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Disparities in attendance at diabetes self-management education programs after diagnosis in Ontario, Canada: a cohort study

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Abstract

Background: Patients newly-diagnosed with diabetes require self-management education to help them understand and manage the disease. The goals of the study were to determine the frequency of diabetes self-management education program utilization by newly-diagnosed patients, and to evaluate whether there were any demographic or clinical disparities in utilization.

Methods: Using population-level health care data, all 46,553 adults who were diagnosed with any type of non-gestational diabetes in Ontario, Canada between January and June 2006 were identified. They were linked with a diabetes self-management education program registry to identify those who attended within 6 months of diagnosis. The demographic and clinical characteristics of attendees and non-attendees were compared.

Results: A total of 9,568 (20.6%) patients attended a diabetes self-management education program within 6 months of diagnosis. Younger age, increasing socioeconomic status, and the absence of mental health conditions or other medical comorbidity were associated with attendance. Patients living in rural areas, where access to physicians may be limited, were markedly more likely to attend. Recent immigrants were 40% less likely to attend self-management education programs than longer-term immigrants or nonimmigrants.

Conclusion: Only one in five newly-diagnosed diabetes patients attended a diabetes self-management education program. Demographic and clinical disparities in utilization persisted despite a publicly-funded health care system where patients could access these services without direct charges. Primary care providers and education programs must ensure that more newly-diagnosed diabetes patients receive self-management education, particularly those who are older, poorer, sicker, or recent immigrants.

Keywords: Diabetes self-management education programs, Utilization of health services, Disparities, Population-based research

Background

Diabetes mellitus is a common and serious chronic disease, and is associated with impaired quality of life, premature mortality and significant economic costs [1-3]. Effective management of diabetes can reduce the risk of complications and morbidity for people with diabetes, but these approaches are complex as they require sustained efforts at behavior modification and long-term preventative pharmacological therapy

[4]. Thus, many jurisdictions have adopted a chronic disease management model centered on patient self-management supported by multidisciplinary health care teams to help address this epidemic [5-7]. Comprehensive diabetes self-care education is necessary to successfully implement and sustain lifestyle changes, and to ensure that patients are utilizing appropriate health services. Reviews of randomized trials have suggested that self-management education can lead to improvements in knowledge, dietary habits, frequency and accuracy of glucose self-monitoring, weight and glycemic control [8-16]. It has also been found to be cost-effective, or even cost-saving [17-19]. Arguably the most important time for

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patients to receive self-management education is immediately after diagnosis. At that time, patients are seeking information about their new condition, and they may be overwhelmed by the many behavioral changes they are asked to adopt almost immediately [20]. Thus, the time immediately following diagnosis represents a critical window when patients are most likely to be interested in chronic disease care and receptive to self-management education.

However, as for other health care services, there may be disparities in utilization of self-management education across different populations. A number of small American studies have used cross-sectional self-reported survey data to show that certain patient subgroups, such as those with lower education or older age, are less likely to report having previously received diabetes education [21-23]. However, in addition to the methodological limitations of the design and data sources of these studies, their results may not be generalizable to health care systems offering publicly-funded universal access for all patients, where many disparities in care might be mitigated. Thus, the purposes of this population-based cohort study were to determine the frequency of diabetes self-management program utilization by patients within 6 months of diagnosis in Ontario, Canada, and to evaluate whether there were any demographic or clinical disparities in utilization.

Methods

This population-based cohort study used health care administrative databases that detail health care utilization by every resident of Ontario, Canada's most populous province with over 12 million residents. These data sources included: 1) the Registered Persons Database, a register of demographic information about all Ontario residents; 2) the physician service claims database, which records all fee-for-service billing claims from Ontario physicians; 3) the discharge abstracts database, which records detailed information about each hospitalization to an Ontario hospital; and 4) the Ontario Diabetes Database, a validated registry of all people diagnosed with non-gestational diabetes in Ontario, which is derived from these three administrative databases [24]. The registry was developed by and is updated annually by the Institute for Clinical Evaluative Sciences, and uses the diagnosis codes recorded on physician service claims and hospitalization records to identify cases of diabetes. The Ontario Diabetes Database does not distinguish between type 1, type 2 or other diabetes, so the analyses could not be divided according to diabetes type. Individuals are linked between all of these databases using their unique health card number, which is used by all Ontario residents to access health care services.

A cohort was defined of every adult aged ≥18 years in Ontario who was diagnosed with diabetes between January and June 2006, according to the Ontario Diabetes Database. Patients who had immigrated within 2 years prior to the diagnosis of diabetes were excluded, as their apparently incident diabetes in the registry might have represented prevalent diabetes at the time of immigration. Baseline demographic and clinical characteristics that might be associated with disparities in utilization of self-management education programs after diabetes diagnosis were defined using the linked administrative data. These included: age, sex, socioeconomic status (derived ecologically as the median neighborhood household income divided into quintiles), immigration within the previous 10 years, rural residence, primary care visits in the year prior to diabetes diagnosis, diabetes diagnosed during a hospitalization, previous cardiac events (hospitalizations for myocardial infarction, angina or coronary bypass within 5 years prior to diabetes diagnosis), previous mental illness (based on a validated method using physician service claims) [25], and medical comorbidity (score of ≥1 on the Charlson comorbidity index) [26].

Most diabetes self-management education in Ontario is delivered through 331 diabetes self-management education programs distributed throughout the province. These programs are funded in whole or in part by the Ministry of Health, and most are hosted by academic or community hospitals, community health centres or First Nations organizations. There was no existing province-wide registry or administrative database with information on diabetes self-management education program visits. Therefore, a registry was compiled by collecting the visit dates and health card numbers of all adults attending any diabetes self-management education program in Ontario during the 2006 calendar year. Data were collected either through data extraction from existing electronic medical records or manual chart abstractions conducted by program staff or trained chart abstractors. These data were then linked to the other population-level health care data through the patients' health card numbers. The primary outcome was a visit to any diabetes self-management education program within 6 months of diabetes diagnosis. This follow-up period after diabetes diagnosis was selected as a reasonable time in which patient self-management education should be implemented [6,7]. Patients who died prior to the end of follow-up were excluded.

To determine whether wait times for diabetes self-management education might contribute to low utilization, a subgroup analysis was performed expanding the follow-up window to 8 months after diabetes diagnosis, among the subgroup of patients who had sufficient follow-up time (i.e., those who were diagnosed with diabetes between January and April 2006).

Bivariate associations between demographic and clinical characteristics and diabetes self-management education

program attendance were examined using chi-square tests of association. To examine the independent effects of these characteristics on program attendance, a multivariable log-binomial regression model was used to estimate adjusted relative risks. All analyses were performed using SAS version 9.2 (Cary, NC).

This study was approved by the research ethics board of Sunnybrook Health Sciences Centre. Local ethics approval was also obtained from 48 additional ethics boards, medical advisory boards or ethics consultations, as requested by individual programs during the course of registry compilation.

Results

There were 50,363 adults newly diagnosed with diabetes in Ontario between January and June 2006. Of them, 1,205 were excluded because they died before December 31, 128 were excluded because of missing address information needed to determine baseline demographic characteristics, and 2,477 were excluded because, as recent immigrants to Ontario, we could not distinguish incident from prevalent diabetes. Of the final cohort of 46,553 people, only 9,568 (20.6%) attended a diabetes self-management education program within 6 months of their diabetes diagnosis. In the subgroup of 31,580 patients who were diagnosed with diabetes between January and April 2006, 20.6% had a program visit within 6 months, growing only to 22.0% when follow-up was lengthened to 8 months.

Unadjusted and fully adjusted associations between the baseline characteristics and diabetes self-management education program attendance are shown in Table 1. Increasing age was associated with decreased attendance in both the unadjusted analysis and in the adjusted regression model, with only 11.9% of patients aged ≥80 at diagnosis attending a diabetes self-management education program. In contrast, increasing socioeconomic status was associated with increased attendance. There were no significant differences in program attendance between men and women. The largest absolute difference in attendance was between patients residing in rural regions versus those in non-rural regions, with nearly one-third of rural residents attending a diabetes self-management education program. Recent immigrants were markedly less likely to attend a program. Patients with no family physician visits in the preceding year and those with seven or more visits were less likely to attend a diabetes self-management education program than those with one to six visits in the preceding year. Finally, patients with mental health conditions or medical comorbidity were somewhat less likely to attend.

Discussion

Only one in five adults with newly-diagnosed diabetes in Ontario attended a diabetes self-management education program within 6 months of diagnosis. The remaining patients therefore either received no formal professional self-management education about their new condition, or they received education during other health care encounters such as visits with their family physician, even though the education that can be provided in this context is often inadequate, in part because primary care physicians often misunderstand patients' informational needs at diagnosis [20]. This low utilization of diabetes self-management education programs occurred despite the fact that these services are available without direct patient charges and often without requiring physician referral, and despite the fact that these services are broadly distributed throughout the province, reducing geographic barriers to access.

Younger patients were more likely to attend a diabetes self-management education program than older patients. This may be due in part to a higher likelihood of type 1 diabetes among young adults with newly diagnosed diabetes. However, the gradient of decreasing utilization with increasing age persisted across all age strata, such that those aged over 80 years were nearly half as likely to attend a self-management education program as young adults. Like advancing age, people with lower socioeconomic status, those who were recent immigrants, and those with mental health conditions or medical comorbidity were less likely to attend a diabetes self-management education program, despite arguably being more in need of self-management support. The observed results are consistent with previous studies, where utilization was found to be lower amongst older adults and those with lower levels of education [22,23,27]. A more recent survey of 295 patients with diabetes in Pennsylvania found that only 45% reported having ever received self-management education, and patients with complications or with poor control were no more likely to have attended [28]. A Canadian survey of 781 patients found that demographic factors did not predict utilization of diabetes education [29]. Surveys of health care providers in the United States and Canada have suggested that barriers to utilization include patient unwillingness, programs' location, languages of service, operating hours, and (in the United States) insurance coverage [30-32]. The disparities in utilization found in this study may also partially explain the observation that patients utilizing education services had lower average costs than non-attendees [17], since older, poorer and sicker patients who would be predicted to have higher health care costs were also less likely to use such services in the first place. Nonetheless, the presence of these disparities in diabetes self-management education program utilization is noteworthy in a publicly-funded health care system where patients are meant to have equitable access to these services. These populations may face other barriers to

Table 1 Associations between the baseline demographic and clinical characteristics, and diabetes self-management education program utilization

		Diabetes self-management education program attendees	Diabetes self-management education program non-attendees	Unadjusted p-value	Adjusted relative risk	Adjusted p-value
		(n = 9,899) %	(n = 39,131) %		(95% CI)	
Age	18-44	1,884 (19.7)	6,564 (17.7)	<0.001	1.00	<Ref
	45-54	2,330 (24.4)	8,008 (21.7)		0.96 (0.91–1.02)	0.177
	55–64	2,599 (27.2)	9,420 (25.5)		0.89 (0.85–0.94)	<0.001
	65-79	2,362 (24.7)	10,085 (27.3)		0.79 (0.75–0.84)	<0.001
	80+	393 (4.1)	2,908 (7.9)		0.52 (0.47–0.57)	<0.001
Female sex		4,453 (46.5)	17,296 (46.8)	0.695	1.03 (1.00–1.07)	0.078
Socioeconomic status	Lowest	1,956 (20.4)	8,379 (22.7)	<0.001	1.00	<Ref
	2	1,940 (20.3)	8,194 (22.2)		1.01 (0.95–1.07)	0.757
	3	1,982 (20.7)	7,434 (20.1)		1.08 (1.03–1.15)	0.003
	4	1,928 (20.2)	6,912 (18.7)		1.11 (1.05–1.18)	<0.001
	Highest	1,762 (18.4)	6,066 (16.4)		1.13 (1.07–1.20)	<0.001
Recent immigrant		541 (5.7)	3,658 (9.9)	<0.001	0.60 (0.55–0.65)	<0.001
Rural residence		1,692 (17.7)	3,684 (10.0)	<0.001	1.59 (1.52–1.66)	<0.001
Primary care visits in year prior to diagnosis	0	627 (6.6)	2,624 (7.1)	<0.001	0.87 (0.81–0.94)	<0.001
	1–6	5,998 (62.7)	21,397 (57.9)		1.00	<Ref
	7–12	2,189 (22.9)	8,943 (24.2)		0.96 (0.91–1.00)	0.047
	13+	754 (7.9)	4,021 (10.9)		0.79 (0.74–0.85)	<0.001
Diabetes diagnosed during a hospitalization		591 (6.2)	2,726 (7.4)	<0.001	0.96 (0.88–1.04)	0.301
Previous cardiac event		367 (3.8)	1,659 (4.5)	0.005	0.95 (0.86–1.04)	0.272
Mental health condition		2,805 (29.3)	11,548 (31.2)	<0.001	0.94 (0.91–0.98)	0.006
Medical comorbidity		499 (5.2)	2,592 (7.0)	<0.001	0.89 (0.81–0.97)	0.010

access and utilization, such as lower health literacy, less ability to navigate the health care system, or occupational or financial barriers to attending programs.

Patients living in rural areas were markedly more likely to attend diabetes self-management education programs, perhaps because other providers of diabetes care, such as family physicians or endocrinologists, are more difficult to access in rural areas. We had hypothesized that patients who had no family physician visits prior to diabetes diagnosis might have had greater utilization of diabetes self-management education programs as an alternative source of primary diabetes care. Instead, these patients were less likely to have program utilization. Interestingly, patients with many family physician visits prior to diagnosis were also less likely to attend, perhaps because such frequent visits are a marker for other comorbidity or high demand health needs that distract from optimal chronic disease management. We had also hypothesized that patients whose diabetes was diagnosed during a hospitalization might be less likely to attend a diabetes self-management education program, reflecting inadequate attention to chronic

disease follow-up upon discharge from hospital. However, attendance did not differ for these patients.

One possible reason for low utilization within the first 6 months after diagnosis could be that wait times for receiving diabetes self-management education services exceeded 6 months. If this were the case, we would expect that examining longer periods of follow-up would lead to ongoing increases in the proportion of patients who attended diabetes education. However, when we reanalyzed the data by lengthening follow-up by one-third to 8 months, the proportion of patients attending a diabetes self-management education program increased by only 1.4%. Hence, it is unlikely that wait times were a significant contributor to low utilization.

This study is unique in a number of ways. It is the first study to examine demographic and clinical predictors of diabetes self-management education program utilization in Canada's universal health care system, where socioeconomic status and insurance are not the overwhelming barriers to health care utilization that they are in other health care systems. The study shows that even in this universal access context, disparities by age, socioeconomic status

and immigration history occur. Virtually all previous studies of diabetes self-management education utilization have relied on small cross-sectional surveys of patients with diabetes; our study examined real-world utilization of self-management education services at a population level in a longitudinal cohort, making it more methodologically rigorous. However, there are some limitations to note. First, although our cohort of patients was linked to large health care databases permitting measurement of many important demographic and clinical predictor variables, other potentially important factors that might be associated with disparities in diabetes self-management education program attendance could not be measured from population-level data, such as education level, employment, health literacy or language proficiency. Second, as noted above, the Ontario Diabetes Database does not distinguish between types of diabetes, so we could not specifically compare predictors of program attendance between type 1 and type 2 diabetes. Third, there are undoubtedly many patients who were referred to self-management education programs who did not ultimately attend. Since our study only captured attendance, these patients would not have been identified. However, our study focused on the outcome measure of program attendance, not on the process measure of receiving a referral to one from a health care provider. Fourth, the influence of variability in the curricula between diabetes education programs could not be evaluated in our study, as these data were not available. However, a Standards Recognition Program for diabetes education has been developed by the Canadian Diabetes Association, so the extent of variability may not be significant. In addition, each program receives at least partial funding from the provincial Ministry of Health, and therefore must adhere to government-mandated standards on curriculum, staffing and access. Finally, our study examined attendance only at formal diabetes self-management education programs. Although these programs are the main sources for self-management education, other sources of self-management education and support (such as an individual nurse working with a primary care physician, or self-management education provided by a pharmacist in a dispensary) could not be captured by this study.

Further research is required to determine what patient, provider and health care system factors contribute to the observed disparity in utilization by vulnerable patients. In addition, interventions to improve utilization of self-management education programs by patients newly-diagnosed with diabetes need to be developed and evaluated.

Conclusions

In summary, patients with diabetes express a strong preference to receive self-management education soon after diagnosis, as they have many immediate issues about management that need to be addressed [20]. In a randomized trial, attending a self-management education program at diagnosis led to improved understanding of the illness, and these changes in illness beliefs were correlated with metabolic changes [33]. However, only one in five people with newly diagnosed diabetes in the publicly-funded health care system of Ontario attended a diabetes self-management education program. Utilization was lower in the population subgroups most in need of self-management support: older, poorer individuals, recent immigrants, and those with mental health conditions or medical comorbidities. Clinicians managing patients with diabetes are doing an inadequate job ensuring that their patients newly-diagnosed with the condition are receiving diabetes self-management education at a time when they are seeking information about the disease [20]. Strategies such as increasing primary care provider awareness of self-management education program services, or facilitating and coordinating referral processes, may increase utilization rates. In the subgroups of the population where disparities in utilization are seen, particular focus is needed to ensure these patients have equitable access to services. For example, placing self-management education programs in poorer neighborhoods or offering evening or weekend opening hours may address disparities for lower income patients who could not otherwise access these programs. Multilingual culturally sensitive programming may improve utilization by recent immigrants. Such strategies are needed to help these disadvantaged patients, who are at increased risk for diabetes complications, to optimize their care.

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