What does ‘undiagnosed’ diabetes really mean?

The prevalence of ‘undiagnosed’ diabetes depends on the underlying (true) diabetes prevalence, screening coverage, the definition of diabetes, and if based on self-report of diagnosis, the degree of recall bias.

As demonstrated by the 2008/09 New Zealand Adult Nutrition Survey,\(^1\) the results of which were recently described by Coppell et al in the Journal,\(^2\) the absolute ‘undiagnosed’ diabetes prevalence also varies by age, gender, and ethnicity, so in reporting a single figure for a particular ethnicity it is important to be mindful that the relative proportions of diagnosed and undiagnosed diabetes can vary substantially across different age groups.

The distinction between ‘self-reported doctor diagnosed’ diabetes, the diabetes status recorded by a primary care practice, and the diabetes status known somewhere in the health system are important, as the differences between these three categories can highlight potential quality improvement opportunities.

Possible reasons that may contribute to recall bias that account for the difference between self-reports and medical records include language barriers and varying levels of health professionals’ ability to communicate complex and unfamiliar concepts clearly. This may lead to patients, family and whaanau having limited understanding and acceptance of disease and low health literacy.

Despite the wide 95% confidence intervals provided by Coppell’s study by ethnicity and age,\(^2\) it would be worth exploring the reasons for the relatively high proportions of Pacific people identified as having ‘undiagnosed’ diabetes. Unpublished data from preliminary analysis by Counties Manukau District Health Board (CMDHB) indicates that rates of diabetes-related blood testing for Pacific peoples are similar to Maaori and higher than non-Maaori/non-Pacific rates in the Auckland metro region. CMDHB has been estimating the population prevalence of known diabetes based on linked datasets using methods similar to the Ministry of Health’s health tracker for a number of years.\(^3\)

Some work has been done to validate the method.\(^4,5\) For the Pacific population in CMDHB, where 40% of New Zealand’s Pacific population live, the prevalence known diabetes by this method is also substantially higher than self-reported diagnosed diabetes for the Pacific people reported in the 2008/09 national survey.\(^2,3\) This suggests recall bias and/or information not being known consistently across health services may be contributing to the discrepancy for Pacific in the 2008/09 Adult Nutrition Survey.

The discrepancy between the records of a given primary care practice, and diabetes status somewhere in the system could occur because patients have moved to a new practice and not all their records were transferred or recorded by the new practice. Statistics New Zealand suggests more than 50% of New Zealanders aged 5 years and over move address over a 5-year period.\(^6\) A local CMDHB analysis also confirmed significant patient churn between practices located in the DHB area.\(^7\)
About 21% of people enrolled in 2010 quarter 1 (Q1) were no longer in the same practice in 2012 Q1. On the other hand, new patients who had registered in the two years since 2010 accounted for about one-quarter of the practice totals. Out of all the patients enrolled in primary care practices located in CMDHB during the two year time period, only 64% of patients were enrolled in the same practice in both 2010 Q1 and 2012 Q1. Shared electronic health records and linkage provide opportunities to ensure that appropriate information generated in various parts of the health system is available to the person’s ‘primary care home’ to facilitate quality care.

Finally, since the ADA published the additional HbA1c criteria in 2010,\textsuperscript{8} it was retrospectively applied to people who took the survey in 2008-2009, thus the undiagnosed diabetes as defined by the recent paper by Coppell et al would also capture the additional people who would be diagnosed by HbA1c $\geq 6.5\%$ (48 mmol/mol) which was not yet the formal diagnostic criterion at the time. While most international population surveys of diabetes generally undertake only one test,\textsuperscript{9} the diagnosis of diabetes clinically should be based on two positive test results in the screening setting.\textsuperscript{8}

These issues highlighted by the definitions of ‘undiagnosed diabetes’ warrant further examination as they are important both for quality improvement in clinical practice, monitoring the diabetes epidemic and future research methodology, and likely apply more broadly than Pacific peoples.

However, these discussions should not detract from the main conclusion of Coppell’s study suggesting that the prevalence of diabetes is likely to continue to increase and cost-effective implementation of diabetes prevention strategies is needed.

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