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Patients' knowledge of their chronic disease

The influence of socio-demographic characteristics

Background

This study investigated which patient socio-demographic factors are associated with being unaware of their chronic disease.

Methods

Secondary analysis of data from the Point of Care Testing in General Practice Trial studying patients with diabetes mellitus, hyperlipidaemia and cardiovascular disease requiring anticoagulation.

Patient questionnaires were compared with their general practitioner's records. Multiple logistic regression analysis was performed, determining which patients were more likely to be unaware of their chronic disease.

Results

A large proportion of patients were unaware of their chronic diseases (27% with hyperlipidaemia, 15% prescribed anticoagulation, 5% with diabetes). Patient factors associated with being unaware include residing in rural or remote regions of Australia.

Discussion

Self management, a pillar of chronic disease management, is unachievable if patients are unaware of their condition. At practice and policy levels, identifying then targeting patients most likely to be unaware of their conditions with evidence based interventions, can facilitate self management.

Keywords

health knowledge, attitudes, practice; health literacy; chronic disease; patients

Evidence shows a significant proportion of Australians do not have adequate levels of health literacy,¹ described as the individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.² More than 50% of people aged 15–74 years lack adequate health literacy levels.³ Older Australians, with a higher burden of chronic disease, were found to be less likely to have adequate health literacy than younger patients.^{4,5}

Health literacy impacts on the effectiveness of chronic disease management,^{6,7} of which patient self management is a central pillar.⁸ Poor health literacy is associated with socio-demographic factors such as age, socioeconomic status (SES), education levels and non-English speaking background.^{6,7} Along with these social determinants of health, low health literacy is associated with poor health outcomes.^{9,10} There is however, a gap in the Australian literature around patients' unawareness of having a chronic condition and associated socio-demographic characteristics, and the impact of unawareness on health outcomes.¹¹

Addressing this gap, we aimed to determine, in patients with diabetes, hyperlipidaemia or cardiovascular conditions requiring anticoagulant therapy, whether socio-demographic factors and the presence of comorbidities were associated with the patient's awareness or lack of awareness of their chronic disease. This data will help general practitioners and policy makers to recognise the patients who are at risk of being unaware of their chronic disease, so that

strategies can be adopted to boost health literacy, thereby facilitating better health outcomes.

Methods

Secondary analysis was undertaken of data from patients participating in the Point of Care Testing (PoCT) in General Practice Trial. Details of that trial are described elsewhere, including eligibility criteria.¹² This was a multicentre cluster randomised controlled trial. Recruited practices were randomly allocated to the intervention or control arm. Randomisation was stratified by geographic area (urban, rural and remote).

Patients were eligible for the PoCT trial if they met the following criteria for each chronic disease of interest:

- diabetes – fasting plasma ≥ 7.0 mmol/L or 2 hour post-glucose load ≥ 11.1 mmol/L
- hyperlipidaemia – eligible for Pharmaceutical Benefits Scheme (PBS) subsidised lipid lowering drugs
- anticoagulant therapy – prescribed warfarin with an INR test result within the therapeutic range for at least 1 month.

Each practice generated a list of eligible patients and the GP or practice nurse reviewed the list to ensure the appropriate selection had been made. Patients could have one or more of these conditions.

Patients were sent a questionnaire at the start of the PoCT trial to gather socio-demographic information and self reported knowledge of their chronic diseases: diabetes mellitus, hyperlipidaemia, and/or cardiovascular conditions requiring anticoagulant therapy (*Table 1*).

The variables used in this analysis were taken from those identified in literature around health literacy:¹³

- age; gender; country of birth; educational achievement; employment status; location

based on Rural, Remoteness, Metropolitan Areas (RRMA) classification;¹⁴ socioeconomic status (SES), using the Socio-Economic Indexes for Areas (SEIFA) classification,¹⁵ and the presence of other comorbidities

- self reported awareness of chronic conditions.

Determining awareness

The GP's assessment of their patients' chronic conditions was obtained from participating practice records. Patients were deemed 'aware'

if they reported a condition consistent with their GP's records. Patients who were unsure or reported not having the condition in their GP's records were called 'unaware'. Patients who reported having a condition contrary to their GP's assessment (using contemporaneous laboratory investigations) were excluded, leaving a dichotomy between 'aware' and 'unaware' patients (Table 2). In case patients did not understand medical terminology for the condition used in the questionnaire, we considered their responses to subsequent questions about the rationale for taking the prescribed medication. If responses to subsequent questions showed understanding of the condition, they were deemed 'aware'.

Statistical analysis

A multivariate logistic regression analysis, using generalised estimating equations, was performed to determine associations between being unaware of a chronic condition and socio-demographic factors. Using this approach, the clustering of patients within practices was allowed for. Odds ratios are presented for each socio-demographic factor with 95% confidence intervals. Statistical significance was set at 5%. All analyses were performed in SAS 9.3.

Results

Baseline questionnaires were sent to 4732 patients with 4453 responses (94.1%). Key characteristics of responding participants are provided in Table 3.

For each condition, there were differing proportions of patients who were unaware of their condition. For patients with hyperlipidaemia, 27% (924/3484) were unaware of their condition. Similarly, for those prescribed anticoagulants, 15% (131/892) were unaware of their condition. In contrast, only 5% (83/1846) of patients with diabetes were unaware of their diagnosis.

The multivariate analysis for patients with diabetes showed being unaware was associated with having no formal education (OR 5.6, 95% CI: 2.3–14.3), living in a rural (OR 2.1, 95% CI: 1.1–4.1) or remote area (OR 2.7, 95% CI: 1.5–5.1), and being born overseas (OR 1.9, 95% CI: 1.2–3.2) (Table 4). In the group with hyperlipidaemia, the multivariate analysis showed men (OR 1.6, 95% CI: 1.3–1.8) and those with a low/medium SES (OR 1.4, 95% CI: 1.1–1.8) more likely to be unaware (Table 4). Participants requiring anticoagulation were more likely to be unaware if they were from a rural (OR 1.9, 95% CI: 1.0–3.6) or remote area (OR 2.4, 95% CI: 1.4–4.2) or if they had no other comorbidities (OR 1.9, 95% CI: 1.3–2.9) (Table 4).

Discussion

This study showed that many patients taking anticoagulants, and those with hyperlipidaemia, are unaware of their diagnosis, in contrast to patients with diabetes. Lack of awareness of a chronic disease was related to location of residence for patients with diabetes

Table 1. Questionnaire: Patients self reporting their chronic diseases		
Do you have cardiovascular (heart) disease requiring anticoagulant therapy?		
YES	NO	NOT SURE
If you are being treated with anticoagulant therapy do you have (Please tick all that apply):		
<ul style="list-style-type: none"> • Prosthetic valve replacement • Deep vein thrombosis • Recurrent deep vein thrombosis • Atrial fibrillation • Other (please specify) • Don't know 		
Are you currently using any of the following treatments for your cardiovascular disease? (Please tick all that apply)		
<ul style="list-style-type: none"> • Warfarin • Heparin • Aspirin • Over-the-counter medication (please specify) • Other (please specify) 		
Do you have diabetes?		
YES	NO	NOT SURE
If yes, do you suffer from: (Please tick one box only)		
<ul style="list-style-type: none"> • Type 1 diabetes • Type 2 diabetes • Don't know 		
Do you have hyperlipidaemia (high cholesterol)?		
YES	NO	NOT SURE

Table 2. Classification of participants as being aware or unaware					
		Patient responses			Total
		Have condition	Do not have condition	Unsure	
GPs' recorded diagnosis	Have condition	Aware	Unaware	Unaware	
	CVD with anticoagulation	761	131	0	892
	Diabetes mellitus	1763	68	15	1846
	Hyperlipidaemia	2560	738	186	3484
	Do not have condition	Wrong (excluded)	Wrong (excluded)	Wrong (excluded)	
	CVD with anticoagulation	802	2975	3	3780
Diabetes mellitus	134	2465	42	2641	
Hyperlipidaemia	246	619	96	961	

Table 3. Key participant characteristics

		Participants with diabetes (frequency %)	Participants with hyperlipidaemia (frequency %)	Participants with CVD requiring anticoagulant frequency (%)
Total		1846	3484	892
Mean age (years, range Q1–Q3)		66 (59–75)	66 (59–75)	66 (58–74)
Gender	Male	1009 (55%)	1841 (53%)	515 (58%)
	Female	837 (45%)	1643 (47%)	377 (42%)
Place of birth	Australia	1364 (74%)	2727 (78%)	678 (76%)
	Overseas	482 (26%)	757 (22%)	214 (24%)
RRMA*	Urban	702 (38%)	1221 (36%)	351 (40%)
	Rural	534 (29%)	962 (27%)	223 (26%)
	Remote	610 (33%)	1301 (37%)	318 (34%)
Number of comorbidities	None	987 (53%)	1746 (50%)	306 (34%)
	1	643 (35%)	1303 (37%)	407 (46%)
	2 or more	216 (12%)	435 (13%)	179 (20%)
SEIFA**	Quartile 1	409 (22%)	641 (18%)	174 (20%)
	Quartile 2	568 (31%)	1076 (31%)	288 (32%)
	Quartile 3	493 (27%)	1040 (30%)	236 (26%)
	Quartile 4	376 (20%)	727 (21%)	194 (22%)
Highest qualification	No formal education	37 (2%)	62 (2%)	6 (1%)
	School leaver	1192 (65%)	2223 (64%)	603 (67%)
	Diploma/certificate	429 (23%)	842 (24%)	213 (24%)
	Tertiary education	163 (9%)	327 (9%)	54 (6%)
	Not specified	25 (1%)	30 (1%)	16 (2%)
Employment	Employed (part time/full time)	474 (26%)	962 (27%)	141 (16%)
	Other	60 (3%)	93 (2%)	19 (2%)
	Retired/home duties	1261 (68%)	2355 (68%)	717 (80%)
	Unemployed	42 (2%)	63 (2%)	8 (1%)
	Not specified	9 (1%)	11 (1%)	7 (1%)

* Rural, Remote and Metropolitan Areas classification

- Urban = Metropolitan zone: M1 (capital cities) and M2 (other metropolitan centres, urban centre population >100 000)
- Rural = Rural zone: R1 (large rural centres, urban centre population 25 000–99 999), R2 (small rural centres, urban centre population 10 000–24 999) and R3 (other rural areas, urban centre population <10 000)
- Remote = Remote zone: Rem1 (remote centres, urban centre population >4999), Rem2 (remote areas (urban centre population <5000))

** Socio-Economic Indexes for Areas; the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD)

- Quartile 1 (Q1) lowest
- Quartile 2 (Q2) low/medium
- Quartile 3 (Q3) medium/high
- Quartile 4 (Q4) highest

and cardiovascular disease requiring anticoagulation. There was an association between being unaware of a chronic condition and having a lower SES, low education levels, and being born overseas.

How the findings relate to the literature

Low health literacy has been associated with lower socioeconomic status, living outside major cities, having less formal education, not speaking English as a first language, and not being employed.¹³ Patients with lower health literacy are more likely to have chronic disease, such as diabetes and heart disease,^{4,5} but our data explores who is more likely to be unaware of their diagnosis. The socio-demographic associations are consistent with the findings of previous studies of patients' awareness of other chronic disease diagnoses. Gill et al¹¹ found 30% of patients told by their GP they have arthritis were unsure of which type they suffered from. Unawareness of the type of arthritis was associated with being male, non-English speaking and having lower educational achievement.¹¹ Unawareness of testing and presence of chronic kidney disease was found to be very high in the AusDiab study,¹⁶ correlating with American data about high rates of unawareness of kidney disease in the affected population.¹⁷ There is a paucity of literature on rates of awareness of hyperlipidaemia or anticoagulation in the Australian context. American research suggests only 35% of patients with total cholesterol >5.2 mmol self reported having high cholesterol.¹⁸

Other studies have demonstrated the effect of locality on self reporting of chronic disease, particularly rural men being more unaware of diabetes than urban men.¹⁹ Lipid disorders are less commonly managed in rural/remote areas,²⁰ and statin prescribing rates are highest in urban areas, decreasing in rural and then remote areas, adjusted for age, gender and SES.²¹ This may contribute to, or may be the result of, fewer patients being aware of having this risk factor. Living in a rural or remote setting is known to be associated with greater health risk factors,

Table 4. Results of multivariate logistic regression							
		Diabetes OR (95% CI)	p value	Hyperlipidaemia OR (95% CI)	p value	CVD requiring anticoagulant OR (95% CI)	p value
Gender			0.68		<0.0001		0.68
	Female	1		1		1	
	Male	1.10 (0.69–1.76)		1.57 (1.33, 1.84)			
RRMA*							
	Urban	1		1		1	
	Remote	2.10 (1.06–4.14)	0.003	1.15 (0.92–1.41)	0.35	2.39 (1.38–4.16)	0.005
	Rural	2.74 (1.49–5.05)		1.15 (0.93–1.42)		1.91 (1.02–3.56)	
SEIFA**			0.10		<0.0001		0.59
	Quartile 4	1		1		1	
	Quartile 1	1.84 (0.86–3.90)		1.19 (0.90–1.58)		0.87 (0.41–1.82)	
	Quartile 2	0.95 (0.43–2.12)		1.44 (1.13–1.84)		1.28 (0.67–2.45)	
	Quartile 3	0.97 (0.42–2.26)		0.87 (0.67–1.12)		1.17 (0.60–2.29)	
Highest qualification			0.02		0.41		0.61
	Formal education	1		1		1	
	No formal education	5.59 (2.31, 13.53)		1.26 (0.74, 2.16)			
Country of birth			0.02		0.20		0.09
	Australia	1		1		1	
	Other	1.92 (1.15, 3.21)		0.88 (0.72, 1.08)			
Current employment			0.18		0.48		0.17
	Unemployed	1		1		1	
	Employed	0.35 (0.10–1.27)		1.15 (0.63–2.09)		0.52 (0.08–3.28)	
	Other	0.19 (0.02–1.94)		0.91 (0.43–1.93)		1.65 (0.22–12.24)	
	Retired or home duties	0.63 (0.17–2.33)		0.98 (0.53–1.81)		0.40 (0.06–2.53)	
Age at consent (years)			0.19		0.0005		0.22
	<45	1		1		1	
	45–50	0.45 (0.12–1.75)		0.86 (0.54–1.37)		0.24 (0.08–0.75)	
	55–64	0.53 (0.17–1.67)		0.67 (0.43–1.03)		0.23 (0.08–0.63)	
	65–74	0.52 (0.15–1.78)		0.81 (0.51–1.28)		0.30 (0.11–0.80)	
	75+	0.99 (0.28–3.45)		1.10 (0.69–1.77)		0.27 (0.10–0.75)	
Number of other comorbidities			0.15		0.31		0.009
	More than one comorbidity	1		1		1	
	No other comorbidities	1.01 (0.63, 1.58)		1.09 (0.93, 1.28)		1.94 (1.30, 2.91)	

* Rural, Remote and Metropolitan Areas classification

** Socio-Economic Indexes for Areas; the Index of Relative Socio-Economic Advantage and Disadvantage

greater prevalence of diabetes, and higher mortality from diabetes (using standardised mortality ratios).¹⁹

Reasons for the findings

Rural health disadvantage is related to socioeconomic factors such as lower incomes and education levels, geographic isolation from services, health service and workforce shortage, and high per capita cost of delivering services to sparsely distributed populations.¹⁹ Independent of these compounding factors, rural patients, some of the most disadvantaged patients in Australia, are most at risk of being unaware of their health problems. Bell and Orphin²² found the barriers to self management of chronic conditions were lack of formal education, poverty and age related physical frailty. They propose the effects of these barriers are multiplied in rural areas with shortages of health professionals and health infrastructure.²²

High rates of diabetes awareness may be associated with the high prevalence of diabetes. Community awareness has been advanced by the National Chronic Disease Strategy and National Health Priority Areas,²³ and emphasis on patient education in best practice diabetes management guidelines.²⁴

For a range of reasons, males across all age groups attend their primary healthcare team less frequently than women,²⁵ and this may contribute to the lower rates of awareness we found among males. Overseas born patients may have language or educational barriers that cause difficulty understanding their health problems.

Implications for practice and policy

Patient awareness of a chronic condition underpins their capacity to self manage that condition. Supporting patients to self manage their chronic diseases can improve health outcomes and quality of life measures.²⁶ These results are particularly important for patients taking anticoagulant therapy, whose lack of awareness of their condition has potential for grave complications. For patients with hyperlipidaemia, the impact of not being aware is serious but not as life threatening. Patients who have hyperlipidaemia with no symptoms, may be less likely to be aware of

this, and might lack motivation for behaviour change. The high rate of unawareness in this group may help explain why there are such low rates of adherence to long term lipid lowering therapy.^{27,28}

These results suggest intensive effort is required to close the gap between the health awareness of patients in the least and most disadvantaged areas of Australia. Health literacy and self management programs could be developed using online platforms or teleconferencing facilities to access those in rural and remote Australia.

For GPs, this study reveals some patient socio-demographic factors associated with unawareness of chronic conditions. In light of these results, GPs can begin to target patients who are at risk of being unaware of their condition using evidence based interventions: providing written materials, illustrative aids, mentors and educators, and by using multimedia to present health information.¹ General practitioners can implement teach-back techniques,²⁹ promote the 'Ask-me-3' program,³⁰ and could consider training to improve interpersonal communication.³¹ Patients who are more likely to be unaware of their chronic condition could be targeted for input from nurse educators and support from a multidisciplinary team.

Beyond the practice level, 'healthy public policy' and organisational practices are required to overcome social determinants of health literacy.³² Partnerships should be encouraged between primary health services and not-for-profit community organisations.¹ A population based approach is required to build health literacy around common conditions,¹ such as those we studied. Socio-demographic information could be included in disease registers and could be used to trigger referral of the most needy to group self-management programs. A broader, whole system approach to health literacy may be required through improving Australians' functional literacy, numeracy and language skills.³¹

What is not clear from this study is the impact of the patient's awareness on their participation in self management and on their health outcomes. Assessing awareness and the relationship with adherence to medications and

lifestyle advice, or markers of health outcomes would help answer this question and would be worthy of further research.

Limitations of this study

A key limitation of this study was that participants might have misunderstood medical terminology in the questionnaire, leading them to be misclassified as unaware of a condition, despite our best efforts as outlined in the methods. To verify the results, the questionnaire could be rewritten using lay-terms for medical conditions. A researcher could administer the surveys offering explanations to patients.

Sampling bias may also be a limitation, although as this was part of randomised controlled trial, this is likely to be minimal. Nonetheless, numbers of Aboriginal and Torres Strait Islander peoples were not large enough to detect any associations with rates of awareness, though evidence suggests there are cultural and linguistic barriers to health literacy.³³

Conclusion

There are a large proportion of patients with common chronic health problems who are unaware of their condition. Several socio-demographic factors have been demonstrated to be associated with being unaware. These patients need to be targeted at a practice and policy level, if self management can effectively function as a cornerstone of our chronic disease model of care in Australia.

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Ethics: The PoCT trial was approved by five independent Australian human research ethics committees and registered with the

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