A community-based approach for the self-management of diabetes

The Diabetes Hamilton support programme and registry

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Summary

The ability to self-manage one's diabetes is challenged by the limited availability of clinic-based resources. This paper seeks to describe and determine the impact of Diabetes Hamilton (DH), a novel, voluntary, community-based programme in Hamilton, Ontario, that aims to facilitate self-management behaviours by supplementing existing resources.

DH registrants who completed a baseline questionnaire from February 2000 to March 2007 were included in the cross-sectional survey (n=3161). A total of 2994 individuals were also included in the trend analysis, examining the impact of DH on self-management behaviours.

Half of DH registrants are female (51.2%), with a mean BMI of 30.8 (SD 7.5), a mean age of 61.6 years (SD 14.6) and a mean age of 48.6 years at diagnosis (SD 16.7). A third of registrants reported insulin use (33.4%) and >90% reported having had an annual blood pressure and cholesterol test respectively. Trend analysis of behaviours showed an increase in cholesterol screening ($p<0.00$), diabetes provider visits ($p<0.00$), and medication use for glycaemic control and vascular protection ($p<0.02$).

Although DH reaches motivated, well-educated individuals in the community, some diabetes self-management behaviours improved. Strategies to engage greater public participation across various demographics (e.g. ethnicity, education, age) are ongoing.

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Key words

diabetes; self-management; community; registry

Introduction

Diabetes mellitus is a common chronic disease that currently affects 285 million people aged 20–79 worldwide: 6.6% of the adult population.[1] Upwards of 3 million Canadians are currently affected, which will reach 3.7 million by 2020.[2] Recent research has demonstrated that the prevalence of diagnosed diabetes in Ontario adults over 20 years of age was approximately 8.8% in 2005;[3] extrapolating from this, Hamilton, with a total population of approximately 505 000, yields an estimated 34 000 adults living with diabetes.[4] The sheer magnitude, impact and growth of diabetes and its consequences suggest that diabetes is now a major public health problem.[5,6]

Understanding the complexity of diabetes and the resources required for optimal self-management highlights the need for community-based approaches. Such an approach should enable any motivated individual in the community to gauge his/her diabetes status, engage his/her health care providers as an informed consumer, and actively participate in and monitor his/her own diabetes therapy. By shifting the responsibility of diabetes care from the health care system alone to include individuals with diabetes, and providing community resources designed to assist individuals, such an approach explicitly recognises that diabetes is a growing societal 'public health' problem with a huge potential impact and that interventions at the community level can mitigate this effect.[5,6] The objective of this paper is to describe Diabetes Hamilton (DH), a novel community-based diabetes programme, and to determine the impact of DH on the improvement of self-management behaviours.

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Diabetes Hamilton

Diabetes Hamilton is a free, voluntary programme available to people with diabetes and health care providers in the Hamilton area. It was conceived in 1999 after conducting a needs assessment of diabetes stakeholders, including individuals with diabetes, family physicians, pharmacists and other service providers, and has been supported by educational grants. DH is a community-based support programme that includes the

following: (a) a voluntary diabetes registry, which involves baseline and annual follow-up health questionnaires; (b) distribution of a quarterly newsletter (*Knowing Diabetes*), with versions for registrants and their health care providers; (c) the development and updating of a comprehensive 'Resource Inventory' of over 100 diabetes-related community resources; (d) a website that offers diabetes information and community resources; and (e) educational events for individuals with diabetes, as well as health care providers. DH is typically staffed by a full-time manager and a part-time assistant, with ongoing support from other diabetes health care providers (physicians, nurses, dietitians, etc) for publication writing purposes and speaking engagements at DH public events. Mailing of questionnaires and inventory updates are organised through the DH office. Data from the voluntary registry are housed and managed by an industry partner.

Since its inception, over 4300 individuals with diabetes, 700 family physicians and 120 other health professionals have been obtaining regular evidence-based diabetes information, offering a discussion platform between patient and health care provider. DH's goals have been to: (a) supplement the limited diabetes specialty services and tools by identifying, developing and providing community-based resources; (b) promote and facilitate diabetes self-management by a broad range of health care providers; (c) create a 'diabetes-friendly' community; and (d) sensitise the city in general to the growing diabetes epidemic. Recruitment strategies include mail-outs, such as personal invitations, multi-media promotion through television, radio and newspaper, and public education events.

Research design and methods

Data from initial registration (baseline) diabetes health questionnaires were collected and stored in a central registry. Questionnaires are mailed to registrants and completion is voluntary, requiring approximately 15–20 minutes to complete. All data for DH are collected through the self-reported questionnaire and not confirmed clinically. Questions cover the following areas: (a) demographics (e.g. date of birth, gender, education); (b) general health information (e.g. height, weight, age of diagnosis); (c) diabetes management behaviours (e.g. blood glucose monitoring, use of oral antidiabetic agents and insulin, activity level); (d) risk factor screening (e.g. foot care, blood pressure and cholesterol testing); (e) risk factor medications (e.g. aspirin, ACE inhibitor); and (f) medical care utilisation and consequences (e.g. recent nurse, dietitian or physician visit, recent heart attack or stroke). The questionnaires were determined to have face validity upon review by diabetes health care providers.

Statistical analyses and mapping

Questionnaire data were categorised as continuous, dichotomous or categorical responses. All initial registrant questionnaires, as of March 2007, were analysed in a cross-sectional methodology for baseline characteristics (n=3161). Descriptive statistics are expressed as means and standard deviations, or as counts and percentages. Chi-square for linear trend analysis was completed using full calendar years only, 2000–2006 inclusively (n=2994). Data from the DH registry were analysed using SPSS, Version 16.0 and OpenEpi Version 2.3.

Datasets regarding self-reported ethnicity, education level, and weight and height (used to calculate BMI) were collated and divided into numbered categories; one map was generated for each category (e.g. BMI <20, BMI >30). Using address information provided at registration, participants were grouped according to the first three digits of their postal code. Each map shows a gradient which divides the ranked postal codes into one of seven colour groups with the highest percentages (e.g. highest prevalence rates for that particular category) being the darkest colour. ESRI's ArcGIS geomatics software version 9.3 was used to create these maps.

Results

Diabetes Hamilton

As of March 2007, 3161 individuals and approximately 550 family physicians had used DH over the previous seven years. Recruitment rates have varied since the inception of DH, with a minimum recruitment rate of 140 in 2004, to a maximum recruitment rate of 875 in 2006. Regular qualitative feedback from registrants demonstrates high satisfaction, with more than 80% of participants stating that DH is helping in their management of diabetes. Annual educational events continue to be well attended by health care providers (200–300 per event) and the general public (300–500 per event).

Diabetes Hamilton registrants

DH registrants are approximately 62 years of age (SD 14.6), with 42% of registrants above the age of 65. The average age of diabetes diagnosis is 48.6 years (SD 16.7) and slightly more than half of the registrants are female (51.2%). Almost 75% of registrants have completed high school education, with approximately 40.5% having completed college or university. The ethnic make-up of registrants is primarily Caucasian (64.4%), with representation from Hispanic, Aboriginal,

African, Middle East, South and East Asian ethnic backgrounds. Additional self-reported demographics are highlighted in Table 1. Medical care usage and diabetes-related consequences are also summarised for all registrants in Table 1. Almost half of the registrants reported seeing a diabetes nurse educator or dietitian within the last year (45.6% and 43.5%, respectively), while 36.3% reported seeing a diabetes specialist within the last year. Heart attack and strokes were reported as occurring in approximately 2.2% of registrants in the previous year. Finally, 73.1% of registrants reported some loss in vision in the previous year, with 11.6% receiving treatment for cataracts specifically.

With respect to diabetes self-care behaviours, risk factor screening and medication use, 60.7% of DH registrants monitor their blood glucose levels at least once per day and 67.9% reported that they received a glycated haemoglobin (A_{1c}) test within the last six months. Lifestyle questions determined that 46.9% of registrants reported being at least moderately physically active (e.g. walking daily), while 15.8% classified themselves as smokers. Approximately 82.7% were prescribed oral antidiabetic agents and 33.4% were on insulin. Almost everyone (99.1%) reported having had at least one risk factor (blood pressure, eyes, kidney or cholesterol) checked in the past year, with 92.1% of registrants having been assessed for three risk factors. Approximately 41.9% of registrants reported taking a low dose aspirin daily, while 38.4% took an ACE-inhibitor and 22.9% took a lipid lowering medication. Table 1 summarises self-reported baseline characteristics for self-care behaviours, risk factor screening and risk factor prevention/management medication use.

Demographics	Variable	n (%)
	Age, mean (±SD)	61.6 (14.6)
	Females	1619 (51.2)
	Age at diagnosis, mean (±SD)	48.6 (16.7)
	Body mass index, mean (±SD)	30.8 (7.5)
	Education: College/university	1280 (40.5)
	Ethnicity:	
	Caucasian	2036 (64.4)
	African	93 (2.9)
	Aboriginal	84 (2.7)
	South Asian	85 (2.7)
	Other	771 (24.4)
Medical care and consequences	Hypoglycaemia hospitalisation in last year	552 (17.5)
	Nurse educator in last year	1439 (45.6)
	Dietitian in last year	1375 (43.5)
	Foot care professional in last year	693 (21.9)
	Diabetes doctor in last year	1148 (36.3)
	Laser treatment in last year	140 (4.4)
	Foot ulcer/infection/amputation in last year	157 (5.0)
	Heart attack in last year	69 (2.2)
	Stroke in last year	46 (1.5)
	End stage renal disease in last year	34 (1.1)
	Cataract in last year	366 (11.6)
	Vision loss in last year	2311 (73.1)
Antidiabetic drug (OAD) use	Insulin secretagogues	915 (28.9)
	Biguanides	1412 (44.7)
	Insulin sensitisers (thiazolidinediones)	242 (7.6)
	Alpha-glucosidase inhibitors	19 (0.6)
	Other	28 (0.9)
	Insulin	1057 (33.4)
Self-care	Blood glucose monitoring: ≥1/day	1918 (60.7)
	A_{1c} test in last 6 months	2146 (67.9)
	Activity:*	
	Moderate	1183 (37.4)
	Great/very great	298 (9.4)
	Smoke	498 (15.8)
Risk factor screening	Urine-albumin test in last 2 years	2064 (65.3)
	Eye exam in last 2 years	2799 (88.5)
	Blood pressure test in last year	3128 (99.0)
	Last blood pressure test result = high	444 (14.1)
	Cholesterol test in last year	2892 (91.5)
	Last cholesterol test result = high	663 (21.0)
	At least 1 risk factor test in last year	3132 (99.1)
	At least 2 risk factor tests in last year	3092 (97.8)
	At least 3 risk factor tests in last year	2910 (92.1)
	At least 4 risk factor tests in last year	950 (30.1)
Risk factor prevention/ management medication	Aspirin	1325 (41.9)
	ACE inhibitor	1213 (38.4)
	Angiotensin II receptor blocker	318 (10.1)
	Beta blocker	487 (15.4)
	Lipid lowering agent	724 (22.9)
	Taking at least 2 of the above	717 (22.7)
	Taking at least 3 of the above	450 (14.2)

*Activity is defined as: moderate (e.g. daily walk, gardening, other chores); and great/very great (e.g. daily jogging, sports, exercise/strenuous, prolonged daily activity).

Table 1. Diabetes Hamilton registrants' self-reported baseline characteristics for demographics, and diabetes management behaviours (n=3161)

	2000 n=640	2001 n=316	2002 n=471	2003 n=206	2004 n=140	2005 n=346	2006 n=875	Chi² value	*p*-value
Self-care									
BGM	599 (93.6)	274 (86.7)	420 (89.2)	189 (91.7)	123 (87.9)	323 (93.4)	795 (90.9)	0.02	0.88
Recent A_{1c}	424 (66.3)	211 (66.8)	313 (66.5)	120 (58.3)	93 (66.4)	241 (69.7)	623 (71.2)	5.58	0.02*
Activity†	322 (50.3)	156 (49.4)	219 (46.5)	97 (47.1)	66 (47.1)	145 (41.9)	411 (47.0)	4.89	0.03*
Smoking	89 (13.9)	56 (17.7)	77 (16.3)	36 (17.5)	27 (19.3)	59 (17.1)	130 (14.9)	0.05	0.83
Medical care (in last yr)									
Nurse	356 (55.6)	143 (45.3)	246 (52.2)	93 (45.1)	53 (37.9)	137 (39.6)	339 (38.7)	49.37	0.00*
Dietitian	327 (51.1)	142 (44.9)	205 (43.5)	97 (47.1)	57 (40.7)	133 (38.4)	350 (40.0)	19.88	0.00*
Diabetes doctor	287 (44.8)	119 (37.7)	221 (46.9)	79 (38.3)	43 (30.7)	91 (26.3)	253 (28.9)	62.64	0.00*
MI	15 (2.3)	9 (2.8)	9 (1.9)	7 (3.4)	2 (1.4)	8 (2.3)	16 (1.8)	0.67	0.41
Stroke	10 (1.6)	5 (1.6)	6 (1.3)	1 (0.5)	2 (1.4)	5 (1.4)	16 (1.8)	0.22	0.64
ESRD	5 (0.8)	2 (0.6)	5 (1.1)	3 (1.5)	1 (0.7)	5 (1.4)	10 (1.1)	0.91	0.34
Foot infect/amp.	54 (8.4)	11 (3.5)	28 (5.9)	10 (4.9)	8 (5.7)	15 (4.3)	45 (5.1)	4.49	0.03*
Cataract	88 (13.8)	21 (6.6)	52 (11.0)	28 (13.6)	11 (7.9)	35 (10.1)	110 (12.6)	0.01	0.94
Screening (in last yr)									
Urine albumin	431 (67.3)	196 (62.0)	312 (66.2)	132 (64.1)	89 (63.6)	215 (62.1)	572 (65.4)	0.51	0.47
Eye exam	584 (91.3)	262 (82.9)	414 (87.9)	177 (85.9)	112 (80.0)	308 (89.0)	788 (90.1)	0.22	0.64
BP	635 (99.2)	312 (98.7)	462 (98.1)	205 (99.5)	137 (97.9)	342 (98.8)	872 (99.7)	1.63	0.20
Cholesterol	464 (72.5)	284 (89.9)	437 (92.8)	183 (88.8)	128 (91.4)	318 (91.9)	820 (93.7)	111.03	0.00*
Medications									
Aspirin	232 (36.3)	104 (32.9)	185 (39.3)	93 (45.1)	50 (35.7)	162 (46.8)	422 (48.2)	33.47	0.00*
ACE inhibitor	211 (33.0)	113 (35.8)	211 (44.8)	79 (38.3)	44 (31.4)	143 (41.3)	353 (40.3)	5.77	0.02*
ARB	31 (4.8)	16 (5.0)	41 (8.7)	19 (9.2)	13 (9.3)	45 (13.0)	135 (15.4)	58.70	0.00*
Beta blocker	96 (15.0)	46 (14.6)	81 (17.2)	32 (15.5)	17 (12.1)	51 (14.7)	154 (17.6)	1.15	0.28
Diuretic	N/A	N/A	N/A	N/A	N/A	83 (24.0)	248 (28.3)	2.38	0.12
LL agent	N/A	N/A	N/A	N/A	N/A	151 (43.6)	480 (54.9)	12.49	0.00*
OAD agent	331 (51.7)	161 (50.9)	263 (55.8)	116 (56.3)	90 (64.3)	234 (67.6)	565 (64.6)	43.11	0.00*
Insulin	273 (42.7)	115 (36.4)	174 (36.9)	75 (36.4)	37 (26.4)	90 (26.0)	241 (27.5)	49.06	0.00*

BGM – blood glucose monitoring; A_{1c} – glycosylated haemoglobin; MI – myocardial infarction; ESRD – end stage renal disease; BP – blood pressure; ARB – angiotensin II receptor blocker; LL – lipid lowering; OAD – oral antidiabetic agent. †Activity is defined as anything including or above moderate activity (e.g. daily walk, chores, gardening). Chi-square test for linear trend is presented. *Statistically significant.

Table 2. Trend analyses for Diabetes Hamilton registrants' initial self-reported diabetes management behaviours (n=2994). Data are expressed as n (%)

Trend analyses for Diabetes Hamilton

Trend analyses of self-reported diabetes management behaviours were undertaken to track differences in baseline characteristics of new registrants from 2000–2006 (Table 2). Analyses demonstrated that physical activity varied over the years, with an overall decrease in the number of those reporting moderate to high levels (p=0.03). There was a significant difference in medical care use and consequences, specifically in consultation visits with diabetes educators, with an overall decrease in reported nurse and/or dietitian or diabetes specialist visits (p<0.00). DH registrants also reported an increase in cholesterol screening (p<0.00) and A_{1c} testing (p=0.02). A statistically significant trend was noted in increased medication use for vascular protection and management including aspirin, ACE-inhibitors, angiotensin II receptor blockers and lipid lowering agents (p<0.02). A similar trend was noted for use of oral antidiabetic agents (p<0.00), while a significant trend towards decreased insulin use was noted (p<0.00).

Data mapping for Diabetes Hamilton participants

Hamilton is Canada's ninth largest city and Ontario's third largest, following Toronto and Ottawa.[7] Hamilton is located in the southern part of Ontario and encompasses the smaller, former municipalities of Stoney Creek, Glanbrook, Ancaster, Dundas and Flamborough.[8] The majority of the population resides within the boundaries of the former city, which can be characterised as follows: the north and east ends were historically the industrial heart of the city; the west end is home to the university; the central downtown core is an area challenged by higher poverty and social issues; and the south or escarpment lands have been developed into sweeping a suburban area over the past 30–50

years.[8] The 'new' city includes smaller historical town centres, each surrounded by a mix of suburban development and rural lands, varied geography, ethnicity and economics. Not only is the city varied geographically, Hamilton varies ethnically and economically, with the outskirts tending towards higher income and education levels, and fewer new immigrants.

Using registrant postal codes, a map was generated illustrating the distribution of BMI, an important diabetes health variable. Figure 1 shows the distribution of registrants throughout Hamilton with an obese BMI classification (>30). The highest prevalence of obese registrants was primarily in the downtown and north end areas of Hamilton, areas which also correspond to a greater concentration of self-identified ethnicities that are at high risk for diabetes (African, Hispanic, Aboriginal, East Asian and South Asian groups).

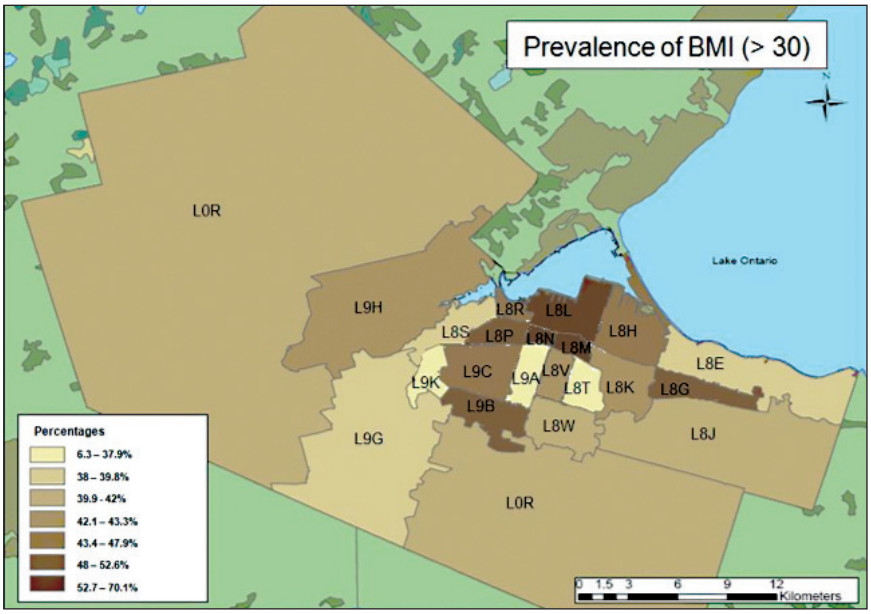

Figure 1. The geographical distribution of Diabetes Hamilton participants with a body mass index (BMI) greater than 30, according to postal codes. Lighter colours reflect lower distribution rates and darker colours reflect higher distribution rates

Discussion

This study emphasises the importance and relevance of a community-based approach to facilitate diabetes self-management. The programme reaches men and women equally in the community, the majority of whom are well-educated, Caucasian and 62 years of age on average. An increase in self-management behaviours, such as having an A_{1c} and cholesterol test, and using pharmacotherapy for vascular protection and management, was noted in DH registrants. These trends may reflect the translation of clinical practice guidelines to the diabetes care community and general public through educational initiatives and publications. Finally, the mapped data illustrate that the prevalence of a diabetes risk factor (BMI >30) among DH membership is highest in the urban city centre.

Registration and participation in DH has several purposes. First, completion of the registry questionnaire sensitises participants to diabetes-related issues and helps them inventory their own behaviours, care and therapies.[9] Second, mailings to participants and their physicians provide the rationale and evidence for issues, tests and therapies.[10,11] Third, the registry provides a measure of the burden of diabetes, locally, which can be used to apprise the community, its hospitals, regional health authorities, municipal and provincial governments, and other health care providers of the need for diabetes-related services.[12] Finally, it facilitates knowledge translation research, as evidence-based guidelines and findings may be disseminated through the questionnaire and regular mail-outs, and subsequently evaluated through self-reported measures or research trials.[13]

However, DH, specifically the diabetes registry, is not without limitations. As with many public health surveillance and monitoring programmes, data are obtained through self-reported questionnaires and surveys. Although self-reporting questionnaires offer many advantages, such as ease in administration and low cost, there are also many limitations.[14,15] Self-reported measures are inherently biased as individuals may have misunderstood the question, have reported inaccurately on past events, or have reported differently based upon societal views or pressure.[14,15] Temporality may also be an issue when dealing with specific disease processes and behaviours, as what was once socially acceptable behaviour may not be socially desirable now.[15] Additionally, the literature suggests that passive knowledge translation through the receipt of educational materials and publications has questionable effects on improving patient and provider knowledge, attitudes and practice.[16,17] Finally, co-interventions are likely to be interacting alongside DH strategies to facilitate self-management, thus potentially modifying the

impact of DH on self-reported behaviours. Ongoing support from diabetes education programmes, medical management and interventions, and other community support groups may be influencing or changing self-management behaviours, which may or may not be reported, and therefore difficult to attribute to DH strategies.

Diabetes represents a heterogeneous metabolic disorder with both genetic and environmental determinants. Optimal management of type 2 diabetes requires early and ongoing lifestyle modification, including physical activity and nutrition, self-management training and pharmacotherapy.[18–20] DH is an example of a novel approach to facilitating diabetes self-management in the community. Such an approach shifts the focus from providing limited health care services to patients in clinical settings, to identifying and developing resources in the community at large that can be easily accessed and used to facilitate diabetes self-management. The accessibility of the programme offers an open avenue for individuals to obtain mail or web-based, evidence-based diabetes information, anytime, anywhere. Future directions for DH may include website enhancements to offer online interactive education programs and web seminars, and online registration and questionnaire completion capabilities. Ultimately, the goals and visions of DH are to continue to provide education and empowerment for those affected by diabetes, and to be responsive to community diabetes needs and reflective of evidence-based diabetes practice.

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Declaration of interests

There are no conflicts of interest declared.

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