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ORIGINAL ARTICLE

Increasing the Detection of FH Using General Practice Electronic Databases

Alistair W Vickery, FRACGP [a*], Jackie Ryan, Nurse Practitioner [b], Jing Pang, PhD [b], Jacquie Garton-Smith, FRACGP [c], Gerald F Watts, DSc, MD, PhD, FRACP [b]

[a]School of Primary, Aboriginal and Rural Health Care, University of Western Australia, Perth, WA, Australia
[b]Lipid Disorders Clinic, Cardiovascular Medicine, Royal Perth Hospital, School of Medicine and Pharmacology, University of Western Australia, Perth, WA, Australia
[c]Cardiovascular Health Network, Royal Perth Hospital, Perth WA, Australia

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Background Familial hypercholesterolaemia (FH) is a common autosomal co-dominant condition that causes premature cardiovascular disease. Awareness of FH is poor and only 10–15% of the affected population is identified. Electronic health records provide an opportunity to increase detection and awareness in general practice

Objective To determine whether a simple electronic extraction tool can increase detection of FH in general practice.

Method An extraction tool applied to general practice electronic health records (EHR) to screen for FH, total cholesterol and low density lipoprotein cholesterol (LDL-c) levels in association with entered diagnostic criteria and demographic data in five general practices.

Results Of 157,290 active patients examined, 0.7% (n=1081) had an LDL-c>5.0 mmol/L representing 1 in 146 of active patients. An additional 0.8% (n=1276) patients were at possible risk of FH. Of those with an LDL-c>5.0 mmol/L 43.7% of patients had no record of being prescribed statins. Twenty patients (0.013%) had a clinical diagnosis of FH entered in the EHR.

Conclusions Patients at high risk of FH can be identified by a simple electronic screening method in general practice. Clinical data entry is variable in general practice. Targeted screening enables clinical assessment of patients at risk of cardiovascular disease and using the DLCNS will enable primary care to increase identification of FH. Approximately one in five patients extracted using this method, are likely to have phenotypically probable FH, making it a useful screening tool.

Keywords Familial hypercholesterolaemia • Electronic health records • General practice

Introduction

Primary care is central to the increased detection and management of Familial Hypercholesterolaemia (FH) to reduce the corresponding burden of premature coronary artery disease (CAD). [1] Familial hypercholesterolaemia is an autosomal co-dominant disorder associated with elevated low density lipoprotein (LDL-c) cholesterol.[2] Heterozygote FH is thought now to occur in approximately 1 in 250 of the population.[3] There are estimated to be 80,000 people with FH in Australasia with only 10–15% of the affected population being identified and the average general practice likely to encounter 50–100 patients with FH, every year.[4] In Australia, the majority of people with FH are undiagnosed, often not treated to adequate targets, and their families are not tested for the possible 50% of affected first-degree

*Corresponding author at: SPARHC, Faculty of Medicine, Dentistry and Health Sciences University of Western Australia M706, 35 Stirling Highway, Crawley WA 6009, Email: Alistair.vickery@uwa.edu.au

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relatives.[5–7] If FH is left untreated, 50% of men will have CHD by age 50 years and 30% of women by age 60 years.[3]

General practitioners (GP) request over 90% of LDL-c measurements in the community,[8] and are crucial in the management of hypercholesterolaemia and other cardiovascular risk factors for the prevention of cardiovascular disease. Commonly used cardiovascular risk calculators do not accurately assess risk in those with FH. Awareness of FH however is low amongst both GPs and specialist physicians. [9,10].

We have previously reviewed the role of FH detection in the community by suggesting a multidisciplinary approach including: a broader primary care awareness and education program; auditing of electronic patient information on general practice databases; and, via pathology providers, to highlight people with very elevated LDL cholesterol at risk of FH.[1]

Over the past 25 years, computer use by Australian GPs has increased such that nearly all general practices in Australia use a computer at their practice.[11] Routinely collected health care data in GP electronic health records (GP EHR) can be mined, to allow identification of disease states and population patterns. [12] General practice EHR systems vary across general practices and extraction systems are required to be able to coordinate with different systems. Some GP EHR systems are capable of effectively extracting clinical data although the quality of the data has been found to be of varying consistency. [13] A number of GP EHR approaches have been used in other countries with varying success [14,15]

We present a simple method to improve detection and to enhance awareness of FH in Australian primary care by using an electronic extraction tool suitably designed for GP EHRs.

Methods

Data Source

De-identified data were obtained using electronic extraction tools in five Perth metropolitan practices over two years using the Canning Tool [16]. This extraction tool is able to extract data directly from more than seven types of GP software which is applicable to over 95% of available Australian general practices. We had access to the databases of five general practices with an average of 5.5 full time equivalent GPs (FTE). Full time equivalent is defined as 37 hours worked per week in typical general practice activities.

Electronic data for active patients (patients with at least one consultation in the previous two years) in the practice contains demographic information, past medical history, prescription details and laboratory test results. Ethics approval was granted from the University of Western Australia Human Research Ethics Committee (Reference: RA/4/1/6280).

Variables

The Canning Tool was modified for specific FH and cardiovascular indicators and compatibility with the practice software. Exclusions (Table 1) were for patients with recorded triglyceride >4.0 mmol/L and those less than 18 years of age as thresholds for diagnosis of FH differ from adults.

Table 1 Extraction criteria for FH included in the Canning Tool.

inclusions	exclusions
Patient attended in the last 2 years	triglyceride >4.0 mmol/L
Age 18-70 years	patients aged <18
History of cardiac event <60 years	
Any coronary arterial disease	
Diagnosis of lipid disorder	
Total cholesterol >7.5 mmol/L	
LDL-c >4.0 mmol/L	
Prescription for statins	

Clinical Information

Active patients with a recorded history of: vascular disease (ie cardiovascular, cerebrovascular or peripheral vascular disease); lipid disorders, including familial hypercholesterolaemia, hypercholesterolaemia, hyperlipidaemia and dyslipidaemia; and prescription of an HMG-CoA reductase inhibitor class medication.

Cholesterol Estimation

Active patients with a total plasma cholesterol at any time recorded as greater than 7.5 mmol/L and LDL-c levels greater than 5.0 mmol/L were extracted. Diagnostic criteria for FH cholesterol estimation are based on untreated levels. Patients who had been prescribed HMG-CoA reductase inhibitors (statins) for lipid lowering who had a recorded LDL-c greater than 4.0 mmol/L were also extracted.

Diagnostic Criteria

Following identification of patients with an adjusted LDL-c greater than 5.0 mmol/L, we were able to include a partial assessment of the Dutch Lipid Clinic Network Score (DLCNS) using those data that were recorded or available. The DLCNS includes assessment of: raised cholesterol and LDL-c concentrations; clinical characteristics such as peripheral vascular disease; coronary artery disease; presence of tendon xanthoma; arcus cornealis; and a family history of premature heart disease.[17] The data extracted did not contain family history or examination findings, therefore the partial DLCNS assessment only included total cholesterol, LDL-c concentrations and a personal history of vascular disease, when that was recorded.

Follow-Up Education and Clinical Assessment by Nurse Practitioner

Data entry in Australian general practice, particularly for family history and coding diagnoses is known to be poor. [18] To help improve awareness and accuracy of diagnosis of

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