

Appendix 4

Stage 2 Interviews

Appendix 4.1 – Interview Guide for Consumers & Carers

Initial Question	Interview Prompts
Can you tell me about your journey since you were first told about your condition(s)?	<p>What experiences have you had generally? (In relation to condition)</p> <p>Tell me about your experiences with health care providers (e.g. GPs, hospital, specialists, physiotherapists, occupational therapist etc.)</p> <p>Can you tell me about any significant events that have happened throughout your journey?</p> <p>How has your condition(s) changed over time? (e.g. times when it seemed better or worse)</p>
You have told me about some of your experiences with a range of health providers. Can you describe one example of a good experience with health professionals?	What do you think made it a good experience?
Can you describe one example of a bad experience with health professionals?	What do you think made it a bad experience?
There is a term we use in health care of “patient-centred care” (PCC). Hearing that term I would like to know what that means to you.	<p>What do you think it should be?</p> <p>Can you give me an example of when you have experienced PCC?</p> <p>Can you give me an example of when you an opportunity for PCC was missed?</p>
How has/have your condition(s) impacted on your life? (E.g. work, family, friends etc.?)	<p>Physical, psychological, financial impacts etc.? Practical challenges (e.g. child care, days off)</p> <p>What is it like organising to see health professionals? (e.g. getting to the appointments)</p> <p>What about the costs of getting treatment?</p> <p>Are there some costs that affect you more than others? (e.g. cost of medicines, cost of seeing health professionals, private healthcare and cost of taking time off work for surgery etc.)</p> <p>What is the most frustrating thing about your medications (e.g., side effects)?</p> <p>Do you ever change your medication according to how your feeling? (Do you discuss this with your HCP?)</p>
Tell me about some of the things you do to manage your condition(s)?	<p>Contact consumer organisations, self-help/support groups, use the internet etc.?</p> <p>Do you use complementary/alternative treatments (e.g. homeopathy, massage, acupuncture) or herbal</p>

	<p>medicines etc. Please expand on any of these that you use and how they help your day to day management and quality of life</p> <p>Tell me about how you have overcome some of these challenges you have talked about?</p> <p>How do you prioritise managing these challenges?</p>
Thinking about your experiences with health professionals again can you talk to me about your specific experiences at the pharmacy/chemist?	<p>Why do you mainly go into pharmacy for?</p> <p>When you go to a pharmacy/chemist do you feel as though you are going there as a patient to get a health service or as a consumer to purchase a product?</p> <p>Can you describe a good experience (what made it good) and also a bad experience (what made it bad)?</p> <p>Do you have a regular pharmacy?</p> <p>Who have you mainly talked to when visiting a pharmacy?</p> <p>There are a lot of different people that work at the pharmacy, what do you think their responsibilities are?</p> <p>What do you think makes a good pharmacist?</p> <p>What do you expect the pharmacist to know about you?</p>
How else do you think the people at your pharmacy can help you manage your condition(s)?	<p>Have you seen pharmacies offering extra services for people with long-term conditions e.g. blood pressure monitoring?</p> <p>What other services could they provide for you?</p> <p>If the pharmacist could do anything other than dispensing medications, what would you like them to do?</p> <p>Is there one thing that community pharmacy needs to do to help you?</p>
What is your most important goal related to your health / the health of the person you are caring for right now?	What do you need to achieve this goal?
What advice would you give to someone who has just been diagnosed with your condition/s?	What should be their priorities?

Appendix 4.2 – How consumers manage their chronic conditions

This is the pre-print (pre-refereeing) version of the following manuscript:

Sav A, King M.A, Kelly F, Kendall E, McMillan SS, Whitty JA, Wheeler AJ. Self-management of chronic conditions in a rural and remote context. The final, definitive version of this paper has been published in *Australian Journal of Primary Health* DOI: [org/10.1071/PY13084](https://doi.org/10.1071/PY13084) (published online 18.10.13) by CSIRO Publishing. All rights reserved. © [Sav A, et al 2013.]

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Self-management of chronic conditions in a rural and remote context

Abstract

Living in a rural or remote environment presents unique challenges for people with chronic conditions, mainly those created by limited healthcare services and the physical and emotional isolation. Yet, research on how people self-manage their chronic conditions in such locations is limited. This study aims to contribute to research and clinical practice by describing the ways in which a diverse group of rural and remote people with a range of chronic conditions and their unpaid carers self-manage their conditions. Using semi-structured in-depth interviews, data was collected from a sample of 32 participants, residing in one of two regions of Australia: Mount Isa/North West region of Queensland and the Northern Rivers area of New South Wales. Our findings suggest that although self-managing in a rural and remote context requires many of the lifestyle changes necessary in urban areas, the uniqueness of the rural lifestyle and the limited availability of healthcare results in, at times, creative forms of self-management. Healthcare professionals and policy makers need to be cognisant of the ways in which rural and remote residents modify self-management strategies to suit their needs, and help them develop self-management plans tailored to the realities of their rural environment.

Summary statement

What is known about the topic?

- Although it is well known that rural and remote environments present unique challenges in managing chronic conditions, research on how people in such locations actually self-manage is limited.

What does this paper add?

- Important insights into how healthcare professionals and policy makers can support the self-management efforts of people who live with chronic conditions in rural and remote locations.

Introduction

Chronic health conditions are currently the leading causes of death worldwide (World Health Organization 2011). They often result in impairment or disability (Australian Institute of Health and Welfare 2012), placing a significant burden on people and healthcare systems. Governments worldwide consider self-management of chronic conditions to be central to the future maintenance of healthcare systems (Kerr 2005). Self-management is defined as the ‘ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions’ (Richard and Shea 2011, p. 261). Essential aspects of self-management include, but are not limited to, learning about treatment options, adjusting medication dosage, changing dietary and physical activity habits, setting goals and seeking support (Barlow *et al.* 2002; (Gallant 2003; Barlow *et al.* 2002). Although self-management may be challenging (Schulman-Green *et al.* 2012), it can enable people to gain a sense of control over their lives (Lorig and Holman 2003), improve their interactions with healthcare professionals and enjoy a better quality of life (Barlow *et al.* 2002).

Extensive scholarly interest has increased our understanding of how people self-manage their chronic conditions, but the voices of people living in rural and remote communities have been relatively quiet. Much of the available research on self-management within a rural context has focussed on particular chronic conditions, such as cancer and mental illness, (Siegloff and Aroni 2003; Purtzer and Hermansen-Kobulnicky 2013; Gorman *et al.* 2007) or targeted specific populations, such as women (Schlegel *et al.* 2009). Other research has focused on the benefits and challenges of implementing a particular self-management education program (Ah Kit *et al.* 2003; Mobbs *et al.* 2003; Battersby *et al.* 2008). Nevertheless, most studies have suggested that place and context have a profound impact on health and illness (Winters *et al.* 2006; Cudney *et al.* 2005; Siegloff and Aroni 2003). Geographic isolation presents unique challenges for those with chronic conditions, including limited healthcare services and supportive resources (Tollefson and Usher 2006; Phillips 2009), the need to travel to access health services and its subsequent impact on finances (Zucca *et al.* 2011) and family (Phillips 2009), and also the physical and emotional isolation from others living with chronic conditions (Winters *et al.* 2006). Although several innovative services, such as telehealth and online support groups, have been implemented to

address some of these challenges, self-management for many rural residents is still an important but difficult task because it must be tailored to suit their rural lifestyle and the available resources.

Overall, existing studies do not provide in-depth understanding as to how rural residents self-manage. An in-depth understanding of the lived experience of people in rural locations is necessary to enable healthcare providers and policymakers to learn from them and determine the best ways to support their needs (Morden *et al.* 2011). Our study aims to contribute to research and clinical practice by describing the ways in which a diverse group of people with a range of chronic conditions and their carers self-manage in a rural context, thereby providing a framework for healthcare professionals to discuss self-management needs and treatment options with these clients.

Methods

Participants resided in one of two regions of Australia: Mount Isa/North West region of Queensland (including Boulia, Longreach, Camooweal, Doomadgee), and the Northern Rivers area of New South Wales (NSW) (e.g. Lismore, Ballina, Newrybar, Goonellabah etc.). According to the Australian Standard Geographical Classification Remoteness Area (ASGC-RA) (Australian Bureau of Statistics 2013) some of these locations were categorised as very remote (e.g. Doomadgee, QLD), whereas others were categorised as inner regional (e.g. Lismore, NSW). Participants were recruited through local primary health care agencies, direct referral from participants, and other organisations within the local health network. All participants had a chronic condition(s), were an unpaid carer for a person with a chronic condition, or both.

Qualitative research methods were used to elicit the participant's voices. Interview time, location and mode of conversation, e.g. face-to-face or telephone, were determined by each participant based on their living circumstances. The in-depth interviews were narrative and focused on the participant's experience of living with a chronic condition(s). Probe questions included the nature and duration of condition(s), daily practical challenges and self-management strategies. Initially, interviews were conducted by two researchers using an interview guide to facilitate a standardised approach. Interviews were audio-recorded and transcribed verbatim.

Data were transcribed verbatim and thematically analysed using the constant comparison method, a key component of grounded theory analysis (Neuman 2010). Data collection and analysis were conducted in a cyclical, rather than linear, process. Data collection ceased when saturation was reached in that the experiences of participants were consistent with previously collected data (Bowen 2008).

Three researchers independently read the transcripts to familiarise themselves with the data and prepare for thematic analysis. To ensure the study focused on the consumer voice, a consumer researcher, who possessed the necessary life skills and experience, was also involved in data collection and analysis. An additional member of the research team randomly reviewed selected samples of data to ensure the authenticity of coding.

QSR NVIVO 10© was used to assist with coding the data into themes and sub-themes. Quotes were coded to ensure the auditability of the analysis: C represented consumer only, CA carer only, CC consumer and carer, IND Aboriginal and Torres Strait Islander (indigenous Australians), CALD culturally and linguistically diverse background person, and CH both a consumer and a healthcare professional. Ethical approval was obtained from Griffith University Human Research Ethics Committee (PHM/12/11/HREC) prior to data collection.

Results

Thirty two semi-structured in-depth interviews, lasting an average of 50 minutes, were completed in May-October 2012. The majority ($n = 21$) were conducted via telephone. The mean age of participants was 61.2 years ($SD=12.03$), and their self-reported chronic health conditions included diabetes, asthma, mental illness, cancer, cardiovascular, respiratory and musculoskeletal conditions (Table 1).

Although many participants did not directly use the term self-management, they were able to articulate personal strategies they applied to deal with their condition(s). The thematic analysis revealed two inter-related core themes that best explained how participants self-

Table 1: Characteristics of the study sample

Participant characteristics		(n = 36)	(%)
Gender	Male	9	28.1
	Female	23	71.9
Location	North West Region Queensland	15	46.9
	Northern Rivers NSW	17	53.1
Carer or consumer	Carer only (CA)	4	12.5
	Carer/consumer (CC)	7	21.9
	Consumer only (C)	21	65.6
Ethnicity	Aboriginal and Torres Strait Islander (IND)	10	31.3
	CALD (e.g. South African, German)	4	12.5
	Caucasian	18	56.5
Chronic illness(s)	One chronic illness only	3	10.7
	Two illnesses only	8	28.6
	Three or more illnesses	17	60.7

managed their conditions in a rural and remote context: managing geographical and social isolation, and dealing with limited healthcare.

Managing geographical and social isolation

As expected in a rural setting, accessing treatment often required large amounts of time and travel (e.g. 905 kilometres from Mt Isa to Townsville, QLD). Participants journeyed to metropolitan areas for treatment and hence, there was a need for extensive preparation, planning and organisation, to arrange transport and accommodation, and ensure uninterrupted treatment.. Carers were often involved in this:

... we've had to gear up all the tablets and I've gone through and I've had to make sure I've got enough to get her through. [CA_1018]

Planning for travel was not confined to medication but also involved monitoring symptoms:

When you're travelling, ... you've still got to monitor. [C(IND)_1081]

One participant recalled how she relied on her partner for transport, which disrupted work commitments, and potentially, finances:

...actually [husband's name] has to drive me... So that means getting... [husband's name] off work and up to the [urban location], you can pretty much count on it being the whole day off work. [C_1062]

Many rural residents were required to pay for travel and accommodation in addition to their healthcare costs, with some relying on the Australian Red Cross to manage the financial burden.

Ironically, isolation could result in self-reliance while simultaneously creating a sense of community due to the shared difficulties associated with being isolated. One participant noted additional sources of help may not be forthcoming, generating creative and collective ways of managing:

self-help you know you've got to help yourself because there is no point expecting other people to do everything for you [C_1008]

The interaction between self-help and a sense of community was common among Aboriginal and Torres Strait Islander participants. They 'helped themselves by helping others' in their close knit rural communities. One participant discussed how he became more proactive in the community upon retirement, which meant he needed to self-manage his own health condition in order to help his community:

...I just go and get what I have to get done so that I can be able to get out there and help my people so if I don't keep myself ...how am I gonna [going to] go out there and talk to those people? [CH(IND)_1010]

Distance emerged as a significant barrier in relation to mobilising support as family members often resided a long distance away. Consequently, more efforts were made to mobilise the limited support networks that were readily available in the local environment. In most instances, partners (or other familial carers) continued to be the first source of support:

...my husband...he massages me for half an hour before I get up....Yeah, he's just constantly doing things to try and alleviate it. [C_1062]

However, social events in the community played a significant role in people's self-management practices. For instance, faith and church membership played a critical role. Attending religious activities not only provided them with a sense of purpose and resiliency, but also enabled a connection with close friends, thereby lessening their sense of social isolation.

Like any people with chronic conditions, participants sought normality in their lives and focused on finding alternative meaningful activities that were achievable despite their condition. This diversion of attention was a fundamental strategy in managing the negative emotions that could accompany chronic conditions. However, in the rural context, alternative activities needed to be selected within the confines of the environment. 'Getting out' had a different connotation for those in rural areas, and was not always possible given the distances and sometimes rugged outdoor environments. The use of indoor hobbies was common, such as meditation, but for those who had mastered the outdoors, it was a particularly soothing strategy.

I've finally figured out how to get out now and I love being outside with the plants. And I've got butterflies that visit me and I've got a family of little green frogs. [C_1157]

Although many of the strategies identified by our participants would also be used by people from urban areas, rural respondents had their own particular way of managing their conditions that fitted with their geographical location and their rural lifestyle. These qualities often gave them the motivation to self-manage as well as the strategies to apply.

My husband we walk together that's one thing because most of my life like when we were children we just walked everywhere in the bush because we lived on bush.
[CH(IND)_1010]

Dealing with limited healthcare

Demand for available healthcare resources is worldwide; however, the increased scarcity of these resources in rural areas resulted in modified approaches to accessing care. Although many participants travelled to metropolitan areas for certain treatments or care, such as seeing a specialist, the majority relied on local healthcare services. With time, many participants became 'experts' of the healthcare system and used the limited resource to the best of their abilities. One of the most basic strategies was to obtain a medical appointment reasonably early in the morning. This was either to reduce the waiting time, or to have more time with the treating practitioner and not feel rushed:

...first up in the mornings he's [general practitioner] pretty fresh, you know. And if he hasn't got a really full agenda then you might get a bit more time. [C_002]

One participant discussed how she had asked the medical receptionist to email her so she could be reminded of the consultation and did not miss her doctor's appointment. This was a strategy made possible by the highly personal relationships that could be developed in a small town:

... you've got to do that with me, you've got to give me memory prompts. [C_1062]

Shortages of General Practitioners in rural areas meant that when appointments were unavailable or needs were not being met; changing to another provider was a difficult, if not impossible, option. Some participants accessed alternative health providers if available (e.g. naturopath) or travelled to other medical clinics to treat their symptoms. This problem was particularly meaningful among Aboriginal and Torres-Strait Islander participants, who found

that only particular medical health services, often the Aboriginal health clinic, was more congruent with their own values and living conditions:

I've been here nearly 2 years [in a remote town] and I've gone to several doctors and I haven't been satisfied I'm actually now going to the Aboriginal medical service.
[C(IND)_1011]

However, the limited availability of some healthcare professionals also fostered creative and original solutions. One participant, who was both a consumer and a healthcare professional, discussed her volunteer work with a remote community and how creative and adaptive solutions were essential:

....we go out and I introduce them [student doctors] to the whole aboriginal community.... and they gotta [got to] leave a PowerPoint with me and they also have to leave a flip chart. So a flip chart if I'm on down the river somewhere doing something, I can get out and do an education under the tree or down the river.
[CH(IND)_1010]

Finally, some participants felt that self-management was the only option when faced with limited healthcare resources, but that this could result in important aspects of care being overlooked. This was articulated by one carer:

That's the biggest problem..., you basically take charge of your own case, there's nobody that sort of holistically looks at the whole thing. [CA_1018]

Discussion

Our findings have confirmed that the process of self-managing in a rural and remote context requires many of the same lifestyle changes required in urban areas. However, the uniqueness of the rural lifestyle and the connection most participants felt with the rural environment was associated with some important nuances that influenced the way in which self-management was expressed. Specifically, the geographic isolation and limited healthcare associated with

rural living generated the need for higher levels of organisation and planning, but also more creative approaches to meeting one's needs and make the most of available resources. These features also resulted in a high level of self-reliance at the same time as increasing reliance on one's immediate family and prompting greater use of the collective strategies. Geographical and social isolation added to the burden of managing a chronic condition, but also provided important motivation for people to continue self-managing. Rural participants had to work with their environments and within the constraints of what was available to them. However, rural activities were used to replace those that were not available, e.g. bushwalking if they had no direct access to a fitness or health care facility.

Our findings are consistent with existing research, which suggests that people in rural and remote locations tailor self-management practices to suit their rural lifestyle (Siegloff and Aroni 2003; Winters *et al.* 2006; Gorman *et al.* 2007). This suggests that although some self-management strategies that are tailored for people in urban areas may also be successfully applied to those in rural areas, additional strategies are likely to be necessary. Further, these strategies will be creative or unpredictable and designed by those in the person's immediate context to suit the relevant community in which they live. At the most basic level, healthcare services and professionals, particularly those situated in urban areas, need to recognise and acknowledge the unique self-management methods used by people from rural areas. This finding also underscores the importance of patient-centred care that is responsive to each individual's unique circumstances and preferences (Sav *et al.* 2013).

Although some participants spoke positively about the support they received from their healthcare professionals to manage their conditions, very few participants had attended one of the structured chronic disease self-management programs that are now often implemented in a rural context (e.g. Stanford Chronic Disease Self-Management Program). Given that strategies need to be tailored to fit the different environment and lifestyle, the value of the "one-size-fits-all" approach to self-management programs (Morden *et al.* 2011; Phillips *et al.* 2013) is questionable in the rural context. In line with other findings (Fry and Bates 2011; Paterson *et al.* 2010), self-management interventions may be more effective in rural areas if they move away from an educational focus to a more collaborative and developmental approach. This model would involve healthcare professionals, sometimes working from a distance, collaborating with rural people to develop locally directed and

innovative forms of self-management that can be incorporated into, and are suited to, everyday rural living (Furler *et al.* 2008). Hence, while healthcare professionals may focus on different self-management practices according to their area of speciality and expertise, they need to recognise the ways in which rural people modify strategies to suit their needs in a rural context.

Limitations and future directions

Our focus on a range of chronic conditions rather than just one, e.g. diabetes, is both a strength and limitation of this research. We were able to articulate the self-management practices that can be common across the majority of chronic conditions, within a rural context, providing healthcare professionals and policy makers with much needed knowledge. However, we did not explore the unique self-management tasks that might be associated with different chronic conditions. Other limitations include a bias towards females in our sample and the use of only qualitative cross-sectional data that gives no sense of change over time. Our non-random purposive sampling process may have excluded some sectors of the population (e.g. those who were not self-managing their condition, those who were most isolated from the community). Although our methodological approach was warranted given the relative paucity of knowledge in this area, it reduces the generalizability of our findings. As self-management is a dynamic process that changes over time as a result of fluctuations in disease states; longitudinal research is needed to understand how and why such change occurs and how self-management evolves in rural areas.

Conclusion

Self-management is currently being hailed as a valuable solution to address health problems of people with chronic health conditions worldwide. However, the voices of those living with chronic conditions in rural and remote communities have not been well articulated. The limited healthcare resources and social and geographical isolation were significant issues related to the self-management of chronic condition(s) in this population. Healthcare professionals and policy makers need to be cognisant of the challenges experienced by people in these areas and help them to develop self-management plans tailored to their environment.

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Conflicts of interest

None exist.

Appendix 4.3 – How pharmacists or pharmacy staff currently assist consumers and carers and what they could do to further support them

This is the pre-print (pre-refereeing) version of the following manuscript:

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**Quality vs. price and convenience: the influence of patient centred care on pharmacy
choice for Australian residents with chronic conditions**

ABSTRACT

Objective

To explore the determinants of pharmacy choice for people with chronic health conditions.

Methods

Semi-structured qualitative interviews were conducted between May-October 2012, across four regions in three Australian states. Purposive sampling was used to recruit participants ($n=97$) with chronic health conditions and unpaid carers. Interviews were analysed via the constant comparison method.

Key Findings

The majority of participants were regular patrons of one pharmacy and five inter-related factors influenced this choice: patient centred care, convenience, price, personal traits and service/medication need. Patient centred care such as providing individualised medication counselling, continuity of care, development of relationships and respectful advice, emerged as an important determinant. There was minimal discussion as to choosing a pharmacy based on the provision of professional services, underscoring the limited consumer knowledge of the standards of care and services that pharmacy offers.

Conclusion

Patient centred care is an important attribute of quality care according to people who are regular community pharmacy users. These findings highlight the need for pharmacy staff to

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implement a patient centred approach to care, thus developing high quality health care services for their customers.

Keywords

Patient centred care, Pharmacists, Community pharmacy, Chronic Disease

INTRODUCTION

There is a global focus on implementing and evaluating health care services to better tackle current health problems, such as chronic conditions, whilst meeting people's needs and ensuring a quality health care experience.¹ This is best demonstrated by the increasing emphasis towards delivering a patient centred approach to care, currently perceived as an integral dimension of high quality health care worldwide.²⁻⁴

The pharmacy profession has increased its focus on patient centred services to address health care needs of people with chronic conditions.⁵ This is particularly important given the rise of such health conditions.⁶ Common chronic health conditions such as mental illness, asthma and diabetes,⁷ are often treated or managed with medications,⁸ and therefore, community pharmacy is ideally situated to assist people with managing their medications and conditions. Recently, the Australian government introduced remuneration for community pharmacy to provide a range of pharmacy practice initiatives,⁹ such as disease management services and medication use reviews.¹⁰ These services enable community pharmacy to focus on prevention or management of chronic conditions or both, thus working with people to improve their health.

Despite these recent changes, there is limited research on the quality of Australian pharmacy services¹¹ from a patient centred perspective. Historically, evaluations of community pharmacy and its services have focused on patient satisfaction via questionnaires.¹²⁻¹⁶ Yet, there are concerns about using patient satisfaction outcomes as an indicator of service quality, such as the lack of well-designed and validated satisfaction instruments.^{17,18} Other studies have investigated consumer perspectives of a specific professional service, without reference to the entire pharmacy experience.¹⁹⁻²¹ Whilst these studies provide significant contributions, it is also important to explore the experiences of community pharmacy as a whole, from the

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perspectives of people living with chronic health conditions and their carers. An exploration of the consumer's experiences (patient centred perspective) is essential to ensure and maintain a high quality health care service.

One approach to exploring pharmacy experiences is to focus on assessing a person's choice of pharmacy,²²⁻²⁴ which can also be viewed as a quality indicator. Arneson *et al* discussed that if a person remains loyal to a pharmacy, it is theoretically because their needs are being met and they are satisfied.²² Convenience is acknowledged as a predominant influence of pharmacy choice,²²⁻²⁴ with people having a strong preference for a pharmacy located near their home.²⁵ Price is another factor identified in the literature.^{12,22} However, most of this literature is somewhat out-dated considering the recent changes to Australian pharmacy practice. Furthermore, these studies do not consider how the attributes of patient centred care influence pharmacy choice.

Given the current health climate and the evolving role of community pharmacy, it is important to explore which factors influence a person's choice of community pharmacy from a patient centred care perspective. This approach is particularly relevant as patient centred care can promote beneficial outcomes, such as improved satisfaction, health and quality of care.²⁶ This study will provide a framework for the pharmacy profession to identify the quality features of patient centred care or services that health consumers' value, thereby enabling pharmacy staff to build on these positive experiences. Consequently, this study aims to explore the determinants of pharmacy choice from a large qualitative study of people with a variety of chronic health conditions.

METHOD

Study design

Participants were recruited from four Australian regions that represent diversity in geographical location, culture and socioeconomic status: Logan-Beaudesert and Mount Isa (Queensland), Northern Rivers (New South Wales) and greater Perth (Western Australia). Eligibility criteria were established to promote diversity in the sample from those newly diagnosed within a six month period, to consumers with one or more established chronic health condition(s). Unpaid carers were also encouraged to participate, as they may be the one who utilises the pharmacy on the person's behalf. To incorporate many different perspectives²⁷ and reflect the multicultural population of Australia, Aboriginal and Torres Strait Islander and culturally and linguistically diverse populations also participated.

Procedure

An interview guide was informed by previous stakeholder research on the same topic (Table 1),^{28,29} and data were elicited using semi-structured, in-depth interviews. To ensure that the interview guide was culturally appropriate,³⁰ comments were sought from a Reference Group comprised of culturally diverse key stakeholders with health care expertise. Furthermore, a consumer researcher was employed to ensure that the project maintained a consumer centred focus. To promote a standardised interviewing method, the first 10 interviews were conducted by two researchers with experience in qualitative data collection (SM, AS), who then discussed their approach with the other interviewers (FK, CC, CM). The first 20 interviews were coded to enable familiarisation with the initial data and further refinement of the interview guide by the research team. Feedback from the research team was obtained throughout the data collection process.

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Individual interviews were conducted during May-October 2012. The interviewer and interview location were informed by the specific needs of the participant and consideration of their personal circumstances, such as cultural background or religious beliefs. Interviews were audio-recorded and averaged 50 minutes in duration. Ethical approval was obtained from a University Human Research Ethics Committee (PHM/12/11/HREC).

[Insert Table 1 here]

Data analysis

Interviews were transcribed verbatim (except for two participants who did not want the interview recorded), a random sample of transcripts was checked for accuracy and a constant comparison method was used to analyse the data.^{31,32} The data were first openly coded into themes using the qualitative data analysis package QSR NVIVO 9[®]. To assist data familiarisation, researchers involved in coding did not code their own interviews. After initial coding, further interviews were explored to develop sub-themes, leading to further category refinement. A research team member (MK) checked the coding for randomly selected transcripts to ensure data credibility. Recruitment continued until data saturation was established, e.g. when participants' experiences and perspectives became recurring and were in line with previously collected data.³³ For this paper, the authors categorised the attributes of patient centred care according to two recent studies that conceptualise this term differently: (i) a concept analysis by Morgan and Yoder,³⁴ e.g. individualised, empowered, holistic and respectful care; and (ii) a qualitative study by Dancet *et al.*,³⁵ who identified humanistic, e.g. emotional support and relationships, and organisational factors, e.g. accessibility and continuity of care related to patient centred care.³⁵

RESULTS

Participants

A total of 97 interviews were undertaken (Table 2); the majority ($n=65$) with female participants. Ages ranged from 16-85 years (mean=57.2 years; SD=13.03). There was a diverse range of chronic health conditions among participants, including: diabetes, mental illness, cardiovascular, respiratory and musculoskeletal conditions. Notably, almost 90% of participants had been diagnosed with two or more chronic conditions.

[Insert Table 2 here]

Participants could be classified according to one of three patron categories: those who are a regular patron of one pharmacy, those with a regular pharmacy who utilise other pharmacies for specific needs, or a casual visitor to various pharmacies. A number of inter-related factors determined this choice: *patient centred care, convenience, personal traits, price and service/medication need.*

Regular pharmacy

A patient centred approach was discussed widely amongst participants who utilised a regular pharmacy. A variety of attributes of patient centred care from both Moran and Yoder³⁴ and Dancet *et al*³⁵ were identified, which is exemplified in the following quote:

... she [pharmacist] makes a point to come over to me and she does it with other customers. She's well dressed, she smiles, she's just nice, she's an educated pharmacist, she takes time to tell you when you're changing your drugs... she explained possible side effects... [C_1150]

The above participant described the pharmacist providing a humanistic approach by smiling and being nice, and an organisational approach by being accessible to customers for counselling purposes. Furthermore, the participant also appreciated being offered or provided with individualised medication advice. This was essential when obtaining a new medication and viewed positively by participants:

...if I go up there with a script, she'll [pharmacist] come out...to explain what it's all for... [C_1053]

Continuity of care was another reason for utilising one pharmacy, as this facilitated awareness of the person's medical history. This enabled staff to apply this knowledge to the unique needs of the individual, e.g. allergy avoidance:

The pharmacist here... is absolutely brilliant, whenever I need a new medication... she resources them... [C_015]

For others, medication safety was a key priority for them and hence, using a regular pharmacy was seen as a way to optimise this via continuity of care:

One chemist, all your pills are together. The chemist can know what you're on; look for drug interactions... [C_1072]

Using one pharmacy promotes the development of a comprehensive medication history, which would assist pharmacy staff to ensure the safe and quality use of medication. Alternatively, other participants viewed this primarily as a matter of convenience, as it can minimise the burden of answering questions or explaining personal circumstances.

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Staff approachability, an organisational aspect of patient centred care, also facilitated a relaxed environment for consumers to ask questions and seek advice:

... he [pharmacist] is very approachable and all the staff are too... you never feel as if you are stupid or asking a silly question... [C_005]

Respectful care was also demonstrated when pharmacy staff acknowledged the associated difficulties in being a 'perfect patient', thus increasing staff approachability:

... they [the pharmacist] were accepting of who you were and you are not an angel and you had done things wrong and that was okay you are human... [C_007]

Caring pharmacy staff were highly valued, as this increased approachability and thus, fostered the development of a relationship. In showing care, pharmacy staff did not identify people solely by their condition(s), provided individualised care by taking the time to ensure that the person's needs were met, and utilised a holistic approach by being concerned about their overall wellbeing:

She's [pharmacist] a very caring person... who has an interest in the whole picture [C_015]

Furthermore, another participant explained that their reason for not visiting a variety of pharmacies was the lack of individualised care:

... when you're away from your pharmacy and you go to a new pharmacy, they don't seem to have that amount of personal care... [CC_016]

A consumer with a disability articulated many reasons why she continued to go to a regular pharmacy; it was convenient, she was not judged, and the staff respected the knowledge she

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had about her own condition(s). However, she described the stigma she experienced elsewhere:

...there's still a lot of pharmacists, and I'm talking mainly about the young ones... think that therefore you must have an intellectual problem. Because you've got the physical disability and you can't move... [CC_1166]

Therefore, providing holistic care where the pharmacy staff saw beyond the person's medical history, e.g. a disability, respected their role as a carer and as a person knowledgeable in their condition(s), fostered relationships.

Providing empowering care in terms of support and encouragement was also important:

...because of being on the [opioid]...he always used to say to me, "(name) you're no junkie, you're the only one who reduces, everybody else they go up." And I knew that he knew that I would one day be normal again... [CC_1065]

The development of a relationship was particularly essential for participants of Aboriginal and Torres Strait Islander background. A community elder expressed the need for their people to be able to trust health care professionals before engaging in conversation about health matters:

...if they go there on a regular basis to that one pharmacy I think that's important... 'cause Aboriginal people they need to trust people. And once they get the feeling they can trust people then they're more likely to open up. [C(IND)_2001]

The significance of a humanistic approach was also emphasised by two Aboriginal and Torres Strait Islander participants. They described that the simple act of a health professional

placing a hand on their shoulder provided a sense of care and safety, and that this was an important attribute for optimal health care.

The majority of participants also selected a conveniently located pharmacy to regularly patronise, e.g. close to their home, in order to reduce the time accessing care. This was a key determinant for some people, even when they perceived a lack of customer service:

...About two or three times it happened that when we got there they haven't got it [medication]...It's annoying and frustrating... We haven't got another one [pharmacy] though. We go shopping at [location name] and we just stop over [at] the chemist, leave a script there... [C(CALD)_1085]

However, the preference for good customer service over convenience is highlighted by the following participant who moved pharmacies:

...Even if I've got to come out [of] the doctors and hop on the bus to go to [location name]...I will rather than go there and put up with that [behaviour]. [C(IND)_1097]

This participant referred to the abrupt and arrogant manner of the pharmacist at her regular pharmacy, located next to their doctor's surgery. Thus, the professional attitude and interpersonal skills of the pharmacist was more important for this participant than convenience. Furthermore, this person had knowledge that they could obtain a better service elsewhere and moved.

For some participants, a factor of pharmacy choice was whether the staff met their service expectations; it was important to obtain exactly what they wanted, when they needed it:

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... you just tell them what you need and they'll give it to you, or if you're not really a 100% sure on what it is, they talk through whatever's available... [C_1107]

Thus, the provision of information to meet their needs was a component of individualised care. Remarkably, some participants described a lack of individualised care with their regular pharmacy, yet continued to utilise them because it would be a burden and inconvenience to change pharmacies. A carer described instances where pharmacy staff repeatedly asked his mother medication questions when she spoke limited English:

Why you have to ask her the same question, "Do you want the cheapest one; do you want the different packaging?" My mum doesn't understand what you're saying and that's the problem...she always say yes and give her wrong medication... [C(CALD)_1133]

The choice of pharmacy was influenced to a lesser extent by the *personal trait or preference* of the individual. Some consumers from culturally diverse backgrounds sought a pharmacy where a staff member spoke the same language or had the same cultural background. When asked about the possible impact of having a pharmacist of the same cultural background, one Samoan participant explained:

... it would draw all the Samoans in... then they'll ask questions and that's the good thing about it... [CC(CALD)_1124]

Price was an important factor for some participants, particularly for low income earners. Participants were frustrated when they were charged various prices for the same medication at different pharmacies. As a result, they were more inclined to shop around for the best price and stay at that particular pharmacy.

Regular and various pharmacies

Trade-offs between pharmacies were also evident with respect to price and meeting different needs. For some consumers, this resulted in feelings of disloyalty and disappointment when they sought other pharmacies to purchase a product because they were cheaper:

We pretty much go to one pharmacy which is up the road here.... The problem is it's a small pharmacy and so therefore all their vitamins... are a lot dearer... so we go to the other pharmacy which is I suppose rude on our behalf. But we're pensioners.
[C_1053]

The provision of a *needed service*, such as medication compounding, could also take precedence when choosing a pharmacy:

...The one we get the [compounded product] from is really weird... we spend a fortune...but...there's no personality with that pharmacy at all, there's no interaction...they wouldn't know who I am if I walked in there...I still go to the pharmacy near our old house... they just know me... you walk in and...hello, how are you? How's your son going? [CA_1013]

Therefore, two or more pharmacies could be utilised by participants for a number of reasons: convenience, better medication price, or availability of different services.

Various pharmacies

Participants without a regular pharmacy placed a higher value on convenience than an individualised service, or used pharmacies infrequently and accessed whatever one was open at the time:

...I don't go to the same one each time, cause if I have to go into one town for something.... I'll go to the pharmacy while I'm there. [CC_1034]

DISCUSSION

Our findings corroborate existing research indicating that people with complex conditions can place a higher importance on interpersonal skills when choosing a preferred health care provider,³⁶ and value specific humanistic aspects of patient centred care, such as smiling and nice staff.³⁵ Participants expressed their gratitude to pharmacists that exceeded their personal expectations of the pharmacist's professional role; which is also described as the 'helping professional' in the literature.³⁷ It is therefore unsurprising that participants chose to remain loyal to a pharmacy where they received this care, emphasising the importance of patient centred care to many people. Unsurprisingly, convenience was also important when choosing a pharmacy for some participants. This was particularly highlighted by those describing the inconvenience of changing pharmacies, even if they were not entirely happy with the care received.

A strength of this study was its inclusion of a large number of participants with varying chronic health conditions and cultural backgrounds. Further analysis to identify the relationships between the three patron groups and participant demographics was not conducted and indeed would be challenging given the qualitative nature of this study. Whilst we relied on self-reported data which can be influenced by bias, a standardised interview guide was used to minimise this risk. Discussions were undertaken throughout the analysis process between all interviewers of different research experience and professional background, e.g. public health, to minimise the potential for interviewer bias. This study recruited consumers with one or more chronic health condition(s); therefore the findings

cannot be generalised to other pharmacy consumers, such as those with minor or acute ailments. Further research to compare these two groups is warranted, as there are likely to be differences in the determinants of pharmacy choice. Finally, whilst this study identified determinants of pharmacy choice, it did not explore the relative importance of these determinants, an area for future research.

The impact of convenience in influencing pharmacy choice is consistent with the literature.^{12,22-24,38} However, it was surprising that some people continued to use their regular pharmacy even after receiving what would be perceived as a lack of individualised, patient centred care. This finding underscores the importance of subjective experiences in determining a person's choice. For some people, the choice of pharmacy is a trade-off between convenience and the inconvenience of going elsewhere, which may over-ride the importance of patient centred care. Alternatively, these consumers may not be aware of better health services elsewhere. Indeed, Victoor *et al.* elaborated on this by suggesting that people may not have adequate information about different health providers to make a completely rational choice.³⁶ It has also been suggested that if consumers have not experienced a higher level of service, such as extensive drug information consultation, then they are likely to remain satisfied with their current care.²³

A variety of consumer personal traits such as cultural background and preferred spoken language could also influence a person's choice of pharmacy, suggesting that there is 'no such thing as the typical patient'.³⁶ The importance of price is consistent with the literature,^{15,22} but is also subject to the individual consumer's circumstances, e.g. low income level or pensioner.

Apart from dose administration aids and home medication deliveries, there was minimal discussion about choosing a pharmacy based on the provision of professional services. Considering these are consumers that are more likely to need these professional services, they seem to be unaware of the range of community pharmacy services available.^{13,39} Although these services are relatively new to Australian pharmacy practice,⁹ further targeted promotion to facilitate their uptake is needed. Given that a recent study has demonstrated that promotion of pharmacy services does not necessarily result in an uptake of use,⁴⁰ this promotion should also aim to raise the profile of pharmacy as a health care destination.

Overall, our findings confirm that selecting a pharmacy is a subjective experience for each individual; the community pharmacy needs to meet the consumer's specific needs. To facilitate this, people need to be able to differentiate between the services that community pharmacies provide and match this to their priorities. However, as demonstrated by our findings, some consumers may lack this skill or knowledge about the ranges of services that are offered. Therefore, more education about the standard of care and professional services that consumers should expect from their community pharmacy is needed; a recommendation identified previously in Australian practice.²⁵

CONCLUSION

Patient centred care, convenience, personal traits, price and specific needs can all influence a person's choice of pharmacy. As pricing and convenience in terms of location are more difficult to change, pharmacy staff can turn their attention to adopting a more patient centred approach to care. This was an important factor for participants with a chronic condition(s) when choosing a regular pharmacy. They appreciated quality service delivered by

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approachable pharmacy staff providing individualised medication supply and advice. Regular pharmacy patrons also valued the formation of relationships and a holistic approach to care.

This is good news for community pharmacy. The profession is moving towards the implementation of professional pharmacy services which fosters relationship development, an important influence of pharmacy patronage. As consumers with chronic conditions are often on multiple medications and require ongoing treatment, they are valuable consumers for pharmacy. It is therefore important that community pharmacy tries to meet their individual needs and provide the quality of care people want.

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Table 1: Interview questions related to pharmacy choice

Why do you mainly go into the pharmacy? (e.g. purpose)

When you go to a pharmacy do you feel as though you are going there as a patient to get a health service or as a consumer to purchase a product?

Can you describe a good and a bad pharmacy experience?

Do you have a regular pharmacy?

McMillan SS, Sav A, Kelly F, King M, Whitty JA, Wheeler AJ. How to catch them and keep them: the influence of patient centred care on pharmacy choice for Australian residents with chronic conditions. The final, definitive version of this paper has been published in *International Journal of Pharmacy Practice* DOI: 10.1111/ijpp.12075 (published online 18.10.2013) by Blackwell Publishing. All rights reserved. © [McMillan.SS, et al 2013.]

Table 2: Participant Data

Participant characteristics		No. of participants (<i>n</i> =97)
Carer/consumer	Consumer (C)	69
	Carer (CA)	12
	Carer/consumer (CC)	16
Race/cultural background	Aboriginal and Torres Strait Islander (IND)	23
	Culturally and linguistically diverse (CALD), e.g. Asian, Middle Eastern, European and Pacific Islander.	19
	Caucasian	55
Interview method	Face-to-Face	49
	Telephone	46
Location	Logan/ Beaudesert	41
	Mt Isa/ North West	15
	Northern Rivers	21
	Greater Perth	20
Chronic condition(s)*	One	10
	Two	19
	Three or more	56

**Data from consumer (C) and carer/consumer (CC) only*

Appendix 4.4 – The impact (i.e. burden) of having a chronic condition on consumers and carers

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‘You say treatment, I say hard work’: treatment burden among people with chronic illness and their carers in Australia

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What is known about this topic

- Treatment burden refers to the consequences people experience as a result of undertaking treatment.
- Treatment burden can have severe consequences on the person, the healthcare system and society.
- Healthcare professionals may lack the tools to detect people overwhelmed by adhering to complicated treatment routines, and hence lack the strategies to ease this burden.

What this paper adds

- The financial cost of treatment is the most concerning aspect of treatment burden, with the cost for treatment being significant for most people.
- Individualised treatment and innovative solutions are needed to reduce treatment burden among people with chronic illness and their carers.
- The findings offer a framework for health professionals to reduce this burden.

Abstract

The aim of this study was to explore treatment burden among people with a variety of chronic conditions and comorbidities and their unpaid carers. The burden of living with ongoing chronic illness has been well established. However, the burden associated with proactively treating and managing chronic illness, commonly referred to as ‘treatment burden’, is less understood. This study helps to bridge this gap in our understanding by providing an in-depth analysis of qualitative data collected from a large sample of adults from diverse backgrounds and with various chronic conditions. Using semi-structured in-depth interviews, data were collected with a large sample of 97 participants that included a high representation of people from culturally and linguistically diverse backgrounds and indigenous populations across four regions of Australia. Interviews were conducted during May–October 2012, either face to face ($n = 49$) or over the telephone ($n = 48$) depending on the participant’s preference and location. Data were analysed using an iterative thematic approach and the constant comparison method. The findings revealed four interrelated components of treatment burden: financial burden, time and travel burden, medication burden and healthcare access burden. However, financial burden was the most problematic component with the cost of treatment being significant for most people. Financial burden had a detrimental impact on a person’s use of medication and also exacerbated other types of burden such as access to healthcare services and the time and travel associated with treatment. The four components of treatment burden operated in a cyclical manner and although treatment burden was objective in some ways (number of medications, and time to access treatment), it was also a subjective experience. Overall, this study underscores the urgent need for healthcare professionals to identify patients overwhelmed by their treatment and develop ‘individualised’ treatment options to alleviate treatment burden.

Keywords: carers, chronic illness, comorbidity, financial burden, treatment burden

Introduction

Chronic illness has become the epidemic of our times. Ongoing health conditions, such as cardiovascular and respiratory illness, cancer and diabetes, are currently the leading causes of morbidity and death (World Health Organization 2011). Chronic illness generally refers to an illness that is prolonged in duration, does not often resolve spontaneously, is rarely cured completely and can be associated with functional impairment or disability (Australian Institute of Health & Welfare 2012). The increasing prevalence of chronic illness contributes to a significant burden on people, the healthcare system and society as a whole. Although the burden of illness is well defined, the burden associated with proactively treating and managing chronic illness, commonly referred to as 'treatment burden', is less understood.

Treatment burden is conceptually different from the burden of illness (May *et al.* 2009). Whereas the burden of illness represents the impact of chronic illness on a person, their family members and the healthcare system, treatment burden refers to the consequences they experience as a result of undertaking or engaging in treatment, such as medications, therapies, medical interventions etc. (Sav *et al.* 2013). A recent review conducted by Sav *et al.* (2013) indicated that treatment burden can be determined by numerous factors such as personal characteristics (e.g. age and gender), illness duration/severity, treatment characteristics (e.g. number and dose of medications) and family circumstances (e.g. level of support).

Ironically, there is evidence that the healthcare system within which people receive treatment can contribute to treatment burden. Despite its purported aim of improving health and welfare, healthcare services can be characterised by burdensome features, such as poor co-ordination between healthcare professionals, poor health professional-patient relationships and a lack of adequate information (Moss & Crane 2010, Eton *et al.* 2012). Ineffective communication between healthcare professionals and patients about treatment can lead to confusion about treatment options and the initiation of unnecessary treatment (Vijan *et al.* 2005, Moss & Crane 2010). Paradoxically, as Eton *et al.* (2012) noted, a healthcare professional's response to poor patient outcomes can be to intensify treatment, resulting in a more complex treatment regimen ultimately leading to greater levels of burden. This additional burden can exacerbate the 'work of being a patient' (Tran *et al.* 2012, p. 2).

This negative cycle clearly indicates a need for healthcare professionals to be more sensitive to their

patients' preferences, explicitly weighing treatment burden against the potential benefits of treatment on an individual basis, in collaboration with the patient. However, from the perspective of healthcare professionals, there can be little appreciation of 'the work' associated with chronic illness management. Healthcare professionals can lack the tools to detect people overwhelmed by the 'work' of adhering to complicated treatment routines, and hence lack the strategies to ease this burden (May *et al.* 2009). If unaddressed, treatment burden can have severe consequences, including recurrence of illness, decline in health, reduced survival and ineffective use of health resources (de Kraker *et al.* 2004, Brod *et al.* 2007, Graves *et al.* 2007, Moss & Crane 2010).

The present study

Although recent research has generally increased our understanding of the nature of treatment burden among people living with chronic illness (Gallacher *et al.* 2011, Bohlen *et al.* 2012), there are still significant gaps. Most research has focused on specific conditions, for example, diabetes, cancer, asthma and cystic fibrosis, rather than on attempting to gain an overall understanding of the concept. While these conditions certainly impose intensive treatment demands and significant treatment burden on individuals, there is a need to understand the experiences of people with all types of complex chronic conditions and multiple comorbidities. Chronic illness rarely occurs in isolation, with most people who report having at least one chronic illness, also report having two or more conditions (Caughey *et al.* 2008). A lack of in-depth understanding among such people is problematic because the treatment burden experiences of people with a particular illness (e.g. medication use for diabetes) may be significantly different from that of a person with multiple and complex health conditions.

Even in these specific populations, most of what we know about treatment burden is based on homogenous samples, in particular, elderly, Caucasian adults (e.g. Vijan *et al.* 2005, Brod *et al.* 2007). There is little emphasis on the experiences of those from culturally and linguistically diverse (CALD) populations, indigenous minority populations (Aboriginal and Torres Strait Islander) or those from economically and socially disadvantaged backgrounds. The experiences of diverse populations are important because at the most basic level, people from economically disadvantaged backgrounds are likely to report more financial burden due to out-of-pocket healthcare costs compared with those in full-time employment. People

from cultural minority populations may also have unique issues, such as particular health beliefs, language barriers and discrimination, which may have an impact on their treatment burden experiences (Wilson *et al.* 2012). Finally, there is absence of research on treatment burden from an unpaid carer's perspective, those who provide assistance with a number of daily activities without pay to people with chronic illness (McNamara & Rosenwax 2010). In addition to sharing some of the treatment burden with the person they are caring for, unpaid carers may experience aspects of burden unique to the carer role (e.g. time, energy, etc.).

This study aims to address these gaps in knowledge by comprehensively exploring treatment burden among people with a variety of chronic conditions and comorbidities and from various backgrounds and their carers. The study contributes to our understanding of treatment burden by providing an in-depth analysis of qualitative data collected from a large sample of adults that included a high representation of people from CALD backgrounds and indigenous populations. The study focused on both common (e.g. diabetes) and unique chronic conditions (e.g. Peutz-Jeghers syndrome) and drew knowledge from both affluent and disadvantaged communities. To our knowledge, no such study has provided such an in-depth and comprehensive analysis of treatment burden.

Methods

The study was guided by the interpretive social paradigm (Neuman 2010), based on the understanding that individuals construct their own reality and that knowledge is experienced in a social context. Given the focus on an in-depth understanding, an interpretive approach using qualitative methods was considered the most suitable study design.

Data collection

Ethical approval for the study was obtained from the Human Research Ethics Committee of an Academic University (PHM/12/11/HREC). Semi-structured in-depth interviews were conducted with people with chronic illness and their carers. In-depth interviews were undertaken with 97 participants across four regions of Australia: Logan-Beautesert, Mount Isa/North West region of Queensland, Northern Rivers area of New South Wales and greater Perth area in Western Australia. These geographical regions were purposively selected as they represent considerable socioeconomic, cultural, geographical (e.g. metropoli-

tan or rural/remote) diversity. Purposive snowball sampling techniques were used initially to locate participants via Reference Group contacts (key stakeholders and representatives from government and non-government organisations), their clients and networks. In addition, participants were recruited via pharmacies, general practices and other healthcare agencies and through other government and non-government organisations.

To participate in the study, participants needed to be: (1) either newly diagnosed (within 6 months) or have a chronic condition(s) for 6 months or more; or (2) an unpaid carer for a person with a chronic condition. Prior to the in-depth interview, a short eligibility process was conducted with each participant who expressed interest in the study to gather information about his/her health status, primary healthcare utilisation, demographics, condition/s status and duration. Eligible participants were then contacted for the in-depth interviews to be conducted.

Procedure

An interview guide was developed, piloted and refined prior to the commencement of the in-depth interviews. A consumer researcher, who possessed the necessary life skills and experience, was appointed to ensure that data collection, data analysis and recommendations maintained a consumer focus. Probe questions included the extent and duration of illness, difficulties with medications, finances, relationships with healthcare professionals and daily practical challenges.

Interviews were conducted personally by four members of the research team and transcribed verbatim upon completion. The location of the interview and the selection of the interviewer were informed by the specific needs of the participant and consideration of their personal circumstances (e.g. age, gender and religious beliefs). The four interviewers were from different professional backgrounds (e.g. public health and healthcare professionals) and had different levels of research experience (senior researchers and investigators). To ensure interviewer consistency, verbal and written interview debriefs were sent to the entire research team by all interviewers throughout the data collection process and interviewers were trained on interviewing techniques.

Semi-structured, in-depth interviews were conducted during May–October 2012, either face to face ($n = 49$) or over the telephone ($n = 48$), depending on the participant's preference and location. Interviews were audio-recorded and on average lasted 50 minutes. Several of the interviews with participants of

CALD background were conducted with a bilingual interpreter upon the request of the participant. Interpreters were respected and trusted by each participant and had well-established links with their relevant ethnic traditions and customs. Participants were advised that they could obtain a copy of the transcript if desired and were provided with a gift voucher as a token of appreciation of their time.

Data analysis

Data collection and analysis were based on an integrated or cyclic, rather than on a linear process, with each analysis set of data informing the collection of the following set. As soon as the interviews were transcribed, each in-depth interview was analysed using an iterative thematic approach and the constant comparison method, which form the key components of grounded theory analysis (Glaser & Strauss 1967). Three researchers read and re-read the transcripts to familiarise themselves with the data and to prepare themselves for the thematic analysis. These researchers used the electronic qualitative data analysis package QSR NVIVO 9[®] (QSR International PTY LTD) to assist with coding the data into themes and sub-themes. In accordance with the constant comparison method, the data were collected and analysed concurrently.

Although the initial coding of data was carried out by three researchers, to increase familiarisation with the data, the researchers did not code the interviews they personally conducted with each participant. The categories were then refined to form sub-themes and all themes and quotes were numbered to ensure the auditability of the analysis. Quotes extracted to illustrate the themes were labelled to represent the source of data, for example, C represented consumer only, CA – carer only, CC – consumer and carer, IND – indigenous person, CALD – culturally and linguistically diverse background person, and CH – consumer and healthcare professional.

Inter-rater reliability of the authenticity of coding (Carney *et al.* 1996) was assessed by another member of the research team randomly selecting samples of data. The data analysis process was also 'subject to scrutiny and review' (Bowen 2008, p. 149) by the entire research team and discussions were held throughout the analysis process. Data saturation with the whole data and subgroups, such as specific cultural groups or chronic conditions, was established when the participants' experiences and perspectives recurred in line with the themes identified in previously collected data. Given the diversity of the sample, it was not surprising that a large sample was required to reach saturation.

Results

Sample demographics

In total, 97 participants were interviewed. Table 1 highlights the demographic and medical characteristics of participants. The mean age of the participants was 57.2 years (range 16–83 years) and there were twice as many females as males. The majority of participants were consumers with chronic illnesses (71.1%). The most prevalent conditions were diabetes, respiratory, cardiovascular disease and musculoskeletal disorders. Additionally, the majority of participants (88.3%) had two or more comorbid conditions (e.g. bowel cancer, diabetes and depression). Finally, participants experienced a range of different chronic conditions with cardiovascular illness being reported as the most prevalent, followed by other conditions (e.g. psoriasis, prolapsed bladder, premenstrual disorder, chronic fatigue, etc.) and diabetes.

Treatment burden

The following four themes were identified as representing treatment burden among people with chronic illness and their carers: financial burden, time and travel burden, medication burden and healthcare access burden.

Financial burden

The most widely discussed burden resulting from treatment of chronic illness, irrespective of participant background and chronic illness, was financial. Participants described feeling concerned and worried about the financial aspect of their treatment. On most occasions, financial burden was instigated by the cost of medication and the cost of consultations with healthcare professionals:

...one medication alone is \$40 a month, another one is \$30 a month ... that's \$70 a month over a period of 20 years – it's a lot of money. [C_1015]

Money spent on obtaining treatment had a negative impact on family leisure and social/sporting activities, with one carer admitting feeling guilty about prioritising her son's medication needs over the broader social and recreational needs of her other children:

...we've had to completely stop any extracurricular [activities], they were doing dancing and swimming, and we've just had to say look guys, I'm sorry, but we just can't do anything, so nobody does anything, it's just all therapy. Which you know that upsets me. [CA_1013]

Table 1 Demographics of the study sample

Participant characteristics	(n = 97)	%
Age		
Mean = 57.2 years		
Range 16–83 years		
Gender		
Male	32	33
Female	65	67
Carer or consumer		
Consumer only	69	71.1
Carer only	12	12.4
Carer/consumer	16	16.5
Ethnic/cultural background		
Aboriginal and Torres Strait Islander (indigenous person)	23	23.7
Culturally and linguistically diverse (e.g. Egyptian, Lebanese, Japanese, Burmese, Italian, Samoan)	19	19.6
Caucasian	55	56.7
Location		
Logan/Beauesert	41	42.3
Mt Isa/North West area	15	15.5
Northern Rivers	21	21.6
Perth greater area	20	20.6
Chronic illness(es)		
One chronic illness only	10	11.7
Two illnesses	19	22.4
Three or more illnesses	56	65.9
Duration of primary illness(es)		
<1 year	5	5.9
1–5 years	18	21.2
6–10 years	17	20
11–15 years	13	15.3
16 years and over	32	37.6
Type of illness(es)		
Cancer (e.g. breast, bowel, brain, liver, prostate)	15	17.7
Diabetes	37	43.5
Cardiovascular (e.g. myocardial infarction, stroke)	68	80
Renal (e.g. renal failure, dialysis, transplant)	7	8.2
Mental health (e.g. bipolar, depression, autism, anxiety, schizophrenia)	24	28.2
Musculoskeletal (e.g. osteoarthritis, fibromyalgia, rheumatoid arthritis, osteoporosis)	20	23.5
Neurological (e.g. Parkinson's, multiple sclerosis, epilepsy)	18	21.2
Respiratory (e.g. chronic obstructive pulmonary disease, asthma, bronchiectasis, sarcoidosis)	27	31.8
Other (e.g. quadriplegic, hypothyroidism, insomnia, Meniere's disease, macular degeneration, polio, reflux, polycystic ovary syndrome, chronic bladder infection, chronic acne, Hashimoto's disorder)	57	67.1

Some participants, particularly those who had retired from paid employment, relied on their savings (e.g. superannuation) and resources provided by other family members to cope with the financial burden. Economically disadvantaged participants prioritised their medications according to cost and their capacity to pay. At times, they decided not to purchase medications that were not covered by pharmaceutical concession. This was particularly the case for low-income earners and/or those without pharmaceutical concession benefits, such as a healthcare card:

...occasionally they say, 'could you try this', and you go to the chemist and its 40 bucks and then you think no I'll go without it. [C_1023]

Private health insurance was partly seen as a solution to financial burden. An elderly woman with comorbidity said:

[without private health insurance], you'd be out in the middle of the dead less sea. [C_004]

Although seen as a partial solution, private health insurance was a financial burden itself as it involved regular payments. Furthermore, even when private health insurance was available, the out-of-pocket expenses were sometimes unaffordable. One participant who had lost her eyesight and developed neuropathy in both legs because of diabetes complications admitted:

...tomorrow I'm going in to get ... [treatment] and I don't know how much we can claim back on that, it won't be very much and it costs \$200. [C_1022]

The internal conflict created by the need for expensive private health insurance was evident in the statement by an elderly pensioner:

I live on vegemite sandwiches to keep my private health cover. [C_1015]

As the above quote indicates, some participants felt that the current healthcare system left them with no choice but to obtain private health cover. Although the cost of treatment was problematic for low-income earners and pensioners, those in full-time paid employment also struggled. These participants described instances where they were absent from work for a number of days while receiving treatment, often losing income for this period. However, they did not qualify for government concessions (e.g. healthcare card), which added to the financial burden they experienced.

Aboriginal and Torres Strait Islander participants were less troubled by the financial burden of treatment than participants of other cultural backgrounds. They attributed this to a newly established healthcare policy called 'Closing the Gap', which is an Australian Government initiative that subsidises medication for indigenous Australians (Australian Government Department of Human Services 2010). When asked to comment on this policy, one participant replied:

Absolutely it's been marvellous and even for my children. [C(IND)_1011]

When asked to comment on the financial burden experienced prior to the introduction of the policy, another indigenous participant with cardiovascular illness replied:

Oh yes. It was [difficult] because you think to yourself. Now where am I going to get this \$60 to pay for this medication? ... Sometimes I just didn't get it because I can't afford it. [C(IND)_1159]

Time and travel burden

Another common source of burden irrespective of gender, age or cultural background was the time required to access, administer and monitor treatment. The time investment necessitated by treatment on a daily basis was viewed by participants as relentless:

...there's always something that you have to do. Each week you either have to go to the dentist or podiatrist or go and get your pills from the chemist or, there's always something. [C_1052]

Participants also complained about the amount of time they spent waiting to obtain treatment, particu-

larly at healthcare clinics and private practices. Not surprisingly, many indicated that they would rather be doing activities they enjoyed. Time and travel burden was particularly problematic among participants with comorbidities. This was because these participants spent significant amounts of time attending healthcare clinics for the treatment of each of their conditions rather than receiving combined care. For example, one man who battled chronic asthma all his life and was recently diagnosed with diabetes and depression commented:

Last year it was a case of I might have six specialist appointments in a week, not doctors, specialists ... Like I was seeing every man and his dog. [C_1053]

Travel to and from primary and secondary health services to obtain treatment was also burdensome for carers, who often transported the person they cared for to and from such appointments:

...this is the carer's concern, cause I drop her off at the door but I want to walk her into where she's going, but I have to drop her off, then I go and circle around for ages looking for parking. [C(CALD)_1124]

Travel burden appeared to be most problematic for participants in rural and remote locations. These participants were usually forced to travel to a metropolitan city to obtain treatment, sometimes 3-4 hours each way. For participants in paid employment, this type of travel was untenable and unsustainable:

You just didn't [access to healthcare specialists] because there were none available. I mean when you are working and you have two kids and your wife is working, you can't travel to ... [metropolitan locations]. [C(CALD)_1038]

As outlined in the above quote, because of work commitments, participants in rural and remote areas found it difficult to access healthcare specialists located in metropolitan areas. Furthermore, working participants often used their holiday time to seek treatment or manage the symptoms of their illness. Some participants had made significant lifestyle changes to accommodate their illness, including relocating to smaller more accessible dwellings that were in closer proximity to treatment.

Finally, the time taken to learn about new treatments and ways to self-manage was particularly problematic for newly diagnosed participants. Participants spent significant time and effort learning and understanding their illness, managing symptoms and their prescribed medications, underscoring the 'hard work' associated with self-management of chronic illness.

Medication burden

One of the key sources of treatment burden was associated with the use of medications. Medication burden resulted from side effects and adverse events from medication use, polypharmacy (multiple medication use), the inconvenience of organising medications and the stigma associated with taking medication.

Some participants described how they had experienced side effects when using new medications. Weight gain/loss, sexual dysfunction, dizziness, nausea, hair loss, nightmares and dry mouth and throat were some of the problems experienced:

...it's affecting me sexually, and I'm not functioning because of the tablets so it's not a good thing. [C(CALD)_1069]

The likelihood of side effects was a major determinant of medication non-adherence among some participants. The side effects associated with medication appeared to be indirectly related to the duration of a person's chronic conditions. This effect was the result of 'trial and error experiments' and participants learning to cope with the symptoms of their illness over time. Consequently, the presence of side effects, or at least the impact of these on participants' lives, diminished as time passed.

Another source of medication burden derived from the need to take multiple medications and the inconvenience associated with organising and arranging those medications as exemplified by the following quote:

So, yeah it's annoying and it's always making sure that you've got them [medications] on hand ... so you're always got your eye on the box to make sure that there's enough there. [C_1026]

Some participants described the frustration they experienced about the inconvenience of having to rely on medication, especially when it interfered with daily activities, such as shopping and employment. Many participants also felt uncomfortable about their treatment, a finding that appeared to be related to the stigma associated with medication use and chronic illness. Male participants, particularly those from a CALD background, commented about how the use of medication reminded them of their illness. They often seemed troubled by the idea of having to rely on medication for the rest of their lives:

Medication, this means you are missing something, that's why they give you the medication. [C(CALD)_1131]

Medication burden was further complicated by confusion about generic versus original-brand medications, particularly for elderly participants. These

participants seemed confused between the generic and the original-brand medications because of the physical similarities between them. Many participants insisted on purchasing original-brand medications only and as a result, they were paying higher prices for their medications, resulting in greater financial burden.

Although many participants discussed the burden associated with medication use, this was not the case for all participants. Regardless of the number and type of medications they were taking, a few participants seemed content with their use of medications. They discussed their medications in a positive manner, often praising the role they played in assisting them to manage their chronic conditions:

Yeah, oh hey, it [medication] saved my life, it gave me a life. [C_1072]

Those who seemed to cope well with medication appeared to have learnt effective methods over time as they experimented with different ways of managing their chronic illness and its treatment.

Healthcare access burden

This type of burden resulted from either systemic healthcare obstacles or unhelpful professional-patient relationships. In relation to the systemic obstacles, a common complaint, particularly among those with low income and without private health insurance, was the waiting periods to obtain treatment:

We still are on the waiting list and nearly 4 years now, so she's used to it now. [C(CALD)_1125]

Much of the discussion around the burden of accessing healthcare was focused on the shortcomings of public healthcare services. Many of those who accessed such services complained about the lack of continuity they experienced when visiting healthcare professionals:

....the public health system. This frustrates me more than anything. When you get an appointment, go and see a specialist, every time you go back you see a different doctor. That is so frustrating. [CC_1041]

Participants from a CALD background and/or those with special dietary practices discussed problems associated with the availability of adequate food options in some hospitals:

...the food, the halal food [food that is processed according to religious guidelines] ... honestly, in the hospitals, it's a big problem. [C(CALD)_1133]

However, in contrast to others, those from a CALD background were less likely to discuss their frustrations with accessing healthcare services. These

participants often expressed gratitude about living in Australia, especially when they compared their lives and health services in their native countries:

Nothing, I miss nothing. Medication for free, operation for free. If I stayed in Egypt as the same, as being there, I'd be died 30 years ago, maybe forty. [C(CALD)_1131]

For participants of Aboriginal and Torres Strait Islander background, issues of structural racism were raised as being problematic. These were combined with culturally specific health beliefs that influenced their willingness to use both primary and secondary health services, such as shame:

I think some of the barriers are that health services have been plain racist from my own experience and professionally I think every other culture is accepted except Aboriginal and Torres Strait Islander. [C(IND)_1011]

The lack of collaboration between different healthcare professionals was also described as a source of burden. For example, a middle-aged woman with multiple chronic conditions, including Hashimoto's thyroiditis (an autoimmune illness caused by an inflammation of the thyroid gland), commented:

It's [the health system] a bit disjointed, I guess, in that you put, you're in silos, you know ... it's a bit sort of like, there's no co-ordination of a lot of it. [C_1052]

The lack of collaboration between healthcare professionals occasionally resulted in contradictory advice on treatment. In some cases, this situation contributed to polypharmacy.

The failure of some healthcare professionals, particularly GPs, to provide sufficient advice and information about treatment options was associated with treatment burden. Some participants spent large amounts of time trying to compensate for the lack of information by searching the internet or joining a consumer health organisation.

Discussion

Of the four components of treatment burden outlined, financial burden emerged as the most problematic with the cost and out-of-pocket expenses being significant for most people. Consequently, the financial burden of treatment is at the centre of the person's experience, as it not only had a detrimental impact on his/her use of medication, access to healthcare services and time and travel associated with treatment but also could be influenced by such matters. For example, it was possible for a person to delay treatment because of cost. On the other hand, travel associated with accessing health-care resulted in financial strain, because of a lack of reimbursement

for travel or loss of employment income. Additionally, treatment burden encompassed a cyclical aspect. For example, contradictory advice on treatment by healthcare professionals (healthcare access burden) could lead to polypharmacy (medication burden), which could then result in both a requirement for extra time to organise medications (time burden) and extra strain on financial resources (financial burden).

The findings corroborate existing research, underscoring the subjective and objective nature of treatment burden (Sav *et al.* 2013). Although treatment burden had an objective component, such as number of medications, and time to access health-care that was experienced by the majority of participants, it was also characterised by subjective experiences. These subjective experiences were determined by a person's conditions, level of complexity, duration, cultural background, age, gender and employment conditions. For example, although financial burden was less common in participants from Aboriginal and Torres Strait Islander background, these participants seemed more troubled by accessing healthcare services, mainly because of barriers such as discrimination. Similarly, while medication burden emerged as an important component of treatment burden, it was more problematic among people with certain conditions (e.g. diabetes and insulin use). Taken together, these findings underscore the need for 'individualised' approaches to alleviating treatment burden.

Ironically, the tasks of self-management, such as organising treatment and changing lifestyle, were identified as contributing to time or travel burden. Despite being hailed as a solution to the long-term management of chronic illness by healthcare providers and policy-makers, it is ironic that such self-management practices represent a significant burden for patients and their carers. Our findings align with a body of literature, which suggests that the burden of self-management can be significant, underlining the notion of the 'hard work' of being a patient (Corbin & Strauss 1985, Gallacher *et al.* 2011). Our study has confirmed the important role this 'work' also plays in the treatment of chronic illness.

Implications for healthcare professionals

Healthcare professionals may be limited in their ability to address some of the treatment burden resulting from cost, which may require structural healthcare policy initiatives. Nevertheless, the voices of participants in this study have several implications for their role in alleviating the burden of treatment for their patients. Because of the subjective and objective nature of treatment burden, there is a need for health-

care professionals to implement 'individualised' treatment methods to alleviate its occurrence and impact. Healthcare professionals need to consider each person's unique circumstances and preferences and offer consumer-directed holistic care that is responsive to their needs. Given that time and travel associated with obtaining treatment were a significant source of burden, it is also important that prescribed treatment tasks are kept to the minimum, which is necessary to minimise the 'hard work' of being a patient.

Healthcare professionals also need to identify patients overwhelmed by their treatment regimen and openly discuss treatment burden issues with such patients. However, because treatment burden is a relatively new concept for healthcare professionals (May *et al.* 2009), in-depth discussions on this issue may not be viable. We agree with Bohlen *et al.*'s (2012) comments, arguing that healthcare professionals may need education strategies to address this health issue. Although education strategies may assist patients and professionals to discuss treatment burden with effect, the constraints faced by healthcare professionals (e.g. short consultation times) may obscure their ability to identify and help burdened patients. Another alternative would be to increase collaboration between healthcare professionals and consumer health organisations (e.g. American Diabetes Association), who can provide educational resources, skills training, self-management and support services (Sav *et al.* 2013). By participating in such organisations, patients may be able to create avenues for experiential learning and a sense of belonging and opportunities for social engagement, which may be difficult to obtain from a healthcare professional (Boyle *et al.* 2009, Sav *et al.* 2013).

Finally, there is a need for greater co-ordinated care between healthcare professionals, particularly for the high proportion of individuals with comorbidities who often have to visit multiple healthcare services for treatment. Our findings confirmed that fragmented care can not only lead to time and travel burden for people but also result in contradictory advice on treatment. Co-ordinated care between healthcare professionals is not straightforward and evidence indicates that it is a complex process, has a number of components and occurs at different levels (Ehrlich *et al.* 2009). However, some patients may only require certain components of co-ordinated care, such as effective communication and information sharing between healthcare professionals, and these components may suffice to make a positive impact in alleviating treatment burden. Hence, healthcare professionals need to assess which components of co-ordinated care are essential for mitigating treatment burden among spe-

cific individuals, underscoring the need for individualised treatment.

Limitations

Our study used qualitative research methods to explore the experiences of participants at one point in time, and hence, complex relationships among themes cannot be established. In addition, we relied on self-reported data, which can be influenced by both interviewer bias and participant bias. However, the potential for interviewer bias arising from different interviewers was minimised by using a standardised interview framework to guide data collection and analysis. Because treatment burden contains subjective components, it would be interesting to examine treatment burden among people using longitudinal data, which would enable a more comprehensive understanding regarding its dynamic nature. Despite our study sample being large and diverse, we recognise that the views expressed by participants may not be generalisable. However, the purpose of qualitative research is to obtain rich and holistic information about a phenomenon of interest from relevant stakeholders, an objective, which, we believe, we have achieved.

Conclusion

The experiences of people with chronic illness and their carers in this study can form a useful framework for healthcare professionals who wish to help plan, in the words of May *et al.* (2009), 'minimally disruptive medicine' for their patients. Clearly, the burden of treatment for chronic illness is a significant issue and will become even more compounded with the projected rise of chronic illness in Australia and around the world. The financial burden of treatment in particular should not be underestimated. There is an urgent need to identify overwhelmed patients and to develop 'individualised' treatment options, as well as innovative solutions that challenge the current paradigm of health-care.

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Conflict of interest

The authors confirm that there is no conflict of interest.

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Appendix 4.5 – How consumers manage their chronic conditions

This is the post-print (final draft post-refereeing) version of the following manuscript:

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Consumer health organisations for chronic conditions: why do some people access them and others don't?

Abstract

Background and Aim: Consumer health organisations (CHOs), which operate outside the mainstream healthcare system with a specific focus on supporting people to self-manage their health conditions, have become widespread. Yet, there has been little systematic research into CHOs, including their perceived benefits and barriers, which encourage or deter their access by people with a variety of chronic health conditions. This study explored the benefits of CHOs in self-management and also the barriers which inhibit their access, from the perspective of people with chronic conditions and their unpaid carers. **Methods:** In-depth, semi-structured interviews were completed with 97 participants across four regions of Australia. The sample included a high representation of people from culturally and linguistically diverse backgrounds and indigenous populations as well as non-indigenous Australians. **Findings:** Three inter-related themes were identified that represented the benefits of involvement and participation in CHOs: knowledge and information, connection and support and experiential learning. However, limited access pathways emerged as a barrier which inhibited a person's entry into CHOs. Furthermore, the person's beliefs and experiences about their own health condition(s) also inhibited their continued participation in CHO programmes. **Conclusions:** Although our findings confirm that CHOs are a valuable resource in alleviating the 'work of being a patient' for some people, there seems to be some barriers which prevent their full access and utilisation. Structured integration systems to increase the reliable delivery and accessibility of CHOs are needed to ensure that people who would benefit from accessing them can do so.

Keywords

Consumer health organisation, chronic illness, self-management, benefits, barriers

Introduction

Chronic health conditions, such as diabetes and cardiovascular disease, have become a worldwide concern, representing almost 63% of all deaths globally (World Health Organization, 2011). With their increasing prevalence, 'self-management' has become a common concept in primary healthcare, being welcomed as a solution to the management of such conditions (Lorig and Holman, 2003). Various benefits to individuals and healthcare systems have been identified when people can effectively self-manage, by becoming more informed, involved and empowered in their own care (Blenkinsopp *et al.*, 2009; Boyle *et al.*, 2009). With an increasing emphasis on self-management, various healthcare initiatives such as 'Living Well' workshops and the Australian Better Health Initiative have been implemented, to provide people with the necessary skills, support and information to effectively self-manage (Boyle *et al.*, 2011). In addition to formal healthcare services (e.g. primary care services), informal organisations that generally operate outside the mainstream healthcare system with a specific focus on supporting people (including to self-manage their conditions), known as consumer health organisations (CHOs), have become widespread.

CHOs are broadly defined as 'organisations that promote and represent the interests of users or carers' (Allsop *et al.*, 2004: 739). Many CHOs exist worldwide, although they vary considerably in their size, financial budgets, focus and activities (Boyle *et al.*, 2007). They can range from a small-scale support group formed by several members who share a common health condition, to national organisations with formal governance structures and larger financial budgets. Coppa and Boyle (2003) outlined that some organisations can be funded or subsidised by governments or health services, while others can be small voluntary groups, relying exclusively on community support. Some CHOs can also receive funding from commercial organisations such as pharmaceutical and medical supply companies. CHOs can also be distinguished between those which are condition based, focusing on a specific chronic condition(s) (e.g. Diabetes Australia, Arthritis Care United Kingdom, Anxiety Alliance, National Schizophrenia Fellowship), and those that are population-based, which focus on a wide range of issues for specific groups, such as carers or cultural minorities (e.g. Children's Health Foundation, Muslim Youth Helpline, National Careline) (Allsop *et al.*, 2004).

CHOs are largely based on the self-help movement of the 1970's, which led to the proliferation of self-help groups: small voluntary group structures formed by people who came together to satisfy a common need (Katz and Bender, 1976). With time, some self-help groups evolved into CHOs, becoming more 'professionalised', larger national entities, with formal governance structures. Many CHOs are now involved in ground-breaking scientific research, media campaigns, parliamentary lobbying, protests against adverse events, and have close links with local, state and national governments (Allsop *et al.*, 2004; Jones *et al.*, 2004). Some continue to maintain self-help roles within them and share a number of core functions including: empowerment and advocacy, the provision of educational resources, skills training, and psychological support; services that may not be adequately offered by the formal healthcare system (Coppa and Boyle, 2003). CHOs can also provide practical, psychological and informational support to consumers and carers/family members in a variety of ways, including newsletters, counselling, alternative therapy, information sessions

and workshops, websites and peer support groups (Young *et al.*, 2010). There is some evidence that participation in such groups makes a significant contribution to user outcomes, including psychosocial wellbeing, expertise, health literacy, and effective coping strategies (Kyrouz *et al.*, 2002; Coppa and Boyle, 2003; Nijsten *et al.*, 2005; Oliffe *et al.*, 2011).

Despite their potential benefits, there has been little systematic research into CHOs. Few studies have focused on the perceived benefits of CHOs from the perspectives of consumers with a variety of ongoing health conditions (e.g. Kyrouz *et al.*, 2002; Coppa and Boyle, 2003; Boyle *et al.*, 2009; Hoffmann and O'shea, 2012). Furthermore, of the studies that have been conducted, many focused on small voluntary type groups, rather than larger national groups, such as the American Lung Association or the Heart Foundation of Australia (e.g. Coppa and Boyle, 2003). Most of what we know is based on homogenous samples, with little emphasis on the experiences of those from culturally and linguistically diverse (CALD), or Indigenous minority populations. In addition, there is an absence of research on how unpaid carers, those who provide assistance with a number of daily activities without pay to people with chronic conditions (Mcnamara and Rosenwax, 2010), access and utilise such organisations to meet their needs as carers.

Commensurate to the narrow understanding of the benefits of CHOs, there is limited research on the barriers that deter people from accessing such organisations (Coppa and Boyle, 2003). Most of the limited research has focused on articulating the barriers that appear to prevent primary healthcare professionals, mainly general practitioners (GPs), from referring patients to CHOs (Young *et al.*, 2010; Boyle *et al.*, 2011). Under-developed referral pathways, the perceived credibility of the information such organisations offer to consumers, and a limited awareness of CHOs among primary healthcare professionals and their role in self-management have been outlined as potential barriers (Laudet, 2000; Salzer *et al.*, 2001; Young *et al.*, 2010). Indeed, research suggests that despite the potential benefits of CHOs, only a small number of people (around 5%) access them (Ellins and Coulter, 2005). However, the barriers that limit a person's involvement and participation in such organisations from a consumer perspective have not been clearly investigated. Much remains to be understood of the personal lived experiences of consumers themselves. Given the potential of CHOs to provide much needed support to people living with chronic conditions, understanding the barriers is important to increase access to, and maximise participation in such organisations.

The research questions addressed in this study were: (a) What are the benefits of CHOs in self-management from the perspective of people with chronic conditions and their unpaid carers? (b) What are the potential entry level barriers that limit a person's access to such organisations? (c) What are the potential progress level barriers, which inhibit the continued involvement of people in a CHO once they obtain entry? Our focus was on large national groups with formal governance structures and also small voluntary self-help groups. The study contributes to research by providing a comprehensive exploratory understanding of CHO experience from a large qualitative study of adults that included consumers and their carers, as well as representation from culturally and linguistically diverse backgrounds and Indigenous populations.

Methods

Sampling and data collection

The study was guided by the interpretive social paradigm (Neuman, 2010) and used qualitative research methods in accordance with its exploratory nature. Given the focus on obtaining an in-depth understanding and the limited research on this topic, an interpretive approach was considered the most appropriate method.

To take part in the study, participants needed to be (a) either newly diagnosed or have a chronic condition(s) for a minimum of six months, or (b) be an unpaid carer for a person with a chronic condition, or (c) be both (e.g. an unpaid carer with a chronic condition). Participants were geographically located across four regions: Logan-Beaudesert, and Mount Isa/North West regions of Queensland, Northern Rivers area of NSW and the greater Perth area of Western Australia. These regions represent diversity in geographical location, culture and socio-economic status in Australia. Because of the inclusive nature of the study, participants were included if they self-reported as having a chronic condition themselves, or were caring for someone that did. To account for potential differences in experiences, we included those who had recently begun to experience a chronic condition, as well as those having lived with such conditions for lengthy periods of time. People could not participate in the study if they were under 16 years of age, did not reside in one of the four data collection sites, did not experience a chronic condition or did not care for someone that did. Having prior contact with, or being a member of a CHO was not part of the inclusion criteria for this study. Instead, the focus was on chronic illness in general, with the aim of trying to elucidate how participants utilised support networks, including CHOs, to better manage their conditions. However, most of the participants elucidated that they had some form of contact with a CHO.

Purposive and snowball sampling techniques were conducted to locate participants. Recruitment was largely conducted via the assistance of a large number of health organisations, such as community pharmacies, general practices, various healthcare agencies, and other government and non-government organisations. These organisations were asked to promote the study in their workshops, newsletters, and meetings by distributing information sheets to their clients and/or networks. Recruitment was also conducted via the assistance of the study's Reference Group, which consisted of a culturally diverse group of key stakeholders with healthcare expertise. A short eligibility process was conducted with each participant who expressed interest in the study, to obtain information about their background demographics, health, condition(s) status and duration, and healthcare system utilisation. Those who participated in the interviews were asked to suggest other people they knew personally who would also be willing to participate.

An interview guide was developed, which was informed by previous stakeholder research on a similar topic (McMillan *et al.*, 2012; Sav *et al.*, 2012). The interview guide was piloted with several people with chronic conditions and comments were obtained from the Reference Group. In accordance with the overarching aim of the study, a consumer researcher was appointed to ensure that data collection and analysis maintained a consumer centred focus. Probe questions (Table 1) in the interview guide involved the extent and duration of health condition(s), self-management practices, coping strategies, support

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networks, involvement and participation in CHO programmes. Ethical approval for the study was obtained from a University Human Research Ethics Committee (PHM/12/11/HREC).

Table 1. Interview questions/prompts relevant to CHOs.

Tell me about your journey since you were first told about your condition(s)?
How has your condition(s) impacted on your life?
Tell me about some of the things you do to manage your condition(s)?
Are you a member of a CHO and why/why not?
How is the CHO helping you manage your condition?

Semi-structured, in-depth interviews were conducted personally by members of the research team during May to October 2012. The interviews were conducted either face-to-face ($n = 49$) or via telephone ($n = 48$). The interviewer and the interview location were informed by the specific needs of the participant and consideration of their personal circumstances (e.g. age, gender and religious beliefs). Initially, interviews were conducted in research pairs (e.g. two research team members) to facilitate a standardised approach. Interviews were audio-recorded (except for two where consent for audio-recording was not provided), transcribed verbatim upon completion and on average, lasted 50 minutes. Four of the interviews with participants of CALD backgrounds were conducted with a bilingual interpreter upon the request of the participant. Interpreters were respected and trusted by each participant and had well-established connections with the participant's cultural values and beliefs. To ensure interviewer consistency, verbal and written interview debriefs were initiated, and feedback from the research team was provided to the interviewers throughout the data collection process. Table 2 summarises the characteristics of study participants.

Table 2. Characteristics of the study sample.

Participant characteristics		($n = 97$)	(%)
Age	Mean = 57.2 years, SD = 13.03		
Gender	Male	32	33%
	Female	65	67%
Location	Rural/remote (e.g. Mt Isa, Queensland)	36	37%
	Urban/metropolitan (e.g. Perth, Western Australia)	61	63%
Carer or consumer	Consumer only (C)	69	7%
	Carer only (CA)	12	1%
	Carer/consumer (CC)	16	17%
Cultural background	Aboriginal and Torres Strait Islander	23	24%
	CALD* e.g. Egyptian, Lebanese, Japanese, German, Bosnian, Burmese, Italian, Samoan	19	20%
	Caucasian	55	57%
Chronic illness(s)	One chronic illness only	10	12%
	Two or more illnesses	75	88%
Type of illness(s)	Cancer	15	18%
	Diabetes	37	44%
	Cardiovascular	68	80%
	Renal	7	8%
	Mental illness	24	28%
	Musculoskeletal	20	24%
	Neurological	18	21%
	Respiratory	27	32%
	Other (e.g., quadriplegic, hypothyroidism, insomnia, Meniere's disease, macular degeneration, polio, reflux, polycystic ovary syndrome, chronic bladder infection, chronic acne, Hashimoto's disorder)	57	67%

*CALD = culturally and linguistically diverse

Data analysis

Transcribed interviews were analysed concurrently using an iterative thematic approach via the constant comparison method (Glaser, 1965). Three researchers read and re-read the transcripts to familiarise themselves with the data, and used the electronic qualitative data analysis package QSR NVIVO 9© (QSR International Pty Ltd, 2010) to code the data into themes and sub-themes in accordance with thematic analysis. Using this approach, data collection and analysis were based on an integrated rather than a linear process, with each interview informing the collection of subsequent interview data.

After initial coding, interviews were further explored to develop sub-themes, leading to their further refinement. Annotated cards were also used during this process to record how the themes were derived and what they represented. All participants were assigned one or more codes in order to ensure the auditability of the analysis. For example, C represented consumer only, CA carer only, CC consumer and carer, IND Indigenous person, CALD culturally and linguistically diverse person, and CH represented a person who was a healthcare professional but who simultaneously was either a carer, someone who experienced a chronic condition, or both. Authenticity of the analysis was ensured with a member of the research team randomly selecting samples of data for review of coding. The data analysis process was discussed and reviewed by the entire research team whose members had different levels of research expertise (e.g. senior researchers to investigators). Data saturation was established for the interviews and the sub-groups (e.g. illness type and cultural background) when the participants' experiences and perspectives became recurring.

Results

Three inter-related themes were identified that represented the benefits of involvement and participation in CHOs from the perspectives of consumers and carers (Figure 1): knowledge and information, connection and support, and experiential learning. Limited access pathways emerged as an entry barrier, which inhibited a person's entry into a CHO. Finally, user beliefs and experiences emerged as a progress barrier, which inhibited the continued involvement in a CHO once a person had participated in CHO programmes.

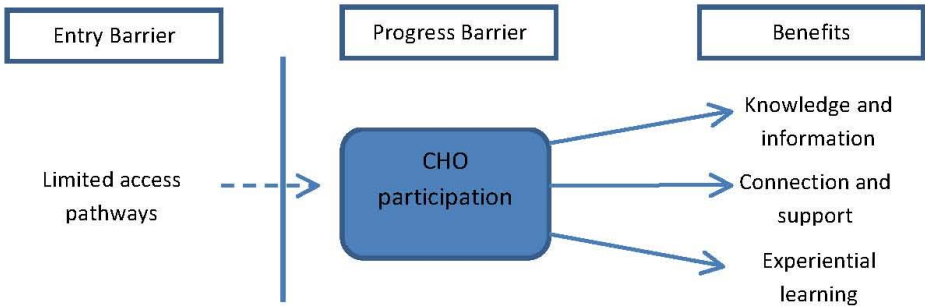


Figure 1. Barriers and benefits of consumer health organisation participation.

Benefits

Knowledge and information. One of the most fundamental reasons for joining a CHO was to obtain knowledge and information, which was a core component of self-management. Participating in programmes offered by such organisations provided invaluable knowledge and information about a person's condition(s), including symptoms, treatment options, practical solutions, and coping strategies, all of which are essential for self-management. For example, one participant with osteoarthritis discussed keeping up to date on information about new developments in treatment:

...it keeps you abreast of modern developments...You know new drugs, new research [C_1001]

Another participant of Indigenous background with multiple conditions indicated that participation in CHO programmes equipped her with the necessary resources to self-manage her illness:

...that's what this programme does for you,... [conducted by the CHO] it gives you the education so you can self-manage, which is brilliant [C(IND)_1164]

CHO programmes, through knowledge and information, instilled confidence in members' self-management practices and ability to cope with their conditions. Quite often, CHOs would have guest speakers to present information to members on a particular chronic condition. A healthcare professional who was an unpaid carer of a young child with asthma discussed the value of information and education provided by CHOs, and encouraged their use by other health consumers:

I actually think they're [CHOs] excellent. I mean I've used them a lot in my work. I do, I think they're an excellent, excellent resource [CC(HP)_1049]

Carers seemed particularly appreciative of the knowledge and information they obtained through CHO programmes. Carers were able to better understand the health conditions which the person they cared for experienced. A consumer/carer of an adult with a mental illness mentioned:

Quite a revelation at first and we got into the swing of it and learnt about it.. we've got an understanding of his condition even though he hasn't [CC_1016]

Connection and support. Emotional, practical and financial support and connection were other important reasons for joining CHOs. Emotional support was particularly important for participants who did not have an extended support network. CHOs provided emotional support and connection by providing advice, understanding and encouragement. One participant claimed to have successfully quit smoking as the result of the emotional support and encouragement she received from a lung support group. She further added that the support group gave her hope and made her realise that she could live a long normal life with her condition. When asked what her main reason for joining a CHO was, an Indigenous woman with multiple health conditions replied:

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They were non-judgemental. I wasn't just another mental case or a hypochondriac. They had understanding and compassion and they had time [C(IND)_1095]

When asked to comment on the emotional support she received from the CHO which she attended, a participant from a CALD background with comorbidity passionately responded:

They are like family to me now [C(CALD)_1134]

Mixing with others, comfort from knowing that they were not alone, and opportunities to participate in social outings were positively discussed. In relation to practical support, some CHOs assisted members with personal care and household duties, with an elderly female with multiple conditions explaining:

... they [carer from a CHO] come around and mowed my lawn for ten dollars...for anything that goes wrong in a home, they'll [CHO] come around and fix it up and it doesn't cost much [C(IND)_1097]

Another participant from a culturally and linguistically diverse background added:

They send this lady, she come two hours three times a week. I can't wash myself, she wash me, she wash the dishes and she cook once a week [C(CALD)_1134]

Another participant with diabetes relied upon the support of CHO to purchase her medication:

....all my pump consumables and things like that I go through [name of CHO]...They're brilliant on their delivery, straight to my door so I don't have to think about it... [C_1121]

CHOs also offered support to the carer, sometimes assisting them to access respite from their role, with a carer admitting:

I don't know how much my husband actually was aware of them [CHO] being there, but for me, it boosted me, it was just what I needed [CA_1149]

Finally, CHOs also provided participants with financial support. For example, a carer for her quadriplegic partner discussed how a CHO and a private donor provided financial support with the purchase of a highly sophisticated massage chair for her partner, which would otherwise have been unaffordable:

[name of CHO] helped. There was actually a private donor, donating so much [name of CHO] came up with a couple of hundred I think [CA_1071]

Experiential learning. For many participants, CHOs created opportunities for experiential learning with others who had similar chronic conditions. Participants described instances where they benefited from other's experiences and learnt about available treatment options. For example, a person who contemplated having surgery suggested:

I met one lady at the class [offered by CHO] who'd had it, the operation ... you're really good when you first have it done and then within five years you just, you're back to where you were [C_1009]

Participating in CHOs also provided members an opportunity to openly discuss their experiences with primary healthcare services and professionals with each other:

The other thing we do again with... [name of CHO] we say you know I have been to see so and so and they were very good [C_1008]

Others found comfort in discussing matters unrelated to their illness, which provided an escape from the realities of everyday life. Furthermore, the ability to share confidential experiences and personal feelings eased the pressure on other relationships (e.g. with a carer, spouse, and child).

Furthermore, the experiential knowledge obtained through interaction with other consumers made members 'experts in their illness,' enabling them to engage in more constructive discussions with their healthcare providers:

...I think coming to the ...[CHO programme's name] it gives us [participant referring to ability], to be able to understand and to be able to talk to the doctors, because we do understand what our health problems are [C(IND)_1163]

Entry barrier

Limited access pathways. An important barrier that inhibited participants' entry into CHOs was the underdeveloped pathways between GPs and such organisations. Access pathways between other medical (e.g. neurologist, physiotherapist) and healthcare providers (e.g. diabetes educator and naturopath) appeared to be more developed than with GPs, with some participants claiming to join a CHO as a result of direct encouragement from such providers. Many participants believed to have received minimal and sometimes no encouragement from their primary physician to seek and join a CHO. When asked about their first encounter and referral processes to CHOs, some participants relied on personal effort and utilization of their own networks (e.g. friends or family members):

I then started to do some research myself and I went to the... [name of CHO] [C_1052]

When discussing her first encounter with a CHO, a young mother with Graves' disease said:

I was just looking at those [advertisements] randomly and I just found the notice there the other day [workshop conducted by a CHO]. There is a talk going on in a couple of weeks' time [C(CALD)_1152]

Another participant who experienced chronic back pain as a result of a workplace injury discussed her need to start a support group with a friend to cope with feelings of isolation and

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loneliness. Discussing her journey in initiating such a support group, she claimed to have received minimal support from primary healthcare professionals (mainly the GP):

I actually wrote to all the doctors at our local medical centre just telling them about our group and asking them to refer patients... we asked if we could just put up a flyer on their notice board as well just telling people about the group. And they just haven't done that [C_1080]

Another participant who developed lung disease as a result of complications from pneumonia described a similar experience:

My GP has been excellent... He's open minded to the use of natural remedies and even encourages them for use. The one thing I have found unusual with him is that... I have been trying to get him to support my lung support group but he thinks I am the only patient he has with lung disease. I find this difficult to believe [C(IND)_1141]

When this participant was asked what he would have preferred to have happened, he replied:

I think the GPs and all that... should be aware of all the carer groups and all the support groups [CC_1016]

When asked which health professional was best placed to provide information about CHOs, another participant corroborated:

Your general doctor...Because they're the ones that most people go to first [C_1060]

Progress barrier

User beliefs and experiences. Although limited access pathways emerged as an entry barrier, user experience inhibited the continued involvement in a CHO once a person had participated in their programmes. Many of these participants previously partook in various programmes but ceased their involvement mainly because of their personal beliefs about their own health condition(s), support needs, and also their experiences of CHOs. There was a sense of belief among some participants that CHOs could not provide any further assistance with their conditions. These participants claimed to have become 'experts' in their health, as a result of learning to live with and self-manage their conditions for an extended period of time. A participant with diabetes mentioned:

... when you've been a diabetic for sixty years, I don't think there's a lot you can learn [CC_1021]

Another who was born with chronic asthma and depression confirmed:

...because I was diagnosed at only fifteen months of age I've never known anything different than having that condition. I came through [CC_1166]

Some participants also questioned the suitability of group programmes for them personally. For example, a participant with chronic obstructive pulmonary disease (COPD) and

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depression, who participated in a CHO programme, questioned the age group and discussed the difficulty of fitting in:

I got there [CHO workshop], there were eight people and they were that old, I mean they were all in you know one foot in the grave... So I've got that big age gap [C_1017]

Others were reluctant to seek social contact through a CHO because contact with others who experienced the same or similar condition(s) became distressing. Several participants even claimed to have become depressed as a result of talking about their conditions and seeing others who developed complications because of participation in CHO programmes:

I didn't want to sit there and listen to everybody else complain all the time 'cause it's depressing [C(CH)_1127]

I joined a... [self-help group] on the computer and I found that in the end, I felt very depressed by it, I thought oh these poor people [C_1014]

Participation in CHOs also provoked feelings of 'incapability' and 'helplessness' in some participants:

I don't class myself as an invalid, so going to places like that... I found it more or less for me, not for other people, for me, like a waste of time [CC(CALD)_1038]

One of the fundamental reasons for not joining or ceasing to be a proactive member of a CHO were the participant's personal beliefs about their desire to discuss their health conditions. Some participants perceived discussing their health conditions as a sign of weakness, with one participant claiming:

I don't want to be whinging about my situation, I don't want to be talking about my depression [C(CALD)_1069]

Discussion

Managing chronic illness can be 'hard work' (Corbin and Strauss, 1985), characterised by obtaining knowledge and information, organising treatment, changing lifestyle, and coping with symptoms. Although the formal primary healthcare system helps support people, most of this 'hard work' rests on people's personal efforts and coping strategies (May *et al.*, 2009). This calls for a greater emphasis on informal healthcare services to provide people the necessary resources to effectively self-manage their chronic conditions. The findings of this study reinforce the notion that CHOs have a complementary role and make a valuable contribution in alleviating the hard work associated with self-managing chronic conditions. Our findings suggest that for most participants, accessing CHOs provide knowledge and information about their condition(s), various treatment options, support and encouragement for healthy lifestyle changes, and a sense of connection and experiential learning that they find empowering. For most participants we interviewed, the resources offered by CHOs were

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fundamental in enhancing the capacity of people to effectively engage in self-management of their chronic health conditions. Given that the management of chronic conditions can be characterised by 'hard work', our findings are consistent with existing literature (Coppa and Boyle, 2003; Nijsten *et al.*, 2005; Sav *et al.*, 2012), which demonstrates the fundamental value of CHOs in alleviating some of this work for consumers and their carers.

The important and complementary role of CHOs in chronic illness management underscores the need for better integration of these organisations into the primary healthcare system. Greater integration of CHOs is also necessary in the context of current health system constraints (Boyle *et al.*, 2009). Primary healthcare systems may not provide consumers with adequate access to the non-clinical and psychosocial aspects of care (e.g. experiential knowledge) that they need in order to effectively self-manage their ongoing health conditions (Boyle *et al.*, 2009). Furthermore, as a result of short consultation times, GPs can be restricted in providing the amount of information or the necessary support and training required for effective self-management (Sav *et al.*, 2012). Our findings indicate that CHOs can provide users with experiential knowledge, a sense of connection and collaboration with other people, emotional support and encouragement, information sharing and practical assistance, all of which may be difficult to obtain within the formal primary healthcare system.

Despite their potential, limited access pathways inhibited some peoples' entry and participation with CHOs, thereby restricting their ability to utilise this largely untapped resource (Sav *et al.*, 2012). The lack of access pathways between CHOs and GPs also seem to be a key determinant of a lack of CHO usage amongst consumers within the literature (Young *et al.*, 2010). Although the reasons for poor referral are complex, research indicates the overriding factors are the physician's concern about the misinformation and the potential for such organisations to cause psychological harm (Steginga *et al.*, 2007). Based on the comments of some participants in our study, interaction with others who experience the same or similar health conditions can indeed be associated with psychological harm (e.g. depression). However, because of the scarcity of research in this area, it is difficult to exactly know if, how and under what circumstances, CHOs can have negative effects on people's health.

Despite the potential value of CHOs in providing psychosocial aspects of care for effective self-management, it is important to recognise that there is no one-size fits all solution. Our findings suggest that some participants may not benefit from involvement in CHOs. As a result of becoming 'experts' in their health, some participants may feel that there is little that CHOs can offer. Some people may even find social contact with others depressing while others can enjoy the company and opportunities for engagement. This underscores the need for consumer-directed holistic care that is responsive to each person's unique circumstances and preferences (Sav *et al.*, 2013). Although CHOs are an important avenue for obtaining assistance and resources, multiple strategies, services and avenues of support are needed to empower people to become more resilient and engage in effective self-management behaviours (e.g. learning about treatments, coping with difficulties, adjusting lifestyle, gaining support etc.) (Coppa and Boyle, 2003).

Our findings corroborate the beneficial impact of such organisations for the majority of people with chronic conditions and their carers. Furthermore, there is a need for further integration into the healthcare system to increase the reliable delivery and accessibility of CHOs. Such integration systems are needed to ensure that people who would benefit from accessing these organisations can do so (Boyle *et al.*, 2003). The National Diabetes Services Scheme (NDSS) is one example of an Australian government initiative that has been successfully integrated into the primary healthcare system. This initiative is administered through Diabetes Australia, a CHO that provides assistance, information and support for people with diabetes (Diabetes Australia, 2013). Most importantly however, it provides subsidised products (e.g. insulin) to people experiencing diabetes, which can minimise the widely reported financial burden of treatment (Sav *et al.*, 2013). Users can purchase subsidised products through NDSS Access Points, usually located in community pharmacies and primary healthcare clinics. The availability of NDSS in community pharmacies not only enables people to obtain subsidised products, but also allows them to more readily access information and advice on diabetes.

In contrast, while CHOs for other common chronic conditions, such as cardiovascular disease, asthma and cancer exist, a NDSS type of initiative is not available for these disease states. Until such initiatives exist for other chronic conditions, GPs must make a personal effort to discuss CHO access and provide information on the range of CHOs, thereby creating pathways for their patients into longer-term supportive communities. A resource kit, which provides information on the range of CHOs available for chronic condition(s), such as one compiled for community pharmacists (Campbell *et al.*, 2013), may be a valuable resource. Because GPs are viewed as being highly trustworthy (Kreuter *et al.*, 2000), their endorsement of CHOs is likely to increase the likelihood that consumers will seek support from such organisations. Finally, referral from other primary healthcare professionals should be explored further to provide GPs an understanding of successful referral processes.

Strategies to increase referral between CHOs and GPs do not only fall on the shoulders of GPs but also on CHOs themselves. CHOs must make proactive efforts to collaborate with GPs and simplify the process for GPs to refer their patients to such organisations for effective self-management (Boyle *et al.*, 2003). At a most basic level, CHOs can disseminate information about their complementary role in self-management via mail-outs, brochures, face-to-face meetings and invitations for GPs to participate in CHO programmes. Additionally, CHOs should also reach out to people who have not been able or willing to access them to self-manage their conditions.

Limitations and strengths of this study

Limitations of this study include the use of qualitative cross-sectional data collection at one point in time, thereby limiting our ability to explain how a person's use of CHO changes over time. Furthermore, the results are based on self-reported data, risking the possibility that some participants' gave a socially desirable response (e.g. benefits of CHO usage). Whilst interviews were conducted by different researchers, we are confident that any risk of interviewer bias was minimised with the use of a standardised interview guide and by sharing debriefs with the research team for each interview. Furthermore, the completion of the initial interviews by pairs minimised the risk of interviewer bias. Although a non-random purposive (snowball) sampling strategy to locate participants may reduce the generalizability of our findings, this particular sampling method enabled us to recruit participants from minority

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groups, from affluent and disadvantaged communities and with a range of chronic conditions. Other entry level barriers might have emerged, including misperceptions about what CHOs are able to offer or how they operate, if our sample consisted of more participants who had no contact with CHOs. Indeed, the strength of our study, in addition to the number of interviews that allowed saturation of themes to be reached, was the ability to obtain a wide range of perspectives from groups of people that are often not included in primary healthcare research. Finally, although our study had representation from culturally and linguistically diverse backgrounds, most of these participants were of Caucasian backgrounds (e.g. German, Bosnian, Italian, etc.). Future research should focus on a broader range of culturally diverse participants to help understand the role of culture in CHO experiences. Despite these limitations, this study provides an inclusive understanding of the benefits of CHOs and the barriers that limit involvement in such organisations, from the perspective of first-hand users, (e.g. people with chronic conditions and their carers).

Conclusion

Overall, this study confirms that CHOs are a valuable resource in alleviating the 'work of being a patient' for some people with chronic conditions and their unpaid carers. The rise of chronic conditions worldwide and the resulting pressures on primary healthcare services are likely to place an even greater emphasis on the role of CHOs in helping people to self-manage their conditions. However, the optimal access and utilisation of CHOs are obscured by the barriers that inhibit user involvement. Such barriers need to be systematically addressed to ensure that the full potential of CHOs is achieved.

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