'expérience des soins.

About 3.8 million Canadians live with a disability.¹ People with disabilities are less able to access care when they require it than the general population is.² Approximately 40% of this population have an unmet medical need owing to difficulty accessing primary care (PC).³ A Canadian study found that patients with disabilities were more socially disadvantaged than patients without disabilities and were more likely to use the emergency department, suggesting that they had unmet health needs.⁴ People with disabilities have higher rates of early death and preventable chronic conditions⁵⁻⁸ and are less likely to be up to date with screening.⁹⁻¹¹ Sometimes their access to diagnosis and treatment is limited.^{8,12} Reasons for this include inadequate finances and transportation¹³ as well as structural issues and lack of appropriate equipment, such as lift or transferring devices, accessible scales, and suitable examination tables.¹⁴ Attitudes of health professionals have also been identified as barriers to accessing health care for people with disabilities.¹⁵

The World Health Organization (WHO) has stated that people with disabilities are more likely than the general population to find health care providers' skills and facilities inadequate, to be treated poorly by health care providers, and to be denied health care services. The WHO statement stresses that people with disabilities require effective access to care to a greater extent than people without disabilities and recommend their needs be met by PC.¹⁶ However, the literature on people with disabilities and their access to high-quality PC is still underdeveloped in Canada. Barriers in accessing care for underrepresented groups have been studied extensively¹⁷⁻²⁰ and were not specifically addressed in this study.

Our objective was to gain understanding of the perceptions and experiences of patients with disabilities in receiving PC and to assess the effectiveness of the novel experience-based study design (EBD) of patient-guided tours.

— Methods —

Experience-based design

This was a phenomenologic qualitative study. We chose EBD, an emerging methodology based on identification of events of high emotional content or key moments (touchpoints), to identify what matters most to patients. *Patients' experience* refers to how well people understand the clinic, how they feel attending the clinic, and how well it serves its purpose.²¹ Feelings captured from multiple touchpoints form the focus of EBD.^{22,23} Patient-guided tours are a form of EBD, as they allow patients to tell their stories starting with booking their appointment, followed by attending the clinic and moving through the environment as they usually would, expressing thoughts and feelings. Moving through the environment allows patients to refresh their memories, recalling feelings and thoughts that might not be identified using other ways of assessing patient

perception of care, such as questionnaires.²⁴ Familiarity with the study environment could reduce the power influence of researchers so that patients are more likely to share their narratives.²⁴ Emerging literature shows patient-guided tours to be an effective way of understanding an experience from the patient's perspective.²⁵

Study design

This study was conducted in an urban, multidisciplinary PC clinic in Toronto, Ont. Patients came to the clinic specifically for the study and led the investigator (author S.W. or clinic Executive Director Deborah Adams [D.A.]) through the different areas of the clinic they would pass through on a "typical visit." Questions were developed by the researchers, informed by the literature on EBD.²⁵ A semistructured interview guide (available on request) was used that included questions about the patient's typical journey through receiving PC, from appointment booking to clinic encounter. Field notes (reflective thoughts, questions) were made by the investigator during the tour. Tours lasted 30 to 60 minutes and were audiorecorded and transcribed verbatim. Following the tour, participants completed a demographic questionnaire and received \$20 compensation for time and transportation costs. Ethics approval was obtained from the Mount Sinai Hospital Research Ethics Board. The study was conducted from June to December 2016. The research team included 2 family physicians (S.W., J.C.C.), the clinic's Executive Director (D.A.), and a social worker (C.H.).

Participants

Convenience sampling was used for recruitment. Patients with disabilities were identified by their health care providers. The Executive Director (D.A.) informed patients about the study, assessed interest, determined eligibility, and obtained consent. The study was highlighted on the clinic website so that participants were able to self-recruit. Recruitment continued until saturation of themes was reached. Saturation was deemed to be obtained when no new trends or themes were emerging. Eligibility included patients who had a disability, were English speaking, and were able to complete the guided tour. Consent came from those able to provide consent for the study or their substitute decision makers.

Our 18 participants had both visible disabilities (eg, physical disabilities requiring walking devices or apparent visual impairment) and invisible disabilities (eg, mental health disabilities or hearing impairment) (**Table 1**). Twenty-seven eligible patients were identified by PC providers; 3 declined, 18 completed the tour, and the remaining eligible patients were not approached, as we had reached saturation.²⁶ No patients were self-recruited through the website.

Data analysis

Thematic content analysis was used to identify, code, analyze, and report patterns within the data.²⁷ An iterative

Table 1. Participant characteristics: N = 17.

CHARACTERISTIC	N	%
Sex*		
• Female	11	69
• Male	5	31
Born in Canada		
• Yes	9	53
• No	8	47
Ethnic background		
• White, North American	7	41
• White, European	4	24
• South Asian	2	12
• Southeast Asian	1	6
• First Nations	1	6
• Middle Eastern	1	6
• Other	1	6
Disability†		
• Physical disability	13	76
• Sensory disability	9	53
• Chronic illness	6	35
• Mental illness	2	12
• Learning disability	1	6
• Developmental disability	1	6
• Other	3	18
Annual income*		
• < \$30 000	10	63
• ≥ \$30 000	6	37

*One participant chose not to answer.
†Multiple responses were possible.

process was used during data collection that allowed findings to inform future interviews. After completion of 4 tours, 3 investigators (S.W., J.C.C., C.H.) read all 4 transcripts and independently coded line by line. The transcripts were collectively reviewed and themes placed into broader categories. After completion of 2 more tours, this process was repeated. One investigator (S.W.) coded the remaining transcripts according to the themes identified. Regular meetings with the team were held to discuss findings and identify emerging themes. At these meetings, findings were compared with previous findings, allowing investigators to identify common patterns. This process was repeated until no new themes were found.²⁶ Investigators reviewed field notes after every 2 to 4 patient-guided tours to identify any needed changes to the interview guide. Verbatim transcription, field notes, and independent analysis by multiple researchers enhanced credibility and trustworthiness of the data. Themes that reached saturation are reported. Once themes were identified, participant feedback was sought for member-checking purposes.²⁶

— Findings —

Themes that reached saturation included the importance of relationships, the importance of multidirectional communication, the effects of disability, and the effects of physical or building issues. Strong positive relationships

with the entire team and particularly with administrative staff had a profound effect on overall patient experience. This, along with effective multidirectional communication with the team, was found to greatly affect access and experience of care. Barriers to accessing care, such as physical and transportation barriers, were often eased when strong relationships and effective communication were present. Barriers related to the disability and physical space also affected access and experience.

Importance of relationships

Relationships, including those of the patient with the PC provider, but often, more important, with the team and administrative staff, were key to many aspects of care. Those describing good relationships with administrative staff reported that they were better able to communicate the effect of their disability, navigate care, and receive appropriate accommodations that allowed them to attend the clinic including coordinating appointments with wheelchair transportation services and other health care providers.

[She] usually asks me (because [of being the] receptionist, she's aware of all these things) ... she knows how I have to book my appointment, how it has to be the earliest one [Participant 8].

It's such a great comfort It's the nicest relationship between the doctor's secretary and me. [I]t's comforting. I know I'll be looked after [Participant 17].

Participants who described a good relationship with the team were more likely to express a positive experience of care and a feeling of empowerment. Patients stated that these positive relationships enabled patient-centred care, allowing patients to “be themselves” and to actively participate in their own care.

Finally, I have a doctor who understands people's disabilities Freedom: it means dignity and humanity [Participant 16].

The more comfortable you make the patient, the more they're actually able to collaborate and cooperate [Participant 13].

A positive relationship was also described as easing barriers related to the patient's disability and challenges of physical space. “[B]ecause we've had that problem so many times ... he said, ‘This time we'll go to that room’ [with an accessible bed]” [Participant 4].

Importance of multidirectional communication

Two-way communication between patients and staff and also between staff was important to this population. Although often enhanced by positive relationships, respectful and clear communication appeared to have

independent effects on access to and experience of care. When patients were unable to express their limitations, it often resulted in poor care. For example, poor communication about wheelchair transportation time meant that patients missed their rides and experienced long waits or required alternative transportation, which they described as anxiety provoking. Financial barriers were another issue that was frequently unknown to providers and resulted in expensive medications being prescribed that were unaffordable.

I had to take Wheel-Trans [a wheelchair transportation service] to get there. [Once I arrived], the appointment was delayed for so long [that] I wasn't seen immediately and I missed my Wheel-Trans ride [Participant 7].

Patients said that they were more likely to trust the health care provider, feel actively involved in their care, and comply with medical recommendations when providers communicated clearly and respectfully.

[S]he explained the reason that my body needs vitamins, for example. And why I have that deficiency and how it will help me; ... I can tell you for sure. I've thrown away medication many times from other doctors [Participant 17].

Communication between health care providers was important. Patients expressed comfort in knowing that their providers were in contact with each other within a system that was difficult to navigate for patients living with disabilities.

Effects of disability

Participants reported that their disabilities affected different aspects of care: access, emotional well-being during visits, and coordination of care. Many participants required specialized transportation services and reported being unable to arrange transportation for urgent appointments, meaning they were less likely to receive necessary care when their need was urgent.

Physical disabilities also prevented some participants from telephoning for appointments without assistance. Some described work-arounds, but often these alternatives were found by chance or by patients asking, as opposed to being offered these options. "One thing I do like is I'm able to e-mail them for an appointment. I didn't know [I could do] that for the longest time and got very frustrated" [Participant 13].

Some participants described feeling anxious or unsettled in the clinic because of their disability.

If someone [doesn't face] me or they don't speak clearly ... I'm having to work at paying attention I don't always hear my name ... and so [I'm] kind of tense [Participant 13 with hearing impairment].

I feel stressed out because I come in and go, "Oh my God, that's a lot of roadblocks [and obstacles]" [Participant 16 with physical disability and mobility issues].

Effects of physical and building issues

Physical space and building issues were troublesome for people with physical and mental disabilities alike.

Participants described physical issues related to uneven ground, usability of ramps, elevator function, doors that were difficult to open, lack of space for mobility aids, and poor signage (Table 2). They said that the physical setting had a substantial effect on their emotional well-being and subsequent clinical encounter.

It's a bad encounter. Like all the staff are great; the health care's great. But the physical obstacles [Participant 1 with physical disability who uses a mobility aid].

The waiting room is ... usually calm, quiet I'm just very calm and comfortable. There's no anxiety, no anxiousness When I'm happy and calm, I listen [Participant 17].

Effectiveness of patient-guided tour method

Participants described this method as particularly effective in conveying in-depth information and said the touchpoints triggered memories and emotions they might otherwise not have remembered. Patients with learning disabilities stated this was an easier method for sharing their experiences than a questionnaire and that it allowed the investigator "to see through their eyes" and communicate things that would have been hard to convey through a survey or interview. Drawbacks voiced by patients included that it was time-consuming and that those who were more severely disabled might be less likely to participate.

Table 2. Building issues and physical barriers

LOCATION	BARRIERS
Outside the building housing the family medicine clinic	No safe crossing (to get to the hospital) Uneven pavement on the sidewalk No clear sign marking the clinic building Lack of parking
Inside the building housing the family medicine clinic	Lack of accessible doors (opening the wrong way, heavy, button for automatic opening not working) Elevator issues (doors close too fast, do not announce floor number, no signs) Steep ramps Small bathrooms; difficult to maneuver wheelchair or walking aid Lack of signage (eg, directions to clinic, marking bathroom)
Inside family medicine clinic	Poor waiting room layout for those with mobility aids (lack of space) Lack of accessible examining tables Difficulty using pedal sink Difficulty maneuvering within examination room

[O]n some level, I was aware of it, but it's ... like, when you're driving, you don't pay attention to every bump on the road ... so I wouldn't have thought of that, and this process surfaced for me things that ... I never consciously thought about [Participant 13].

You could just ask me some questions over the phone, or in person, but to actually walk me through and see the process happen itself is ... different. It's got more verve [Participant 14].

Additional quotations pertaining to each theme are presented in **Table 3**.

— Discussion —

To our knowledge, this is the first time EBD has been used to assess experiences of people with disabilities in accessing PC. Strong positive relationships with the entire health care team and clear and respectful

communication profoundly affected access and overall experience of care for those with disabilities. Although these issues are not unique to this population, their importance could be amplified, as they enable appropriate accommodations. Physical issues and the disability itself were not as central to patients' experiences as expected. Physical barriers, transportation, communication, client and provider attitudes, and coordination of care²⁸ have been described as affecting the quality of health care received by people with disabilities. As in our study, the WHO²⁹ has described relationships as one of many external factors affecting health care of those with disabilities. A recent study also highlighted the importance of good communication in improving access to care for people with disabilities.³⁰ Our findings indicate communication affects access but also suggest that many barriers related to the disability and physical space were eased by strong relationships and good communication with the health care team. A study by Potvin et al³¹ describes the need for support in booking appointments for patients with

Table 3. Additional quotations pertaining to each theme

THEME	QUOTATIONS
Importance of relationships	<ul style="list-style-type: none"> • “They’re treating me above and beyond. It feels like family. That’s what it does. That’s the comfort level I have” [Participant 17] • “[The clerk] knows my situation, so she always tries to get me 1:00 [appointments]” [Participant 8] • “... while you’re here, do you want to go across the street [to the hospital] and we’ll do this [test]?” [Participant 3]
Importance of multidirectional communication	<ul style="list-style-type: none"> • “[T]hings that are assumed known or assumed understood, patients don’t necessarily understand ... the same way” [Participant 13]
Effects of disability	<ul style="list-style-type: none"> • “I’m so scared that I would fall, because I’m so high [on the examination table] when ... they put me down” [Participant 4] • “I’ve been under this stigma my whole life. I’ve had to battle mental illness my whole life I like a bit of anonymity” [Participant 14]
Building issues	<ul style="list-style-type: none"> • “Well, when I come to the doctor it’s already stressful enough [for] someone in my condition. And I should be coming into a welcoming environment. Instead, this is an obstacle course” [Participant 16] • “I’m always relying on the kindness of strangers to tell me what floor I’m on and push the buttons for me” [Participant 8]
Patient-guided tour method	<p>Touchpoints triggered memories and emotions</p> <ul style="list-style-type: none"> • “I don’t think I would have volunteered it ... in an interview, I don’t think I would have identified it” [Participant 13] <p>Easier method for sharing experiences</p> <ul style="list-style-type: none"> • “Because I can tell you exactly what I’m feeling coming here, versus having to put it in a [spreadsheet]. I can’t be bothered” [Participant 2] • “For me, it’s easier when I’m there to show you” [Participant 16] • “Because I want to show you physically how things can be improved [on why she feels experience-based design is superior to other methods]” [Participant 16] <p>Allowed the investigator “to see through their eyes”</p> <ul style="list-style-type: none"> • “[I]t’s almost like being there. It’s almost like putting yourself in the patient’s shoes” [Participant 14] • “I believe in the whole experience. Just saying something is only part of the experience. But physically experiencing something together with the verbal feels a little more, like, ‘Aha! [T]hat makes sense.’ It’s more lived” [Participant 14] • “When you come on a tour with me, you see through my eyes” [Participant 16] <p>Unsuitable method for all participants</p> <ul style="list-style-type: none"> • “Maybe if I was on crutches or, you know, [were] more disabled than I am, maybe I would have concerns coming along” [Participant 18]

disabilities. Although the semistructured interview guide did not address the booking process specifically, many participants reported challenges in scheduling appointments. Given this early finding, we asked subsequent participants about their booking experience.

Building issues and issues related to individual disability have been described as affecting patients' experience¹⁵; however, in our study, these were not the central barriers to accessing care.

Results of this study could inform quality improvement initiatives in PC for patients with disabilities. The role of strong relationships in easing barriers to care is likely not apparent to many health care teams. Physicians often believe that the only barriers for patients with disabilities relate to access.³² Encouraging strong relationships between patients with disabilities and the entire health care team, as well as effective communication, could raise awareness of issues facing patients with disabilities that are unknown to the medical team, thus enabling patient-centred care, including accommodations specifically for patients with disabilities. Staff training is needed to highlight these barriers and their role in suggesting potential accommodations²¹ such as using e-mail to book appointments for people with a hearing impairment, offering flexible appointment times, or providing lower height-adjustable beds for those with certain physical disabilities.

Our findings support the WHO recommendation to gather data on rehabilitation needs, unmet needs, and associated health conditions for patients with disabilities. The WHO recommends that service providers carry out access audits, in partnership with local disability groups, to identify physical and information barriers that could exclude people with disabilities.¹⁶ Collecting demographic data on patients is increasingly encouraged internationally, with the US Affordable Care Act mandating that health care organizations collect data on disability status.³³ Research indicates that health care organizations collecting demographic data are more likely to focus on inequities and improve quality of care.³⁴ By identifying people living with disabilities and being aware of their needs, organizations will take the first step to better serving this population.


Improving experience and access issues might encourage patients with disabilities to seek PC when needed, thereby improving preventive care, increasing equity of care, and addressing the Institute for Healthcare Improvement's triple aim to improve patients' experience and population health, while reducing overall costs.³⁵

Limitations

This study involved participants describing their experiences and not the actual experience, which could be a limitation, although our aim was to assess perceived experiences and this tour allowed an in-depth analysis of patient narratives. Study participants were people with disabilities who were motivated to access care

and were able to participate in the tour; therefore, their experience could be biased. Although saturation was achieved, participants had heterogeneous disabilities, so issues specific to some disabilities might not have been described. Participants were English speaking, and most were white North Americans or Europeans. Issues of safety were not directly addressed in this study and might be considered for future studies. This study was conducted at an urban, multidisciplinary practice; however, findings could be relevant to any PC team. One of the investigators who conducted the tours was also part of the analysis team. Despite anonymous transcripts, she could have been aware of patients' identity. Two other investigators were on the analysis team to minimize the effect this awareness could have had. One of the interviewers was a clinician at the study clinic, and we tried to minimize effects on patient reporting by ensuring that she did not interview any participants who were under her care or known to her.

Conclusion

Strong positive relationships, not only with the PC provider, but with the team and administrative staff, as well as clear and respectful communication, profoundly affected access and overall experience of care, sometimes easing barriers experienced by those with disabilities. These findings can guide changes required in PC to improve quality of care including access, equity, experience, and patient-centred care. Changes might include raising awareness, training staff, and modifying processes to better accommodate patients living with disabilities. Patient-guided tours proved to be effective in eliciting patient experiences and emotions. 

Dr Walji is Lecturer at the University of Toronto and a family physician in the Department of Family Medicine at Mount Sinai Hospital, Sinai Health System, Toronto, Ont. **Dr Carroll** is Professor, a clinician scientist, and Sydney G. Frankfort Chair in Family Medicine in the Department of Family and Community Medicine at the University of Toronto. **Ms Haber** is a clinical social worker in the Department of Family Medicine at Mount Sinai Hospital.

Acknowledgment

We thank **Deborah Adams** for her tremendous assistance in setting up and conducting the patient-guided tours.

Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr Sakina Walji; e-mail sakina.walji@sinaihealth.ca

References

1. Arim R. *A profile of persons with disabilities among Canadians aged 15 years or older*, 2012. Ottawa, ON: Statistics Canada; 2015. Available from: <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2015001-eng.pdf>. Accessed 2016 Aug 3.
2. Jha A, Patrick DL, MacLachlan RF, Doctor JN, Chan L. Dissatisfaction with medical services among Medicare beneficiaries with disabilities. *Arch Phys Med Rehabil* 2002;83(10):1335-41.
3. Popplewell NTA, Rechel BPD, Abel GA. How do adults with physical disability experience primary care? A nationwide cross-sectional survey of access among patients in England. *BMJ Open* 2014;4(8):1-9.
4. Lofters A, Guilcher S, Maulkhan N, Milligan J, Lee J. Patients living with disabilities. The need for high-quality primary care. *Can Fam Physician* 2016;62:e457-64. Available from: <https://www.cfp.ca/content/cfp/62/8/e457.full.pdf>. Accessed 2021 May 31.

5. Campbell ML, Sheets D, Strong PS. Secondary health conditions among middle-aged individuals with chronic physical disabilities: implications for unmet needs for services. *Assist Technol* 1999;11(2):105-22.
6. Lennox NG, Kerr MP. Primary health care and people with an intellectual disability: the evidence base. *J Intellect Disabil Res* 2007;41(Pt 5):365-72.
7. Haverkamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep* 2004;119(4):418-26.
8. Disability Rights Commission. *Equality treatment: closing the gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Leeds, UK: Disabilities Rights Commission; 2006. Available from: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DRC-Health-FI-main.pdf>. Accessed 2021 May 31.
9. Armour BS, Thierry JM, Wolf LA. State-level differences in breast and cervical cancer screening by disability status: United States, 2008. *Womens Health Issues* 2009;19(6):406-14.
10. Chan L, Doctor JN, MacLehose RF, Lawson H, Rosenblatt RA, Baldwin LM, et al. Do Medicare patients with disabilities receive preventive services? A population-based study. *Arch Phys Med Rehabil* 1999;80(6):642-6.
11. Reichard A, Sacco TM, Turnbull HR 3rd. Access to health care for individuals with developmental disabilities from minority backgrounds. *Ment Retard* 2004;42(6):459-70.
12. Dejong G, Palsbo SE, Beatty PW, Jones GC, Knoll T, Neri MT. The organization and financing of health services for persons with disabilities. *Milbank Q* 2002;80(2):261-301.
13. Maart S, Jelsma J. Disability and access to health care—a community based descriptive study. *Disabil Rehabil* 2014;36(18):1489-93. Epub 2013 Jul 5.
14. Kirschner KL, Breslin ML, Iezzoni LI. Structural impairments that limit access to health care for patients with disabilities. *JAMA* 2007;297(10):1121-5.
15. Maart S, Eide AH, Jelsma J, Loeb ME, Ka Toni M. Environmental barriers experienced by urban and rural disabled people in South Africa. *Disabil Soc* 2007;22(4):357-69.
16. World Health Organization. *World report on disability 2011*. Geneva, Switz: World Health Organization; 2011. Available from: https://www.who.int/disabilities/world_report/2011/report.pdf. Accessed 2021 Jun 1.
17. Miller NA, Kirk A, Kaiser MJ, Glos L. Disparities in access to health care among middle-aged and older adults with disabilities. *J Aging Soc Policy* 2014;26(4):324-46.
18. Agency for Healthcare Research and Quality. *National healthcare disparities report, 2013*. Rockville, MD: US Department of Health and Human Services, Agency for Healthcare Research and Quality; 2014.
19. Kaiser Family Foundation. *Immigrants' health care coverage and access. Fact sheet #2231*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured Fast Facts; 2001.
20. Jones GC, Sinclair LB. Multiple health disparities among minority adults with mobility limitations: an application of the ICF framework and codes. *Disabil Rehabil* 2008;30(12-13):901-15.
21. Gage M. *Making emotional connections through participatory design*. Boxes and Arrows; 2002. Available from: <http://boxesandarrows.com/making-emotional-connections-through-participatory-design/>. Accessed: 2018 Dec 5.
22. Bak K, Macdougall L, Green E, Moody L, Obarski G, Hale L, et al. Hindsight is 20/20: lessons learned after implementing experience based design. *Patient Exp J* 2014;1(2):12-9.
23. Tsiakanas V, Robert G, Maben J, Richardson A, Dale C, Griffin M, et al. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer* 2012;20(11):2639-47. Epub 2012 Apr 29.
24. Miaux S, Drouin L, Morency C, Paquin S, Gauvin L, Jacquemin C. Making the narrative walk-in-real-time methodology relevant for public health intervention: towards an integrative approach. *Health Place* 2010;16(6):1166-73. Epub 2010 Aug 6.
25. NHS Institute for Innovation and Improvement. *The EBD approach—experience based design: using patient and staff experience to design better healthcare services. Guide and tools*. Coventry, UK: NHS Institute for Innovation and Improvement; 2009. Available from: <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Experience-Based-Design-Guide-and-Toolkit.pdf>. Accessed 2021 Jun 2.
26. Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ* 2008;337:a1035.
27. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101.
28. Lawthers AG, Pransky GS, Peterson LE, Himmelstein JH. Rethinking quality in the context of persons with disability. *Int J Qual Health Care* 2003;15(4):287-99.
29. World Health Organization. *International classification of functioning, disability and health (ICF)*. Geneva, Switz: World Health Organization; 2001.
30. McClintock HF, Kurichi JE, Barg FK, Krueger A, Colletti PM, Wearing KA, et al. Health care access and quality for persons with disability: patient and provider recommendations. *Disabil Health J* 2018;11(3):382-9. Epub 2017 Dec 30.
31. Potvin LA, Fulford C, Ouellette-Kuntz H, Cobigo V. What adults with intellectual and developmental disabilities say they need to access annual health examinations. System navigation support and person-centred care. *Can Fam Physician* 2019;65(Suppl 1):S47-52.
32. Morrison EH, George V, Mosqueda L. Primary care for adults with physical disabilities: perceptions from consumer and provider focus groups. *Fam Med* 2008;40(9):645-51.
33. Office of Minority Health. *Reducing health disparities with improved data collection: new refined data standards for race, ethnicity, sex, primary language, and disability status*. Rockville, MD: US Department of Health and Human Services; 2011.
34. Hasnain-Wynia R, Baker DW. Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions. *Health Serv Res* 2006;41(4 Part 1):1501-18.
35. Institute for Healthcare Improvement. *The IHI triple aim*. Boston, MA: Institute for Healthcare Improvement; 2018. Available from: <http://www.ihf.org/engage/initiatives/TripleAim/Pages/default.aspx>. Accessed 2021 Jun 2.

This article has been peer reviewed.

Cet article a fait l'objet d'une révision par des pairs.

Can Fam Physician 2021;67:517-24. DOI: 10.46747/cfp.6707517