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Consumer experiences of Chronic Obstructive Pulmonary Disease in regional Australia: A mixed methods study and logic model to identify consumer-experience mechanisms to avoid hospital and enhance outcomes

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Abstract

The objective of this study to explore consumer experiences of their care for Chronic Obstructive Pulmonary Disease (COPD) in a regional Australian hospital and to ascertain consumer identified contexts and mechanisms that can enhance consumer-experience outcomes. A sequential, explanatory mixed methods design was employed including a retrospective audit of COPD admissions and re-admissions and semi-structured interviews with a sample of consumers (n=12). Themes were synthesised using a realist framework and the Expanded Chronic Care Model to develop a logic model. Audit data identified above national average hospital admission rates and length of stay for treatment of COPD. Interview data revealed three key themes namely contexts of care, mechanisms for providing care, and outcomes of care. A logic model was constructed to highlight the necessary contexts and consumer-identified mechanisms that can be enacted to achieve consumer-valued outcomes. The model outlined factors at individual, provider and system levels in a regional and rural setting including interaction and relationships with health care providers; consumer capability; workforce; care pathway; capacity to offer services and support; and continuity of care. This research identifies that positive and continuous relationships are one of the most important consumer-identified mechanisms for influencing COPD consumer experience of their care and capacity to self-manage to stay out of hospital. This research challenges regional and rural health services to harness relationships and connectedness to improve consumer experiences and the impact of care for COPD consumers. The logic model provides a template to assist health services to rise to this challenge.

Keywords

Rural, person-centred care, patient experience, COPD, program logic

Introduction

One in seven people aged over 40 years have Chronic Obstructive Pulmonary Disease (COPD).1 Australians with COPD living outside metropolitan areas experience higher rates of hospitalisation and mortality.2 Potentially preventable hospitalisations (PPH) occur when “the hospitalisation could have potentially been prevented through the provision of appropriate preventative health interventions and early disease management in primary care and community-based care settings.”3 Whilst PPH rates often reflect accessibility of affordable primary health care, there is a growing argument that sociodemographic factors (income, education), lifestyle factors and health behaviours4,5 are also strong predictors of peoples’ risk of hospitalisation.6 Furthermore, a significant proportion of consumers with COPD perceive their admission was not preventable.7

Strategies aimed at enabling and supporting COPD consumers to better manage their condition significantly reduce emergency presentations, hospital admissions and general practice appointments.8 These effective strategies include health coaching, online communities and tailoring services to the consumer.9 Pulmonary rehabilitation programs (PRP) and Hospital Admission Risk Programs (HARP) are also evidenced based ways to help people with COPD become informed activated clients in rural areas.10 However limited access to appropriately skilled health care professionals,11 combined with low education and/or lack of peer support among rural chronic disease consumers...
Consumer experience of COPD in regional Australia, Moran et al.

significantly heightens feelings of vulnerability and reduces ability to self-manage.\(^\text{12}\)

Relationship-centred care argues that we need to attend to the complex social interactions that play out in health care settings and situations and that this fundamentally requires us to value and use “relational concepts” and “relational practice” – the way we interact in the delivery of health care.\(^\text{13}\) Despite a significant body of evidence exploring the importance of person centred care in COPD,\(^\text{14}\) and ways to improve COPD management\(^\text{15}\) there are very few studies examining consumer informed approaches to COPD management in rural areas.\(^\text{16}\) Additionally, there is a lack of understanding on how COPD management in rural areas interacts within complex social interactions.

Driven by the need for a better way forward for COPD management locally, the aims of this research were to:

- understand the profile of people presenting and/or admitting to a large regional health service who have COPD;
- understand their experience of their admission and illness; and
- use this information to build a consumer-informed program logic based on realist synthesis framework of the contexts, and mechanisms required to assist consumers with COPD to achieve valued experiences and outcomes in rural areas.\(^\text{17}\)

**Methods**

This study used a sequential, mixed methods design\(^\text{18}\) with a quantitative followed by a qualitative data phase. The Good Reporting of A Mixed Methods Study (GRAMMS) checklist has been used to describe this study.\(^\text{19}\) Data from the two sources were synthesised using a program logic approach.

**Quantitative data phase**

A retrospective audit of health service utilisation data from acute, subacute and community programmes on COPD admissions and re-admissions over a 12-month period to a regional health service in Australia was carried out. The regional health service comprises two hospitals and numerous subacute and community services. A more detailed review of hospital records was also undertaken of people who were re-admitted within 28 days of admission. The audit aimed to examine COPD patients requiring hospitalisation in the region, informing identification of participants for the qualitative phase and development of the logic model. Consumer data was included in the audit if the consumer presented to the emergency department or was admitted (or readmitted) to the health service for treatment relating to a primary diagnosis of COPD between July 2016 and July 2017. Table 1 outlines variables extracted from consumer medical records or discharge summaries according to data source.

**Qualitative data phase**

Out of 394 consumers who met the above quantitative inclusion criteria, 100 consumers who were resident in the local government areas serviced by the health service and aged over 18 years were randomly selected using an Excel random selection algorithm and invited to participate in the study. Invited consumers had the opportunity to “opt in” to the study by contacting the project officer (GC) directly. Interviews were semi structured using an interview schedule that was informed by the COPD-X guidelines, findings from the literature review, the Flinders Cue and Response interview tool\(^\text{20}\), medical record audit and the aims of the study. Interviews were voice-recorded and transcribed verbatim.

### Table 1. Data sources and variables of interest

<table>
<thead>
<tr>
<th>Variable</th>
<th>Data source</th>
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<td>Timing of presentation and/or admission</td>
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<td>Involvement with subacute/community programs</td>
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<tr>
<td>Polypharmacy (hospital record review)</td>
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</table>
**Ethics**

Ethical approval was granted by the local Human Research Ethics Committee, LNR/17/AWHEC/12. Informed consent was obtained from each interview participant.

**Data analysis**

**Quantitative data phase**

Audit data extracted from routinely collected medical records were transferred into a Microsoft excel spreadsheet and descriptive analyses were undertaken.

**Qualitative data phase**

Framework analysis was used for the qualitative data phase. The a priori issues for this research were reflected in the interview questions and included: Characteristics of clients who are admitted or re-admitted to the regional health service for management of COPD; Experiences of clients who are admitted or re-admitted for management of COPD; and Barriers and Enablers for supporting COPD clients in their decision process and action planning in relation to presentation to the health service for COPD management.

Analysis followed the five stages of Framework analysis. All researchers were involved in data familiarisation and identifying a thematic framework. Three researchers (AM, GC & RP) then tested and populated the thematic framework through indexing and charting. All researchers contributed to mapping and interpreting results.

**Data synthesis**

Themes arising from both data phases were synthesised to develop a program logic theory using the Expanded Chronic Care Model and realist synthesis framework.

Program logic provides a structure for exploring the complex relationships between health practice and outcomes, often involving diagrams or flow charts that convey the relationships between contextual factors, mechanisms and outcomes. The Expanded Chronic Care Model outlined key factors in the delivery of effective consumer care outcomes including the interactions of various factors between consumer, their providers and the healthcare system and aspects of prevention and health promotion. The use the Expanded Chronic Care Model as a basis for realist synthesis enables extraction and exploration of how contexts and mechanisms relate to various outcomes, identifying what works best for whom and in what circumstance.

For the purpose of this research, the term context refers broadly to any stakeholders, organisational, geographic, socio-economic, cultural or political conditions that influence outcomes; mechanism refers to the facilitators and/or barriers that are present in particular contexts that influence outcomes; and outcomes refer to consumer identified and valued measures of the outcomes of their care relating to their COPD management.

**Results**

**Quantitative data phase**

Audit data identified 503 admissions (394 individuals) to acute hospital beds for treatment of COPD over the one-year period with an average length of stay 5.5 days (range 1-57 days). Males (n=223, 56.6%) and those aged between 70 – 79 years (18.4%) represented the greatest proportion of individuals admitted (Figure 1).

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**Figure 1. Hospital admission data by gender, age and hospital (n=394)**
Over 11 months of the audit, 57 individuals were readmitted within 28 days of discharge. The majority of ED presentations (n=378) were admitted to acute hospital beds (75.9% hospital 1, 62.8% hospital 2). Factors such as the season and the time of day had little bearing on presentation rates (Figure 2). A large percentage of consumers admitted to either hospital were either ex or non-smokers (62.3%). Of the 17 hospital records reviewed in depth, 76.5% of consumers had four or more co-morbidities.

Over the two-year audit of subacute support services 162 consumers received support from the Hospital Admission Risk Program (HARP) and Pulmonary Rehabilitation Programs (PRP) (Figure 3). Approximately one in five consumers (22.2%) admitted for COPD related illness were known to the HARP, and under one in five (17.5%) were known to PRP. Most of those under the care of the HARP or PRP were from the regional centre (Modified Monash Model, MMM 2), with very few from outlying rural areas (MMM 3+) 24. MMM scores range between 1 and 7, where higher MMM reflect increased remoteness and reduced population size.

Qualitative data phase
Twelve consumers including 7 men and 5 women opted into the research and consented for interviews (Table 2). Three consumers were from outlying rural townships (MMM Score 5) and the remaining nine from the regional centre (MMM 2). Three consumers undertook the interview with their carer present. Two consumers were excluded from data analysis as their primary diagnosis was lung cancer and their interview information portrayed a very different experience of care compared to those with a primary diagnosis of COPD.

Themes and sub-themes emerged from the interviews and are described below (and illustrated in Appendix 1).

**Theme 1 - Contexts of care**

*Sub-theme individual level: values and motivation; knowledge and skills; health status*

Individual consumer circumstances and context significantly influence their experience COPD management. Consumer contexts include their health status, pre-existing values, self-motivation to learn more about their condition, and having the knowledge and skills to act. (Refer to Appendix 1, Section 1.1). Participant 7 discusses how they value being independent and having control over their health:

*"I'm a big on if you've got something wrong with you, you manage it, get on with your life, and do what you have to do." [P7, Lines 388-390]*

For some, experiences over the years of having COPD have contributed to their capacity and motivation to self-manage:

*"it was due to a succession of errors and stupid things happening in hospital over 10, 15 years, that made me notice and go no. I'm not just going to be a patient. I've got to be really proactive and take care of myself ...." [P2, Lines 264-268]*

Acquiring the skills and resources to be prepared for exacerbations and knowing when to seek medical help is

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**Figure 2. Emergency Department (ED) presentations by month and hospital (n=378)***
important to participants. Participant 9 describes how he
knows his body and how he uses this information to be
proactive about his management [Appendix 1, Section 1.1],
whereas Participant 4 describes the plan of action he has
to manage COPD changes.

...if this develops more, I’ll be getting the nebuliser out and using
that as well. [P3, Lines 393-398]

Participant 7 describes a willingness to learn more and
describes the need for people with chronic illness to
continually learn about their condition:
The other thing too I think for, well for people in the hospitals to
probably recommend to patients in my condition is to learn as much
as possible. [P7, Lines 372-373]

An individual’s health status (COPD severity and the
presence of comorbidities) also influenced their experience
COPD management. For example, participants who
identified they were in a palliative stage of COPD describe
realistic expectations of their management and the need
for support to navigate end of life care, such as help with
advanced care planning.

Table 2. Interview participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
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</tr>
<tr>
<td>P12+</td>
<td>M</td>
<td>MMM 2</td>
</tr>
</tbody>
</table>

+Excluded from data analysis

Figure 3. Number of COPD consumers attending support programs (n=162)

HARP – Hospital Admission Risk Program; PRP Pulmonary Rehabilitation Program

[subacute program]

[0 10 20 30 40 50 60]

Number of consumers attending support programs in 2016 & 2017

Hospital 2  Hospital 1
I don’t know what will happen this year if I get chronically sick. We’re on a plan of keeping me comfortable and just send me to the fourth floor. (Palliative Care unit) [P8, Lines 372-373]

Sub-theme provider level: workforce availability, skills, values and attributes
The context of service provision encompasses participant perceptions of the level of care (or lack thereof) provided by the workforce. Participants expressed that their experience of COPD management and how they are assisted to self-manage is heavily influenced by the availability and responsiveness of the workforce and their skills, values and attitudes.

Consumers valued staff being available. This availability was particularly evident in sub-acute and community-based programs:

... Every Tuesday, they had somebody come in from anywhere in the hospital, whether it was diabetes, the pharmacy, lung problems, medications, anything. [P5, Lines65-68]

In contrast Participant 9 describes his experience of the disjointed care in acute setting due to not seeing the one doctor at each bedside rounding, and how this leads to misinformation and mistrust:

You get to see the main doctor once. Then, from there on, his assistants come around. They report to him and then they report back to you. ... Why he doesn’t come every morning and see his patients [P9, 100-113]

Being caring emerged as a workforce attribute that participants valued and recognised as shaping and influencing their COPD management. This was seen as even a more important context than skills and knowledge.

I think it comes across as their level of caring. But whether they get it right or not, the fact they give a damn. [P7, Lines 427-428]

A number of participants perceived that there is a stigma associated with COPD and link this to how they are valued and treated by health professionals. This in turn is seen to impact on levels of trust and capacity to advocate for themselves. For example, Participant 7 describes the attitude displayed by health professionals regarding her difficulties in managing all aspects of her condition.

...when they’ve been around a while and they’re pretty well abusing you because you can’t lose weight, or whatever it is because you’re not trying. That was a doctor that said that. [P7, Lines 412-413]

Other participants reported a skilful and knowledgeable workforce:

... The nurse is very good, very knowledgeable and very helpful, and so is the doctor. Any urgent treatment needed he will either do there or send me off to the hospital [P9, Lines 543-547]

Sub-theme system level: availability of services within settings, clinical pathways
Participants further described how their experience of COPD management is dependent on system level factors such as the availability of services, within all settings (acute and community), as well the presence, or lack thereof, of clinical pathways. Both service availability and clinical pathways were recognised by the consumer as being impacted by the rural and regional settings in which they live.

Whilst some participants reported being able to access services, others reported not being offered follow-up or a pathway to care. Participant 2 reported:

In the hospital she organised for me to start the pulmonary rehab program up there, to keep up my strength... That also went over into the physio and the occupational therapist organising for some pressure mats and some rails at home. Then the rental program... [P2, Lines 44-57]

In contrast, Participant 3 who despite being in the latter stages of the disease, when questioned about the offer of supports and services, emphatically indicated that they had not been provided any follow-up to help with their COPD management. (Appendix 1, section 1.3.2)

Theme 2 - Mechanisms for providing care

Sub-theme Interaction and relationships
Consumers describe that their experiences with the management of their COPD are highly dependent on developing and maintaining effective interactions and relationships between themselves, health and medical practitioners, family and carers. They recognised that staying connected enhances wellbeing and self-management:

You really do need a solid network of something, you really do. [P8, Line 407]

Inherent in their experiences were concepts of trust, being respected as the expert in their care and being treated holistically. Data indicated that relationships impact on consumer trust in the health service and feeling in control of their own management. Mutual trust is described as the foundation of these relationships. When trust is placed in the consumer by the health professional and in the health professional by the consumer, outcomes are optimal:

... you’re on your way to staying out of hospital. [P6, Lines 392-394].
Conversely, Participant 4 (Appendix 1 Section 2.1) describes how his lack of trust in hospital staff has led to a reluctance to seek medical advice. Where relationships are developed and maintained and where there is mutual trust, consumers were more likely to describe proactive and timely care.

Another strong aspect of effective relationships and interactions that emerged in the interviews was that the relationship is shaped by the extent to which the consumer’s expertise is acknowledged. Participants described that being an expert is about being pro-active in managing their condition, knowing how and when to self-manage and being respected by health professionals to do so.

*I’ve always got antibiotics on standby … and my prednisolone.* [P4, Lines 98-104]

Participants’ expertise in self-management included excellent understanding of the role of the acute setting. They know where hospital fits in the continuum of care and are attuned to when they require more acute management strategies and need to go to hospital. Participant 1 describes how he self-manages his symptoms:

*I monitor it (sputum) because if I started to go funny I’d say now doctor, now the colour’s changing and I’ve got a spare sputum thing-oh in the cupboard there. So, if it goes funny, I can whack it in there…Make an appointment, shoot up and see him and say hey pathology.* [P1, Lines 560-566]

Participant 2 describes how he manages his medication, even when admitted to hospital:

*…this is a constant long-term treatment and I’ll do what I do…I take care of myself in that. I’m just one step ahead for when the system fails down a little bit.* [P2, Lines 240-249]

Consumers also reported situations where the relationship isn’t nurtured:

*Some [hospital staff] are a bit hard and brittle I suppose because they’re [used to it]. They can be a bit short with you and it sort of makes me worse.* [P4, Line 313]

Strongly linked to interactions and relationships was the concept of holistic care. This was particularly noted in the acute setting as well as in GP Clinics that were fully government rebated. Participant 3 discusses how his last admission was for chronic pain and issues that were unrelated to his COPD, however his COPD medication was overlooked.

*Nobody in hospital really worried about it [my COPD] because I was in there for other things. Mine is a mixture of MS and crushed vertebrae (sic) and sclerosis and … I yelled out and I abused the nurses. Where is my Seretide? Where is my Seretide?* [P3, Lines 62-67]

Participant 8 discusses her acceptance that her COPD is part of a number of co-morbidities and they are related:

*Well that’s part of the illness, right… the group has informed me of these progressions of the illness… I know my daughters have no idea that my legs are linked to my lungs.* [P8, Lines 245-249]

**Sub-theme continuity of care**

Participants identified effective relationships are maximised if there is continuity in relationships with health providers and the communication is timely and delivered appropriately. This is described by Participant 6 who identifies how he was left confused after a consultation with a doctor in the hospital and by Participant 9 (Appendix 1, Section 2.2) who describes the impact of disjointed communication in the acute setting and how this led to misinformation and mistrust in hospital staff.

*But no one tells you in the hospital what is going on. That’s their biggest failing as far as I’m concerned.* [P6, Lines 225-226]

Participants describe how it is important to have the same health professionals who understand your capability and condition, but also for different care settings to liaise with one another:

*But in the hospital, it’s hard because those that see you regularly when you go in they know what you’re capable of, but when you get someone who doesn’t know you, I think sometimes you got to go through the rigmarole all over again.* [P7, Lines 28-31]

Participants experience of care in the acute setting was described as more disjointed and less personal compared to their primary care experiences. In contrast participants described how they were (mostly) well supported to self-manage through good primary care (GP, pharmacist) and through interventions provided by sub-acute and community services (HARP, hospital in the home, pulmonary rehabilitation),

*…The important part is if you’ve got enough confidence in your doctor to be able to give you that, you’re on your way to staying out of hospital.* [Participant 7, Lines 392-394]

**Sub-theme capacity to offer services and support**

Consumer’s experience of care also relates to the capacity of the health system to offer services and supports, particularly in the rural and regional settings in which these consumers live. Rurality impacts on access to care and outcomes. Participants identified issues around referrals to metropolitan centres that were impracticable and unrealistic given their lung condition; lack of flexibility of
support services to accommodate for rurality; and frequent changes of staff in General Practice (GP) clinics,

“they tried to get me to go meet a doctor from Melbourne …but I said to the doctors here, I can’t travel. I physically can’t travel…”  
[P6, Lines 113-114]

One participant discusses how the rural pharmacies don’t often stock the medication they require thus have to travel long distances to obtain the medication that enables them to self-manage.

“We can go to the chemist down here and you’ve got to wait two days for your medication. If you’ve only got one pill left, well you’re stuck.”  
[Participant 9, Lines 495-496]

**Theme 3 - Outcomes of care**

**Sub-theme Individual level: not being a burden; responsive, timely access to care; locus of control**

A key theme from these interviews was the impact of positive or negative interactions and relationships with health practitioners and the influence this has on consumers’ perspective of care and the outcomes that were achieved. The outcomes that consumers want from their COPD management include not being a burden on others or the health system, receiving timely, effective and appropriate support based on their needs, and being equipped to have an element of control over their health. The responses also highlight that consumers understood that outcomes were not only about them as individuals; they also related to providers and the wider health system.

Participant 4 describes their desire not to be a burden on the health system and potentially impacting on other people receiving care:

“I usually drive myself to the hospital, because I think of the Ambulance drivers, there’s more people out there that need them urgently, you know. That’s the way it is.”  
[P4, Lines 106-108]

Receiving the support to self-manage is highly valued by participants as this enhances their locus of control. Participants valued timely management strategies tailored to the severity of their COPD. Participant 2 describes how when his symptoms are at their very worst, he is able to go straight to the Emergency Department and receive treatment without waiting:

“It’s improved so much that we can go straight into A&E now, rather than be sat in the waiting room and wait for the list to go through.”  
[P2, Lines 148-150]

Participant 6 describes the impact of being provided with an action plan after his fourth admission to hospital in one year and how this has enabled him to feel in control and equipped to better self-manage:

Last time I left was the first time I was actually given this plan. First time ever. That plan gives me what I should do when I get crook…. In the past, it was “see you later.”  
[P6, Lines 28-34]

**Sub-theme Provider level: improved clinical outcomes**

Achieving clinical improvements was also regarded as an important outcome.

*After the eight weeks, I was doing two minutes up and down in the chair and I was walking up and down 100 steps. It was brilliant*

[P5, Lines 43-45]

**Sub-theme System level: monetary and resource use**

Consumers reported that they understood the monetary and resource challenges faced by health services. They indicated that the outcomes of the care provided to them should help preserve those resources:

“I know what the beds are worth, and I know what ICU beds are worth. I know there are other people that can use the beds.”  
[P2, Lines 382-387]

**Synthesis and formation of logic model**

The Expanded Chronic Care Model offered guidance on understanding key factors that determine better consumer outcomes. The Expanded Chronic Care Model was employed to synthesise and extract themes and sub-themes into key factors at individual, provider and system levels. A realist synthesis framework was then applied to examine how different factors may interplay within the social complex interaction, and to illustrate the contexts and mechanisms which influence consumer outcomes.

The program logic (Figure 4) illustrates what mechanisms will generate the outcomes and what features of the context will affect whether or not those mechanisms function. Geographic locality was a major environmental and social determinant within the Expanded Chronic Care Model that underpinned each key factor regardless of whether it was an individual, provider or system level or whether it was a context, mechanism or outcomes. The various rural locations, as outlined in the Modified Monash Model, are unique as they explain specific context, mechanisms and outcomes at the individual, provider and system levels. For example, with a shortage of rural workforce, consumers rarely obtained continuity of care which resulted in worse clinical outcomes. Rural consumers were highly motivated. This coupled with trust and respect from their provider and health system, allowed them to exercise high locus of control in order to manage their conditions.

The program logic also highlights how each of the individual, provider and system level has different outcomes or goals. For provider and healthcare system levels, their ultimate outcomes were improved clinical indicators and saving resource use, respectively. In
contrast, consumers desired were timely access to care, not being a burden and high degree of locus of control. In the ideal scenario, positive contexts coupled with effective mechanisms will yield desirable outcomes for consumers, providers and health systems.

Discussion

This study presents a unique understanding of the context, mechanisms and outcomes of regional and rural consumers with COPD who have been admitted to hospital. The audit data demonstrates that the cohort of COPD consumers examined have a higher admission rate (1.42 per 1000) ratio than the state average of 1.25 and that those admitted to the regional health service examined stay for longer than other Australian public hospitals (5.5 day mean stay compared to 3.8 day mean stay Victorian public hospitals (COPD consumers) 2015-16). These numbers are consistent with remoteness indices whereby admission rates and separations increase as distance from metropolitan centres increase.

The qualitative data illustrates the consumer experience, whilst the program logic model, based on the realist synthesis framework and the Expanded Chronic Care Model, presented in this study identifies varying factors that can be targeted to influence a COPD consumer’s experience of care and the outcomes of value to them. Consumers identified a number of factors that were important to them which included feeling respected, trusted and listened to as the expert; being less of a burden on the health system; feeling in control; timely and appropriate treatment; effective treatment; and feeling enabled to self-manage. The program logic articulates the importance of rural and regional as a geographic determinant that influences each context, mechanism or outcome at the individual, provider or healthcare system level. Findings from this research can inform the development, testing and refinement of propositions that facilitate more efficient and targeted relationship-centred interventions in the regional health service to improve COPD consumer-valued outcomes.

This research identifies that relationship centred care plays a key role in shaping consumer experiences of their management and capacity to be effective in self-management strategies in different health care settings in regional areas. For example, whilst there were a number of examples of mutual trust and strong consistent relationships in primary care settings, there were few described in the acute care setting.

Our findings indicate that many people hospitalised for COPD in the regional catchment studied are not being
offered appropriate supports and services in order to achieve the outcomes that matter to them, or are not able to take the opportunity to participate in programs to develop their self-management skills. In other instances, some may already have effective self-management skills and appropriate supports in place, and these are not being recognised by health professionals, particularly in the acute setting. Furthermore, clients’ efforts at self-management and staying out of hospital are sometimes hindered by deficits in what should be a prepared pro-active practice team or by lack of continuity of care.

Through program logic we demonstrate how the mechanisms that assist consumers achieve their desired outcomes traverse the individual, provider and system levels. The interplay of these mechanisms on the contexts produces the outcomes. For example, if an individual consumer is highly motivated, knowledgeable about their health and is able to access support services, their desired outcomes may not be realised if they are not offered services and supports or if the interactions and relationships with service providers lack trust, effective communication and continuity of care, or fail to recognise the consumer as expert. Conversely, in situations where a consumer may have limited motivation and skills in self-management, enhanced consumer outcomes and positive experiences can still be achieved if the mechanisms identified in the model are applied.

As recently communicated by leading rural COPD researchers, the primary goal of a national action plan around COPD should be to empower people with COPD, their families, and caregivers to recognize and reduce the burden of COPD. A prepared pro-active team, in all sectors of health and support services, should work in a collaborative manner and be competent in supporting education and self-management. Inherent in this is putting the client at the centre of the care, understanding their values and preferences, enhancing relationships and ensuring that these drive the services and supports received. The importance of enabling and supporting people with chronic conditions from regional communities to effectively self-manage, and the impact good self-management can have on emergency attendance and hospitalisation rates is reinforced in this study.

Study limitations

Our findings have limited generalisability as data were derived from two hospital sites across two state jurisdictions. However, this study uniquely draws together COPD consumer perspectives using a program logic approach. As such the consumer-informed contexts, mechanisms and outcomes of value identified in this research can be used in other rural or regional health settings to realise consumer-informed improvements their COPD care.

Conclusion

This research identifies that positive and continuous relationships are one of the most important mechanisms for influencing COPD consumer experience of their care and capacity to self-manage to stay out of hospital. Rural and regional communities, through their connected nature, are in a unique position to improve experiences and the impact of care for COPD consumers. The logic model produced from this research provides a template for rural and regional health services to identify areas where they can better target efforts to improve consumer valued outcomes of care.

References


25. Victoria SG0. Standardised admission rate ratio (COPD) - comparison by geographical areas by selected group (Victoria = 1). In. Victorian health information surveillance system: State Government of Victoria; 2014.

