Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management

Researchers:

Professor Amanda J. Wheeler, Griffith University
Dr Fiona Kelly, Griffith University
Associate Professor Jennifer A. Whitty, University of Queensland
Dr Michelle A. King, Griffith University
Professor Elizabeth Kendall, Griffith University
Acknowledgements

Griffith University would like to thank the Department of Health for funding this project as part of the Fifth Community Pharmacy Agreement Research and Development Program, managed by The Pharmacy Guild of Australia.

Special thanks go to all participants for sharing their personal stories and opinions with us, to the consumer and health professional champions who assisted us with recruitment, and also the consumer health and pharmacy organisations for their continued assistance. We thank Peter Walsh for his advice, support and feedback on publications and this report, Iona MacDonald for proofreading all of the reports and Amanda Trapnell for desktop assistance. Additional acknowledgement is given to the project’s Advisory Panel and Reference Group for their advice and support (Appendix 1).

Project Team

Lead Researchers
Professor Amanda J. Wheeler, Griffith University
Dr Fiona Kelly, Griffith University
Associate Professor Jennifer A. Whitty, The University of Queensland
Dr Michelle A. King, Griffith University
Professor Elizabeth Kendall, Griffith University

Research Team
Dr Adem Sav (Senior Research Assistant), Griffith University
Sara S. McMillan (PhD Candidate), Griffith University
Claire Campbell (Consumer Research Assistant)

Research Support
Ciara McLennan, (Pharmacist Research Assistant)
Nicholas Moir (Research Assistant), Griffith University
Brittney Williams (Research Assistant), Griffith University
Beth Hunter (Project Manager), Griffith University
Rhonda Knights (Business Support Officer), Griffith University
Gabor Mihala (Data Management), Griffith University

This report was produced with the financial assistance of the Australian Government Department of Health. The financial assistance provided must not be taken as endorsement of the contents of this report.

The Pharmacy Guild of Australia manages the Fifth Community Pharmacy Agreement Research & Development which supports research and development in the area of pharmacy practice. The funded projects are undertaken by independent researchers and therefore, the views, hypotheses and subsequent findings of the research are not necessarily those of the Pharmacy Guild.
Executive summary

Globally, chronic conditions are the leading cause of mortality, and increasing numbers of Australians have more than one chronic condition. Although medication assists people to manage chronic conditions, treatment can create associated burden for people. How treatment burden is experienced by people with more complex conditions and multi-morbidities, and their carers, is poorly understood. Community pharmacy is ideally placed to support these consumers and carers, mainly due to accessibility and pharmacists' expertise on the quality use of medication. The Pharmacy Guild of Australia engaged Griffith University to investigate consumers', carers' and health professionals' perspectives on treatment burden, their views of patient centred care, and the role of community pharmacy in assisting people to manage their condition(s) or caring role(s).

Research design

Three stages of research were conducted from November 2011 to July 2014 across four regions. Participants included healthcare stakeholders, health professionals (pharmacists, health workers, medical and allied health practitioners), consumers with chronic conditions, unpaid carers, or people who are both. Findings from each stage informed the next stage of the research.

Stage One: Literature review and key stakeholder consultations

1. A systematic literature review was undertaken to identify current evidence about the burden of treatment, the nature and impact of patient centred care, and role of community pharmacy.
2. Stakeholder consultations explored the views of health advocates, representatives from consumer health and health professional organisations on: treatment burden, patient centred care, and the role of pharmacy.

Stage Two: Semi-structured interviews and discussion groups using the nominal group technique

3. In-depth, semi-structured interviews explored consumer and carer experiences of managing chronic condition(s), associated burden, and what they considered as 'patient centred' care. Participants' expectations, use and choice of community pharmacy services were explored.
4. Consumer, carer and health professional nominal groups were used to elicit creative ideas for future pharmacy services to support chronic condition management, and insight into services they prioritised. Health professionals considered this from the viewpoint of their consumers to explore disparities in views.

Stage Three: Survey and discrete choice experiment (DCE)

5. Stage Three investigated consumer and carer preferences for related pharmacy services and measured:
   a) Level of treatment burden experienced by consumers with chronic condition(s);
   b) Quality of life reported by consumers and carers; and
   c) Priorities and preferences for the availability and delivery of community pharmacy services.

Health professionals completed an abridged survey for comparison with consumer and carer data.

Key results and recommendations

In total, 661 consumers and carers and 322 health professionals participated in one or more of the research stages from four regions (Logan-Beaudesert and Mt Isa/North West in Queensland, Northern Rivers in New South Wales, Greater Perth in Western Australia). Interviews were conducted with 21 key stakeholders (Stage One) and 97 consumers and carers (Stage Two), nominal groups involved 103 consumers and carers and 61 health professionals (Stage Two), and 602 consumers and carers and 297 health professional/health workers completed the survey (Stage Three). The key findings and recommendations of the research are summarised below.

a. Treatment burden

Treatment burden is a dynamic multidimensional concept, consisting of medication, lifestyle, financial, healthcare access, and social components. Consumers and carers who experienced treatment burden were likely to be younger, have co-morbidities, have an unpaid carer, or to report experiencing diabetes or another endocrine condition. Burden emerged as a key issue for carers. The financial component was the most
burdensome for many consumers and carers, reducing ability to access medication or pharmacy services (e.g. dose administration aids). Approximately 25% of Stage 3 consumer or carer participants had delayed or not purchased a medication in the previous 12 months because of cost; and they had to weigh up the benefits of the medication with respect to their financial situation. Alternatively, affordability was a lesser concern for those with access to Government subsidies, e.g. Closing the Gap (CTG) but was still important. There was limited awareness of the availability, eligibility, or both, of lower co-payments amongst some participants, with 8.3% of Stage Three participants unaware if they had reached Safety Net entitlement.

Opportunities for community pharmacy: There is untapped potential for community pharmacy to further support unpaid carers and reduce carer burden. Key areas include recognition and support of carer responsibilities through seamless medication supply and targeted assistance.

Pharmacy-specific recommendations: Education is vital for consumers and carers to ensure that they understand financial entitlements and pharmacy services related to their medication use. Moreover, pharmacy services need to consider a range of payment methods to facilitate access to medication and services, such as pharmacy accounts or advocating for direct payments via Centrelink. Greater accommodation of carer’s needs is required through recognition of their role, seamless supply of medications and targeted pharmacy services to alleviate carer burden. A carer card or template signed by carers and the consumers they care for could offer clarity on the carer role, grant power of attorney or permission to obtain specific information, and identify the carer for targeted support services.

System-based recommendations: Co-payment and other financial benefit systems for consumers with chronic conditions require review to better reduce financial burden and improve adherence, whilst maintaining health system sustainability. Introduction of greater subsidies for specific pharmacy services that encourage medication adherence such as home deliveries and dose administration aids is recommended.

b. Patient centred care
Consumer and carer views on patient centred care reflected a spectrum from personalised service through to care that incorporated one or more attributes of patient centred care, such as empowering, respectful, individualised and holistic care. In practical terms, consumers appreciated a caring health professional who took the time to determine their individual needs, provided tailored medication advice, considered their social context beyond their chronic condition(s), and respected and valued their knowledge and expertise. Patient centred care encouraged loyalty to one pharmacy, as participants were less inclined to choose new services if they believed their current pharmacy service offered care that was responsive to their needs.

Opportunities for community pharmacy: Simple changes that can be easily implemented in pharmacies and do not require longer consultations, are just as likely as complex interventions to bring about desired outcomes. Importantly, changes need to be applied consistently by the whole pharmacy team rather than as brief short-term interventions by one or two individuals. Community pharmacies are more likely to have a loyal customer base if they adopt a patient centred approach.

Pharmacy-specific recommendations: Review of tertiary and industry training is needed to integrate patient centred care into routine practice. Pharmacies would benefit from a patient centred toolkit to support the requisite changes. These range from simple changes, such as open dialogue and respecting consumer and carer treatment and brand choices, to more complex interventions, including multicultural training for staff, and developing skills to assess and address barriers to understanding, such as limited English skills or health literacy.

c. Community pharmacy services
Consumers and carers expressed a desire for new and extended pharmacy services that promote streamlined, convenient and on-going access to medication, such as home deliveries, text message prescription reminders, and prescription renewal. There was a strong preference amongst consumers and carers to access their
pharmacist to continue the supply of their regular medication(s) to treat chronic condition(s) for a predefined period, as well as medications previously used for symptom flare-ups. Consumers and carers wanted to see their GP for any new health problems and for an annual check-up. Health professionals/workers also expected consumers to prefer access to a continued medication supply service from a community pharmacy, suggesting a degree of awareness of this issue in the health system.

The concept of community pharmacy becoming a healthcare destination, or health hub, emerged through different stages of the study with a range of meanings, from simply advertising available pharmacy services, to more complex signposting or active referral to other health services or programs. Consumers and carers also discussed, and had a strong preference for, the co-location of services (e.g. a one-stop shop). Pharmacy support staff and GP groups discussed the use of an information portal or service directory for consumers. Younger consumers and carers, as well as those with a higher treatment burden, were more likely to choose to access the new pharmacy services proposed.

**Opportunities for community pharmacy:** There is an emerging opportunity for pharmacy to act as a healthcare destination that both connects people to relevant information and services, and provides more streamlined medication support through expansion of the current continued medication supply service. As younger participants were more likely to have a higher level of treatment burden, providing youth-friendly services is another important avenue for community pharmacies to explore.

**Pharmacy-specific recommendations:** Advocating for community pharmacies to become a health hub and implement various strategies that can improve access to services is important. This can range from training pharmacy support staff in healthcare navigation, to facilitating links with other health workers and consumer health organisations in the community, co-location or active referral and care coordination. Development of services tailored to specific populations such as carers and young people is needed.

**System-based recommendations:** Extending the pharmacist’s role to provide continued medication supply for a designated time period such as six months should be explored. Methods used to achieve this need to optimise patient safety and collaboration with other health professionals involved in the treatment of chronic conditions. Expanding the 5th CPA Continued Dispensing service would provide a mechanism for this innovative service.

**Strengths and limitations of the study**

The size and diversity of the sample and the combined qualitative and quantitative approach are the greatest strengths of this research. The sample reflected a diverse group of extensive health service users with a range of chronic conditions from affluent and disadvantaged communities. A wide spectrum of health professionals/workers and organisations participated in the study. Despite the study sample being large and diverse, there was high participant representation from less-studied populations, including older, culturally diverse and indigenous consumers and carers. Limitations of the study include the use of qualitative cross-sectional data collection conducted at four specific points in time, more than one mode of survey data collection and reliance on self-reported data, which can be influenced by researcher and participant bias. A consumer researcher was involved throughout the project to improve validity of interpretation. On-going discussions were held with a Reference Group to ensure the validity and reliability of the findings.

**Conclusion**

This research reveals many opportunities for community pharmacies to assist consumers with chronic conditions and their carers. The creative solutions proposed by consumers and carers have real potential to positively impact on treatment burden. Advocacy for continued medication supply by pharmacists and strengthening collaborative practices between primary care practitioners and community services is a priority. Pharmacy provides a unique opportunity for preventative proactive intervention through tailored patient centred pharmacy services with particular groups such as younger consumers and those experiencing financial burden.