

Patients living with disabilities

The need for high-quality primary care

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Abstract

Objective To compare the potential risk factors for lower-quality primary care, the potential markers of unmet needs in primary care, and the willingness to participate in future research among primary care patients with versus without physical disabilities.

Design A waiting room survey using a convenience sample.

Setting A family health team (FHT) in Kitchener-Waterloo, Ont, with a designated Mobility Clinic.

Participants A total of 40 patients seen at the FHT Mobility Clinic and 80 patients from the general patient population of the same FHT.

EDITOR'S KEY POINTS

- Team-based primary health care services designed specifically for patients with disabilities seem to be a promising option for providing high-quality care for this population. In this exploratory study, the authors surveyed patients of an Ontario family health team Mobility Clinic (serving patients with physical disabilities), as well as patients from the general population of the same family health team.

- The authors compared potential risk factors for lower-quality care, potential markers of unmet needs in primary care, and the willingness of the patients in both groups to link their medical records and primary data with provincial administrative databases for future research studies.

- Patients seen in the Mobility Clinic had physical disabilities severe enough such that most reported being unable to walk around their neighbourhood without difficulty. These patients were of lower income, older, more likely to be male, and more likely to report poorer self-rated health.

- Male sex, lower socioeconomic status, and the competing health needs suggested by disability and poor self-rated health are all characteristics that put patients at risk of receiving less preventive care and all were more prevalent among the Mobility Clinic group.

This article has been peer reviewed.
Can Fam Physician 2016;62:e457-64

Main outcome measures Socioeconomic status and social capital, number of self-reported emergency department visits and hospitalizations in the preceding year, and willingness of the patients in the 2 groups to participate in future research studies.

Results Patients from the Mobility Clinic were more than twice as likely to be receiving benefits or social assistance (75.0% vs 32.1%, $P < .001$), were twice as likely to report an annual household income of less than \$40 000 (58.6% vs 29.2%, $P = .006$), and were more likely to report their health status to be fair or poor (42.5% vs 16.2%, $P = .002$). Half of Mobility Clinic patients had visited the emergency department at least once in the preceding year, compared with 29.7% in the general patient population ($P = .027$). When asked if they would be willing to provide their health card number in the future so that it could be linked to health care data for research, 82.5% of Mobility Clinic patients agreed versus 55.0% of those in the general patient population ($P = .004$).

Conclusion In this study, patients with disabilities were at a social disadvantage compared with their peers without disabilities and were more likely to use the emergency department, suggesting that they had unmet health needs. Future research should continue to explore this patient population and to investigate if an interprofessional primary health care team approach focused on patients with disabilities can help to increase quality of care.

Patients handicapés

Nécessité de soins primaires de grande qualité

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Résumé

Objectif Comparer les facteurs de risque susceptibles de diminuer la qualité des soins primaires, les marqueurs indiquant la présence de besoins de santé non satisfaits et l'intérêt à l'égard de la participation à des recherches futures, et ce, chez des patients des soins primaires avec ou sans handicap.

Type d'étude Une enquête de salle d'attente par échantillonnage arbitraire.

Contexte Une équipe de santé familiale (ESF) possédant une *Mobility Clinic* à Kitchener-Waterloo(Ontario).

Participants Un total de 40 patients fréquentant la *Mobility Clinic* et de 80 patients de la population générale fréquentant la même équipe de santé familiale.

Principaux paramètres à l'étude Le statut socioéconomique et le capital social des patients des deux groupes, le nombre d'hospitalisations et de visites aux services d'urgence déclarées pour l'année précédente, et leur intérêt à participer à des recherches futures.

Résultats Les patients de la *Mobility Clinic* étaient plus de deux fois plus susceptibles de recevoir des prestations de l'assistance sociale (75,0 % vs 32,1 %, $P < ,001$), de déclarer un revenu familial annuel de moins de 40 000 \$ (58,6 % vs 29,2 %, $P < ,006$), et ils étaient plus susceptibles de juger qu'ils avaient une santé passable ou mauvaise (42,5 % vs 16,2 %, $P < ,002$). La moitié des patients de la *Mobility Clinic* avaient visité le service des urgences au moins une fois au cours de l'année précédente, par rapport à 29,7 % de ceux de la population générale ($P < ,027$). Lorsqu'on leur demandait s'ils accepteraient de fournir le numéro de leur carte de santé à l'avenir comme contribution aux données pour la recherche sur les soins de santé, 82,5 % des patients de la *Mobility Clinic* étaient d'accord, contre 55 % pour ceux de la population générale ($P < ,004$).

Conclusion Les patients handicapés de cette étude étaient désavantagés sur le plan social par rapport à leurs pairs non handicapés et ils étaient plus susceptibles de visiter le département des urgences, ce qui laisse entendre que certains de leurs problèmes de santé étaient non satisfaits. Les recherches à venir devraient poursuivre l'étude de ce groupe de patients et déterminer si l'utilisation d'une équipe interdisciplinaire en soins de première ligne axée sur les patients handicapés pourrait contribuer à améliorer la qualité de leurs soins.

POINTS DE REPÈRE DU RÉDACTEUR

- L'existence d'équipes créées spécifiquement pour traiter des personnes handicapées semble être une option intéressante pour assurer à cette population des services de santé de grande qualité. Dans cette étude exploratoire, les auteurs ont mené une enquête auprès de patients de la *Mobility Clinic* d'une équipe de santé familiale de l'Ontario (qui traite des personnes handicapées), mais aussi auprès de patients de la population générale qui fréquentent cette même clinique.
- Les auteurs ont comparé, dans les deux groupes, les facteurs susceptibles d'augmenter le risque d'une moindre qualité des soins, les marqueurs pouvant indiquer la présence de besoins primaires non satisfaits, et l'intérêt manifesté par les patients pour que leur dossier médical et leurs données de santé primaire soient inclus dans les bases de données administratives provinciales en vue de recherches futures.
- Les patients vus à la *Mobility Clinic* étaient suffisamment handicapés pour que la plupart se disent incapables de circuler facilement dans leur voisinage. Ces patients étaient plus souvent des hommes, n'avaient pas de bons revenus, étaient plus âgés et étaient plus susceptibles de se considérer en moins bonne santé.
- Être un homme, appartenir à une classe socioéconomique inférieure, nécessiter des soins particuliers à cause de handicaps et se juger en moins bonne santé sont toutes des caractéristiques qui font que le patient risque de recevoir moins de soins d'ordre préventif; toutes ces caractéristiques sont présentes dans le groupe fréquentant la *Mobility Clinic*.

Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2016;62:e457-64

Primary care is one of the key components of the health care system.¹ High-quality primary care includes effective disease management, the provision of preventive services, individualized care that takes a patient-centred approach, and the integration of care across multiple illnesses and domains of care.²⁻⁵ Access to high-quality primary care is thus critical for disease prevention and for effective management of overall health and well-being, particularly for those who are socioeconomically disadvantaged and those with physical and other disabilities who might have a “thinner margin of health.”^{6,7}

Despite this need, system-level and provider-level barriers to receiving the highest-quality primary care have been identified for people living with disabilities, such as less focus on prevention owing to competing health needs, less knowledge on the part of providers, and less likelihood of physical examination owing to office limitations. These barriers partly explain the high and presumably inefficient use of health care services by this population.⁷⁻⁹ Previous research has identified that people with complex medical conditions, including people with disabilities, are less likely to receive some preventive health services, which might also contribute to their disproportionate use of emergency department care.¹⁰⁻¹⁹ Also, people with disabilities are more likely to be of lower socioeconomic status and to have less social capital, both of which further put them at risk.^{14,15,20,21} Individuals living with disabilities have also reported considerable problems accessing high-quality health care, despite being high users of the health care system.⁷ However, the literature on people with disabilities and their access to high-quality primary care is still underdeveloped in Canada. More literature in this area is needed, as is more evidence that could lead to development of policies that improve primary care service delivery to this vulnerable population. Some of this evidence could be provided by research that links clinical data from primary care with provincial-level health data.^{22,23}

Considering the advent of team-based primary care in many parts of Canada, team-based primary health care services designed specifically for patients with disabilities seem a promising option for providing high-quality care for this group. Family health teams (FHTs) are a type of primary care delivery model established in Ontario as of 2005 in which community-centred interprofessional health teams provide primary care for patients in their community.²⁴ In this exploratory study, we surveyed patients at an Ontario FHT-operated Mobility Clinic (serving patients with physical disabilities), as well as patients from the general population of the same FHT. For these 2 groups, we aimed to compare potential risk factors for lower-quality care, specifically socioeconomic status and social capital; potential markers of unmet needs in primary care, specifically number

of self-reported emergency department visits and hospitalizations in the preceding year; and the willingness of patients to link their medical records and primary data with provincial administrative databases for future research studies.

METHODS

Study setting

The Centre for Family Medicine (CFFM) FHT, located in Kitchener-Waterloo, Ont, operates a Mobility Clinic run by an interprofessional team consisting of a family physician, a family medicine resident, nurses, a chiropractor, an occupational therapist, a social worker, and a pharmacist. It caters to patients of the FHT who have mobility issues due to spinal cord injury, high risk of falls, substantial arthritis, multiple sclerosis, or stroke. The clinic provides a variety of primary health care services such as preventive screening, assessment of secondary complications, and in-home assessments that might otherwise be difficult given the patient's mobility impairment. Patients are referred by 1 of the 19 family doctors in the FHT. The CFFM has a total patient population of approximately 27 000. The clinic has been in existence since January 2010 with approximately 20 patients attending the Mobility Clinic each month. The Mobility Clinic runs 1 half-day per week, with support provided via electronic medical record or e-mail outside of designated clinic time.

Sample frame

From January to May 2014, we conducted a waiting room survey using a convenience sample. Mobility Clinic patients were approached by a research assistant (N.M.) at the weekly Mobility Clinic, and other FHT patients were approached during another half-day per week. Any adult (18 years and older) who was capable of providing informed consent was eligible to participate in the study, with the research assistant providing physical assistance in survey completion for those who required it. For an allotted 4-month data collection period, and assuming that 50% of patients would agree to the survey, we expected that 40 patients from the Mobility Clinic would participate in the survey. We aimed to obtain participation from twice as many patients from the general patient population of the same FHT. Among the general patient population, 30 to 40 patients were approached each week, with between 8 and 10 people agreeing. Among Mobility Clinic patients, approximately 5 patients were approached each week, with 2 to 4 people agreeing. Targets of 40 Mobility Clinic patients and 80 patients from the general patient population were achieved after 16 weeks.

Survey instrument

The study survey included demographic questions about

socioeconomic status, level of disability, self-rated health, and social capital. These questions were based on the Canadian Community Health Survey, a validated, cross-sectional, self-report survey administered on a regular basis nationwide by Statistics Canada. The study survey also included closed-ended questions on emergency department and hospital visits in the preceding year and willingness to link medical records with administrative data in future studies. Two slightly different versions of the survey were created, each tailored to one of the subgroups in the study. Specifically, the Mobility Clinic survey asked about frequency of use of the Mobility Clinic. Each survey was estimated to take 10 to 15 minutes to complete.

Data analysis

Descriptive analyses were performed to describe

demographic data and patient characteristics. Simple measures of association (χ^2 tests) were used to determine the relationships between patient responses and demographic characteristics. All statistical tests were performed at the 5% level of significance, using 2-sided tests, and analyzed with SPSS software.

Research ethics boards at St Michael's Hospital in Toronto, Ont, and McMaster University in Hamilton, Ont, approved the study.

RESULTS

The sociodemographic characteristics of survey respondents are summarized in **Table 1**. Patients from the Mobility Clinic were significantly more likely to be newer to the FHT ($P=.016$), to be 60 years or older ($P=.020$), and to

Table 1. Sociodemographic characteristics of survey respondents recruited from the FHT Mobility Clinic or from the general patient population of the FHT

CHARACTERISTIC	MOBILITY CLINIC (N=40),* N (%)	GENERAL PATIENT POPULATION (N=80),* N (%)	P VALUE
Time with the FHT, y			.016
• <3	10 (25.0)	7 (8.8)	
• ≥3	30 (75.0)	73 (91.2)	
Age, y			.020
• <60	15 (37.5)	48 (60.0)	
• ≥60	25 (62.5)	32 (40.0)	
Sex			.048
• Male	21 (52.5)	27 (33.8)	
• Female	19 (47.5)	53 (66.2)	
Marital status			.063
• Married or common law	20 (50.0)	54 (67.5)	
• Widowed, separated, divorced, or single	20 (50.0)	26 (32.5)	
Level of education			.083
• Postsecondary or some postsecondary	25 (62.5)	62 (77.5)	
• Less than postsecondary	15 (37.5)	18 (22.5)	
Source of income			<.001
• Wages, salary, or self-employed	6 (15.0)	45 (57.7)	
• Benefits or social assistance	30 (75.0)	25 (32.1)	
• Other or none	4 (10.0)	8 (10.2)	
Household income			.006
• <\$40 000	17 (58.6)	21 (29.2)	
• ≥\$40 000	12 (41.4)	51 (70.8)	
Health status			.002
• Excellent, very good, or good	23 (57.5)	67 (83.8)	
• Fair or poor	17 (42.5)	13 (16.2)	

FHT—family health team.

*Not all patients answered all questions.

be male ($P=.048$) compared with those in the general patient population. They were more than twice as likely to be receiving benefits or social assistance (75.0% vs 32.1%, $P<.001$), and were twice as likely to report an annual household income of less than \$40 000 (58.6% vs 29.2%, $P=.006$). They were significantly more likely to report their health status to be fair or poor (42.5% vs 16.2%, $P<.002$). Half of the Mobility Clinic patients reported not being married or in a common-law relationship compared with 32.5% of those in the general patient population ($P=.063$).

Fifteen patients surveyed at the Mobility Clinic (37.5%) were at the clinic for their first assessment, with 10.0% having previously attended for 5 visits or more. Nearly three-quarters (72.5%) of Mobility Clinic patients reported being unable to walk around their neighbourhood without difficulty or mechanical support (Table 2). Of those, 24.1% required a wheelchair for mobility. Ninety-five percent of respondents from the general patient population reported having no mobility issues (data not shown).

Table 3 describes the social capital of patients in the 2 groups. No significant differences were noted between patients of the Mobility Clinic and the general patient population. In both groups, more than 40% of respondents reported having many close friends and relatives, and almost all respondents reported having someone to love them and make them feel wanted at least some of the time.

We compared the self-reported number of emergency department visits and hospitalizations in the preceding year for survey respondents. Half of Mobility Clinic patients had visited the emergency department at least once in the preceding year, compared with 29.7% in the general patient population ($P=.027$). There were no significant differences in the percentage of patients who reported hospitalizations (12.5% for Mobility Clinic patients vs 13.8% for the general patient population; $P=.849$).

When asked if they would be willing to provide their health card number in the future so that it could be linked to health care data for research, 82.5% of Mobility Clinic patients agreed versus 55.0% of those in the general patient population ($P=.004$). When asked if they would be willing to be contacted in the future for participation in research, 87.5% of Mobility Clinic patients said yes versus 67.5% of those in the general patient population ($P=.026$).

DISCUSSION

In our exploratory study of patients of an Ontario FHT, we found that patients seen in the CFFM Mobility Clinic had physical disabilities severe enough such that most

Table 2. Functional status of the 40 survey respondents recruited from the FHT Mobility Clinic

FUNCTIONAL STATUS QUESTIONS	N (%)
1. Are you usually able to walk around your neighbourhood without difficulty or mechanical support?	
• Yes	11 (27.5)
• No	29 (72.5)
• Total	40 (100.0)
2. If no to question 1, are you able to walk at all?	
• Yes	25 (86.2)
• No	4 (13.8)
• Total	29 (100.0)
3. If yes to question 2, do you require mechanical support (eg, braces, cane)?	
• Yes	24 (96.0)
• No	1 (4.0)
• Total	25 (100.0)
4. If no to question 1, do you require help from another person to walk?	
• Yes	14 (48.3)
• No	14 (48.3)
• Did not answer	1 (3.4)
• Total	29 (100.0)
5. If no to question 1, do you require a wheelchair to get around?	
• Yes	7 (24.1)
• No	22 (75.9)
• Total	29 (100.0)
6. If yes to question 5, do you require the help of another person with the wheelchair?	
• Yes	2 (28.6)
• No	5 (71.4)
• Total	7 (100.0)

FHT—family health team.

reported being unable to walk around their neighbourhood without difficulty. These patients were of lower income, older, more likely to be male, and more likely to report poorer self-rated health. We found no differences in the number of self-reported hospitalizations in the preceding year between these patients and patients surveyed from the general patient population of the FHT. We did find significant differences in self-reported emergency department use, with Mobility Clinic patients being more likely to report at least 1 visit in the preceding year, and in willingness to participate in future research, with Mobility Clinic patients being more likely to agree.

Table 3. Social capital of survey respondents, as determined by questions derived from the Canadian Community Health Survey, stratified by if patients were recruited from the FHT Mobility Clinic or from the general patient population of the FHT

SOCIAL CAPITAL QUESTIONS	MOBILITY (N = 40), N (%)	GENERAL (N = 80),* N (%)	P VALUE
How many close friends and relatives do you have?			.380
• Few (0-4)	14 (35.0)	22 (27.5)	
• Some (5-9)	7 (17.5)	23 (28.8)	
• Many (≥10)	19 (47.5)	35 (43.8)	
Do you have someone to help if you are confined to bed?			.895
• All, most, or some of the time	32 (80.0)	64 (81.0)	
• A little or none of the time	8 (20.0)	15 (19.0)	
Do you have someone to take you to the doctor if needed?			.859
• All, most, or some of the time	35 (87.5)	70 (88.6)	
• A little or none of the time	5 (12.5)	9 (11.4)	
Do you have someone to prepare meals if you are unable?			.323
• All, most, or some of the time	31 (77.5)	67 (84.8)	
• A little or none of the time	9 (22.5)	12 (15.2)	
Do you have someone to help with daily chores if you are unable?			.371
• All, most, or some of the time	33 (82.5)	69 (88.5)	
• A little or none of the time	7 (17.5)	9 (11.5)	
Do you have someone who shows you love and affection?			.988
• All, most, or some of the time	38 (95.0)	75 (94.9)	
• A little or none of the time	2 (5.0)	4 (5.1)	
Do you have someone to love you and make you feel wanted?			.367
• All, most, or some of the time	39 (97.5)	74 (93.7)	
• A little or none of the time	1 (2.5)	5 (6.3)	

FHT—family health team.

*Not all patients answered all questions.

Our findings have several important implications. Male sex, lower socioeconomic status, and the competing health needs suggested by disability status and poor self-rated health are all characteristics that put patients at risk of receiving less preventive care and all were more prevalent among the Mobility Clinic group.^{13-15,25-28} It is not clear how these variables intersect, but patients with disabilities certainly seem to be a group at risk of receiving lower-quality primary care based simply on their sociodemographic characteristics. Interestingly, high-cost users of the health system in Ontario are more likely to be older, to be of lower socioeconomic status, to have multiple chronic conditions, and to report poorer self-rated health.²⁹ Multivariate regression analyses in future studies might help to elucidate the intersection of these variables and to determine if there are any synergistic effects.

The increased emergency department use by the patients of the Mobility Clinic is in line with previous research and suggests that patients with disabilities have more unmet health needs than their peers

without disabilities do.^{18,19,30} This finding is particularly compelling because all patients in the study were well connected to primary care and were receiving team-based care. Although high emergency department use for patients with disabilities has been connected to difficulties accessing primary care and accessing prescriptions,¹⁹ that is unlikely to be the case in our study sample, suggesting that having a regular family physician is not enough to mitigate this health care gap. Exploring the specific reasons for emergency department visits for patients with disabilities, and if there are feasible targeted interventions for these visits to be avoided, will be an important element of future research. Of importance, we should explore and learn from what the emergency department is doing right for these patients.¹⁹ Since the Mobility Clinic patients are at higher risk of health issues, eliminating or decreasing emergency department use in line with that of the general population might not be realistic or completely attainable. However, understanding the emergency department use will be important to know if unnecessary use can be

averted. As part of future work, we also plan to investigate if increased time with the Mobility Clinic is associated with a decrease in emergency department visits. It is conceivable that, while the emergency department use was higher than among the general clinic population, use might decrease for patients in the Mobility Clinic over time compared with use before attending the Mobility Clinic. Nearly 40% of Mobility Clinic patients interviewed were there for their first visit. Interestingly, in a previously conducted survey, more than 70% of patients of the Mobility Clinic reported improved access to care when their condition worsened.³¹

Of importance, future research should also further elucidate the unmet needs in primary care for this patient population using qualitative methods. For example, transportation issues and fear or distrust of physicians have been reported as reasons for unmet needs in Canada and could feasibly be of particular concern for patients with disability.³² Greater health care needs are known to be associated with increased likelihood of reporting unmet needs.³² Home care, physical or occupational therapy, and case management have also been reported as sources of unmet needs for patients with disability.³³ Physical comfort, respect for expressed needs, help with self-care, and coordinated care are all key dimensions of patient-centred care that should also be assessed, and intervened on, for people with disabilities in future work.^{3,34} Literature from the United States on patient-centred medical homes, which are very similar to Ontario's FHTs, shows that they improve outcomes for patients with chronic diseases and might hold promise for providing high-quality care for patients with disabilities.³⁵⁻³⁷ These patient-centred medical homes include the following key elements: care coordinators; call lines for patients 24 hours a day, 7 days a week; electronic medical records; quality improvement plans that make use of information technology; behavioural change support for patients; and regular learning opportunities for staff.³⁵⁻³⁷ Making sure that these elements are incorporated or strengthened in our current primary care system will be of paramount importance for patients with complex needs.

The reason for our finding that Mobility Clinic patients were more likely to be willing to be involved in future research cannot be directly ascertained from this study, but it might reflect an acknowledgment on the part of patients of their unmet health care needs and a desire to see this care gap investigated and acted upon. In the health literature, patients with disabilities have reported having to educate their physicians about their impairments and associated health issues, and have reported much higher rates of unmet health needs (particularly those that are structurally based) compared with those without disabilities.^{7,38} Interestingly, we found no difference in social capital between the 2 groups of patients. Considering that there seems to be a clear relationship

between social capital and individual health,²¹ this positive finding needs to be explored further using more in-depth qualitative analyses. We also plan to conduct future research that links provincial health care data to patient medical records, allowing comparisons of emergency department use, hospitalizations, and preventive care for patients with disabilities seen in the Mobility Clinic with other patients with and without disabilities in the province. The feasibility of such work is strengthened by patients' expressed willingness to participate.

Limitations

This study has several limitations. First, owing to its exploratory nature, the study sample was relatively small and might not be representative. However, we detected some statistically significant differences in the patient groups that should be further explored in larger studies. Second, the study was voluntary and was conducted using a convenience sample. Third, some patients required assistance to complete the survey and might have succumbed to social desirability bias when answering sensitive questions, such as those relevant to social supports. Fourth, the surveys used in this study were not formally validated beyond face validity. However, they were slightly modified from items on the Canadian Community Health Survey, which is a validated, well established survey by Statistics Canada.

Conclusion

In this study, we found that patients with disabilities were at a social disadvantage compared with their peers without disabilities and were more likely to use the emergency department despite being well connected to primary care, suggesting that they had unmet health needs. Future research should continue to explore this patient population and to investigate if an interprofessional primary health care team approach focused on patients with disabilities can help to increase the quality of care for this vulnerable group. 

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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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