Routine identification of patients with disabilities in primary care: a mixed-methods study

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Abstract

Background

People with disabilities experience barriers to receiving healthcare and often have worse health outcomes, but data on disability is rarely routinely collected in a standardized way.

Objective

This study examined how patients responded to being asked about disabilities as part of a routine, self-administered sociodemographic survey.

Methods

We conducted a mixed-methods study in a multi-site primary care organization. We compared the characteristics of people who responded to a question about disabilities to those who did not respond using logistic regression. We also compared survey responses to data available in medical charts. In-depth interviews were conducted with a sample of patients following survey completion.

Results

Over 28 months, 15,221 patients were offered the survey and 14,247 (93.6%) responded to at least one question. Of these, 11,275 (79.1%) patients answered the question about disabilities. Older patients, patients who rented their home, and non-White patients were less likely to respond to the question. When comparing survey responses to data from medical charts we identified discrepancies. Patients interviewed reported they had difficulty judging what

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constituted a disability. Stigma related to mental illness and substance use led them to avoid disclosing those conditions.

Conclusions

Directly asking patients whether they have a disability may be challenging given confusion about what constitutes a disability and stigma associated with certain disabilities. Future research should examine whether asking about barriers faced in accessing health services could adequately identify patients with disabilities and also be used to identify tangible actions an organization could take to lower barriers to care.

Keywords: social determinants of health; primary health care; health services for persons with disabilities; disabled persons; disability evaluation

Introduction

Over one billion people globally experience some form of disability.¹ People with disabilities and their contexts are heterogenous but certain health disparities are consistent.² People with disabilities have higher rates of cardiovascular disease, diabetes and obesity^{2,3} and report higher rates of chronic pain, sleep disorders and depression than the non-disabled.⁴ They are also at increased risk of injury, violence, and abuse.² People with intellectual disabilities and with severe mental illness are more likely to develop physical illnesses.^{5,6}

Despite greater health needs, people with disabilities typically experience barriers to healthcare.² They have lower rates of cancer screening, report difficulties accessing primary care, and have lower satisfaction with the healthcare system.^{7–10} Social factors may also contribute to worse health outcomes as people with disabilities are more likely to experience poverty, have lower educational attainment and have reduced access to transportation.² People with disabilities experience discrimination as a result of how other characteristics intersect with their disability.¹¹

One obstacle to reducing these inequities is limited data.^{12,13} In the absence of routinely surveying patients, physicians often miss or underestimate disabilities reported by their patients.¹⁴ In the United States, certain organizations routinely collect data on disability status¹⁵ but it remains uncommon.^{12,16} Existing research is limited but suggests that patients with and without disabilities appreciate being given the opportunity to describe their disabilities.¹⁶

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Since 2013, our organization has surveyed patients about whether they have disabilities as part of a sociodemographic survey offered to all patients with answers integrated into the electronic medical record (EMR).¹⁷ The objective of this study was to examine non-response bias, compare patient responses to other data available in the chart, and to understand the experience of patients who responded to the survey.

Methods

Setting and context

A sociodemographic survey [**APPENDIX 1**] for use in a variety of health settings was developed by three academic health science centres and the local public health unit in Toronto, Canada with the support of the regional health authority.^{17,18} This self-administered survey included a question on disabilities, with options developed based on definitions and categories outlined by the Ontario Human Rights Commission.¹⁹ In pilot testing the question was stated as ‘Do you have any of the following disabilities?’.¹⁸ Subsequently, the question was stated as ‘Do you have any of the following?’ [**FIGURE 1**], with the rationale being that some patients could feel the term ‘disability’ was stigmatizing or that some patients may not consider a chronic illness as a disability.²⁰

In 2013, the survey was implemented at **XXXXXXX**, a large, primary care organization in **XXXXXX**, Canada.¹⁷ The organization serves approximately 45,000 patients at six sites. Prior to implementation, clerical staff were oriented to the sociodemographic survey and how to address questions from patients. The survey was routinely offered to all patients on an electronic tablet or on paper when patients arrived for an appointment. Only English versions of the survey were available. Data from electronic tablets was immediately uploaded to the patient’s EMR, while data from paper surveys was later entered by staff. A companion could assist with completing the survey if the patient was unable to do so themselves.

Study design

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Details of our methods have been described elsewhere.²¹ In brief, we used a mixed-methods sequential explanatory design.²² The quantitative component of the study occurred first, as part of ongoing quality improvement initiatives and was deemed by XXXXXX to not require formal ethics approval after institutional review. The qualitative component occurred subsequently and was approved by the XXXXXX Research Ethics Board. An advisory group, made up of patients and representatives from local hospitals, the regional health authority and the provincial quality improvement agency, supported this study.

Quantitative data and analysis

We extracted data from the EMR on patients who were offered the survey between December 1, 2013 and March 31, 2016 and answered at least one question. Data consisted of answers to the sociodemographic survey, age, postal code, health insurance claims and the presence of diagnostic codes. Postal code was used to establish which quintile of average neighbourhood income the patient resided, a common proxy for individual income in Canadian studies.^{23, 24, 25} Insurance claims were used to identify patients as living with mental illness or substance use, based on a previously validated methodology.²⁶ Existing diagnostic codes in the EMR were used to identify which patients were living with diabetes, HIV and developmental disability. These conditions were identified as priorities by the practice and codes were updated routinely based on a structured search of the EMR and physician validation.

Non-responders were defined as those that selected “prefer not to answer”, “don’t know”, or left the question blank. Since patients could select multiple answers for the disability question, two steps were taken to resolve incompatible responses. If the patient indicated that they had no

disabilities but still proceeded to select at least one of the disabilities, they were considered to have left the question blank and their disability answers were set as missing. If the patient selected “prefer not to answer” or “do not know” they were recorded as missing or unanswered.

To assess non-response bias, we examined sociodemographic differences between patients who responded (responders) and did not respond (non-responders) to the disability question. We compared age, gender identity, sexual orientation, preferred language, immigration status, race/ethnicity, housing status, mental illness and average neighbourhood income quintile between the groups using chi-square tests for categorical variables and the Mann-Whitney U-test for age (non-normally distributed continuous variable). We pre-specified two-tailed p-values of less than 0.01 as our threshold of a significant difference. Variables that were significantly different between the groups were included in a logistic regression model to estimate adjusted odds ratios (AOR) and 95% confidence intervals (95% CI). Anticipating that preferred language, immigration status and race/ethnicity would be highly correlated, *a priori* we decided to only include race/ethnicity in our regression model. To compare self-reported disability to information in the EMR, we used percentages. We compared self-reported chronic illness to the presence of a diagnostic code for HIV and/or diabetes, self-reported developmental disability to the presence of a diagnostic code for development disability, and self-reported mental illness or drug or alcohol dependence to identification through health insurance claims.

Qualitative data and analysis

To evaluate the experience of patients in answering a question about disabilities two research staff interviewed a convenience sample of patients immediately after they completed the

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sociodemographic survey. Demographics were collected from patients interviewed and reviewed iteratively to ensure diversity in terms of age and gender representation. Patients were eligible if they were aged 18 or older, could converse in English and had completed the sociodemographic survey that day. Interviews explored the experience of completing the survey, how questions were understood and potential uses and harms of the data collection initiative. Interviews were audio-recorded and transcribed verbatim. Coding was completed in NVivo 11 (QSR International) by a team of five coders. Using the interview guide a small number of codes were created *a priori*, with further codes emerging from the data. A codebook was created from a subset of interviews, and the remaining data was subsequently coded. After the initial coding was complete a sub-theme analysis of the codes was conducted, and themes were discussed with the entire study team to identify the key findings.

Results

Quantitative results

During the 28-month study period, 15,221 patients were offered the survey and 14,247 (93.6%) responded to at least one question. Of these 11,275 (79.1%) responded to the question about disabilities. Of those that responded, 6,949 (61.6%) identified no disabilities, 2,989 (26.5%) identified one, 915 (8.1%) identified two, 311 (2.6%) identified three, and 111 (1.0%) identified four or more concurrent disabilities. Chronic illness, mental illness, and physical disability were the three most commonly reported disabilities.

Responders to the disability question differed significantly from non-responders with respect to gender, age, spoken language, immigration status, housing status, ethnicity, sexual orientation and average neighbourhood income quintile [**TABLE 1**], but were similar with respect to the presence of severe mental illness. The odds of responding to the question about disabilities were consistently lower among patients who chose ‘prefer not to answer’ or ‘do not know’ or left the question blank for questions about gender identity, housing status, ethnicity, or sexual orientation [**TABLE 2**]. Adults aged 50-59 years (AOR: 0.81 (95% CI 0.70-0.93), $p=0.0039$) and aged 70 years and older (AOR: 0.78 (95% CI 0.65-0.94), $p=0.0071$) had lower odds of responding to the question on disabilities when compared to individuals aged 30-39 years. People who rented had lower odds of responding than those who owned their home (AOR: 0.79 (95% CI 0.70-0.88), $p<0.0001$). Patients who identified as non-White had lower odds of responding compared to individuals who were White (AOR: 0.69 (95% CI 0.63-0.77), $p<0.0001$). In our adjusted analysis, neighbourhood income quintile was not significantly associated with responding.

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When we compared self-reported disabilities to other data in the EMR we found that patients may have chosen not to disclose a disability. Of those who had had a record of a mental health-related visit, 76.8% did not report that they had a mental illness on the survey. Of those who had had a visit for psychotic disorders, 38.2% did not report that they had a mental illness on the survey. Of those who had had a record of a visit related to substance use, 62.2% did not report that they had drug or alcohol dependence issues on the survey. Of those with diabetes or HIV based on their medical chart, 60.5% reported that they did not have a chronic illness on the survey.

Qualitative findings

We interviewed a diverse group of 27 patients [**APPENDIX 2**]. Our interviews with patients revealed two key themes. First, patients reported difficulty in judging whether a condition they had fit the options provided in the question, several which used the term “disability”. Patients felt that simply having been diagnosed with a condition did not equate with living with a disability if they were currently not experiencing impairment. One participant reported, *“I have some vision loss ... I have macular degeneration so like I am not driving... I wasn't sure whether you'd consider that a disability because I'm not blind.”* The options ‘chronic illness’, ‘mental illness’ and ‘drug and alcohol dependence’ caused the greatest confusion, reflecting the fluctuating nature of symptoms and behavior. One patient stated, *“I don't know what they mean by chronic illness ... something that's going to kill you or just something that you're going to have for all the rest of your life.”* Another participant, when discussing choosing the option “mental illness” noted, *“I don't want to be like labeled with it like for the rest of my life... if it's temporary”*.

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Another participant noted, *“I know that I have ... certain ... mental disabilities and stuff— but ... I’ve never [been] diagnosed with anything ... so I can’t say exactly what I have.”* These findings fit with our quantitative results that found a discrepancy between medical diagnoses and patient self-reported disabilities.

Second, patients reported concerns about the stigma associated with self-identifying mental illness and drug and alcohol dependence. One patient noted, *“when you say ‘mental illness’, I think that’s a whole bag of things ... people [are] ... a little bit less likely to want to admit that kind of things. There’s a stigma attached.”*. Another patient noted, *“...Definitely mental illness and drug or alcohol dependence [were stigmatizing]. I think that although like it is a problem it’s a ... bit weird to like, kind of admit that or like circle it”*. These findings fit with our quantitative results that found that many patients with a medical visit for mental illness or substance use did not self-identity as having these conditions.

Discussion

We studied the experience of patients in a multi-site primary care organization who were asked to self-report on disability as part of a routine sociodemographic survey. We found that most patients responded to the question about disability. Non-responders were more likely to have not responded to other questions on the survey and tended to be older, non-White, and rent their home. We found a discrepancy between answers on the survey to information in the chart. Through interviews we found that patients were not sure whether their health conditions fit into the options provided, particularly those that were identified as a disability. Many patients were concerned about stigma related to mental illness and drug and alcohol dependence.

The strengths of this study include our pragmatic implementation of the survey, our large sample on which to base our quantitative findings, and our mix of quantitative and qualitative methods. Limitations of this study include that it reports on a single institution, albeit one that consists of multiple clinic sites serving a diverse population. Another limitation is that patients who were interviewed were not stratified into those with and without disabilities. We also do not know how many surveys were completed by a caregiver rather than the patient. Finally, data in the EMR may not always be correct, and hence may not be an appropriate gold standard for the presence or absence of a disability.

Our findings fit with other published work. A study of 303 patients surveyed in three out-patient clinics found 77% were comfortable with healthcare organizations collecting data on disabilities¹⁶, a proportion similar to the proportion that responded in our study. In our study, of

those who responded, almost 40% identified at least one disability. This is a higher proportion than a study conducted of 128,636 new outpatients at Mayo Clinic, Rochester, MN who were surveyed using the question ‘*Are you disabled?*’ where 11.6% responded ‘yes’.²⁷ The difference is most likely as a result of how our question was worded. We found evidence of possible underreporting of certain conditions, likely as patients did not consider these conditions as a disability particularly if the disease was under good control (e.g. HIV infection or diabetes), or felt stigma around reporting a condition (e.g. substance use).

An alternative approach would frame disability as it relates to how people experience their context rather than as a medical condition. Future research could examine barriers faced to accessing health care and other necessary services. This would be less stigmatizing, clarify the purpose of the question, and answers would be actionable by health organizations. For example, health organizations could use this data to introduce accommodations for specific patients. A starting point could be questions developed by Morris et al. based on the US Department of Health and Human Services recommended questions that ask patients about disabilities related to hearing, vision, motor function, cognitive ability, communication, learning and the ability to conduct activities of daily living.²⁸

Conclusion

Our study helps advance our understanding of how patients respond to being surveyed about disabilities.²⁹ While data collection has been identified as a key part of improving health of people with disabilities³⁰ it remains uncommon. Routinely collecting data on accessibility could help providers identify accommodations that are needed to improve access, could make care plans more patient-centred, and when aggregated, could be used to proactively identify issues with access and health disparities.^{19,19}

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Figure legends

Figure 1: Question used to routinely ask patients to self-identify disabilities.

Table 1: Sociodemographic characteristics of patients who responded to the question on disabilities compared to non-responders

	Responders n = 11275	Non-responders n = 2972	P-value
Gender			<0.0001
Male*	4599 (40.8%)	1088 (36.6%)	
Female	6396 (56.7%)	1475 (49.6%)	
Other**	99 (0.9%)	29 (1.0%)	
Prefer Not to Answer/Do Not Know/Missing	181 (1.6%)	380 (12.8%)	
Age			0.0094
< 10 years old	156 (1.4%)	41 (1.4%)	
10-19 years	162 (1.4%)	41 (1.4%)	
20-29 years	1536 (13.6%)	383 (12.9%)	
30-39 years	2806 (24.9%)	655 (22.0%)	
40-49 years	2165 (19.2%)	570 (19.2%)	
50-59 years	2032 (18.0%)	573 (19.3%)	
60-69 years	1422 (12.6%)	399 (13.4%)	
70+ years	996 (8.8%)	310 (10.4%)	
Median (IQR)	44 (33 – 57)	46 (34 – 59)	0.0003
Language [spoken]			<0.0001

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English*	10568 (93.7%)	2578 (86.7%)	
Other	652 (5.8%)	288 (9.7%)	
Prefer Not to Answer/Do Not Know/Missing	55 (0.5%)	106 (3.6%)	
Immigration Status			<0.0001
Born outside Canada	4548 (40.3%)	1334 (44.9%)	
Canadian Born*	6502 (57.7%)	1342 (45.1%)	
Prefer Not to Answer/Do Not Know/Missing	225 (2.0%)	296 (10.0%)	
Housing Status			<0.0001
Own home*	4577 (40.6%)	897 (30.2%)	
Rent	4917 (43.6%)	1229 (41.3%)	
Other	1023 (9.1%)	271 (9.1%)	
Prefer Not to Answer/Do Not Know/Missing	758 (6.7%)	575 (19.4%)	
Ethnicity			<0.0001
White*	6333 (56.2%)	1209 (40.7%)	
Non-white	4296 (38.1%)	1241 (41.8%)	

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Prefer Not to Answer/Do Not Know/Missing	646 (5.7%)	522 (17.6%)	
Sexual Orientation			<0.0001
Heterosexual*	8829 (78.3%)	1955 (65.8%)	
Gay/Bisexual /Lesbian /Queer /Two-Spirit /Other	1757 (15.6%)	365 (12.3%)	
Prefer Not to Answer/Do Not Know/Missing	689 (6.1%)	652 (21.9%)	
Mental health			0.8454
Severe mental illness***	321 (2.8%)	82 (2.8%)	
Neighbourhood Income Quintile			<0.0001
Q1	2690 (28.2%)	820 (33.0%)	
Q2	1578 (16.5%)	423 (17.0%)	
Q3	1481 (15.5%)	391 (15.8%)	
Q4	1493 (15.6%)	323 (13.0%)	
Q5	2307 (24.2%)	524 (21.1%)	

* χ^2 for categorical, Mann-Whitney U-Test for Continuous Age

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***** Includes trans-FTM, trans-MTF, intersex, “other”, and those who selected multiple gender terms***

****** Includes patients with a bill submitted that includes the diagnostic code for schizophrenia, bipolar disorder, psychosis, paranoia or psychosis not otherwise specified***

Table 2: Adjusted odds ratios and 95% confidence intervals for the association between responding to a question about disabilities and socioeconomic variables

Covariate		AOR (95% CI)	P-Value
Gender	Female	1.08 (0.97 - 1.19)	0.1537
	Other (Intersex/Transgender/Other)	0.77 (0.47 - 1.26)	0.3063
	Prefer Not to Answer/Do Not Know/Missing	0.28 (0.22 - 0.35)	<0.0001
	Male (reference)		
Age	< 10 years old vs. 30-39 years old	1.58 (1.04 - 2.40)	0.0308
	10-19 years vs. 30-39 years old	1.13 (0.74 - 1.72)	0.5809
	20-29 years vs. 30-39 years old	0.99 (0.84 - 1.17)	0.9271
	40-49 years vs. 30-39 years old	0.87 (0.75 - 1.01)	0.0659
	50-59 years vs. 30-39 years old	0.81 (0.70 - 0.93)	0.0039
	60-69 years vs. 30-39 years old	0.82 (0.69 - 0.96)	0.0158
	70+ years vs. 30-39 years old	0.78 (0.65 - 0.94)	0.0071
Housing status	Renting vs. Own home	0.79 (0.70 - 0.88)	<0.0001
	Other vs. Own home	0.87 (0.73 - 1.04)	0.1276
	Prefer Not to Answer/Do Not Know/Missing vs. Own home	0.51 (0.43 - 0.61)	<0.0001
Ethnicity	Non-White vs. White	0.69 (0.63 - 0.77)	<0.0001

Routine identification of patients with disabilities in primary care

	Prefer Not to Answer/Do Not Know/Missing vs. White	0.5 (0.42 - 0.59)	<0.0001
Sexual orientation	Gay/Bisexual /Lesbian /Queer /Two-Spirit /Other	1.06 (0.92 - 1.22)	0.4402
	Prefer Not to Answer/Do Not Know/Missing vs. Heterosexual	0.42 (0.36 - 0.49)	<0.0001
Average neighbourhood income quintile*	Q2 vs. Q1	1.03 (0.89 - 1.18)	0.7111
	Q3 vs. Q1	1.01 (0.87 - 1.16)	0.9321
	Q4 vs. Q1	1.11 (0.95 - 1.29)	0.1971
	Q5 vs. Q1	1.04 (0.91 - 1.19)	0.5757

*Q1 is the lowest average neighbourhood income quintile, and Q5 is the highest average neighbourhood income quintile.