A case control study of diabetic patients who default from primary care in urban New Zealand

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Received 14 June 2006; accepted 18 September 2006
Available online 23 March 2007

Abstract
Aim. – Diabetic patients defaulting from specialist care have worse metabolic control and complications than those attending regularly. We have compared the clinical characteristics of defaulters and more regular health care attenders on a population basis in a multi-ethnic community.

Methods. – We performed a 2:1 case control study of those defaulting from care for at least 10 months identified from a cross-sectional household survey of known diabetes in inner urban South Auckland, New Zealand. Thirty-seven cases and 52 controls with type 2 diabetes were examined (28 and 36 having retinal photography).

Results. – Defaulters were less likely to have been damaged by their diabetes (including less severe/proliferative retinopathy 16.7% vs. 0%, respectively, \( P < 0.05 \)), more likely to have worse foot care (95% vs. 79% poor nail or skin care, \( P < 0.05 \)) but had similar metabolic control as regular attenders. Most patients could either give no reason for default (40%) or claimed that their diabetes had gone (14%). Twenty-four (65%) reported that nothing could lead them to start attending for diabetes care.

Conclusion. – We conclude that unlike those defaulting from specialist care, many, but not all, of those with diabetes defaulting from all care generally have comparable metabolic control and less complication than regular attenders. The patients had a range of attitudes to their diabetes suggesting that attracting such patients back into care, prior to a major clinical event or the development of symptoms, is unlikely without major effort.

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Résumé
Caractéristiques des patients diabétiques citadins échappant au système de soins en Nouvelle-Zélande : étude cas témoins.

Buts/hypothèse. – Les patients diabétiques échappant au suivi par des spécialistes ont un moins bon contrôle métabolique et davantage de complications que ceux suivis régulièrement. Nous avons comparé les caractéristiques cliniques des patients échappant totalement au système de soins et des patients suivis plus régulièrement, en partant d’un recrutement fondé sur la population dans une communauté multiethnique.

Sujets et méthodes. – Une étude cas témoins (2/1) a été menée sur des sujets diabétiques connus échappant totalement au système de soins depuis au moins dix mois, identifiés à partir d’une enquête transversale en population, dans la cité d’Auckland sud, en Nouvelle-Zélande. Trente-sept cas et 53 témoins diabétiques de type 2 ont été examinés.

Résultats. – Par rapport aux patients suivis régulièrement, les patients sans suivi avaient moins de complications du diabète (incluant moins de rétinopathie sévère/proliferative : 16,7% vs. 0 % respectivement, \( P < 0.05 \)), des pieds en moins bon état (79 vs. 95 % d’ongles mal entretenus ou de lésions cutanées, \( P < 0.05 \)) mais avaient un contrôle métabolique identique. La plupart des patients soit ne pouvaient donner aucune raison pour l’absence de suivi (40 %), soit disaient que leur diabète avait disparu (14 %). Vingt-quatre (65 %) déclaraient que rien ne pourrait les conduire à entreprendre un suivi pour le diabète.

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Conclusions/interprétation. – À la différence des patients échappant au suivi par les spécialistes, les patients diabétiques échappant totalement au système de soins ont dans l’ensemble un contrôle métabolique comparable et moins de complications que les patients suivis régulièrement. Les patients non suivis ont une perception de leur diabète qui suggère que d’énormes efforts seront nécessaires si on veut les réintégrer dans le système de soins avant la survenue d’un événement clinique majeur ou le développement de symptômes.

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Keywords: Type 2 diabetes; Default; Footcare; Blood pressure; Retinopathy

Mots clés : Diabètes de type 2 ; Suivi médical ; Pied diabétique ; Pression artérielle ; Rétinopathie

1. Introduction

Intensive management of type 2 diabetes reduces complications [1–3]. Patients with type 2 diabetes who default from specialist clinics have poorer blood pressure and glucose control [1,2]. However, in New Zealand and other countries, type 2 diabetes is now managed predominantly in primary care, although default remains an issue [4–8]. In multietnic South Auckland, New Zealand, 6.3% of those with known diabetes defaulted from primary care [9] particularly if diagnosed when asymptomatic or after gestational diabetes and were younger, knew less about diabetes, less satisfied with past care and less likely to require medication. Studies of such “defaulters” are notoriously difficult. We now describe a nested case control study comparing the metabolic characteristics and complications of “defaulters” with “non-defaulters” from primary care.

2. Method

Between April 1992 and August 1995, 27,419 households were surveyed, of which 25,039 (91%) participated and 1488 people with known diabetes [diagnosed by random glucose ≥11.1 mmol/l or by fasting hyperglycaemia (≥7.8 mmol/l at the time) on at least two occasions or one occasion and symptoms, or by OGTT] completed a detailed questionnaire [10]. “Defaulters” were defined as those reporting no diabetes care from any health professionals in the previous 10 months (taken as it implies three missed quarterly appointments) as previously reported [9]. None had type 1 diabetes, but other rarer forms of diabetes were not excluded (e.g. LADA, secondary diabetes). As a defaulter attended the study, two controls (“non-defaulters”) with type 2 diabetes were randomly selected from the subjects in the house-to-house survey database using an electronic randomiser, group matching for gender, ethnicity and 20-year age group. Patients were invited for a more detailed, face-to-face assessment by letter, then by phone, and if still neither attending nor refusing, the house was visited. Every effort was made to recruit cases and controls into the study.

Barriers to diabetes care were assessed using three standardised open-ended questions enumerating whether and why they were worried about their diabetes, how they would improve local diabetes services, and what they believed prevented themselves or others from looking after their diabetes properly. Each barrier to diabetes care response was then given a code to facilitate analyses (maximum of three responses were coded). These were then mapped onto up to five barrier groups through the consensus of three coders: internal (including co-morbidities), external physical (systems barriers such as out of pocket expenses, distance, travel), educational (perceived knowledge deficits), internal psychological (e.g. emotional and readiness to change) and external psychological (i.e. psychosocial such as family and other support). Validation of the method is described elsewhere [11,12].

Sitting blood pressure was measured using a standard mercury sphygmomanometer by one observer (mean of two recordings to the nearest 2 mmHg). Weight was measured to the nearest kg in light clothes without shoes and height to the nearest cm using a portable stadiometer (CMS, London). Laboratory measures were undertaken in the local hospital laboratory, which participated in national Quality Assurance programmes. Glycated haemoglobin was measured using cation exchange high performance liquid chromatography (Biorad Diamat, Biorad, USA: upper limit of reference range 6.2%). Total cholesterol, HDL cholesterol, triglycerides, serum and urinary creatinine were measured using Hitachi 717 autoanalyser (Hitachi, Japan). Urinary albumin in mg/l was measured by immunoturbidimetric assay (Cambridge Life Science, Cambridge, UK) on a Cobas Faran centrifugal analyser (Roche, Berne, Switzerland).

At the face-to-face session, an appointment was negotiated for ophthalmological assessment at a mutually agreed time within 4 weeks. Retinal photography was undertaken in the eye with the worst retinopathy on dilated fundoscopy using a retinal camera ((Topcon Optical Co., Tokyo, Japan) and graded by two observers masked from the clinical examination results. If fundoscopy was similar in both eyes, the right fundus was used unless obscured, in which case the left fundus was used. Direct fundoscopy was undertaken by one observer (G.C.).

Comparisons made using SPSS v13 (SPSS Inc., Chicago, USA) included Chi squared (or Fisher exact test if small samples), analysis of variance or logistic regression (using both direct and forward conditional approach with the latter shown). All comparisons were two sided and \( P < 0.05 \) taken as significant. The North Health Ethics Committee approved the study.

3. Results

Of the 107 “defaulters”, 10 had moved/died and 22 had subsequently received care; 37/75 (49%) cases and 52/71 (73%) controls participated. Those diagnosed after gestational
diabetes accounted for 11% of cases and 14% of controls, but 40% of those moving and 36% of those not participating in the follow-up study (P < 0.05). As expected from the full cohort (described in [9]), defaulters were more likely to have received education after leaving school but less likely to have a diabetic partner, have a card allowing greater healthcare subsidies and were less likely to be prescribed medication (Table 1). There were no differences in perceived barriers to care (Table 1). Glycaemic control and lipids among defaulters were comparable to controls (Table 2). Defaulters did have worse skin and/or nail care, but neuropathy assessment was similar. The proportion with raised blood pressure; microalbuminuria and/or raised creatinine were non-significantly higher in controls. Attendance at the subsequent ophthalmological assessment was 76% (28/37) among defaulters and 69% (36/52) among controls. Defaulters had significantly less severe or proliferative retinopathy, and non-significantly less maculopathy and cataracts.

A logistic regression showed that after adjusting for all variables, the presence of callus remained significantly more common and the presence of severe/proliferative retinopathy remained significantly less common among defaulters (Table 3). The prescription of insulin therapy, blood pressure medication and antihyperglycaemic medication remained less common in the defaulters.

Responses by cases to “If you have not seen anyone about your diabetes recently, why is this?” were cost (two (5%)), transport (one (3%)), a doctor who “growled” (one (3%)), a belief that the diabetes had gone (five (14%)), that they felt all right, did not need to attend, that their diabetes was not a serious problem, that it was their choice or that they were “being stupid” (13 (35%)) while the others (40%) indicated that there was no particular reason for their default. In response to “What can be done to help you get your diabetes assessed regularly”, 24 cases (65%) replied “nothing”, adding that action was up to them, that nothing could be done, that no action was necessary or that they were lazy. These responses were in spite of significant prompting during the interview. Eight subjects wanted assistance with making appointments or making diabetes services available to them and two subjects wanted further education. Other individuals wanted “support”, reduced costs or self-testing equipment.

### 4. Conclusion

This study adds to our earlier report by assessing the clinical features of those with no care after a mean time of 20 ± 13 months and clearly shows that defaulters had less “severe” diabetes than non-defaulting controls. From the ear-
lier study, we knew that fewer defaulters were receiving medication and more had been detected while asymptomatic [9]. We also knew that less self-reported complications were present, but we did not know whether this was due to the lesser likelihood of complication detection because of the lower utilisation of health services, denial or actuality. Although the numbers in the study are small and there is clear heterogeneity, the average metabolic control in the cases was at least as good and probably better than that among the controls. Similarly, the prevalence of complications in cases was similar or less than that in controls. The non-significantly lower prevalence of microalbuminuria, the lower prevalence of severe and proliferative retinopathy would suggest a comparable or lower degree of other microvascular disease. The only risk factor for complications worse among the cases was their poorer foot care. Diabetes knowledge was similar in cases and controls. This lack of complications among defaulters, and the suggestion that the disease is not threatening may be a limitation to attracting patients to regular care.

One specific area of concern from this study is the continuing poor foot care in inner urban South Auckland [13]. Callus and both poorly and untrimmed nails were present in the majority of controls and in nearly all of the non-regular attenders for diabetes care. This majority of this group were on no medication, particularly those whose glycaemic control was managed with diet alone. This group has now been recognised as having significant rates of macrovascular complications and being less likely to be adequately monitored [14]. Generally, assessments would still be expected to occur quarterly, hence the minimum time of 10 months (i.e. three visits).

Additional questions could be asked in this case control study, not asked in the initial household survey. We had hoped that the reasons and solutions for default would have been defined, but the majority implied an active or passive decision not to attend for care and that “nothing could be done to help”. In our previous analyses, such attitudes were present in a large number (but lesser proportion) of patients [11] and we wonder whether this was related to particular personality types and psychosocial barriers to care [15] or the way that diabetes education and services were being provided [16]. Whether case management would help this subset of patients is possibly an area for further research. The questions were asked by an experienced diabetes educator, used to working with Māori and Pacific patients, and it is unlikely that our failure to elicit further information was due to cross-cultural or communication issues. At the time, the area had a number of Māori and Pacific community educators and we found that language and cross-cultural issues among Polynesians (unlike with other non-European groups) were not major barriers to care [11]. In view of the major benefits in reducing cardiovascular risk in these subjects [3], it remains important to attempt to attract such patients into ongoing care.

One further approach likely to be of benefit is the use of computerised, systematic recall by e.g. nurses [17] and this is increasingly being used in New Zealand.

The greater personal cost in terms of time and out of pocket expenses by attending health services is suggested by the (non-significantly) greater proportion of non-regular attenders for diabetes care in paid employment and lesser number in possession of a community services card. The latter may reflect a combination of income threshold and lack of knowledge of how to access benefits (and perhaps services). The costs of diabetes are known to influence health care utilisation in both South Auckland [18] and elsewhere [19]. These findings have a number of caveats. The study was very difficult to undertake. While the response rate from the controls was acceptable, that for the defaulters was poor and the impact of this is uncertain. It is not too surprising that non-attenders for clinical care are also less likely to participate in studies. However, we had substantial self-reported data on the cases who did not attend: they were younger and more mobile patients and more likely to have been diagnosed during pregnancy. Whether their participation would have meant that the costs would have had more complications with worse metabolic control is unpredictable. The extent to which the high proportion of Māori and Pacific patients, and the lower socio-economic setting influenced the findings is unclear and numbers are too small to assess these statistically.

We conclude that those defaulting from care are a heterogeneous group including those with existing damage and risk factors but with a high proportion who appear to be in a window, where silent damage is likely to be occurring, but who remain uninterested to act. As a group apparently largely disinterested in their diabetes, they clearly would require a great deal of effort to ensure that they remain in care. We wonder how many patients go through this phase and its contribution to complications.

Acknowledgements

This study was funded by the Health Research Council (HRC). We thank Eli Lilly and Novo Nordisk for their support. We are grateful to the South Auckland Diabetes Project team (now known as the Diabetes Projects Trust) and the people of South Auckland for their involvement in the work of
the South Auckland Diabetes Project. We thank Caroline Hope for her assistance with the retinal work.

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