

Discordance in Perceptions of Barriers to Diabetes Care Between Patients and Primary Care and Secondary Care

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OBJECTIVE — We sought to compare perceived barriers to diabetes care between people with diabetes and different health professional groups.

RESEARCH DESIGN AND METHODS — This was a cross-sectional, postal, open-questionnaire survey conducted in the Waikato district, New Zealand. A total of 3,890 individuals with diabetes participated, as well as 436 primary and secondary health professionals.

RESULTS — Barriers were reported in 69.7% of patients. Psychological barriers were most important (55.5%), followed by systems barriers (25.7%), and then knowledge as least important (15.3%). Psychological barriers were ranked first among general practitioners (91.0%), but systems barriers were ranked first by other health professionals (38.8–100%). General practitioner and patient barrier group rankings were similar ($r_T = 0.976$, $P < 0.05$). Of specific barriers among individuals with diabetes, strictness of treatment regimen was the most frequently reported (42.3 vs. 0.1–16.8%) ($P < 0.001$) and 2.5 (95% CI 2.4–2.7)- to 3.4 (3.2–3.7)-fold more than the 2nd through 4th ranked barriers. Motivation was the most common specific barrier reported by general practitioners (86%), practice nurses (31.5%), and the diabetes team (85.7%). Practice and hospital nurse/dietitian rankings were most comparable with patients ($r_T = 0.457$ and 0.466 , respectively, both $P < 0.05$). A major area of patient–health professional discordance was the influence of other health problems, which was ranked 2nd among patients but 10th–18th among health professionals.

CONCLUSIONS — The most important barriers to diabetes care perceived by patients are psychological and particularly relate to the strictness of the regimen. Discordance between patients and different health professionals exists in the perception of the importance of different barriers to diabetes care.

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Much of the organ damage caused by diabetes is now preventable with tight metabolic control (e.g., glucose, blood pressure, lipids), self-care activities, regular review, and timely intervention (1,2). In spite of this, preventable complications of diabetes continue to occur (3). This is often due to the presence of systems and personal barriers to the implementation of diabetes care (4,5). Few studies of either patient or provider perceptions of barriers to care have been undertaken globally. The Diabetes Atti-

tudes Wishes and Needs (DAWN) Study recently showed psychological barriers to be important, with a high proportion of patients having diabetes-related worries and poor psychological well being (6). However, a range of other barriers relating to the health system, knowledge deficits, other health conditions (including the nature of diabetes and obesity) and extent of support from peers have also been identified as important (4,5). A framework to categorize these barriers, the Barriers to Diabetes Care Tool, includ-

ing psychological barriers, was developed and validated in South Auckland, New Zealand (5).

Such barriers are related to clinical care (e.g., self-glucose monitoring [7]), and their identification can assist individual patients with their care (8). Perceptions of barriers can guide prioritization of diabetes care at a service level. Such perceptions may differ between patients and primary and secondary care. We have used the Barriers to Diabetes Care Tool to compare the perceived barriers to diabetes care among patients and health professionals with a major diabetes role. The hypothesis tested in this “Waikato Barriers to Diabetes Care Study” was that perceptions of barriers to diabetes care differ significantly between patients and both primary and secondary health care professional groups.

RESEARCH DESIGN AND METHODS

This was a cross-sectional postal survey of patients, general practitioners, practice nurses, and hospital medical, nursing, and dietetic staff across the Waikato district, New Zealand. The Waikato District Health Board covers 21,220 km² and had a population of 317,751 at Census 2001. Of these, 20% identify as Māori (New Zealand’s indigenous group) and 6% in a variety of non-European ethnic groups. There is one major town with a population of 115,000. The mean income is below the general New Zealand population (9). The study was approved by the Waikato Ethics Committee.

Individuals with diabetes surveyed were those on the eye screening register or seen in the diabetes or eye service clinics in the previous 2 years. All general practitioners and practice nurses on the list of their primary care organization were included. Hospital staff was identified through the staff list and included all medical specialists, senior ward nurses, and nurses and senior allied health workers in relevant areas (e.g., cardiology, renal). All members of the district diabetes services were invited to participate.

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Abbreviations: DAWN, Diabetes Attitudes Wishes and Needs.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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Mail survey and mail survey tool

The formatting of the questionnaire, mail survey method, and follow-up of non-responders were undertaken using the Dillman method (10). The mail out included a two-sided survey form, information sheet, stamped addressed envelope, and consent form for patients (to link survey data with medical record data). The questionnaire included:

- the four-item “Barriers to Diabetes Care” open-question tool tailored to patient or health professional situations (e.g., What do you feel prevents you/your patients from looking after your/their diabetes? How would you improve your diabetes care/diabetes care in the area? Are you worried about your/your patients’ diabetes—if so why/why not? Do you have any other comments about ways which may improve services for you/others?)
- 7 questions for health workers or 14 questions for patients (including age, sex, and ethnicity). The questionnaires were expected to take between 2 and 5 min to complete, although some subjects were expected to write significantly more.

Postal surveys are often associated with a low response. A range of strategies were put into place to maximize response. These strategies included shortening the questionnaire, using a stamped addressed envelope, distributing through primary care organizations to their members, a media campaign in the local and Māori press, and a Hospital Grand Round presentation. Follow-up included posting a second questionnaire within 3–4 weeks and then telephone follow-up. As the tool was written in English, groups with English as a second language and Māori were offered face-to-face interviews.

Data handling

Ethnicity was assessed by self-identity, although hospital-allocated ethnicity was also available (11). Open responses were entered into a spreadsheet as short sentences/comments covering each barrier/set of barriers, and multiple fields were created for each response. The responses were cross-referenced with the 30 specific barrier groups defined in the South Auckland work (Table 1) (5). A further four specific barriers were identified (Table 1). All responses were uncoupled from identifying information for coding. The cross-referencing to one or more specific

barriers (“barriers”) was undertaken by triangulation. The 34 barriers themselves can be mapped onto 5 major barrier groups (Table 1): educational/knowledge, internal physical, external physical/systems, psychological, and external psychosocial.

Statistics

Data were analyzed using SPSS for Windows (version 14.0; SPSS, Chicago, IL). All tests were two tailed. Comparisons of demographic data were made using χ^2 tests and ANOVA. Although the questions, process, and coding have been previously validated (5), the reproducibility of the coding was reassessed using responses from a sample of 50 patients (selected using an electronic randomizer). All responses from this sample were recoded blind of the original coding. Overall, 159 specific barrier codes were generated, and κ was 0.68 (substantial agreement [12]).

Comparisons of the number of barriers were made using ANCOVA. As the number of barriers differed between participant groups, it was felt inappropriate to compare proportions with individual barriers. Comparisons between participant groups were therefore made by comparing ranking using weighted rank correlation with the top-down correlation coefficient shown (r_T), based on Savage scores (13). The closer the r_T is to 1.0, the greater the concordance between groups. In Table 2, $0.10 > \alpha > 0.05$ is taken as significant; in all other cases, $P < 0.05$ was considered statistically significant. Where the ranking was the same between barriers, the mean of the Savage scores were taken.

RESULTS— Overall, 6,802 patients were invited, of whom 577 had either died, moved with no forwarding address, or did not have a diagnosis of diabetes according to eye clinic records. Lists of health professionals were current. Table 2 shows the characteristics of all participants. Response rates ranged from 62.8 to 91.3%. Among patients, response rates were similar from urban and rural areas but higher among European New Zealanders (69.1%) than Māori (46.4%) and other ethnic groups (35.6%). Patients were older than health professionals ($P < 0.001$). Over 17,000 comments were received. Patients and practice nurses reported the least number of barriers, with some reporting no barriers. The most number of barriers reported was 20. The

adjusted number of barriers per patient did not differ by sex or ethnicity but did differ by age ($P < 0.001$). Those aged 26–45 years reported 4.41 (95% CI 3.78–5.05) barriers compared with 2.47 (1.08–3.86) among those aged <25 years, 2.88 (2.51–3.25) among those aged 45–60 years, 1.76 (1.36–2.17) among those aged 61–79 years, and 1.86 (0.91–2.82) among those aged ≥ 80 years.

Table 3 shows the frequency of major barrier groups by participants. The most frequently reported perceived barriers were psychological among patients and general practitioners. External physical (systems) was the most commonly reported barrier by practice nurses and secondary service staff. Educational barriers were ranked lowest by patients. While internal physical barriers were ranked lowest by health professionals, almost one-quarter of patients reported internal physical barriers. The top-down correlation coefficients showed concordance between the general practitioners and patients, as well as between the various secondary service professional groups and with the practice nurses.

Table 4 shows the top 10 barriers by participant group. The most frequent patient barrier was the strictness of the regimen. Motivation was the most frequent barrier reported by general practitioners, practice nurses, and the diabetes team. Hospital doctors reported diabetes knowledge most frequently, and hospital nurses/dietitians reported inappropriate care most frequently. Although the first four barriers had similar frequencies among the health professional groups, the strictness of regimen was reported 2.52 (95% CI 2.37–2.69)- to 3.42 (3.16–3.72)-fold more frequently, respectively, than the 2nd–4th barriers among patients. “Other health conditions” was ranked 2nd among patients but between 10th and 18th among health professionals. Service capacity being overwhelmed by diabetes was seen as a significant barrier among health professionals (particularly hospital staff) but 33rd (out of 34) among patients.

The ranking was compared within the psychological, psychosocial, and external physical major barrier groups, as they each included 8–11 barriers. Barrier rankings were significantly correlated between patients, and all provider groups and between-provider groups for psychological ($r_T = 0.673$ – 0.995 ; $P < 0.05$ to $P < 0.0005$) and psychosocial ($r_T =$

Table 1—The barriers-to-care groups and their definitions (adapted from ref. 5)

Barrier to care	Description
Psychological	
Western health belief	Believe science/professionals should find a cure/do more
Spiritual health belief	Believe cause/cure should be sought spiritually/within
Alternative health belief	Prefers to use alternative health models/treatments
Public health belief	Believes the public should bear more financial responsibility for health care
Self-factors	
Motivation	Psychological: motivation, attitudes, laziness, denial
Self-efficacy	No confidence, external locus of control, low self-efficacy
No symptom cue	No physical symptoms
Priority setting	Others' needs have priority over own (e.g., children, elders)
Negative perceptions of time	Not enough time (education provided too quickly)
Emotional	Fear, shame, emotional anxiety, worry, lack of hope
Precontemplative	Strictness of regime, giving up things I enjoy
Educational	
Low diabetes knowledge	Lacks general/specific diabetes knowledge
Low knowledge of service	Unaware of services available
Educational (in general)*	
Internal physical	
Self-factors/other health conditions	Diabetes (e.g., amputation) and non-diabetes related (e.g., arthritis)
Physical effects of treatment	Pain of glucose monitoring, drug side-effects
Obesity*	Being overweight/obese already
External physical	
Personal finance	Income in relation to costs
Service/physical access	Transportation, wheelchair entry
Limited range of services	Timing of format of services (e.g., evening clinics, home visits)
Appointment system/staffing levels	Insufficient staffing for adequate service
Lack of community-based services	No local clinic that is identified as own
Unhelpful health professional in past	Past encounter with health professional leading to conflict or without expected communication or clinical expertise
Information management*	Includes continuing professional education, research, audit
Diabetes epidemic*	Increasing numbers with diabetes or its complications will increase demand on services
Psychosocial	
Unsatisfactory/inappropriate diabetes care or education	Wrong information provided or information provided in inappropriate way
Group pressure	Pressure from others not to adhere to advice
Prejudice	Impression of discriminatory practice due to diabetes or for other reasons
Lack of public awareness of diabetes	Others behave without adequate knowledge or acceptance of diabetes
Lack of family support	Family consumes diabetic patient's food, resists change of lifestyle
Family demands	Pressure to spend time/money on the family rather than their diabetes care
Unsupportive macroenvironment	Feeling of lack of support in the community, e.g., access to low-fat foods
Communication	Language differences (translation)
Inappropriate cultural messages	Attitude, ethnicity of workers, appropriateness of communication

* New barriers identified in this study.

0.740–0.979; $P < 0.05$ to $P < 0.0005$) barriers. External physical barrier ranking differed markedly with patient rankings correlating with general practitioners ($r_T = 0.897$; $P < 0.005$) and hospital nursing/dietetic staff ($r_T = 0.792$; $P < 0.01$) but not other health professional groups ($r_T = 0.374$ – 0.618). The diabetes team rankings for external physical barrier correlated with hospital nursing/dietetic staff ($r_T = 0.837$; $P < 0.025$) and hospital doctors ($r_T = 0.894$; $P < 0.005$).

CONCLUSIONS — We have shown in this large geographically defined area that patients perceive psychological issues as the most important barrier to diabetes care, with the strictness of the diabetes regimen, including dietary, exercise, self-glucose monitoring, clinician review, and medication activities, as by far the major perceived barrier to care. Our use of open questions and subsequent ranking of barriers provides unprompted insight into the issues that patients per-

ceive as most important at the time of the study, rather than the more traditional approach of providing potential barriers and asking for their importance to be graded. The international context of our findings is supported by the recent DAWN Study (6), which also showed psychological barriers to be important across a number of countries. In the DAWN Study, self-reported success with regimen adherence was relatively low in both type 1 (46%) and type 2 (39%) diabetes but greater for

Table 2—Characteristics of participants

	Patients	General practitioners	Practice nurses	Hospital doctors	Hospital nurse/dietitian	Diabetes team
Invited	6,225	232	220	94	54	23
Responded	3,890 (62.5)	166 (71.6)	149 (67.7)	59 (62.8)	41 (75.9)	21 (91.3)
Age (years)	65 ± 15	47 ± 8	46 ± 9	47 ± 8	43 ± 11	46 ± 7
Male	1,854/3,661 (50.6)	117/162 (72.2)	4/130 (3.1)	49 (84.5)	2 (4.9)	4 (19.0)
European	3,085/3,890 (79.3)	130/158 (82.9)	123/132 (93.2)	46 (79.3)	39 (95.1)	17 (81.0)
Maori	589/3,890 (15.1)	3/158 (1.9)	9/132 (6.8)	1 (1.7)	1 (2.4)	2 (9.5)
Other	216/3,890 (5.6)	25/158 (15.8)	0/132 (0)	11 (19.0)	1 (2.4)	2 (9.5)
No barriers (%)	30.3	0.6	42.6	6.8	0	0
No. of barriers (95% CI)	2.15 (2.07–2.23)	8.75 (8.13–9.36)	4.38 (3.35–5.41)	6.69 (5.71–7.68)	9.79 (8.89–10.69)	11.71 (9.94–13.49)

Data are n (%), means ± SD, or n/N (%) unless otherwise indicated.

self-care behaviors than lifestyle behaviors (6). Our study puts the DAWN Study findings into context locally, ranking psychological barriers against the other barriers faced by patients.

The extent and importance of psychological issues among patients suggest a major unmet need. Although interventions for psychological and psychosocial problems have advanced since the sentinel review by Rubin and Peyrot in 1992 (14), evidence for the efficacy of the “pure” psychological interventions remains limited (15,16). More complex combinations of both educational and behavioral techniques appear to be more successful, with chronic disease management techniques, particularly case management, even more so (17–20). Several other interventions that improve metabolic control beyond usual care may also have an impact partly through improving psychological support, including the use of a diabetes passport (21) and diabetes support groups (22). Our study would suggest that a large gap in the develop-

ment and introduction of psychological and behavioral interventions remains unfilled. In the DAWN Study, major deficiencies were identified among primary and secondary care physicians and nurses in their ability to identify and evaluate psychological needs and to provide psychological support, and availability of outside expertise in emotional and psychological matters was also a major deficiency (6). Access to professional psychological resources was associated with a greater tendency to referral (6).

Two key areas of discordance between patients and health professionals were inadequate diabetes knowledge (ranked highly by all professional groups [in the top four] but by only a relatively small proportion of patients) and the importance of other health conditions (second most important barrier for the former; far less for the latter). Further work is required in these areas.

Patients and providers have been previously shown to substantially differ in perceptions and attitudes (23), particu-

larly of adherence to regimen (6). Our findings suggest that there are also major differences in perceptions of barriers between health professional groups. While general practitioner barrier group ranking was most concordant with the patients, secondary care health professionals also reported psychological and psychosocial barriers very frequently (indeed more often than either general practitioners or patients). Discordance in ranking between patients and secondary care service providers may therefore have resulted from a different perspective, or because the secondary services in this district see a skewed range of cases toward the most difficult, and had better insight into the limitations of the secondary care system. Their responses therefore probably reflect the sum of all barriers for more complex patients, as well as their position within the larger secondary care organizations. We did not ask for a ranking within responses, and some responses were very long.

These differences in perspective sug-

Table 3—Comparison of major barriers to care groups between participants

	Patients	General practitioners	Practice nurses	Hospital doctors	Hospital nurse/dietitian	Diabetes team
Major barrier groups						
Psychological	55.5 (1)	91.0 (1)	35.6 (3)	72.9 (3)	94.7 (2)	95.2 (2)
Educational	15.3 (5)	67.5 (4)	26.2 (4)	57.6 (4)	81.6 (4)	81.0 (4)
External physical	25.7 (2)	83.7 (2)	38.8 (1)	86.4 (1)	100 (1)	100 (1)
Internal Physical	23.9 (4)	33.7 (5)	13.4 (5)	47.5 (5)	39.5 (5)	42.9 (5)
Psychosocial	24.8 (3)	80.7 (3)	38.0 (2)	74.6 (2)	94.7 (2)	95.2 (2)
<i>r</i> _T						
vs. patients		0.976*	0.332	0.332	0.470	0.470
vs. general practitioners		0.355	0.355	0.493	0.493	
vs. diabetes team			0.953†	0.953†	0.953†	—

Data are percent. Numbers in parentheses show ranking within the group. Top-down coefficient: * $\alpha < 0.05$; † $0.10 > \alpha > 0.05$.

Table 4—Top Barriers to care for each participant group

	Patients		General practitioners		Practice nurses		Hospital doctors		Hospital nurse/dietitian		Diabetes team	
	%	Rank	%	Rank	%	Rank	%	Rank	%	Rank	%	Rank
Motivation	11.4	5	86	1	31.5	1	52.5	4	76.3	3	85.7	1
Inappropriate care	12.4	4	71.3	2	28.2	2	55.9	3	84.2	1	57.1	8
Diabetes knowledge	14.5	3	70.1	3	27.5	3	57.6	1	78.9	2	76.2	3
Strictness of regimen	42.3	1	69.4	4	26.2	4	42.4	6	73.7	4	76.2	3
Public health belief	4.4	17	58.6	5	17.4	9	28.8	12	47.4	9	57.1	8
Cost	9.8	8	56.7	6	22.1	6	25.4	13	52.6	7	52.4	11
Limited range of services	7.1	13	51	7	17.4	9	33.9	7	47.4	9	61.9	6
Staffing levels	9.5	9	49.7	8	22.1	6	57.6	1	71.1	5	81	2
Health system issues	9	11	36.3	9	24.8	5	45.8	5	50	8	76.2	3
Western health belief	2.7	20	33.1	10	2	27	16.9	16	15.8	20	14.3	23
Unsupportive macroenvironment	9.9	7	31.8	11	13.4	13	27.1	11	55.3	6	57.1	8
Cultural	1.5	25	28.7	12	10.7	18	32.2	9	34.2	13	33.3	15
Local service needed	2.7	20	25.5	13	13.4	13	23.7	14	47.4	9	61.9	6
Self-efficacy	10.5	6	22.3	14	19.5	8	13.6	18	23.7	16	33.3	15
Other health conditions	16.8	2	17.8	18	11.4	16	30.5	10	31.6	14	38.1	12
Time	9.1	10	12.1	20	17.4	9	10.2	19	13.2	21	38.1	12
Diabetes epidemic	0.1	33	10.8	21	9.4	19	33.9	7	39.5	12	33.3	15
r_T												
vs. patients			0.391*		0.457†		0.296		0.466†		0.275	
vs. general practitioners					0.921‡		0.526†		0.803‡		0.687§	
vs. diabetes team					0.746§		0.644§		0.508†		—	

Top-down coefficient: *0.10 > α > 0; † α < 0.05; ‡ α < 0.001; § α < 0.01.

gest that planning diabetes services will require representatives from all groups and careful facilitation. How to balance resource allocation for physical needs (which have randomized controlled trial evidence) and those to address psychological needs (which help the implementation of such evidence) may be difficult. New resources may be needed, for example, to implement additional training for existing health workers, to increase time for patient-health worker interactions, and to explore new approaches to care.

There are a number of limitations to this study, in spite of our unexpectedly high response rate with such complete questionnaires. The variation in the number of responses between participant groups makes comparisons between them difficult: We do not know if this reflected their interest and knowledge in diabetes or their time and interest in completing the mail survey. The high response and comments about being swamped by the diabetes epidemic certainly suggest an overall interest in responding. The high proportion of practice nurses reporting no barriers, and their low mean number of barriers reported, may suggest that their question-

naires were incompletely considered and not completed. Further studies among this group are recommended. Socioeconomic status was not assessed, yet it is likely to be a major determinant of external barriers. (Questions relating to this were excluded in the interests of achieving a higher response rate.) The patient sample is heterogenous in other ways, and we have not compared subgroups in this report. This sample includes not only responders, but also those selected due to their participation in the local retinal screening/secondary services. We have previously shown that those with no ongoing primary care for their diabetes are younger and more likely to be employed, with less severe complications and comparable metabolic control (24). Whether nonparticipants in the current study have more, less, comparable, or dissimilar barriers remains unknown. This is particularly so for Māori and other non-European patients who had lower response rates. The use of a mail survey may have eliminated more of those with lower educational and literacy levels. Finally, this is a study in one geographically defined area across New Zealand. How this applies to other populations in other health care systems is currently unclear.

Cross-national comparisons of barriers (25) and reviews of barriers to care (26) suggest that similar findings might be found elsewhere.

In conclusion, we have shown that a majority of patients have barriers to diabetes care and self-care, particularly those relating to the strictness of the regimen and other health conditions. There is some discordance in the perceived relative importance of these barriers with health workers, many of whom see system barriers as being of major importance. Our findings suggest that methods for overcoming barriers, including systems for their identification and handling, may assist in improved diabetes outcomes. Increasing psychological support for patients should receive a higher priority in district-based service development: How this should be best delivered requires urgent attention.

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