

Why do people with chronic disease not contact consumer health organisations? A survey of general practice patients

Frances M. Boyle, Julie H. Dean, Charlotte E. Young and Allyson J. Mutch

School of Public Health, The University of Queensland, Herston, QLD, Australia

Aim: Consumer health organisations (CHOs) are non-profit or voluntary sector organisations that promote and represent the interests of patients and carers affected by particular conditions. The purpose of this study was to examine, among patients with chronic disease, what differentiates those who contact CHOs from those who do not and what stops people from making contact. **Background:** CHOs can enhance people's capacity to manage chronic disease by providing information, education and psychosocial support, but are under-utilised. Little is known about barriers to access. **Methods:** Data were from a baseline telephone survey conducted as part of a randomised trial of an intervention to improve access to CHOs. Participants constituted a consecutive sample of 276 adults with diagnosed chronic disease recruited via 18 general practitioners in Brisbane, Australia. Quantitative survey items examined participants' use and perceptions of CHOs and a single open-ended question explored barriers to CHO use. Multiple logistic regression and thematic analysis were used. **Findings:** Overall, 39% of participants had ever contacted a CHO for their health and 28% had contacted a CHO specifically focussed on their diagnosed chronic condition. Diabetes, poorer self-reported physical health and greater health system contact were significantly associated with CHO contact. The view that 'my doctor does it all' was prevalent and, together with a belief that their health problems were 'not serious enough', was the primary reason patients did not make contact. **Conclusion:** Attitudinal and system-related barriers limit use of CHOs by those for whom they are designed. Developing referral pathways to CHOs and promoting awareness about what they offer is needed to improve access.

Key words: chronic disease; consumer health organisations; primary care; self-management; voluntary groups

Received 1 May 2015; revised 7 August 2015; accepted 13 October 2015; first published online 17 November 2015

Introduction

The concept of chronic disease self-management has been embraced by health systems in countries throughout the world in an effort to stem the human and health systems costs associated with the rising prevalence of long-term chronic conditions (Epping Jordan *et al.*, 2004). Chronic disease care requires health professionals and patients to

adapt their approaches to manage the ongoing demands of these conditions and limit their progression. Increasingly, general practitioners (GPs) are expected to work with patients to develop care plans, lead multidisciplinary teams and help their patients learn self-management skills (Bodenheimer *et al.*, 2002; Oldroyd *et al.*, 2003; Department of Health and Ageing, Commonwealth Government of Australia, 2013; Eaton *et al.*, 2015). People who engage in self-management have better health outcomes including improved self-care, enhanced health status and more efficient health services use (Bodenheimer *et al.*, 2002;

Correspondence to: Frances M. Boyle, School of Public Health, The University of Queensland, Public Health Building, Herston Road, Herston, QLD 4006, Australia. Email: f.boyle@uq.edu.au

© Cambridge University Press 2015

Eaton *et al.*, 2015). Educating and supporting patients in self-management presents challenges for GPs who face competing time and resource demands (Bodenheimer *et al.*, 2002; Oldroyd *et al.*, 2003; Department of Health and Ageing, Commonwealth Government of Australia, 2013; Eaton *et al.*, 2015). Accordingly, patients may not receive the self-management support needed to adapt successfully to chronic conditions requiring behavioural change and psychosocial adjustment. Meeting patients' diverse needs and fostering self-management requires a mix of clinical and non-clinical resources (Fisher *et al.*, 2014; Morris *et al.*, 2015).

Consumer health organisations (CHOs) have long been a part of the health care landscape (Baggott and Jones, 2014). These non-profit or voluntary sector organisations promote and represent the interests of patients and carers affected by particular conditions. The provision of information, care and support to those experiencing a particular condition is the leading priority for most CHOs, but the scope of activities is often much broader, including awareness raising and involvement in research, policy, health promotion and prevention (Baggott and Jones, 2014). As an existing resource offering flexible and low-cost services that can extend, reinforce and complement clinical care for people with chronic disease, CHOs constitute part of a wider system of self-management support (Morris *et al.*, 2015).

Kurtz (1997) identifies five basic processes that typify CHOs: giving support; imparting information; conveying a sense of belonging; communicating experiential knowledge and teaching coping methods. CHOs provide unique opportunities for peer support by linking people with similar conditions and enabling sharing of personal knowledge and experiences (Fisher *et al.*, 2014). Their non-clinical focus also enables flexible and ongoing support that is integrated into people's everyday lives and promotes broader well-being (Morris *et al.*, 2015). CHOs are well placed to meet the varied support needs and preferences of patients through a range of support options including printed information, newsletters, links to other resources, telephone and online support and information, and educational activities. Engagement with CHOs may be active (eg, attendance at group meetings) or 'at a distance' (eg, use of written materials or social media) and ongoing, occasional or one-off.

Evidence of outcomes following contact with CHOs, although scarce, is encouraging. A review of 45 studies of the effectiveness of CHOs in supporting people across diverse range of conditions showed improvements in knowledge, mastery, coping, control and psychosocial well-being (Kyrouz *et al.*, 2002). Quantitative and qualitative explorations of specific CHOs suggest high levels of satisfaction and emotional, informational and practical support benefits for users (Beesley *et al.*, 2009; Boyle *et al.*, 2009; Sav *et al.*, 2014). Recent reviews highlight the contributions of peer support to health-related outcomes (Fisher *et al.*, 2014) and the benefits of facilitating access to voluntary and community services for primary care patients with psychosocial problems (Mossabir *et al.*, 2015). Two randomised controlled trials (Grant *et al.*, 2000; Blakeman *et al.*, 2014), both in the United Kingdom, demonstrate modest health improvements for general practice patients actively linked to community resources.

Yet, CHOs remain a relatively untapped health system resource. A UK survey of 2157 adults with a chronic disease found only 5% had ever contacted a CHO (Ellins and Coulter, 2005), whereas a Canadian survey of 267 patients with diabetes found between 3 and 13% had used a diabetes support organisation (Gucciardi *et al.*, 2006). Low uptake is characteristic of many community-based health interventions and a limitation of chronic disease self-management programs. Cost, transport, limited mobility, poor literacy, time constraints, limited or inaccurate information, and lack of encouragement to make contact have been implicated as access barriers (Graziani *et al.*, 1999; Jordan *et al.*, 2008; Mahomed *et al.*, 2008). Recommendation or endorsement by a doctor influences whether people use services (Graziani *et al.*, 1999; Jordan *et al.*, 2008; Mahomed *et al.*, 2008; Beesley *et al.*, 2009; Boyle *et al.*, 2009; Sav *et al.*, 2014). Few studies of access to CHOs are available but one Australian qualitative study of 97 people with chronic disease (Sav *et al.*, 2014) identified lack of referral pathways from general practice as a prominent barrier.

Greater understanding of users and non-users of CHOs is needed to identify the nature of barriers that exist and whether these might be addressed to improve the reach of organisations. Data collected by telephone survey in the baseline phase of a randomised controlled trial of an intervention to

improve CHO access (Boyle *et al.*, 2011) provided a unique opportunity to investigate this issue in a community-based sample of general practice patients with diagnosed chronic disease. This study reports on (i) What differentiates those who contact CHOs from those who do not? and (ii) What stops people from making contact?

Methods

Study design and setting

The source of data was the baseline phase of a randomised controlled trial designed to evaluate whether a print-based information package increased CHO use among general practice patients with diagnosed chronic disease. The consecutive sample of 276 trial participants was recruited by 18 GPs from 11 different practices in Brisbane, Australia. Participation involved completion of a telephone survey, random allocation to receive the information package or standard care, and completion of a follow-up telephone survey approximately four months after the first. Full details of the trial are provided elsewhere (Boyle *et al.*, 2011). The data presented in this study were collected in the first telephone survey, which used a questionnaire containing quantitative measures to assess views and characteristics associated with CHO contact and a single open-ended question to explore barriers to CHO contact. Participants completed a computer-assisted telephone interview (CATI) within two weeks of recruitment and before being randomised to an intervention or usual care group. The CATI method is a well-established data collection technique enabling trained interviewers to administer a pre-programmed questionnaire by telephone. Responses are automatically entered and coded during the interview enhancing the timeliness and quality of data (De Vaus, 2002). Up to 10 call-backs were made to maximise response rates. Interviews took 10–20 min. The study was approved by The University of Queensland's Behavioural and Social Sciences Ethical Review Committee.

Participants

Participant recruitment involved a two-stage process: the recruitment of GPs, followed by the

recruitment of patients with diagnosed chronic disease. A random sample of 200 GPs was invited by mail to participate in the study but only eight GPs were recruited in this way. Chain referral, or snowball sampling, where respondents are asked to refer the researcher to one or more members of the target group was used to enlist further GPs. During a specified recruitment period of up to three weeks, participating GPs asked consecutive eligible patients if they would agree to join the study. Eligibility criteria were age 18 years and over; sufficient English language skills to complete a telephone interview; and a diagnosis of diabetes, arthritis, osteoporosis, ankylosing spondylitis, asthma, chronic hepatitis, haemochromatosis or renal disease based on standard diagnostic criteria. These conditions were selected because they are prevalent and contribute to a large proportion of the burden of morbidity in Australia (Australian Institute of Health and Welfare (AIHW), 2014) and had active CHOs in the study catchment area.

Measures

CHO contact was the primary outcome variable. All participants were asked: 'Have you ever contacted a community health organisation?' and 'Have you ever contacted [a CHO relevant to their main diagnosed chronic condition]?'. The following short definition of CHOs was read to all respondents: 'By consumer health organisations, we mean organisations, associations or support groups that provide information or other forms of support to people with particular health conditions'. The names of several local CHOs were read out and respondents were asked to indicate if they had ever contacted any of these or any other similar organisations. Those who had were asked to name the organisation(s). Two members of the research team subsequently checked the responses and any that did not meet the definition (eg, hospital clinic) were removed. All participants were asked whether their GP had ever told them about any such organisations.

To explore *perceptions of CHOs and barriers to contact*, participants were read a list of reasons why people might not choose to contact a CHO (the question was worded to be suitable for all participants regardless of whether they had

made contact) and asked to respond using a five-point scale ('strongly agree' to 'strongly disagree'). The items were devised specifically for the study with reference to relevant literature. Participants who had never contacted a CHO were also asked a single open-ended question: 'Overall, what would you say is the main reason you have not contacted a consumer health organisation?'. Responses were entered as close to verbatim as possible.

Sociodemographic information including age, sex, ethnicity, marital status, education and work-force participation was collected.

Health service utilisation was assessed by summing the number of self-reported GP and specialist consultations, hospital, and accident and emergency attendances in the last three months.

Physical and mental health were assessed using the SF-12 Version 2 (Ware *et al.*, 2005), a widely used measure with well-established psychometric properties across a range of conditions (Busija *et al.*, 2011). A physical and mental component summary score is generated for each respondent. Scores >50 indicate above average health.

Data analysis

Quantitative data were analysed using SPSS 15.0 (SPSS, 2006). The statistical significance of associations between a range of variables and whether or not participants had ever contacted a CHO was assessed using χ^2 tests (for categorical variables) and *t*-tests (for continuous variables). The 0.05 level of probability was applied and all variables that were significantly associated with CHO contact were included in a multiple logistic regression analysis to assess the independent contribution of each of those variables.

Thematic analysis was used to identify relevant and important themes based on responses to the open-ended question asking participants to nominate the main reason for not contacting a CHO. Following guidelines proposed by Braun and Clarke (2006), responses were read multiple times by a member of the research team who generated initial codes to identify ideas contained in the data and subsequently grouped these into categories and themes. Independent coding of a subset of responses was undertaken by a second research team member, with any differences

resolved through discussion among all research team members.

Results

Sample characteristics

In total, 374 eligible patients were invited by 18 GPs to join the study, and 276 (73.8%) completed the interview (Figure 1). Completers did not differ significantly from eligible non-completers in terms of sex, age or main chronic condition (nominated and recorded by the recruiting GP). The majority of study participants were women (66%), married or living with a partner (57%), with an average age of 63.9 years (SD = 14.70, median = 65.0) and at least some secondary-level education (83%). Most were Australian-born (78%) and a small minority (10%) spoke a language other than English at home. Four participants (1.4%) identified as Aboriginal or Torres Strait Islander. Slightly more than half the participants (54%) had some form of private health insurance. The majority were retired (59%), with only 24% in the paid workforce. Musculoskeletal conditions (arthritis, osteoporosis and ankylosing spondylitis) were the main diagnosed chronic conditions for 52% of the 276 participants, followed by diabetes (23%) and asthma (15%) and smaller numbers with kidney disease (6%), chronic hepatitis (2%) and haemochromatosis (2%).

What differentiates those who have contacted a CHO from those who have not?

Just over one-third of participants (38.8%; 107 of 276) reported ever having contacted a CHO for their health and 27.5% (76 of 276) had contacted a CHO specifically focussed on their main diagnosed chronic condition. Those who had ever contacted a CHO differed significantly from those who had not (Table 1).

Patients who had been told about the organisation by a GP were significantly more likely to make contact than those who had not (52 versus 35%), whereas those with a main diagnosis of diabetes were far more likely to have contacted a CHO than those with other conditions (84 versus 25%). Participants who reported six or more GP, specialist or hospital visits in the preceding three months were more likely to have made contact (50 compared with 31–37% of those who had

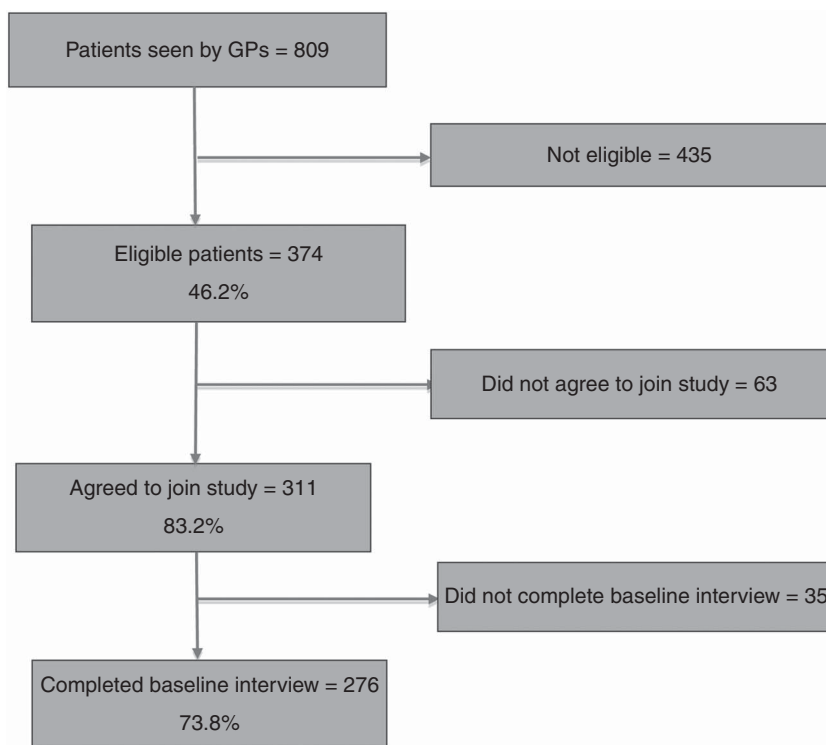


Figure 1 Participant flow and response rate. GP = general practitioner.

less health service use). Participant with poorer self-reported physical health scores more likely to have made CHO contact: 43 compared with 26% of those who reported better health.

Multivariate analysis showed high levels of health service use, poorer self-reported health and a main diagnosis of diabetes remained statistically significant and made independent contributions to CHO contact after adjusting for other variables in the model (Table 2). Greater health service use and poorer health status were each associated with an almost three-fold higher likelihood of having ever contacted a CHO [adjusted odds ratio (AOR) 2.9, 95% confidence interval (CI) 1.3–6.1, $P = 0.01$ and AOR 2.8, 95% CI 1.2–6.4, $P = 0.01$, respectively]. Those with diabetes were a striking 27 times more likely (AOR 26.9, 95% CI 10.9–66.6, $P < 0.001$) irrespective of the other variables in the model. Classification tables were used to assess goodness of fit. Overall, the logistic regression model correctly classified 77% of cases.

Participants' views on barriers to CHO contact

Participants were presented with a series of statements to elicit their views on barriers to CHO contact (Table 3). By far the most commonly endorsed reason (agreed or strongly agreed) for not contacting a CHO was that the doctor gave all the care and information needed. Those who had never contacted a CHO were significantly more likely to hold this view (90 versus 82%, $P < 0.04$) and were also significantly more likely to indicate their health problems were not serious enough (63 versus 44%, $P < 0.002$). Lack of knowledge about what CHOs offered (66%) or the organisations that existed (53%) were relatively common barriers for all participants, whereas slightly fewer cited lack of time (44%), cost (43%), difficulty getting to CHO activities (43%) and not feeling well enough (33%) as barriers. Group processes were also identified as barriers, including concern regarding pressure to get involved (45%), feeling burdened by others' problems (33%), not

Table 1 Characteristics of the 276 study participants and bivariate associations with CHO contact

Variables	<i>n</i>	Ever contacted CHO (<i>n</i> = 107) [<i>n</i> (%)]	Never contacted CHO (<i>n</i> = 169) [<i>n</i> (%)]	<i>P</i> -value ^a
Age (mean years)	276	63.93	63.86	0.97
Sex				0.63
Male	95	35 (36.8)	60 (63.2)	
Female	181	72 (39.8)	109 (60.2)	
Education ^b				0.64
No qualification	48	18 (37.5)	30 (62.5)	
Secondary	116	45 (38.8)	71 (61.2)	
Certificate	71	25 (35.2)	46 (64.8)	
Degree/diploma or higher	40	19 (47.5)	21 (52.5)	
Marital status				0.24
Married or living with partner	158	66 (41.8)	92 (58.2)	
Other	118	41 (34.7)	77 (65.3)	
Private health insurance				0.30
Yes	150	54 (36.0)	96 (64.0)	
No	126	53 (42.1)	73 (57.9)	
Employed in paid workforce				0.86
Yes	66	25 (37.9)	41 (62.1)	
No	210	82 (39.0)	128 (61.0)	
GP told about CHO ^c				0.02
Yes	64	33 (51.6)	31 (48.4)	
No	210	73 (34.8)	137 (65.2)	
Main condition				< 0.001
Diabetes	64	54 (84.4)	10 (15.6)	
Other	212	53 (25.0)	159 (75.0)	
Health service usage (last 3 months)				0.03
1–2 visits	99	31 (31.3)	68 (68.7)	
3–5 visits	95	35 (36.8)	60 (63.2)	
6 or more visits	82	41 (50.0)	41 (50.0)	
SF-12 – physical health				0.02
Average or below (score <50)	211	90 (42.7)	121 (57.3)	
Above average (score 50+)	65	17 (26.2)	48 (73.8)	
SF-12 – mental health				0.99
Average or below (score <50)	103	40 (38.8)	63 (61.2)	
Above average (score 50+)	173	67 (38.7)	106 (61.3)	

CHO = consumer health organisation; GP = general practitioner. Bold values are statistically significant.

^a χ^2 test for all variables except for age, where a *t*-test was used.

^bMissing data for one participant.

^cMissing data for two participants.

wanting to be part of a group (36%) and being put-off by what others had said (15%).

What stopped participants from contacting a CHO?

The purpose of the single open-ended item was to expand and contextualise the quantitative results concerning barriers to CHO use. The 169 participants who had never contacted a CHO provided a total of 234 responses (some responses contained more than one distinct reason for non-contact). Analysis of responses identified three main themes that represented the vast majority of comments

made. These were reliance on the doctor; not sick enough or no need; and difficulties reaching the organisation. Following review of all responses, illustrative quotes were selected to capture the breadth of each theme across different chronic conditions (Table 4).

Reliance on the doctor

Approximately 20% of comments from those who had never contacted a CHO reinforced the view strongly expressed in the quantitative results that the doctor provided all needed care and information. Participants were generally satisfied

Table 2 Multiple logistic model for CHO contact

Variables	<i>n</i>	Crude OR (95% CI)	Adjusted OR (95% CI)	Adjusted <i>P</i> -value
Health service usage (last 3 months)				
1–2 visits	99	1.0	1.0	
3–5 visits	95	1.3 (0.7–2.3)	1.2 (0.6–2.5)	
6 or more visits	82	2.2 (1.2–4.0)	2.9 (1.3–6.1)	0.01
SF-12 – physical health				
Above average (score 50 +)	65	1.0	1.0	
Average or below (score <50)	211	2.1 (1.1–3.9)	2.8 (1.2–6.4)	0.01
Main condition				
Other	212	1.0	1.0	
Diabetes	64	16.2 (7.7–34.1)	26.9 (10.9–66.6)	<0.001
Told by GP about CHO ^a				
No	210	1.0	1.0	
Yes	64	2.0 (1.1–3.5)	1.6 (0.7–3.4)	0.28

CHO = consumer health organisation; OR = odds ratio; CI = confidence interval; GP = general practitioner.

^a Missing data for two participants.

Table 3 Reasons for not contacting a CHO, showing percentage of study participants who agreed/strongly agreed or disagreed/strongly disagreed with each statement

Reason for not contacting CHO	Ever contacted (<i>n</i> = 107) (%)	Never contacted (<i>n</i> = 169) (%)	All (<i>n</i> = 276) (%)	<i>P</i> -value ^a
Doctor gives all needed care and information	82.1	90.5	87.2	0.04
Don't know enough about what CHOs offer	62.3	68.3	65.9	0.31
Health problems are not serious enough	43.9	63.3	55.8	0.002
Don't know what organisations exist	49.5	55.6	53.3	0.32
Could feel pressure to get involved	46.7	44.0	45.1	0.65
Not enough time	46.7	42.6	44.2	0.50
It would cost too much money	36.4	47.0	42.9	0.09
Too hard to get to CHO activities	44.9	41.1	42.5	0.54
Don't like being part of an organisation/group	34.9	36.1	35.7	0.83
Could feel burdened with others problems	32.7	33.3	33.1	0.91
Not enough energy/not well enough	31.8	33.3	32.7	0.79
What others have said has put you off	19.8	11.3	14.6	0.05

CHO = consumer health organisation.

^a χ^2 analysis.

to rely exclusively on their doctor for the management of their condition and so did not need to contact a CHO. Some commented they would seek additional services if their doctor no longer provided them with the information they required, but, more often, participants underlined the pivotal role of the doctor in facilitating CHO access. The strong suggestion was that initiating contact with a CHO would be highly unlikely without direction from the doctor.

Not sick enough

Many participants believed their health problems were 'not serious enough' to justify contacting a

CHO or that they had 'no need at this stage'. This emerged as the major theme with almost half of the comments reflecting this view. CHOs seemed to be viewed as something of a 'last resort' with participants stating they would consider making contact should their health decline in the future.

Difficulties reaching the organisation

A relatively small number of participants highlighted difficulties in reaching or engaging with an organisation for their health needs. Consistent with the quantitative data, access issues featured less prominently than the attitudinal factors just described, and were mentioned by <10% of

Primary Health Care Research & Development 2016; **17**: 393–404

Table 4 Barriers to contacting CHOs and illustrative quotes

Barriers	Illustrative quotes
Reliance on the doctor	<p>'I don't need to, my doctor provides it all' (0660, female with asthma aged 42)</p> <p>'I leave it to my doctor, I get all my care and information from her' (0188, male with arthritis aged 49)</p> <p>'I have not been recommended by my doctor to call them. I'm still waiting' (0475, female with osteoporosis aged 54)</p> <p>'Doctor will tell me if I need to contact an organisation I will contact them if I need it ... the doctor hasn't mentioned about them at this point' (0184, male with asthma aged 82)</p>
Not being sick enough	<p>'I never thought of it ... I suppose I don't think of myself as very sick' (0185, female with diabetes aged 78)</p> <p>'At this stage I don't need it, I can manage myself, but if somewhere down the track I need it, then I will definitely contact them' (0496, female with asthma aged 58)</p> <p>'Unless there's something seriously wrong with me, I won't go' (0564, female with osteoporosis aged 73)</p> <p>'I'm not bad enough at this point' (0212, female with arthritis aged 62)</p>
Reaching the organisation	<p>'Worries about how much it costs and how far to travel' (0798, male with arthritis aged 55)</p> <p>'I don't have a car, I rely on public transport, it's expensive to get around by taxi' (0179, female with osteoporosis aged 82)</p> <p>'I don't really know about the organisations and no one has recommended me to one' (0464, female with chronic kidney disease aged 52)</p> <p>'I don't think there would be a health organisation that could help me with my health condition' (0042, female with asthma aged 56)</p>

CHO = consumer health organisation.

participants. Time, cost and transport were explicitly mentioned. Other responses conveyed limited awareness of the existence of CHOs and what they might offer. In direct contrast to the major theme above, three respondents stated they were too unwell to contact a CHO.

Discussion

Our findings confirm that a minority of general practice patients with diagnosed chronic disease are likely to make contact with a CHO and they are likely to differ from those who do not make contact in a number of ways. People with diabetes were a striking 27 times more likely to have contacted a CHO than those with other conditions, whereas patients with higher levels of health care use or poorer self-reported health were three times more likely to have had contact.

The view that 'my doctor does it all' was strongly held among study participants. Being advised to contact a CHO by their doctor did not retain significance in its own right, suggesting patients with diabetes, more health service contacts and poorer health are more likely to be referred. Our findings underline the vital role of the doctor in

facilitating contact. Highly consistent across the quantitative and qualitative responses was the view among participants that their health problems were not serious enough to warrant CHO contact. Difficulties reaching an organisation were raised as secondary barriers and generally reflected a limited awareness of CHOs and their role.

CHOs are a long-standing tradition in the health care landscape and, while many CHOs exist (Baggott and Jones, 2014), our findings concur with studies that suggest their ability to reach patients with chronic disease is limited (Ellins and Coulter, 2005; Gucciardi *et al.*, 2006). Levesque *et al.* (2013) conceptualise access on a broad continuum from the perception of needing care through to the benefits of receiving care. In our study, the primary barriers to CHO contact reflected attitudinal and system-level factors corresponding to earlier points on that access continuum, specifically: approachability (information provision about the service, and the availability of the service beyond face-to-face contact) and acceptability ('suitability for my stage of the condition'). It may be that other dimensions of access could become more important, if patients had increased access to CHOs earlier in the continuum.

Primary Health Care Research & Development 2016; **17**: 393–404

Other studies have shown a doctor's recommendation to be an important determinant of whether patients act on health information including the use of community-based services (Graziani *et al.*, 1999; Jordan *et al.*, 2008; Mahomed *et al.*, 2008; Beesley *et al.*, 2009; Boyle *et al.*, 2009; Sav *et al.*, 2014). Our study contextualises this finding in relation to CHOs by showing the extent to which patients rely on the doctor both to recommend and legitimise CHO contact. The prevailing view that 'the doctor does it all' suggests many patients are unlikely to seek support beyond the confines of the clinic without confirmation from the doctor that further support was warranted and would be of benefit. This strong reliance on the doctor is at odds with the emphasis on patient empowerment, shared decision-making and development of self-management skills that feature heavily in new approaches to chronic illness care and with the realities of the clinical environment where time and other pressures limit opportunities for the delivery of patient education and psychosocial support (Bodenheimer *et al.*, 2002; Oldroyd *et al.*, 2003; Eaton *et al.*, 2015). Yet, the ways in which patients use health services and relate to health professionals are strongly embedded in patterns developed over extended periods of time with strategies for accessing and using services adapted and established as a routine part of everyday life with a chronic condition (Gately *et al.*, 2007). Much heterogeneity also exists in terms of the extent to which both patients and their clinicians embrace shared decision-making (Hoffmann *et al.*, 2014). The perception of CHOs as 'a last resort' indicates a lack of awareness of their contributions to health promotion and health maintenance. Together with the belief that one must be 'sick enough' to seek additional support services, it also highlights challenges associated with the transition from acute to chronic models of care and a shift in emphasis from reactive to proactive care.

Issues such as cost or transport, while often identified as impediments to access (Graziani *et al.*, 1999; Mahomed *et al.*, 2008; Levesque *et al.*, 2013), did not appear as primary barriers. Although some participants referred to cost and transport in open-ended responses, the view that CHOs equate to attendance in a physical space suggests many may be unaware of the range and flexibility of support options.

Challenges of engagement exist between CHOs and the formal health system (Jordan *et al.*, 2008; Morris *et al.*, 2015; Sav *et al.*, 2014). In our study, the very high CHO contact among those with diabetes shows the critical value of formal linkages between the two sectors. Referral to the peak diabetes CHO (Diabetes Australia) is an accepted part of standard diabetes care (Young *et al.*, 2010) as the CHO is responsible for the administration of the National Diabetes Services Scheme established by the Australian Government to provide subsidised services and products (such as insulin-injecting devices and glucose monitors) (AIHW, 2006). Accordingly, Diabetes Australia is a CHO that has become highly visible and integrated with the health system leading many GPs to see 'definite advantages' of referral (Young *et al.*, 2010). For patients there is a financial driver in the form of subsidised products as well as other potential benefits of contact.

Improving access to CHOs calls for action at patient, health care provider, CHO and system levels. Developing referral pathways from primary care to CHOs would help promote access by building awareness and legitimising contact for patients rather than relying on *ad hoc* self-referral. Structured practice-based approaches to direct patients to CHOs include social prescribing, patient navigator or linking schemes (Mossabir *et al.*, 2015) and lower-intensity interventions, such as printed referral materials (Boyle *et al.*, 2011). Health system-driven approaches that facilitate the development of formal linkages between CHOs and GPs, as in the case of Diabetes Australia, are clearly beneficial for improving referral pathways. Critical to successful linkages are demonstrable benefits for patients, GP confidence in the organisation and its reputation (Young *et al.*, 2010). Promoting greater understanding of the role and contributions of CHOs could be achieved through greater prominence in clinical practice guidelines and professional training. CHOs also need to ensure their messages are conveyed clearly to health professionals and the public to avoid misperceptions.

A strength of our study is the inclusion of a relatively large consecutive sample of general practice patients. However, caution needs to be exercised in generalising the findings. Our sample is restricted to patients recruited from 18 GPs over a short period of time and includes only participants

who could speak English well enough to complete a telephone interview. Other minority groups, including Indigenous Australians, are under-represented. Response rates also need to be considered. Although respondents and non-respondents did not differ on key sociodemographic variables, it is not possible to know whether they differed in other ways. Although the research team worked closely with the GPs throughout the recruitment period, responsibility for recruitment was relinquished to the GPs and it is possible that some eligible patients with unknown characteristics were missed for unknown reasons. It is also important to note that this study draws on the baseline phase of a randomised controlled trial designed to evaluate whether an information package would increase CHO use. Sample bias may have been introduced if participants who were willing to commit to a trial and the two scheduled follow-ups it entailed shared particular characteristics that distinguished them from non-participants, such as a higher level of motivation to seek community support. Whether a one-off survey may have produced different results is uncertain.

Our measure of CHO contact is a blunt single-item question with unconfirmed reliability. Further information is not available on the outcomes, nature or patterns of that contact (eg, frequency, timing, recency of contact). All data collected was by self-report and therefore subject to reporting error, including social desirability. The cross-sectional survey design is another limitation of the study and directionality of associations between variables cannot be established. Despite these limitations, the study combines quantitative and qualitative data for a detailed account of patients' views of CHOs and influences on CHO reach. Analysis of free-text responses to a question inviting participants to nominate barriers extends and contextualises our findings. To our knowledge, it is the first study to systematically investigate barriers to CHO contact in a large and broadly representative group of general practice patients.

Further research to refine and evaluate the outcomes of efforts to improve CHO access is warranted. More needs to be discovered about the most effective and appropriate ways to improve integration of CHOs with the formal health system, acknowledging that these may vary greatly given the wide diversity of organisations that exist. Case studies of effective models of

integration would enhance understanding of features of success. Longitudinal data on patterns of CHO participation and their outcomes are needed. Little is known about what happens after initial CHO contact and who benefits from what type of contact. Incorporating outcomes from GP, CHO and patient perspectives would help guide a comprehensive research and policy agenda. While our study is focussed on the Australian setting, rapidly increasing rates of chronic conditions globally call for collaboration across health professionals and the community. The international literature highlights growing recognition of the potential role for CHOs (Baggott and Jones, 2014) and peer support initiatives (Fisher *et al.*, 2014) alongside limited connections between formal professional care and CHOs (Mossabir *et al.*, 2015).

Conclusion

CHOs are recognised as part of a comprehensive multi-strategy approach to chronic disease self-management, but a disconnect exists between patients and available support services. Our findings indicate there are missed opportunities for CHOs to support health promotion and maintenance for people earlier in the trajectory of chronic illness. A key challenge is better engagement between CHOs and the formal health system that is underpinned by accurate information about how CHOs can contribute.

Acknowledgements

The authors thank all survey participants and the GPs who assisted with their recruitment for their time and willingness to be part of the study.

Financial Support

The research reported in this paper is a project of the Australian Primary Health Care Research Institute, which was supported by a grant from the Australian Government Department of Health and Ageing. The information and opinions contained in it do not necessarily reflect the views or policy of the Australian Primary Health Care Research Institute or the Australian Government Department of Health and Ageing.

Conflicts of Interest

None.

Ethical Standards

The study was approved by The University of Queensland's Behavioural and Social Sciences Ethical Review Committee. The authors assert that all procedures contributing to this work comply with the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research.

References

- Australian Institute of Health and Welfare (AIHW).** 2006: *Australia's health 2006*. Canberra: AIHW.
- Australian Institute of Health and Welfare (AIHW).** 2014: *Australia's health 2014*. Australia's health series no. 14. Cat. no. AUS 178 Canberra: AIHW.
- Baggott, R. and Jones, K.** 2014: The voluntary sector and health policy: the role of national level health consumer and patients' organisations in the UK. *Social Science & Medicine* 123, 202–9.
- Beesley, V.L., Janda, M., Eakin, E.G., Auster, J.F., Chambers, S.K., Aitken, J.F., Dunn, J. and Battistutta, D.** 2009: Gynecological cancer survivors and community support services: referral, awareness, utilisation and satisfaction. *Psycho-Oncology* 19, 54–61.
- Blakeman, T., Blickem, C., Kennedy, A., Reeves, D., Bower, P., Gaffney, H., Gardner, C., Lee, V., Jariwala, P., Dawon, S., Mossabir, R., Brooks, H., Richardson, G., Spackman, E., Vassilev, I., Chew-Graham, C. and Rogers, A.** 2014: Effect of information and telephone-guided access to community support for people with chronic kidney disease: randomised controlled trial. *PLoS One* 9, e109135.
- Bodenheimer, T., Lorig, K.R., Holman, H. and Grumbach, K.** 2002: Patient self-management of chronic disease in primary care. *The Journal of the American Medical Association* 288, 2469–75.
- Boyle, F., Mutch, A., Dean, J., Dick, M.L. and Del Mar, C.B.** 2009: Consumer health organisations for people with diabetes and arthritis: who contacts them and why? *Health & Social Care in the Community* 17, 628–35.
- Boyle, F., Mutch, A., Dean, J., Dick, M.L. and Del Mar, C.B.** 2011: Increasing access to consumer health organisations among patients with chronic disease: a randomised trial of a print-based intervention. *Primary Health Care Research & Development* 12, 245–54.
- Braun, V. and Clarke, V.** 2006: Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101.
- Busija, L., Pausenberger, E., Haines, T., Haymes, S., Buchbinder, R. and Osborne, R.** 2011: Adult measures of general health and health-related quality of life. *Arthritis Care & Research* 63 (Suppl 11), s383–412.
- Department of Health and Ageing, Commonwealth Government of Australia.** 2013: National primary health care strategic framework. Retrieved 1 May 2015 from www.health.gov.au/internet/publications/publishing.nsf/Content/NPHC-Strategic-Framework
- De Vaus, D.** 2002. *Surveys in social research*. St Leonards, NSW: Allen & Unwin.
- Eaton, S., Roberts, S. and Turner, T.** 2015: Delivering person centred care in long term conditions. *British Medical Journal* 350, h181.
- Ellins, J. and Coulter, A.** 2005. *How engaged are people in their health care? Findings of a national telephone survey*. Oxford: Picker Institute Europe.
- Epping Jordan, J.E., Pruitt, S.D., Bengoa, R. and Wagner, E.H.** 2004: Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care* 13, 299–305.
- Fisher, E.B., Coufal, M.M., Parada, H., Robinette, J.B., Tang, P.Y., Urlaub, D.M., Castillo, C., Guzman-Corrales, L.M., Hino, S., Hunter, J., Katz, A.W., Symes, Y.R., Worley, H.P. and Xu, C.** 2014: Peer support in health care and prevention: cultural, organizational, and dissemination issues. *Annual Review of Public Health* 35, 363–83.
- Gately, C., Rogers, A. and Sanders, C.** 2007: Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science & Medicine* 65, 934–45.
- Grant, C., Goodenough, T., Harvey, I. and Hine, C.** 2000: A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector. *British Medical Journal* 320, 419–23.
- Graziani, C., Rosenthal, M.P. and Diamond, J.J.** 1999: Diabetes education program use and patient-perceived barriers to attendance. *Family Medicine* 31, 358–63.
- Gucciardi, E., Smith, P.L. and Demelo, M.** 2006: Use of diabetes resources in adults attending a self-management education program. *Patient Education and Counseling* 64, 322–30.
- Hoffmann, T.C., Légaré, F., Simmons, M.B., McNamara, K., McCaffery, K., Trevena, L.J., Hudson, B., Glasziou, P. and Del Mar, C.B.** 2014: Shared decision making: what do clinicians need to know and why should they bother? *Medical Journal of Australia* 201, 35–39.
- Jordan, J.E., Briggs, A.M., Brand, C.A. and Osborne, R.H.** 2008: Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *Medical Journal of Australia* 189, S9–13.
- Kurtz, L.F.** 1997. *Self-help and support groups: a handbook for practitioners*. Thousand Oaks, CA: Sage.
- Kyrouz, E., Humphreys, K. and Loomis, C.** 2002: A review of research on the effectiveness of self-help mutual aid groups. In White, B.J. and Madara, E.J., editors *American self-help clearinghouse self-help group sourcebook*, seventh edition. *Primary Health Care Research & Development* 2016; 17: 393–404

- Cedar Knolls, NJ: American Self-Help Group Clearinghouse, 71–85.
- Levesque, J.-F., Harris, M.F. and Russell, G.** 2013: Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal of Equity in Health* 12, 18.
- Mahomed, R., Patterson, E. and St John, W.** 2008: Factors influencing possible participation in chronic disease self-management courses. *Australian Journal of Primary Health* 14, 19–26.
- Morris, R., Kirk, S., Kennedy, A., Vassilev, I., Mathieson, A., Jeffries, M., Blickem, C., Brooks, H., Sanders, C. and Rogers, A.** 2015: Connecting local support: a qualitative study exploring the role of voluntary organisations in long-term condition management. *Chronic Illness* 11, 140–55.
- Mossabir, R., Morris, R., Kennedy, A., Blickem, C. and Rogers, A.** 2015: A scoping review to understand the effectiveness of linking schemes from healthcare providers to community resources to improve the health and well-being of people with long-term conditions. *Health & Social Care in the Community* 23, 467–84.
- Oldroyd, J., Proudfoot, J., Infante, F.A., Powell Davies, G., Harris, M.F., Bubner, T., Holton, C. and Beilby, J.** 2003: Providing healthcare for people with chronic illness: the views of Australian GPs. *Medical Journal of Australia* 179, 30–33.
- Sav, A., McMillan, S.S., Kelly, F., Whitty, J.A., Kendall, E., King, M.A. and Wheeler, A.J.** 2014: Consumer health organisations for chronic conditions: why do some people access them and others don't? *Primary Health Care Research & Development* 15, 418–29.
- SPSS.** 2006: *SPSS for Windows, Rel 15.0.0*. Chicago, IL: SPSS, Inc.
- Ware, J.E., Kosinski, M., Turner-Bowker, D.M. and Gandek, B.** 2005: *How to score Version 2 of the SF-12 health survey*. Lincoln, RI: Quality Metric Incorporated.
- Young, C.E., Mutch, A.J., Boyle, F.M. and Dean, J.H.** 2010: Investigating referral pathways from primary care to consumer health organisations. *Australian Journal of Primary Health* 16, 260–67.