

Practising family medicine for adults with intellectual disabilities

Patient perspectives on helpful interactions

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Abstract

Objective To explore the perspectives of adults with intellectual disabilities (IDs) on helpful interactions with their family physicians.

Design Exploratory, qualitative study.

Setting Vancouver, BC.

Participants Purposive sample of 11 community-dwelling adults with IDs.

Methods In-depth, semistructured interviews were conducted face to face with participants. Interviews were audiorecorded and transcribed verbatim. Research team members read the transcripts, which were then coded into categories and subcategories and discussed at collective analysis meetings. The main study themes were generated through this iterative, collective process.

Main findings Two themes about helpful interactions were identified: *helping patients understand* and *helping patients navigate the health care system*. The first theme reflected helpful ways of communicating with patients with IDs. These approaches focused on plain-language communication and other strategies developed jointly by the patients and their physicians. The second theme reflected ways in which the family physicians helped adults with IDs manage their health needs despite the complex constraints of their socioeconomic situations.

Conclusion Adults with IDs want to play an active role in managing their health as they age, and helpful interactions with family physicians make this possible.

EDITOR'S KEY POINTS

- In this study, adults with intellectual disabilities described how their family physicians approached interactions with them in helpful ways. Helping patients understand information during physician-patient interactions and helping patients navigate the health care system were key aspects of this process.
- Strategies to support family physicians to engage in helpful approaches, including education and further research, are needed given the increasing number of community-dwelling adults with intellectual disabilities in the aging population.

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Soigner des adultes souffrant de déficience intellectuelle en médecine familiale

Ce que pensent les patients des interventions utiles

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Résumé

Objectif Étudier le point de vue d'adultes souffrant de déficience intellectuelle (DI) sur les échanges fructueux avec leur médecin de famille.

Type d'étude Étude qualitative exploratoire.

Contexte Vancouver, C.-B.

Participants Un échantillon raisonné de 11 déficients intellectuels adultes vivant dans la communauté.

Méthode On a tenu des entrevues en profondeur semi-structurées individuelles avec les participants. Ces entrevues ont été enregistrées et transcrites mot à mot. Les membres de l'équipe de recherche ont lu les transcrits, les ont codés en catégories et en sous-catégories pour ensuite les analyser lors de discussions en groupe. Les principaux thèmes de l'étude ont été identifiés par le processus itératif collectif.

Principales observations On a identifié deux thèmes à propos des interventions utiles : *aider le patient à comprendre et aider le patient à naviguer dans le système de santé*. Le premier thème concernait les façons utiles de communiquer avec le patient atteint de DI. On utilisait alors un langage simple ainsi que d'autres stratégies développées conjointement par le patient et son médecin. Le second thème avait rapport avec la façon dont le médecin de famille aidait les déficients intellectuels adultes à gérer leur besoins en santé, en dépit des diverses contraintes résultant de leur situation socioéconomique.

POINTS DE REPÈRE DU RÉDACTEUR

- Cette étude a permis à des déficients intellectuels adultes de décrire comment leur médecin de famille les aidait par leur façon de communiquer avec eux. Ces interventions visaient surtout à les aider à comprendre les informations reçues durant la rencontre et à naviguer dans le système de santé.
- Il y a lieu de développer des stratégies pour inciter les médecins à adopter des moyens de communication utiles, incluant des séances de formation, compte tenu du nombre croissant d'adultes souffrant de déficience intellectuelle dans la population vieillissante.

Conclusion En vieillissant, les adultes souffrant de DI veulent prendre leur santé en main; ils peuvent y parvenir grâce à des interactions utiles avec leurs médecins de famille.

Cet article a fait l'objet d'une révision par des pairs.
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Internationally, there is growing acknowledgment that community-dwelling adults with intellectual disabilities (IDs) are a vulnerable population, susceptible to health inequities across the life course.^{1,2} Consensus guidelines for primary health care for this population in Canada have been published.³ Yet, despite acknowledgment of the unique primary health care needs of adults with IDs, there is a scarcity of research that includes the perspectives of members of this population. The purpose of this article is to present findings from a larger study about aging in adults with IDs who live in the community, with a focus on the perspectives of these individuals on helpful interactions with their family physicians.

The practice of family medicine for individuals with IDs has been the focus of a small body of literature. Research with family physicians has identified several factors that affect quality of care in this population. In a survey of 300 family physicians, participants identified patients' communication difficulties as a main barrier.⁴ Other scholars have described several other factors that impede high-quality care, including an inability to understand what the patient was trying to convey, limited comprehension on the part of the patient, inadequate time during appointments, an inability to obtain a comprehensive medical history, lack of interprofessional communication among health care providers involved in a patient's care, and inconsistent documentation.⁵⁻⁸ These factors might also result in physicians lacking knowledge about patients' important medical diagnoses and medication profiles.⁹

Another area of research has focused on the education needs of family physicians. In studies examining barriers to high-quality care, physicians themselves identified inadequate education as an issue affecting their ability to provide appropriate care for adults with IDs.⁵ Phillips et al¹⁰ surveyed family physicians (N=252) in Australia about their educational needs and found that 60% of respondents reported that their previous training was not adequate, particularly for medically complex adults with IDs. As well, almost all of the participants (94%) expressed interest in obtaining further education and training in this area.

There are a few studies about family physician care for this population that include the perspectives of individuals with IDs themselves. Jones et al¹¹ interviewed 6 adults with IDs in a study about barriers to primary care. Findings illustrated several challenges, including communication issues, wait times, patients feeling anxious, and behaviour of family physicians, such as infantilizing patients with IDs.¹¹ In a qualitative study of 27 women with IDs, researchers found that participants felt rushed during appointments and thought that their physicians sometimes relied too much on support workers for information rather than talking directly to them.¹² Similarly, Wullink et al¹³ found that patients' main concerns about communication focused on the amount

of time spent with their physicians, being excluded from conversations, and not understanding what their physicians were saying.

Research to date has focused almost exclusively on the perspectives and educational needs of family physicians. Research that included adults with IDs mainly relied on secondary analysis of large databases rather than first-person accounts of their experiences with family physicians. This study further contributes to this small body of research by exploring the perspectives of adults with IDs on the characteristics of helpful interactions with their family physicians.

METHODS

An exploratory, qualitative study was conducted with community-dwelling adults with IDs living in Vancouver, BC, between April 2009 and March 2010. The larger aim of the study was to explore the experiences of aging among this group. In this article, we present the findings specific to the participants' experiences with their family physicians. Ethics approval for the study was obtained from the University of British Columbia.

To recruit participants, we posted flyers in common areas at local community living agencies and attended meetings of groups of adults with IDs to explain the study. Inclusion criteria were age older than 40 years and the ability to converse in English. We used purposive sampling,¹⁴ which helped ensure variation in characteristics such as sex, living situation, and medical complexity.

Data were collected through in-depth, semistructured interviews conducted by a social worker (S.B.) who had extensive experience working with adults with IDs. Participants were asked about their experiences of accessing health care and their interactions with health care providers. Interviews lasted between 30 and 60 minutes and took place at times and locations of the participants' choosing. Participant recruitment continued until data saturation was achieved.

Verbatim transcripts of the interviews were analyzed for themes using a collective analysis process.¹⁵ Each researcher read the transcripts several times to get a sense of each interview as a whole, and the transcripts were coded into categories and subcategories that were discussed at collective analysis meetings. For this study, 2 authors (J.B. and A.P.) retrieved the coded data pertaining to family physicians, and the collective analysis process was repeated to generate the main themes presented below.

FINDINGS

Eleven adults with IDs, aged 43 to 59 years, participated

in the study. Four of the participants were men and 7 were women. All of the participants lived independently in the community, with varying levels of support. Participants reported having between 0 and 7 chronic health conditions, with an average of 2 chronic conditions. All participants reported that they had visited their family physicians within the past year; as well, 7 had been to walk-in clinics, 1 had been to the emergency department, and 2 had been admitted to hospital.

Participants spoke about helpful interactions with their family physicians in 1 of 2 ways: they described how they were helped to understand what the doctors were saying to them; and they described how the doctors helped them navigate the health care system.

Helping patients understand

Participants described how it was often difficult to grasp what their doctors were saying to them: “The biggest concern I have ... like if I go to the doctor, I find myself not understanding what they’re talking about.” A key strength of some family physicians was their ability and willingness to support patients’ understanding through a variety of communication strategies. For many of the participants, this meant using “plain language,” which one participant described as follows:

When the doctor is doing interviews, make sure it’s in plain language so people with intellectual disability understand what you’re talking about. If you use long words or don’t explain what’s going on, we don’t understand it and it’s hard for us to figure out what you’re doing and it upsets us and we get concerned Explain it to us. Don’t just say, “Well, you need a hip replacement and you got this, blah, blah, blah,” in these long technical languages that we don’t know about. I mean, we’re not walking dictionaries and it’s hard for us to look up words, some of us.

Sometimes patients would ask directly for this kind of help. For example, a participant said, “If I can’t understand what he’s saying I always ask him to explain it to me—what the word means—because he uses a new word and all that.” Others recognized that their doctors had limited time, and they would not ask for an explanation. A participant described a typical interaction with his family physician when asked if his doctor always explained things in a way that he understood: “Sometimes no. Like he kind of says things quickly, then he leaves.” However, in this case the participant found support by asking the receptionist for clarification of his medical information.

Recognizing that plain language was not always achievable, the participants found it helpful when their physicians supported their use of alternative communication strategies. One of these was bringing someone

with them to the appointment. Two of the participants were a couple, and they attended appointments together so they could discuss the information afterward. Another participant, when he did not have someone to accompany him, used a tape recorder during appointments and played the information back later when he was with someone who could “translate” the information into plain language.

Helping patients navigate the health care system

Participants’ other substantial concern was being able to manage their health needs given the complex constraints of their socioeconomic situations. Most of the participants had disability pensions as their only source of income, and because many services were not covered through the provincial health insurance program, access could present a challenge. For these reasons, being able to navigate the health care system was a critical skill and participants shared experiences of how their family physicians had helped them in very practical ways.

For those community-dwelling participants who were managing multiple chronic illnesses, their main concern was accessing medications. They were aware that some medications might not be covered under their provincial plan and, in addition, many expressed concern that their situation would worsen as they grew older. Specifically, they were worried that once they turned 65 and were officially “seniors,” they would lose medical benefits as “persons with disabilities”: “Maybe getting to the seniors’ age and figuring out when you become a senior if you’ve got to pay [for] the medication once you leave the disability status. That’s what I’m worried about.”

The participants were dependent on family physicians to be aware of the nature of their medical benefits, and specifically which medications were covered and which were not. Above all, they did not want to be left with a prescription for a medication they could not afford. One participant said:

And we’re finding out sometimes the doctors don’t even know what’s covered. My friend, her doctor gave her ... one prescription [that] was covered and one prescription [that] wasn’t. If that’s affecting your health, you need that medication to get better. That’s not good.

Given the depth of these concerns, it was meaningful to the participants when their doctors found ways to help them obtain medications that would otherwise be out of reach. One participant explained that his physician applied for special coverage for an expensive medication he could not otherwise afford. When such medications were not approved for special coverage, physicians often provided free samples. This practice was described by several of the participants.

Researcher: Are those the samples that you got?
 Participant: Yeah, yeah. Otherwise I would be paying \$89 for them. They're quite expensive.
 Researcher: So your doctor accommodates you by giving you samples?
 Participant: Yes, right now he is.

While it is not ideal to put family physicians in the position of giving medication samples to low-income patients, the participants clearly valued their physicians' commitment to their health while recognizing the reality that their financial situation as persons with disabilities did not allow for purchasing medications that were necessary but not covered through the provincial program.

DISCUSSION

Similar to other studies of adults with IDs,¹¹⁻¹³ communication emerged as an important area of concern for these patients. The use of plain language and other individualized communication strategies was identified as important in their interactions with their family physicians. Unlike other studies, which focused heavily on the presence of support workers during physician-patient exchanges, the participants in this study were often alone when seeing their family physicians. This difference placed greater emphasis on the need for effective physician-patient communication, including the use of patient-generated communication strategies.


This study extended previous research by identifying substantive areas of concern for patients. For example, participants expressed concern about the costs of accessing health care, in particular medications, and how their physicians helped them. Given that most adults with IDs have low incomes¹⁶ and have limited access to paid employment,¹⁷ acknowledgment of these sociocontextual factors beyond their diagnoses of ID is important in the patient-physician relationship. Because the patients' primary (and in some cases, sole) contact with the health care system was through their family physicians, there was a clear need for physicians to educate their patients with IDs about government-funded health benefits, particularly as they aged and their needs became more complex.

Limitations

This study had several limitations: we only interviewed participants who were able to converse in English, and this excluded the perspectives of adults with IDs from other language groups and those who were nonverbal. As well, we focused on participants who were living independently, with supports, in the community and did not include adults living in more structured living situations, such as group homes or home shares. As

a result, their perspectives are not represented here. We also acknowledge that not all adults with IDs have access to family physicians, a situation faced by many Canadians.¹⁸ However, by focusing on the perspectives of those who do have family physicians, this study begins to shed light on how these relationships can be helpful from the patients' perspectives.

Conclusion

Adults with IDs are a unique patient group. In this study, they have described how their family physicians have approached interactions with them in helpful ways. In particular, helping patients understand information during physician-patient interactions and helping patients navigate the health care system were key aspects of this process. Strategies to support family physicians to engage in helpful approaches, including education and further research, are needed given the increasing number of community-dwelling adults with IDs in our aging population. 

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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

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References

- World Health Organization. *Ageing and intellectual disabilities—improving longevity and promoting healthy ageing: summative report*. Geneva, Switz: World Health Organization; 2000.
- World Health Organization. *Atlas: global resources for persons with intellectual disabilities*. Geneva, Switz: World Health Organization; 2007.
- Sullivan WF, Heng J, Cameron D, Lunsby Y, Cheetham T, Hennen B, et al. Consensus guidelines for primary health care of adults with developmental disabilities. *Can Fam Physician* 2006;52:1410-8 (Eng), e154-68 (Fr).
- Millar L, Chorlton MC, Lennox N. People with intellectual disability. Barriers to the provision of good primary care. *Aust Fam Physician* 2004;33(8):657-8.
- Cook A, Lennox N. General practice registrars' care of people with intellectual disabilities. *J Intellect Dev Disabil* 2000;25(1):69-77.
- Lennox NG, Diggins JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *J Intellect Disabil Res* 1997;41(Pt 5):380-90.
- Van Schroyen Lantman-de Valk HJM, Metsemakers JFM, Soomers-Turlings MJ, Haveman MJ, Crebolder HF. People with intellectual disability in general practice: case definition and case finding. *J Intellect Disabil Res* 1997;41(Pt 5):373-9.
- Ziviani J, Lennox N, Allison H, Lyons M, Del Mar C. Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *J Intellect Dev Disabil* 2004;29(3):211-25.
- Lennox NG, Green M, Diggins J, Ugoni A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *J Intellect Disabil Res* 2001;45(Pt 3):226-32.
- Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health. *J Intellect Disabil Res* 2004;48(Pt 2):142-9.

11. Jones MC, McLafferty E, Walley R, Toland J, Melson N. Inclusion in primary care for people with intellectual disabilities: gaining the perspective of service user and supporting social care staff. *J Intellect Disabil* 2008;12(2):93-109.
12. Wilkinson J, Dreyfus D, Bowen D, Bokhour B. Patient and provider views on the use of medical services by women with intellectual disabilities. *J Intellect Disabil Res* 2013;57(11):1058-67. Epub 2012 Sep 14.
13. Wullink M, Veldhuijzen W, van Schroyensteen Lantman-de Valk HMJ, Metsemakers JFM, Dinant GJ. Doctor-patient communication with people with intellectual disability—a qualitative study. *BMC Fam Pract* 2009;10:82.
14. Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs* 1997;26(3):623-30.
15. Boeije HR. *Analysis in qualitative research*. Thousand Oaks, CA: Sage Publications; 2010.
16. Canadian Association for Community Living. *Assuring income security and equality for Canadians with intellectual disabilities and their families*. Ottawa, ON: Canadian Association for Community Living; 2013.
17. Crawford C. *The employment of people with intellectual disabilities in Canada: a statistical profile*. Toronto, ON: Institute for Research on Inclusion and Society; 2011.
18. Sanmartin C, Ross N. Experiencing difficulties accessing first-contact health services in Canada. *Health Policy* 2006;1(2):103-19.

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