Appendix 3.4 – Expectations of Community Pharmacy Support for People with Chronic Health Conditions

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Community pharmacy in Australia: A health hub destination of the future
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Abstract

Background: Rates of chronic illness are rising in Australia and as medications are frequently used in the management of a range of chronic conditions, community pharmacists are in an ideal position to better assist these consumers. There is currently limited information as to how pharmacy can do this from the perspective of consumer health organizations, health advocates and professional support organizations.

Objectives: To explore new roles, opportunities and any associated barriers for community pharmacy to better assist consumers with chronic illnesses.

Methods: Representatives of non-government consumer health organizations (n = 10) were interviewed from the key health priority areas emphasized by the Australian government. Health advocates (n = 3), innovative health care professionals (n = 4) and representatives of health care professional organizations (n = 4) from pharmacy and medicine also participated. Interviews were analyzed via thematic analysis.

Results: Twenty-one in-depth interviews were conducted. The core finding was the potential for community pharmacies to become a health hub destination, whereby pharmacy staff assist consumers with chronic conditions to navigate the health system (e.g., provide information on support services), manage their medications, and provide health advocacy. Participants expressed their concern that consumers may not be aware of the breadth of the pharmacist's expertise and that further collaboration is needed with non-government consumer health organizations and other health providers. Emphasis was placed on the improvement of the pharmacist's current role, particularly in the area of medication advice and...
Introduction

The increasing prevalence of chronic illnesses is of global significance, causing an estimated 36 million deaths in 2008. Given that the majority of Australians reported the presence of one or more long-term conditions in 2007–2008, and health expenditure exceeded $100 billion for the first time in this period, appropriate and effective delivery of health care for consumers with chronic illness is of paramount importance. Currently, many Australians regularly visit their community pharmacy for advice and to obtain medication to treat or relieve symptoms or prevent the progression of chronic conditions. As community pharmacy has been viewed as highly accessible, pharmacists clearly have a role to play in improving the health care for these consumers. In particular, the pharmacy profession has been shifting toward care delivery that is more patient-centered, with pharmacists in many countries providing management programs for chronic conditions including asthma, arthritis, mental illness, diabetes, cardiovascular health and osteoporosis. In Australia, while community pharmacists are still focused on dispensing medication, they have also integrated a range of professional services into their practice such as medication reviews and disease-specific management programs. The expansion of the pharmacist’s role is strongly advocated by two peak pharmacy organizations in Australia, and the suitability of pharmacists to provide professional services in the primary care setting is well articulated in the literature. Previous studies have also shown that the provision of disease-specific services in community pharmacy is generally well received by users, due to the accessibility and convenience of these services.

Another key source of support for consumers with chronic conditions is consumer health organizations (e.g., Parkinson’s Australia, Alzheimer’s Australia). These organizations provide psychosocial support and a range of informational resources to better enable consumers and their carers to manage their conditions. These groups are in a unique position to gain further understanding of what their consumer members need from the health system, including community pharmacy. Furthermore, these organizations may also refer their members to community pharmacy for additional services. Therefore, it would be valuable to seek their opinions of the role that community pharmacy can play to better assist the consumers they represent. However, there is limited information on the perceived role of community pharmacy from the perspective of consumer health organizations. One Australian report explored the views of consumer health organizations in relation to consumers’ experiences, expectations and needs of community pharmacy. Personalized service from the pharmacist and greater provision of medication information were key recommendations from the focus groups. Similarly, professional organizations, government bodies and consumer health organizations identified the need for improvements in relation to pharmacist engagement within the community, the level of privacy and provision of written and verbal information to support consumers. Another Australian project reported that “community pharmacy may not be initially seen as part of the central strategy by patient support organizations.”

Despite the evolving role of the pharmacist in chronic disease management, they are underutilized as health care professionals. Although the reasons for underutilization are complex, one very important issue is the lack of consumer awareness of the breadth of skills pharmacists have. Research suggests that consumers...
perceive the pharmacist’s primary role as medication providers, or mainly view the community pharmacy as a place to purchase quality medications. One Australian study has also corroborated the belief that the core function of a pharmacy is the provision of medicine and advice, highlighting the limited awareness of consumers and consumer advocates (e.g., support group representatives) about the services offered by community pharmacy. There is clearly a misalignment between how consumers (and their advocates) view the pharmacist’s role and what pharmacists can actually offer.

Given that the Australian government has emphasized the management of chronic illness as a strategic priority area, there is a significant opportunity for community pharmacy to be of greater assistance to these consumers. However, considering the lack of knowledge about the role of community pharmacy, it is necessary to first understand the perspectives of those who will influence the utilization of such services in the future (i.e., non-government consumer health organizations, health advocates and health care professional organizations). Consequently, this raises the question: how can community pharmacy better assist consumers with chronic illness to manage their condition(s)?

The aim of this exploratory study was to identify the views of key stakeholders (i.e., individuals representing non-government consumer health organizations and health advocates) with respect to the role of community pharmacy in supporting consumers with chronic illness(s). The study also sought to identify the opportunities and barriers for community pharmacy in chronic illness management from the viewpoints of health care professional organizations from pharmacy and medicine. Furthermore, the themes identified will be used to develop an interview guide for a much larger study involving consumers with chronic illness(s) and carers.

Method
Study design
A list of non-government consumer health organizations, health care professional organizations, health advocates and innovative health care professionals were obtained by the following methods: prior researcher knowledge from working in the health sector, discussion with a Reference Group comprising of members with knowledge in the field and recommendations from study participants. Additional participants were also identified during the completion of the in-depth interviews via a snowball sampling strategy. As both non-government consumer and professional organizations are nationally recognized, additional contact details were obtained from the Internet. Innovative health professionals were identified as leaders in their field who also had extensive experience in organizational and pharmacy practice.

Consumer health organizations were purposively selected as representing the following disease groups: arthritis, asthma, diabetes, cancer, mental health and cardiovascular health. These health areas have been identified as high priority by the Australian Government as they contribute to significant morbidity, mortality or both. Up to two people participated from each selected organization to facilitate exploration of different perspectives within the organization. These perspectives included policy development (e.g., CEO/board member) or program implementation (e.g., program officer). Health advocates were drawn from organizations and innovative individuals that supported culturally and linguistically diverse (CALD) communities, carers and health consumers. Health care professionals were selected from peak organizations representing medicine and pharmacy.

Researchers initially contacted the CEO of each organization (via phone and email) to identify if the organization would be interested in participating in the study and the individual(s) that would best represent their views/interests. In some instances, individuals were contacted to participate directly (e.g., Health advocates and individuals recommended by the Reference Group and study participants).

Semi-structured interviews were used, giving stakeholders the opportunity to express their opinion(s) and experiences, enabling exploration of a number of areas: concerns related to the management of a chronic illness and medication use that community pharmacy could assist with, views of the current and future role(s) of community pharmacy and potential barriers in developing these role(s). An interview guide (Table 1) was developed after reviewing the literature, piloted with a past senior member of a consumer health organization, discussed and further refined by the project team prior to the commencement of the interviews. The interview guide was further modified as the interviews progressed to enable exploration of new information.
Table 1
Interview guide regarding community pharmacy

<table>
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<th>Question</th>
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<tr>
<td>How do your members currently use community pharmacy to help them manage their chronic illness(es)?</td>
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<tr>
<td>What is the organization/individual perspective on the role that community pharmacies currently have in the management of consumers with chronic illness(es)?</td>
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<tr>
<td>Can you describe the types of services that community pharmacy currently provide for health consumers to support them to manage their chronic illness(es)?</td>
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<tr>
<td>Can you tell me how the role of community pharmacy in assisting consumers with chronic illness(es) has evolved?</td>
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<td>Do your members comment about problems or concerns that consumers with chronic illness(es) have with their medication(s) for their chronic illness(es)?</td>
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<tr>
<td>What are some of the main problems or concerns that you think consumers with chronic illness(es) have?</td>
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<tr>
<td>How could community pharmacy help your members to manage their chronic illness(es)?</td>
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<tr>
<td>What is [insert organization/individual]'s perspective on the role that community pharmacy could have in the management of consumers with chronic illness in the future?</td>
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<tr>
<td>What types of services do you see community pharmacy providing in the future to better support health consumers to manage their chronic illness(es)?</td>
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<tr>
<td>What issues do you think community pharmacy might face in moving toward new models of care or services to support consumers with management of their chronic illness(es)?</td>
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*These questions are a guide only. The interview framework was altered for each participant depending on their position and background.

**Procedure**

On confirmation of an individual’s verbal agreement to participate, the study information sheet and interview guide were emailed to each key stakeholder. Two researchers (SM, AS) from different health backgrounds (pharmacy and public health) conducted semi-structured interviews with participants between January and March 2012. Informed consent was obtained from all participants prior to the commencement of the interview and their confidentiality was assured. All interviews were recorded and transcribed verbatim by the interviewers (SM and AS), who also conducted peer-debriefing sessions. This initiated an informal coding process, enabling the research team to familiarize themselves with the data and inform changes to the interview guide. The study received ethical approval from a University Human Research Ethics Committee (PHM/12/11/HREC).

**Data analysis**

The interview questions pertaining to this study was independently analyzed by an experienced researcher (SM) using thematic analysis, a common approach used to analyze qualitative data in health care research. The researcher had a pharmacy background, however tried to utilize an inductive approach by not engaging with the literature prior to data analysis. As the study aimed to explore an under-researched area, a semantic approach to thematic analysis was used to provide a description of the entire data set. This method of analysis would also enable the researchers to identify important themes for future exploration. Once familiar with the data from reading and re-reading the transcripts, the researcher used the electronic qualitative data analysis package QSR NVIVO 9 to organize the data into broad codes. Further categorization of these codes occurred in the next stage of the analysis. To ensure credibility and trustworthiness of the data, in-depth discussions were undertaken with two other researchers (AS, FK) around the analysis process and findings, thus verifying the researcher’s judgment. Written transcripts were also returned to some participants to ensure that their perspectives were truly represented. Interviews continued until data saturation was achieved (i.e., no new themes were identified). Although the participants were from different organizations, they all came from a health background and were advocates for better health care. In this respect, participants could be classified as a relatively homogenous group. Furthermore, rich data was obtained from each interview, which facilitated reaching data saturation. Data for all participants were analyzed with the following identifiers used for participant quotations: a non-government consumer health organization representative (CHO), innovative health care professional/representative of a health care professional organization (HCP) or a health advocate/consultant (HA).

**Results**

**Study participants**

Participants (n = 21) included three board members (policy development) and seven
personnel (program implementation) from non-government consumer health organizations (CHO), with two of these participants representing a culturally and linguistically diverse (CALD) organization. Three consumer health advocates (HA) were recruited including two consumer health organization representatives and an individual not aligned with a particular organization. Three representatives of pharmacy organizations, a representative from a medical organization and four innovative practitioners (HCP) also participated. Eleven participants were from Queensland and 10 from other Australian states. Interviews were undertaken at a time and place convenient for participants, either face-to-face (n = 10) or via telephone (n = 11). The interview duration averaged 64 min (range 42–84 min).

Themes

Three main themes emerged from the data and were interconnected: the pharmacist’s current role, pharmacy as a health hub and barriers for expanding role(s) (Fig. 1).

Pharmacist’s current role

Although the interviews were primarily focused on how community pharmacy and its staff can better assist consumers, all participants alluded to the current role that pharmacy plays in this area. Three key themes emerged in relation to this: accessibility, advice and product supply and improvement and extension of the pharmacist’s role.

Some participants discussed that consumers viewed community pharmacists as highly accessible health professionals in terms of cost and location, particularly as there was no consultation fee involved. In addition, the approachability of pharmacists was discussed in terms of being easy to talk to, with participants acknowledging that some consumers may feel more comfortable talking to a pharmacist than a GP. One participant commented on the neutrality of the pharmacy as a health destination, where consumers could freely discuss concerns with the pharmacist without perceived risk of serious repercussions:

...I think there’s a lot of personality that comes into play in your relationship with your doctor... I think that sometimes there’s a fear of speaking openly... I think that the pharmacy provides a neutral place where they can go in and they can say

Pharmacy as a health hub

- Accessibility
- Advice and product supply
- Improvement and extension

Barriers for role development

- Current remuneration model
- Disputed care
- Limited awareness of pharmacy role

Fig. 1. Key themes to emerge from the data.

Well, this is what they told me. I have to take. Can you tell me how it goes? (CHO_13).

Pharmacists were also available for medication and health care advice without an appointment. This was emphasized by representatives from consumer organizations when discussing the difficulty in obtaining a doctor’s appointment. However, interviewees also acknowledged that pharmacists were not accessible if they were predominantly focused on dispensing prescriptions:

They’re not. How can they be when they’re two counters back, banging away on the keyboard. If you asked for the pharmacist, yeah, they’ll come out when they’re ready. But if they’re busy, I’m too busy. I haven’t got time (HCP_9).

Comments were consistent with the general view that the pharmacist’s primary role was to dispense medications and provide medication advice. Some participants also discussed how pharmacists use their knowledge to clarify if a doctor’s appointment was necessary and to provide non-prescription medication. However, health care professionals in particular perceived room for improvement in the pharmacist’s medication supply and management role:

All I see is the pharmacy being a stocking of the products that I need to buy... They really don’t provide any advice at all for my conditions. Most of the time I’m interacting with a pharmacy assistant who doesn’t really have a clue... (HCP_39).

...the only thing that they ever ask you is, would you like the cheaper brand?... There’s a huge opportunity to do it better (HCP_21).

This need for role improvement was also particularly expressed by an NGO representative, who raised concerns that pharmacists are
inconsistent in providing medication information to consumers:

... even though there was mandated staff brought in and they’re paid money to do it... pharmacists are not complying with the provision of CMI (consumer medicines information) and that is critical if we’re going to manage a chronic disease (CHO_14).

However, the majority of participants discussed the value of more recent extensions to the traditional pharmacist supply role such as home medication reviews (HMRRs) and dose administration aids for the community. Participants commented on how well pharmacists were providing such professional services, including medication deliveries. The following participant emphasizes the value of pharmacists in taking a holistic approach to a medication supply role:

So your pharmacists that deliver the drugs, I think are wonderful, because they’re a different face coming into the house. They know who’s in the house, and how the house is looking and how the person is looking... (RA_17).

In consideration of the pharmacist’s knowledge and training, the need for extending their role to assist in improving health care for consumers with chronic conditions was discussed in further detail:

...we’re overtrained and undervalued... we probably are out of all of the health professions the most overtrained for what we currently get the opportunity to do (HCP_5).

Pharmacy as a health hub

A key theme to emerge in relation to extending the role of the pharmacist was the strong belief in the value of the community pharmacy becoming a health hub; a health care destination that involved more than just the provision of medication advice:

...it’s not about the drugs, it’s about supporting them to lose weight... to do more exercise, to eat more proper foods and all the rest of it... this concept of being a health hub, being seen as what I call the health coach, needs to be part of the future of community pharmacy (HCP_7).

For the consumer to register with them [pharmacists], and work out a management care plan and have the pharmacist monitor their signs and their symptoms as part of their self-management plan (SIC_016).

This model of care could address some of the gaps in the health care system identified by participants:

...it can certainly be considered a kind of across the board issue, in terms of CALD [cultural and linguistically diverse] communities not knowing what is available and where to get that information (CHO_20_participant 2).

The services that clients are accessing are quite varied and disjointed... I think sometimes the GPs [general practitioners] become quite overwhelmed at the number of services that are out there and not knowing what they do. So it’s difficult to get them to refer (HCP_11).

The above quotes demonstrate that consumers need assistance in accessing non-government consumer health organizations and health care professionals, as the health system can be viewed as complex and disjointed. Therefore, participants identified that there was a need for pharmacists to assist consumers in the following areas, as attributes of a health hub concept; health care system navigation (signposting), medication management and health advocacy.

There was an acknowledgment among participants that consumers find it difficult to navigate the health system and to identify the support services and health professionals they individually require. Community pharmacies as accessible health care destinations could address this issue from two perspectives: a clinical triage role to other health care professionals and a more holistic approach by connecting consumers to non-government consumer health organizations for psychosocial support. This would include raising awareness of various health services and actively connecting consumers to these services within the health system.

...having them as a referral base to not just the GP, but to other ancillary services... (HCP_11).

There’s a role that I think the community pharmacy can and should play in assisting in connecting people up. It’s that point I mentioned before about navigating the system. I think we would strongly encourage community pharmacy to see itself as part of an interconnected system, and to play a role in connecting people with diabetes to the other things that might be useful for them (CHO_15).

...you know linking them with services, linking them with information and really raising awareness around things. Providing them with information about adherence to their medications... (CHO_19).

There was a strong emphasis that medication use reviews (other than home medicines reviews
(HMRs), which are conducted by accredited pharmacists within the consumer’s home) should be a service provided in the pharmacy as part of a health hub. This was identified as a strategy to address medication confusion, especially around generic versus branded medications. There was also consensus for pharmacists to continue to provide medication counseling, particularly for consumers taking multiple medications (polypharmacy) or those newly diagnosed:

...the pharmacist is ideally placed to be questioning the person about all of the medications that they are taking, so as they are filling a script for something, they should be having a bit of a chat to them...you know particularly older people polypharmacy is a huge deal (CHO_3).

...If I hear something from my doctor, but it didn’t really register because I was kind of in shock and the doctor has given me a prescription and says, here go down to the pharmacy, I need the pharmacist then to be able to reinforce those messages (CHO_12).

Acting as a health advocate was also viewed as a natural extension of the medica
tious management role, whereby the pharmacist can optimize the quality use of medicines while ensuring that consumers are satisfied with their overall health care. This can also encompass individualized and empowering care by supporting consumers to self-manage their condition(s).

...do I really need that medicine? If I do, what is the absolute minimum dose and the minimum amount of time I need to take that medicine...I think it’s possible that pharmacists...could play a role in helping people ask those questions of their prescribers, and possibly could even advocate on behalf of people who come into the pharmacy and deal directly with the doctor (HA_18).

They really want the health professional, and this would equally apply to community pharmacy, to not just, say, focus on their biomedical measure like their blood glucose level, but how are they going and how are they coping and what are the issues for them and what are their needs? (SIC_015).

Barriers for role expansion

Participants acknowledged that there were structural and societal barriers facing community pharmacy in terms of becoming a health hub, with the current remuneration model identified as the over-arching barrier.

Participants expressed that pharmacists are concerned with the supply of commercial products because the pharmacy is primarily a business, and the current environment typically had unsuitable space for professional services such as counseling. This was particularly discussed by participants not representing a consumer organization:

...there’s that commercial aspect of it. That’s a priority and that’s important for them. They’re not necessarily government funded to come out and discuss case by case issues (HCP_11).

The lack of privacy was also discussed as an influential factor as to whether consumers would seek advice from community pharmacy. Innovative practitioners and health care professional organization representatives also emphasized that in the past, there was no real push to change the current pharmacy model, which focused on product supply and prescription volume. One participant highlighted the difficulty in changing the culture:

...I think it’s been too easy to make money the other way, I think change is hard...I think there’s some things that pharmacists are frightened of (HCP_021).

Further to this, there was also discussion about the unsustainability of community pharmacy as it stands. The recent regulations requiring price disclosure in Australia, and a potential decline in revenue for the supply of generic prescription medications may be the catalyst needed for change:

...people are starting to feel the financial pressure with the retail model, because the government has made reforms around the PBS [Pharmaceutical Benefits Scheme] and the remuneration model for purely supply... (HCP_5).

Although the various attributes of a health hub destination were discussed by participants, there was also acknowledgment of the simple need for the pharmacist to step out of the dispensary to engage and become more proactive with health consumers. One participant also discussed the possibility of utilizing pharmacy assistants to provide medication education to consumers after further training in this role:

...as long as the pharmacy assistants...had good training and they had the support of the pharmacists...to be doing it as part of their role, I think actually they could still do quite a good job (CHO_8).

Another barrier raised by participants was the lack of coordinated care between pharmacists and other health care professionals. One interviewee
attributed this to the current pharmacy model where community pharmacists worked in a silo and there was limited opportunity to contribute to multidisciplinary teams:

I think pharmacy, especially community pharmacy, very much works in a silo. It's not all their fault... it's the way the system sort of has developed... There needs to be more information flow between health professionals, including pharmacists... (HCP_21).

A lack of communication or engagement with other health care professionals may negatively impact on their perception of the role that pharmacists can play. The implementation of personally controlled electronic health records, which was recently launched in Australia,29 was identified as one way to improve this communication and delivery of health care by interviewees.

Interviewees acknowledged that a challenge facing the pharmacy profession was that some consumers were unsure of what pharmacists could do other than supply medication. Consumers lacked the confidence to ask for medication advice and did not want to be seen as a bother:

...I think the key area about managing the conditions is for consumers to feel confident, have the knowledge and the skills that it's okay to go in and ask for a review of your medicines by the pharmacist... (CHO_14).

Although consumers needed to be more proactive in seeking help, it was suggested that pharmacists should promote their professional skills and engage further with consumers to address this barrier.

Discussion

This study set out to explore the perspectives of non-government consumer health organizations and health advocates as to how community pharmacy can better assist consumers with chronic illness. Overall the core finding of this study was the potential for community pharmacies to move beyond medication supply and become a health hub destination that assisted consumers with chronic conditions across three key domains: health care system navigation, medication management and eventually, health advocacy. Although the shift for pharmacy to provide professional health services has been emphasized both nationally30 and internationally,31,32 the notion that they could provide consumer support to navigate the health system and act as health advocates broadens the patient-centered approach to care. Barriers associated with an extended health care role were also discussed and reinforce those reported in the literature.33,34

Participants emphasized the accessibility of pharmacy, because many consumers use the pharmacy as a primary point of contact.35 Furthermore, pharmacies were identified as a neutral health care destination, providing independent advice and support to consumers. However, the importance of privacy and confidentiality to deliver professional services was emphasized, with participants agreeing that it was imperative for pharmacy to designate appropriate areas for this purpose. This is in line with existing research: lack of privacy and the capacity for confidential conversations are potential barriers for community pharmacists to better assist consumers with new services or medication and health information counseling.36,37 Considering that some chronic conditions are sensitive in nature, or consumers may regard their condition(s) as such, privacy and confidentiality are important matters.

Innovative practitioners and representatives of health professional organizations also acknowledged that pharmacists are underutilized health professionals, a finding which has been previously reported.18,37 Furthermore, it was evident that there is a current disconnect in the health system, with participants emphasizing the difficulties for consumers to find the resources, support and services they need. This was identified as a particular problem when first diagnosed with a condition. Furthermore, this gap in the health system was recently highlighted in an Australian study that also interviewed community based service providers.38 Our study identified that pharmacists are ideally placed to address this disconnect in the health system by navigating (or signposting) consumers from two perspectives: to other health professionals in a clinical triage role and to non-government consumer health organizations, thereby providing a more holistic approach to care. This can be viewed as complementary to the pharmacist's current role in the provision of medication advice. As consumers may have difficulty recalling information from medical consultations, and the degree of information understood at initial diagnosis may be reduced due to increased emotional status,39 the pharmacist's role in recapping information is critically important. Our findings corroborate research, which reports that pharmacists are often sought to reinforce or
clarify directions.\textsuperscript{37} GPs have also acknowledged that due to time constraints, the community pharmacist may be better placed to reinforce medication information.\textsuperscript{32}

However, GP participants also acknowledged that there were aspects of their current role that pharmacists needed to improve on, such as the provision of consumer medicines information (CMI) leaflets. This is not the first call for pharmacists to improve this service.\textsuperscript{17,35} Low rates of CMI leaflet supply by community pharmacists have been identified, particularly for repeat prescription items where the consumer had previously used the medication.\textsuperscript{32} If community pharmacies are to become a health hub destination, it is vital that pharmacists have the time to provide CMI and medication counseling tailored to the needs of the customer, as well as any additional information (e.g., health promotion).

Community pharmacists in Great Britain and New Zealand (NZ) have extended their contribution by conducting medication use reviews (MURs).\textsuperscript{24,39} This has been identified as a positive role for community pharmacists by NZ GP's, with the pharmacist's medication knowledge being utilized to increase patient understanding and medication adherence.\textsuperscript{32} Therefore, the pharmacist is a suitable health professional to emphasize and tailor counseling for the consumer and participants in our study suggested that pharmacists could extend their current role by conducting medication reviews. The information gathered from these consultations could result in the pharmacist advocating on behalf of the person and ensuring the quality use of medications. Indeed, the novel concept of pharmacists undertaking a health advocacy role was also identified in a recent study exploring the integration of Australian pharmacists in GP practices.\textsuperscript{41} This role is consistent with current professional practice standards, which states that the pharmacist 'accepts responsibility for advocating on behalf of consumers consistent with the professional role and expertise of the pharmacist.'\textsuperscript{45} Although medication reviews such as HMRs are conducted by accredited pharmacists in Australia, it is an opportune time for community pharmacists to progress toward a health advocacy role by introducing medication reviews such as the MedsCheck program into their practice.\textsuperscript{35} This service is similar to MURs, with pharmacists remunerated for reviewing and discussing the consumer's medications, providing medication and lifestyle related education and developing an individual action plan.\textsuperscript{32} Pharmacists are required to designate a private area for MedsCheck consultations and ensure they have the time to perform them.\textsuperscript{44} The importance of changes to policy and the practice environment in order for MURs to reach their full potential in improving consumer understanding of their medications has been highlighted in a recent study.\textsuperscript{40}

Although there was discussion about what a health hub should involve, less information was provided by participants as to how the profession can move toward this goal. Furthermore, participants identified that there were multiple barriers facing pharmacists to improve care and become a health hub, including the current model of practice. It was acknowledged by an innovative health care professional that some Australian community pharmacists may be anxious of change and are supportive of the current model, a finding consistent with the literature.\textsuperscript{32} Similarly, this has been reflected in New Zealand research, pharmacists recognized the need to embrace change and incorporate further services into their role but were still supportive of the status quo.\textsuperscript{33} Given the challenges facing pharmacists to expand their role(s), the current tasks undertaken by pharmacy assistants may be easier to change. One interviewee in the current study promoted the idea of utilizing pharmacy assistants to provide further information, as long as they were trained appropriately. This might suggest that the current strain placed on the pharmacist's time could be reduced if pharmacy assistants extended their roles. Alternatively, mandatory accreditation of pharmacy technicians, as seen in Great Britain,\textsuperscript{46} would allow technicians to focus on dispensing tasks, enabling the pharmacist to deliver other health services.

Of concern is that non-government consumer health organizations perceived that some consumers may lack the confidence to seek the pharmacist's advice. Furthermore, they may be unaware of the breadth of the pharmacist's expertise beyond the supply of medication, which is consistent with existing knowledge.\textsuperscript{32,35,15,19,47} Our study confirms that further promotion of the pharmacist's role is needed for the entire community. However, a recent paper asserted that Scottish consumers were inclined to seek professional services from their GP, and an increase in service uptake did not follow on from an increased knowledge of pharmacy services.\textsuperscript{47} The authors proposed that this could be due to a level of uncertainty of pharmacists training, privacy concerns, and perception of a better relationship
with their GP who has a broader understanding of their medical history. However, there are notable differences between the Australian and British health systems; further research is needed to determine if these results apply in the Australian context. For example, there is no GP consultation fee and consumers predominantly register with one GP surgery in Great Britain, which could promote rapport and trust development. The pharmacist is more accessible to Australian consumers who are required to make a co-payment to see a non-bulk billing GP. The authors suggested that to increase the utilization of pharmacy services, pharmacists need to obtain support from GPs. As GPs have raised concerns about fragmentation of care resulting from consumers alternatively accessing health services via pharmacies, it is critical that pharmacists engage collaboratively with the primary care team. We also recommend that pharmacists discuss the provision of services within the pharmacy setting and communicate with the consumer's network of health care professionals as noted in the interviews. A collaborative relationship between primary care providers is necessary, and it has been acknowledged that a team-based approach is an important attribute of the Chronic Care Model. In addition, there is the potential for e-health records to improve the co-ordination of services. When implementing pharmacy services, the current study suggests that this collaborative approach should extend to non-government consumer health organizations, as consumers with chronic conditions will often seek their advice and support. These organizations can advise and refer them to their local pharmacy and vice versa.

The majority of participants who commented on remuneration identified that this should occur for pharmacists to provide further professional services. Although participants from non-government consumer health organizations appeared to have limited knowledge of the pharmacy system (i.e., more system/professional barriers were discussed by health care professionals), some participants still identified a need for remuneration. A recent international systematic review identified that remuneration was not a barrier for the provision of public health services such as health promotion and smoking cessation counseling. However, others have identified that remuneration is a facilitator to practice change, indicating that remuneration may be a requirement for more extensive clinical services such as medication reviews and counseling. This is emphasized by the pharmacy practice incentives funded by the Australian Government Department of Health and Ageing since 2011. There are new opportunities for community pharmacists to be remunerated for services currently delivered in pharmacy (e.g., dose administration aids, staged supply, community services support and clinical interventions) and novel initiatives (e.g., primary health care and working with others). These initiatives indicate an exciting time for community pharmacy in Australia, signifying that the health hub concept is a vision of the not too distant future.

Limitations

The investigators sought a variety of opinions from representatives of key organizations; however we employed purposive sampling and obtained a small number of participants, including only health professionals representing the disciplines of pharmacy and medicine. As such, the findings may not reflect the views of all non-government consumer health organizations, health professionals or health advocates. Furthermore, no distinction was made between individual practitioners and those representing organizations when organizing the data and extensive analysis between the three groups could not be conducted. As an exploratory study, an aim was to identify general themes to inform the development of an interview guide. Therefore, comparisons between the groups were not made. Considering the lack of literature in this area, further research is needed. Although there is an increased risk of bias due to the reliance of self-reported data from participants when representing whole organizations, this was identified as the most effective way to collect the information. As some of the interviewees were located interstate or preferred to conduct the interview by phone, the lack of non-verbal cues may have adversely influenced the data collection process.

Conclusion

This study confirms the need for pharmacists to extend their health care role in chronic illness management, a need emphasized by professional pharmacy organizations over the last decade. Pharmacists can better support consumers with chronic illness by assisting them to navigate a disconnected health system in two ways: via a clinical triage role by referring consumers to health care professionals, and recommending
non-government consumer health organizations with an emphasis on a holistic approach to care. Furthermore, participants proposed for community pharmacists to ultimately extend their roles in medication management and advice toward health advocacy.

While funded practice initiatives have been recently introduced by the Australian government, further support and policy guidance is needed if community pharmacists are to incorporate these roles into daily practice. Furthermore, the pharmacy profession needs to actively promote their expertise and roles to consumers, and collaboratively work with health care professionals and non-government consumer health organizations. Additionally, there is a clear need for investigation into how community pharmacy can address the barriers identified by interviewees. While participants were clear about the major issues for change, they were less clear about the 'how to' change. Although multiple challenges arose from the interviews, this study demonstrates that there is a strong belief that community pharmacy can proceed in the right direction by becoming a health hub destination of the future.

Acknowledgments

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References


Appendix 3.5 – Organisational Philosophy on Patient Centred Care and Related Initiatives or Programs

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


**Title:** Patient-centred care: what consumer health organisations say and do

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**Key words:** patient-centred care, chronic illness, community pharmacy, health care service, individual patients, consumer health organisations, self-management
Abstract

Chronic disease increasingly impacts individuals and society and there have been calls to move beyond disease specific, evidence based treatment and accommodate the complexity of multiple comorbidities. Although patient-centred care has been touted as a way forward, it remains an ambiguous concept with variable application in health care. Greater clarity is needed alongside a stronger knowledge base on the perspectives of health consumers with complex needs and service providers, including parallel service providers such as consumer health organisations (CHO).

This study explored CHO patient-centred policy, related practice, and views on the potential value of pharmacy delivered patient-centred care. In-depth interviews were conducted with 15 organisational representatives until no new themes emerged. Data were concurrently thematically analysed by three researchers from a public health or pharmacy background. Participants called for a paradigm shift in power away from the paternalistic biomedical model to shared power that values consumer choice and promotes active engagement in health. There was disparity between articulation of policy and practice, with CHOs often more patient-centred than they claimed to be. Participants described a wealth of innovative services, yet utilisation of these resources appears limited. Selected CHOs adopted strategies that health professionals can learn from, such as combining multiple elements of patient-centred care and seeking to build consumer capacity to self-manage. Health professional education, current infrastructure and remuneration were cited as barriers to more widespread delivery of patient-centred care. However, participants suggested creative solutions to address selected factors, some specific to pharmacy. Both pharmacy and CHO are under utilised health care resources and there is potential for synergy between these sectors to promote patient-centred care. Pharmacy could learn the principles of patient-centred care from CHO and also increase utilisation of CHO services through direct referral.
Introduction

Concepts like patient-centred care, autonomy, empowerment and shared decision making are being touted as an ‘ethical imperative’ and are formalised in international documents such as the ‘Salzburg Statement on Shared Decision Making.’[1-5] This is increasingly important given the growing prevalence and related burden of long term medical (chronic) conditions, the ageing population in countries such as Australia and rising numbers of people with multiple comorbidities.[6-8] Despite significant advances in health care, the burden or ‘work’ of managing multiple chronic conditions has disproportionately shifted to the health consumer, leading to psychological distress and negative impacts such as absenteeism and financial burden for individuals and families.[3, 9-12] The ‘work’ of managing chronic conditions can include health system navigation as a consumer; coordinating health care across multiple providers; negotiating relationships with health providers; adhering to complicated treatment regimens; and learning to monitor disease progression and or treatment effectiveness.[13] This level of complexity has resulted in significant treatment burden with respect to medications, time, travel, financial and health care access burden.[10]

Continued emphasis on disease specific treatment guidelines contributes to this complexity and prioritises the chronic condition(s) over the person. A ‘minimally disruptive’ approach to medicine has been recommended that prioritises the patient perspective, accommodates their daily life and beliefs, considers related treatment burden and explicitly addresses the complexity of multiple comorbidities.[3] However, not all health professionals are able to recognise when people become overwhelmed by treatment burden,[3] acknowledge or build on their knowledge of or capacity to self-manage chronic condition(s),[14] or effectively involve consumers in their own care.[1] Consumer health organisations have attempted to address these gaps in health care through programs or services that are more patient-centred. Examples include self-management programs or member support services that inform, empower and develop the capacity of consumers and carers to self-manage.[15, 16] However, utilisation of these organisations by consumers and health professionals can be variable. [15, 16]
Even though there is a global drive towards patient-centred care and shared decision making[1, 5], substantial ambiguity is associated with these concepts.[17-20] Greater clarity is needed on patient-centred care, [3] alongside a stronger knowledge base on the perspectives of health consumers with multiple chronic conditions and services providers, including parallel service providers such as CHO. Researchers have used a range of frameworks to conceptualise patient-centred care.[17, 19-23] In a recent concept analysis, Morgan and Yoder described four key domains of a higher-order model of person-centred care, holistic, individualised, respectful and empowering care.[21] Holistic care has been defined as an approach to care that recognises, understands and values the entire person beyond a singular dimension like a chronic disease or medication use, and responds to their needs in this context. Respectful care identifies people as active health consumers competent to make decisions about their own care, supports their strengths and abilities, and recognises their right to choose health care aligned to their preferences and beliefs. [21] Empowering care has been defined as care that “encourages autonomy, self-confidence and self-determination, facilitates a person’s participation in decision-making through effective communication and negotiation.”[20] Empowering care featured prominently in a systematic review exploring the benefits of patient-centred care and was linked to patient satisfaction and perceived quality of care.[20] However, risk of bias limits the conclusions that can be drawn from a number of the studies reviewed and greater context is needed on how this translates to the Australian context. Patient-centred care has also more traditionally been viewed from the health professional perspective, [17] and greater clarity is needed from consumers, carers and parallel service providers such as CHOs.

The aim of this study was to explore the insights of CHO representatives from three perspectives, the treatment burden encountered by the consumers or carers who access their services, the organisation’s views of patient-centred care, and on the potential for community pharmacy to further support consumer members in managing their chronic conditions. Exploration of the CHO perspective on patient-centred care sought to understand how it was articulated as policy and integrated with CHO programs or services. This paper reports CHO perspectives on patient-centred care and related implications for community pharmacy. Specific questions pertaining to treatment burden and community pharmacy have been addressed elsewhere[24, 25].
Methods

Fifteen semi-structured, in-depth interviews were conducted with senior representatives from 12 Australian CHOs between January and March 2012. Interviews explored each organisation’s perspective on patient-centred care, particularly as it related to the consumers or carers they represent. In-depth interviews were considered the most appropriate method due to the exploratory nature of the study,[26] and to provide a safe environment for participants to provide detailed perspectives that may not be forthcoming using alternative data collection methods such as focus groups.[27] An interview guide was developed, piloted with a senior member of a CHO and refined prior to the commencement of the interviews (Table 1). Fortnightly analysis discussions amongst the research team throughout data collection facilitated further refinement of the interview guide to accommodate relevant themes as they emerged. Using a sampling framework guided by national health priorities (e.g., asthma, cardiovascular disease, arthritis)[28] and developed in consultation with the project Advisory Board and key stakeholders from a range of consumer organisations and practitioners from medicine, nursing and pharmacy. Participants were purposively sampled to reflect diversity across the CHOs. Additional participants were identified during the course of the interviews via the snowballing technique as a means of recruiting people less likely to be identified by formal recruitment methods.[29, 30] Where possible, participants from different areas of the organisation were interviewed to obtain views from both policy development and program implementation perspectives.

[Please insert Table 1 here]

Upon verbal agreement to participate, the study information sheet and interview guide were emailed to each participant and informed consent was obtained. Four participants were male and the remaining participants were female. Nine of the 12 organisations operated at a state level (i.e. Queensland) and the others at a national level. The average interview duration was 64 minutes, and seven were conducted face-to-face and five via telephone. Initially, participants were asked to describe the typical members of their organisation, the services they provided, and organisational perspectives about patient-centred care. Data saturation was considered to have occurred when no new ideas were heard during interviews. All interviews were recorded and transcribed verbatim and any identifying information was removed. The transcripts were returned to selected participants on request to ensure that they represented a valid reflection of the participant views. [31]The study received ethical approval from the University Human Research Ethics Committee (Ref: PHM/12/11/HREC).

Data analysis
Thematic analysis was used to review the in-depth interviews. Thematic analysis is a commonly adopted approach to analysing qualitative data in health care research, particularly when it is exploratory in nature.[32] To prepare the data for thematic analysis, written summaries were disseminated to the research team for their review following each interview. Two researchers with a pharmacy background and one public health researcher read and re-read the transcripts to familiarise themselves with the data. These researchers then used the electronic qualitative data analysis package QSR NVIVO 9 to code the data into themes and sub-themes. Ongoing analysis discussions amongst the three researchers allowed for reflection on analysis, revealing nuances in the data which may otherwise have been missed. These also provided opportunities to develop and refine coding frameworks limit researcher bias and ensure that findings were authentic and credible. [31] One researcher (FK) took responsibility for coding and describing specific theme(s) across the patient-centred care related data. The key elements of patient-centred care proposed in Morgan and Yoder's recent concept analysis are used as a framework for data analysis.[21]
Findings and discussion

Consumer health organisation representatives (participants) both acknowledged the importance of patient-centred care and reinforced existing conceptual ambiguity. Although ambiguity was reflected in the patient-centred care spectrum described, there was consensus on the need to move beyond the one-dimensional biomedical model and redress long-established power imbalances between health professionals and consumers. Three concepts commonly mentioned included: (i) patients being at the centre of or in control of their care, (ii) shared decision making or patients engaged as partners in care, and (iii) individualised care tailored to meet the specific needs of patients. Terminology used by CHO representatives included patient engagement, control, responsibility, power, patient voice, shared decision making, and patient choice. These terms reflect a perceived need for active consumer engagement as part of the health care team.

Participant descriptions of patient-centred care contrasted between a broad conceptual approach and articulation of specific domains or examples of application. However, organisational description of what CHO considered patient-centred care to be was sometimes superficial when compared to narratives of the patient-centred services or programs delivered by that organisation. This may reflect ambiguity in the literature, emphasis on program delivery over policy articulation or a more informal approach to patient-centred care. Alternatively, patient-centred care may be so integrated into the CHO philosophy or practice that it has become habitual and more difficult for people to describe the individual processes. When the framework proposed by Morgan and Yoder [21] was applied to the data, it became apparent that different CHO utilised the key elements of patient-centred care to varying degrees. Greater detail is provided below describing the status quo across these CHO, identifying potential opportunities for community pharmacy and highlighting areas for further exploration.

Elements of patient-centred care
Only a minority of participants described policy that encapsulated all four elements of patient-centred care. Those that did were from CHO's that emphasised the importance of developing consumer resilience and capacity to self-manage:

We encapsulate that... by what we call a resilience statement. I’ll read the statement out and this is primary - everything that we do. To uphold and maintain a resilience-based approach by acknowledging the right and capacity of each individual to make choices, decisions and to take responsibility for their lives, actions and direction. To effectively work within a partnership model to maintain the individual resilience within each person. So that’s how we would encapsulate a client-centred approach (13).

Individualised care followed by holistic care were the domains most frequently mentioned by participants. Although there was an emphasis on shared decision making, three underpinning concepts conceivably critical to this were at times absent in participant accounts. These included respectful care, a holistic approach to health care and empowering people to participate in decision making. However, the limited description of patient-centred care in CHO policy was juxtaposed with CHO programs, which were clearly aligned to varying degrees with one or more elements of patient-centred care. For example, empowering care varied from more passive consumer education to active development of self-management skills.

Individualised care
Individualised care was the attribute most frequently discussed when participants were asked what their organisation considered patient-centred care to be. Participants acknowledged the importance of not applying a ‘one size fits all’ approach for particular chronic diseases, and CHOs appeared to utilise an array of strategies to both identify and address individual needs of consumers and carers.

It’s not just about learning to get on the bus again, but it’s about living a life that’s going to be meaningful for them and purposeful. Obviously, that’s unique to every individual (13).

These strategies, aligned with descriptions of individualised care in the literature [20], entailed exploring the patient journey, considering peoples’ unique health concerns, personality or preference and delivery of customised interventions. Individualised care was viewed as integral to capacity building and respectful care, particularly in those organisations where all four domains of patient-centred care were encapsulated in service delivery:

Patient centred care is saying to the consumer, or the patient, what are your needs, tell us about your journey so far with your condition, what’s been good, what’s been bad, you know...how could we fix it...so that’s how we’re working on patient-centred care and that’s what we’re trying to promote in other health professionals (03).

Organisations used innovative and multi-layered services to accommodate factors such as geographical isolation, competing commitments, severity of, or changes in health condition and continuing access to the social benefits of services once health had improved. Partnerships emerged as an important sub-theme of individualised care. Examples included partnerships with individuals through service delivery, involving consumers in resource development or service delivery, active engagement with community leaders and relevant cross-referral to other services through inter-organisational collaboration:

Her continuing to come to the social group here with people that she knows, still at that regular Friday time it’s been really supportive for her. So I think making some of those exceptions within your services for the good of the client and for their therapeutic needs and their goals is what person centred care is about (11).

Our resources are developed in consultation with them [clients]. Also, in the way we deliver, that our workers mostly work after hours and on weekends because, again, with new arrivals, the priority is to take care of themselves and their families (20).

Holistic care
Organisational representatives described holistic care from two perspectives; care for health consumers, and health system infrastructure. A central theme was the need to move away from a singular dimension or episode of ‘problem solving’ care to consider the whole person in a ‘cycle’ of ongoing care:

That's where patient-centred care is falling down... People are still just getting episodes of care, they're going to their GP, their GP is just saying, oh what's your problem? Addressing the problem and then they go away again, rather than a planned and a coordinated cycle of care that somebody with diabetes needs on an annual basis (12).

That meant transitioning from the ‘body-centric’ approach that labels health consumers (e.g. an asthmatic or diabetic), prioritises a single aspect of medical care and limits focus to specific therapeutic measures of success, to conferring equal priority to consumers’ state of wellbeing or psychosocial health:

It becomes a very body part-centric approach and the reality is most people have comorbidities and they also are a person first and then they have a condition. They don't want that condition to define them as such (19)

They [health consumers] really want the health professional, and this would equally apply to community pharmacy, to not just, say, focus on their biomedical measure like their blood glucose level, but how are they going and how are they coping and what are the issues for them and what are their needs? (15).

When CHO's actively embraced the philosophy of holistic care, every contact with members was viewed as an opportunity to consider the social context beyond the issue at hand. There was emphasis on building the service around the patient and their needs by considering factors such as location, age and cultural beliefs. Many participants recognised a need to collaborate with other providers when consumer requirements were beyond the remit of their organisation. This

reflects more proactive processes than more traditional reactive problem solving approaches to health:

We also try to ascertain what else we might be able to help this person with, so again...it’s taking that holistic approach...that a person might well phone in about one particular thing... when you are talking to that person... it opens up a whole series of other things that we can actually help them with (02).

Although participants in this study espoused the importance of considering the person beyond the health condition, they described examples of a more narrow approach by health professionals, and attributed this to particular health conditions and particular social factors such as age:

... I think that if you’ve got a diagnosed mental illness... quite often your physical health is neglected - I think that’s by health professionals as well. I think quite often their physical ailments or symptoms are overlooked and it’s written off as being psychological... it’s also true in reverse. I think that people who are frail aged, aren’t necessarily treated for their psychological ailments. I think that they’re just quite often written off as just being old. I think that there is a great need for a more holistic approach regardless of age or disability (13).

Holistic care features less frequently in the literature than other domains and the complexity of engaging in a person’s social context has been proposed as a factor.[20] There was acknowledgement that transitioning to holistic care relied on health professionals acquiring skills such as motivational interviewing. Currently, vocational health education incorporates aspects of communication skills and health beliefs to encourage a more patient focused approach. However, these can be delivered as stand-alone modules, and the continued dominance of evidence based medicine may mean that they are not considered as relevant as therapeutic topics. Integrating motivational interviewing with therapeutic content could improve perceived relevance, provide important context and promote skill development. More recent recognition of the significance of peoples’ cultural beliefs in health professional competency standards and education may translate to a more holistic approach by new graduates.[33-35] However, this does not consider other factors integral to a holistic approach such as age and comorbidities nor how to promote

behaviour change across the entire health sector. Participants felt that health system infrastructure further limited holistic care through remuneration models driven by volume (e.g., paid by appointment or medicine dispensed), generic government initiatives, lack of coordinated care, and health professionals working in isolation. Further research could explore health professional attitudes towards holistic care alongside perceived need for change at the individual practitioner level, in tertiary curricula and high level infrastructural change.

Respectful care
Participants recognised that respectful care also required going beyond a ‘one size fits all’ philosophy, associating it with both the right to choose and the importance of promoting capacity to make informed decisions. Although some participants merely acknowledged that people should have the right to choose, others emphasised the importance of taking time to understand these decisions and ensure that they are informed. Tension emerged when selected health professionals working for CHOs appeared resistant to consumers questioning their clinical recommendations, describing it as challenging to accommodate choices not aligned with evidence based treatment guidelines. Such tension may reflect reluctance amongst health professionals to transfer power in health care to consumers or identify deficits in health professional education, or both. For example:

Obviously, you tailor your care as a professional person to each individual patient with respect to his or her wishes (06).

As practitioners, we want all of our patients to be compliant because we perceive ourselves to be the experts and we know what’s best, as opposed to actually saying, the person with the illness that - the patient, the client actually has a right to live a life (17).

Managing consumer and carer capacity to decide was described along a spectrum from recognising those disinclined to control decisions about health care, to targeted development of consumer capacity to self-manage. This included recognition of the need to avoid assumptions, and the potential for positive relationships to facilitate conversations exploring individual preferences:
We actually are getting feedback that some people just like to be told what to do and then they don’t have to take responsibility and they don’t have to think about it (17).

I think personally that patient-centred care has to be a choice thing though and I feel that’s a really important issue…. I don’t think it’s on to impose patient-centred care across the whole spectrum (14).

The findings of Schembri and Sandberg reflect a similar spectrum categorised as three types of patients: those who wanted direction from their doctor (passive), those who wanted to be in control (monitoring), and those who sought a model of care closely resembling the principles of patient-centred care described here (partnering).[36] The concept of capacity also emerged in relation to health professionals and it is important to consider emerging tensions, institutional or health professional prejudice when promoting patient-centred care.

Empowering care
Empowering care is the element of patient-centred care that has been associated with tangible benefits in a systematic review of randomised controlled trials.[21] It has been defined along a spectrum from increasing health consumers’ desire for or building on their knowledge about chronic illness, through to strategies that build consumer capacity to engage more as partners in their care. Empowering care featured less commonly in participants’ description of organisational policy, yet was clearly apparent in descriptions of selected CHO services. Accounts of empowering care indicated that participants valued building consumer capacity to more actively engage with their health care more than passive provision of health related information. The goal of this approach was for consumers to become more self-reliant and have diminishing need for CHO services as their capacity to self-manage increased. Building confidence, knowledge and skills were all viewed as integral to increasing consumer capacity to self-manage:

A person can’t become a patient at the centre of their care unless they have adequate knowledge and adequate skills so the self-management programs are designed to give them knowledge and skills. (14).

We should in the long run do ourselves out of a job. We’re not there to create dependence.
We’re there to get people to be functioning to their optimum performance... independent of us (13).

Although there was clear acceptance that enabling self-management is positive, current power imbalances in the health system may restrict this, ultimately detracting from consumer empowerment. For example, time-restricted, problem focused appointments with general practitioners who ‘prescribe medication not information, not education.’ There was appreciation of the potential for more empowering care delivered via community pharmacy given that it is considered a less threatening environment and is a frequent point of contact for consumers. This finding aligns with research exploring key themes of patient-centred professionalism for community pharmacy amongst pharmacy, consumer and other health stakeholders.[37] However, in this study it was tempered by a perception that pharmacists are generally too busy to provide patient-centred care and that significant change management was required to realise the opportunity:

My view has always been the pharmacists have never made the most of that. If you want to deliver patient focused care, how on earth can it be done with the chemist sitting out the back doing scripts (09).

The traditional task focused dispensing role of community pharmacy could limit introduction of patient-centred care, particularly whilst it remains the mainstay of remuneration for pharmacy services. The introduction of pharmacy based professional services that consider the person beyond the prescription could represent initial steps towards pharmacy becoming a more patient-centred health destination.[24] Even so, if a patient-centred approach was adopted by all pharmacy staff and it could nurture relationships with consumers and carers, and reinforce the notion of pharmacy as a safe health space.
Interviews revealed the existence of innovative initiatives and commendable role models for delivering empowered care amongst CHO's. Principles to guide delivery of such care were evident in participant anecdotes, and included establishing and building on realistic goals, relating strategies to consumer priorities, and encouraging reflection on how strategies have worked. Strategies employed ranged from mutual discussion of care plans through to health consumers writing their own case notes:

We want people to set a realistic goal, achieve it, build on success and move on to another one (19).

We might have a carer that rings up and says I’m really exhausted and I can’t cope et cetera. We have an option right then, we can say I know what you need - you need a night off and we’ll put somebody in there. We can turn around to that person and say, what has worked for you in the past? So one approach looks at a Band-Aid but the other approach looks at building resilience that will help in the long-term (13).

Although the notion of empowering care is proclaimed as beneficial, there is limited information on how well this is supported by evidence and who it actually benefits; health consumers or health professionals. [20] Existing evidence suggests that it can encourage health professionals to ask questions, and improve consumer perceptions of service quality. However, it is important to note that positive health outcomes are more likely to be associated with strategies that facilitate active consumer and carer engagement through improved confidence. [20] Greater insight into consumers’ actual experiences of empowering care is needed to explore the concept further and inform development of relevant health care models.

It became clear that CHO’s deliver a plethora of patient-centred services or programs, and participants described variable service utilisation with missed opportunities for consumers and carers. They attributed this to lack of consumer awareness or limited referral from health professionals. Articulation of the value of these programs and services needs to improve alongside increased referral by health professionals. There is opportunity to address this via health professionals frequently visited by consumers, including general practitioners and community pharmacists. For community pharmacists this reflects an opportunity to become part
of the cycle of care by assessing peoples’ needs, providing medicines management advice and acting as a referral agent to relevant CHO services.[24] Similar to services incorporated into pharmacy contracts in the United Kingdom.[38, 39] Although participants saw value in both pharmacist referral to CHO and pharmacist delivered patient-centred care, they proposed a number of barriers, including, limited pharmacist accessibility when dispensing, the retail oriented image of pharmacy and limited relationships between consumers, carers, and pharmacists. The ‘traditional’ pharmacist was viewed as a reactive, problem solver rather than a health professional who would take a proactive and holistic approach to a person’s wellbeing. Significant changes in attitudes, behaviour and the pharmacy environment are needed alongside a major culture change to dispel the image of pharmacists as a ‘shopkeeper’.

Limitations

This study explored patient-centred care from a service-provider perspective, providing first-hand insight into the perceptions of key stakeholders from CHO. However, like all research, there are limitations. Sampling was guided by national health priorities, and unique perspectives of CHO representing other chronic illness may not be reflected. Purposive sampling was deemed the most appropriate method of ensuring that diverse perspectives amongst stakeholders were included across these priority areas [28]. The research relied on cross-sectional data to explore stakeholder perspectives which provides important insight but does not account for changes in health care policy over time. Although self-reported data (in-depth interviews) can introduce social desirability responses and interviewer bias, it was deemed the most appropriate method for this exploratory study. Interviewer bias was minimised through the use of a standardised interview framework and the two interviewers conducting the initial ten interviews together. Although involvement of researchers from both pharmacy and public health backgrounds strengthened the study, it does not account for the interpretative view-points of other health related disciplines, people who work for CHO or analysis through the lens of a consumer with a chronic health condition.
Conclusion

These findings provide important insights into the status quo of how CHOss view and deliver patient-centred care, and underscore the importance of a health care model where the consumers feel that they are valued and respected members. A collaborative, multidisciplinary health care environment is needed which will ensure that consumers feel supported in managing their chronic illness, thus helping to alleviate potential treatment burden.

The wide range of innovative patient-centered services available to the Australian public is reportedly under utilised by consumers and referral from health professionals appears limited. Pharmacy is also under utilised as a health care resource and the goals of both converge so that pharmacy could learn to adopt the principles of patient-centred care already delivered through CHOss, thereby increasing consumer access to relevant services in existence.

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Declaration of conflicting interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Table 1: Interview framework for questions relating to patient-centred care

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>Can you please briefly outline your current position in [CHO name] and what this involves?</td>
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<tr>
<td>Do you interact directly with “your members”? If so, please elaborate on this.</td>
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<tr>
<td>Could you describe the range/different types of members or membership categories that [CHO name] represents?</td>
</tr>
<tr>
<td>Could you describe the different types of services that are provided to each of the member categories to support them in managing their chronic illness(s)?</td>
</tr>
<tr>
<td>What is [CHO name]’s mission statement or chief organisational aim and what are the types of things it is doing or planning to do to achieve this?</td>
</tr>
<tr>
<td>Does [CHO name] actively involve its members in the planning and implementation of policies and activities being undertaken to achieve its mission?</td>
</tr>
<tr>
<td>Could you please tell me what [CHO name]’s perspective is on patient-centred care?</td>
</tr>
<tr>
<td>Can you tell me about a typical consumer member, their chronic illness(s), early diagnosis, and disease progression and other typical comorbidities?</td>
</tr>
</tbody>
</table>

*The interview framework is a guide and questions were adapted according to participant’s organisation and position or background.*
References


Appendix 3.6 – Could pharmacies be the missing link between Consumer Health Organisations and health consumers?

Could pharmacies be the missing link between Consumer Health Organisations and health consumers?

Claire Campbell, Fiona Kelly, Adem Sav, Sara McMillan & Amanda Wheeler

In 2007-2008, 75% of Australians reported having a chronic disease.¹ The cost of treating this large proportion of the population is substantial. Estimates from 2011 indicate that treatment of cardiovascular disease alone cost the Australian health system $11.5 billion.² Looking beyond the dollar figure how much is it costing individuals? Chronic disease is not only expensive, but it significantly reduces the quality of life for those who are living with such conditions. Traditionally, healthcare has focused primarily on a biomedical model which emphasises treating a particular illness or alleviation of immediate physical symptoms. While this approach addresses the dominant clinical elements of chronic disease, it does not always account for the other aspects of treatment burden such as side effects (e.g. hair loss from chemotherapy), physical limitations (e.g. immobility), psychological impacts (e.g. depression, isolation), or substantial financial impacts. This highlights the need for a more holistic, patient-centred approach to care where the consumer is treated as a whole person, not just as a sufferer of a certain disease.

What are Consumer Health Organisations?

The term Consumer Health Organisations (CHOs) encompasses an array of health consumer supports which exist through; not-for-profit groups (e.g. Multiple Sclerosis Australia), federal and state government run initiatives (e.g. HACC- Home and Community Care), community groups (e.g. Asperger's & Autism Support group), charity services (e.g. St Vincent de Pauls Society), all of which provide a broad range of additional supports, which can be overlooked during a typical interaction with health professionals. Programs offered by CHO can improve the quality of life for those living with a chronic disease by providing support beyond what primary healthcare typically involves.
Figure 1. Types of burden experienced by health consumers and the assistance available to health consumers through CHOIs and support services.

How do they help?
The type of support provided varies greatly and caters for an array of consumer or carer needs (Figure 1). Assistance is provided to address the broad range of challenges experienced when living with or caring for someone who has a chronic disease or disability. Some of this assistance is focused on specific therapeutic conditions (e.g., asthma, diabetes) when run through CHOIs such as Asthma Australia, or Diabetes Australia. This can include the latest information regarding the condition, emerging treatments, practical advice on how to self-manage, as well as psychological support through sharing experiences with other consumers. Some other CHOIs offer support services that provide broader assistance for other aspects of
life including financial assistance, telephone counselling, home maintenance, carer respite
days through to transport alternatives (Table 1: Pharmacy Resource).

The missing link!

CHOs have much to offer health consumers that could alleviate a significant amount of day-
to-day difficulties they are experiencing, yet some of these services are reportedly
underutilised. If consumers remain largely unaware of such organisations and programs,
unsure of where they can be found or unable to select the most appropriate program for them,
then it is likely that people will continue to miss out and persevere with these additional,
avoidable stresses.

So what can pharmacists and pharmacy staff do?

Traditionally pharmacies have supplied medicines and provided advice for health consumers
managing chronic conditions. This role has expanded to include extra services such as blood
pressure monitoring and home medication reviews. As many consumers and carers visit the
pharmacy on a monthly basis this provides an opportunity for community pharmacy staff to
further support consumers, by referring them to CHO’s or by bringing these CHO support
programs to their attention. Consumers have stated how approachable pharmacy assistants
are and they are often considered the face of community pharmacy since they can be the main
person a customer interacts with. Therefore, it is important to consider referring customers on
to CHO support services next time you’re assisting them – by doing this you’ll be further
evolving the role community pharmacy plays in caring for customers and you may make the
world of difference to their quality of life.

A Pharmacy Resource

Table 1: Pharmacy Resource has been developed to inform pharmacists and pharmacy staff
about some of the key organisations and extra services that are available to health consumers
via CHO’s. This resource gives a glimpse into the broad array of services that are currently
out there to assist those affected by a chronic disease and demonstrates how many different
elements of burden that result from a chronic disease can be improved through CHO support.
While this is not an exhaustive list of consumer supports groups and programs, it does
highlight some key organisations for disease-specific groups as well as other programs or
schemes that are run for consumers living with a disability or chronic disease, or for the
people who care for them.
CHO support has been categorised into services or programs for disease-specific groups, carers, culturally and linguistically diverse (CALD) groups, Aboriginal and Torres Strait Islander (ATSI) peoples and other living assistance and information services. In addition there are some state specific health directories noted at the bottom and the national and state based organisations that offer more disease-specific programs. The resource shows the wide range of services and programs provided both across and within organisations. For example the Cancer Council offers different levels of service to accommodate individuals at any stage of their diagnosis. This includes telephone counselling for the newly diagnosed, guidance on how to break the news to family and friends, advice on choosing the right treatment, tips for managing side effects and impacts of the cancer (e.g. the Wig and Turban service for those who experience hair loss), a peer support program that is offered to comfort those who feel isolated since their diagnosis (i.e. Cancer Connect), and even an avenue for survivors of cancer to share their experiences (Walk for Life). Additionally, separate organisations exist for specific cancer types and provide alternative services designed to accommodate for the different challenges those diagnosed may face, for example, breast cancer sufferers may require a different type of support to men diagnosed with prostate cancer. This type of multifaceted support is not exclusive to those living with cancer, equivalent support is accessible for all types of diseases, such as multiple sclerosis, asthma, Parkinson’s disease and arthritis to name a few.

In addition to this tailored disease-specific support, there are also services and organisations which aim to alleviate some of the burden which most people living with chronic diseases will experience, for example, local transport services (e.g. patient assisted travel scheme), financial support (e.g. No Interest Loan Scheme), and medical equipment hire; in fact most other requirements have been addressed in some way. Conversely the integral support that carers provide to people living with chronic diseases or disabilities does not go unrecognised. There is a large support network for carers; offering practical advice, transport concessions, respite services and most importantly emotional and social supports. Currently, state health departments have referral and advice services in place, through hotlines (i.e. Health Direct Hotline) and websites (Table 1). It is intended that this Resource aids the exposure of the public to these extra support service, by providing pharmacies with a valuable starting point for the referral of consumers to CHOs, and potentially make a significant difference to individuals coping with a chronic disease.
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References

### PHARMACY RESOURCE FOR CHRONIC ILLNESS

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Appendix 3.7 – Interview Guide for Stakeholder Consultations

Projects Overarching Aim

The Chronic Illness Project will form the basis of recommendations for models of care for community pharmacies to assist patients with chronic health conditions and complex treatment regimens to manage their illness.

Rationale for Key Stakeholder Interviews

These key stakeholder interviews are being conducted with stakeholders across the healthcare system, from both consumer and professional organisations to inform the exploration of health consumers’ perspectives and expectations. More specifically, this information will assist the project team in developing further questions for consumer interviews, ensuring that the project fully explores the perspectives of consumers and their experiences and expectations of community pharmacy in managing their chronic illness.

These interviews will focus on some of the following issues:

- organizational perspective on treatment burden (especially of the consumers they represent)
  Definition: Treatment Burden is the impact that chronic illness(s) has on an individual his/her family and/or carers
- organisational perspective on patient-centred care (especially for the consumers they represent)
- how community pharmacy could better support your members to manage their illness(s)
- recruitment issues and cultural needs

Consumer recruitment

As we had outlined in the key stakeholder letter, we also seek your organisation’s support to identify consumers that have a chronic illness and their family members and carers, to see if they would like to participate in the project. To assist this process, your organisation will be provided with an information sheet (both electronically and in hard copy) to give to those consumers who may be interested in participating or to your members who may be interested in recruiting consumers. We will discuss this with you further at the interviews conclusion.

These following questions are intended as a guide only and questions may change depending on the organisation being interviewed and the responses provided. Not all questions may be asked in the 60 minute interview.
Section 1. I’d like to start today’s interview with some questions about yourself.

1. Can you please provide me a brief outline of your current position in the (insert organisation) and what it involves?

2. Do you interact directly with “your members”? If so, could you elaborate on this please?

Section 2: In this section, we would like you to respond to the following questions from your point of view as (current role) at (insert organisation):

3. Could you describe the range/different types of members/membership categories that (insert organisation) represents?

4. Could you describe the different types of services that are provided to each of the member categories to support them in managing their chronic illness(s)?

5. What is (insert organisation)’s mission statement/Chief organisational aim and what are the types of things it is doing/planning to do to achieve this?

6. Does (insert organisation) actively involve its members in the planning and implementation of policies and activities being undertaken to achieve its mission?

7. Could you please tell me what your (insert organisation)’s perspective is on patient centred care is?

8. The impact that each member’s chronic illness(s) has on them, his/her family and/or carers is increasingly being referred to as the burden of chronic illness. One aspect of this is treatment burden, which involves managing and treating the illness. Can you tell me what (insert organisation)’s perspective on treatment burden is for its members?

Section 3: This section is about I’d now like to ask you some more details about your consumer members:

9. Can you tell me about a typical consumer member, their chronic illness(s), early diagnosis, and disease progression and other typical co-morbidities?

10. How does a member typically manage their chronic illness(s)?

11. What do your consumer members say about the impact of their chronic illness(s) on themselves as individuals/ or family/ or carers?

12. Do your consumer members prioritise their health conditions?

13. Do these priorities change and if so, in what way and why?

Section 4: In this section, we are interesting in your views about the role of community pharmacy helping your members manage their illness
14. How do your members currently use community pharmacy to help them manage their chronic illness(s)?

15. How could community pharmacy help your members to manage their chronic illness(s)?

Project Recruitment Questions (For all stakeholders, including professional organisations e.g. Pharmaceutical Society of Australia, Australian Medical Association)

- What advice would you offer the project team to help us raise awareness and promote the study to your consumer members?

What specific cultural needs do you think the project team needs to consider when recruiting your consumer members/health consumers?