Consumers’ experience of the Opioid Replacement Therapy Program conducted in the Central Highlands and Grampians Regions of Rural Victoria

FINAL REPORT
May 2018

Prepared by:
Dr Tejaswini Patil, A/Prof. Penelope Cash and Dr Wendy Penney
Faculty of Education and Arts
Acknowledgements

- This project would not have been possible without funding from Ballarat Community Health as lead agency for the Orticare Grampians and Loddon-Mallee Pharmacotherapy Network.
- The research team would like to thank the reference group for their time and expertise in guiding this project.
- The research team acknowledges the generous support of pharmacy staff in assisting with participant recruitment.
- Finally, the research team is indebted to the participants who openly, honestly and bravely shared their experiences of participating in the ORT program so that health professionals and other consumers could benefit from the study findings.

To cite this report:


Contact: Dr Tejaswini Patil
Email: t.patilvishwanath@federation.edu.au
Executive Summary

This research project is the result of a partnership developed between Ballarat Community Health and Federation University Faculty of Education and Arts. The purpose of the partnership was to convene a research team to explore consumer experiences of Opioid Replacement Therapy (ORT) in the Grampians and Loddon Mallee region in North Western Victoria. The aim was to generate knowledge about the consumer experience of participating in an ORT program. Through better understanding of consumers, the results might inform health practitioners and support the development of evidence-informed guidelines to help improve future ORT programs. By exploring consumer perspectives of ORT a significant gap in the literature begins to be addressed.

We used qualitative interview research methodology based on interpretive phenomenology, which enabled the research team to understand the phenomena of ORT from the consumers’ perspective. In-depth interview methods were used to draw out the lived experiences of consumers. The research questions were developed in consultation with members of the reference group. Membership included stakeholders: two consumers, a General Practitioner, a Pharmacotherapy Advocacy Mediation Service (PAMS) representative and a community Pharmacist. Sixteen individuals (participants) who were consumers of the ORT program in the selected locations of Ballarat, Bendigo, Ararat, Maryborough and Stawell consented to be part of the research project. The findings generated as a result of the open interview questions were grouped into four main themes. Sub themes were created following manual coding by the researchers and use of NVivo qualitative data analysis software.

Results

We found that the majority of participants - despite identifying some challenges - indicated that ORT is beneficial and can be described as a catalyst for ‘normalising’ and ‘stabilising’ their lives. Correspondingly, most participants discussed the psycho-social impacts of ORT treatment. They described financial, social and emotional burdens imposed because of the cost of the medications and also onerous restrictions on the number of take-home doses allowed. Whilst most were happy and complementary about the relationship they had with their Pharmacist, the physical setting of the dispensing room was seen as too obvious and this led to participants feeling stigmatised. A lack of privacy and the feeling of ‘being judged’ and ‘gazed upon’ was reported. Another key finding was that systemic barriers existed as consumers faced a lack of coordination between key services, namely General
Practitioners (GPs), prescribers, dispensers, Centrelink, social services and other allied healthcare services.

The findings that reflect the voices of consumers inform three main recommendations. These are: Health Policy Provisions; Service Provision, and Improving Community Attitudes and Reducing Stigma. Based on the findings and team discussions, nine key recommendations are presented below.

**Recommendations**

**Health Policy Provisions:**

1. Review the cost of dispensing fees incurred by consumers, with the aim of reducing cost and ensuring equity.
2. Review restrictions on supervision and take-home doses, based on risk.
3. To increase the number of prescribers and General Practitioners in rural areas.

**Service Provision:**

4. Offer optional case management models based on psycho-social principles of caring for, and working with, ORT consumers. Connect key services such as GPs, prescribers, Pharmacists, community health, hospitals, Centrelink and other social services for program optimization.
5. Improve access to social services including social housing, training/education/employment and financial management.
6. Improve access to counselling services for consumers through community based allied services.

**Improving community attitudes and reducing stigma:**

7. Explore opportunities to engage prescribers, medical practitioners, Pharmacists and other health professionals in discussion about educational opportunities about how they might improve consumer experience of ORT programs.
8. Explore different strategies to reduce stigma and improve privacy in the pharmacy setting.
9. Provide information campaigns in the broader community about the benefits of ORT and the reduction of stigma associated with drug use.
INTRODUCTION

In seeking to address a gap in knowledge about consumers’ experience of participating in an Opioid Replacement Therapy (ORT) program, this project offers new insights into the nature of such experiences from the consumers’ own perspective. This research invited participation from consumers partaking in an ORT program provided by designated pharmacies in five rural communities in Victoria: Ballarat, Bendigo, Maryborough, Ararat and Stawell. These five centres have pharmacies that are part of the Orticare Pharmacotherapy Network (Grampians and Loddon Mallee) that dispense opioid replacement therapy for people choosing to address their substance use.

Through qualitative individual or dyad interviews with participants, this research explores consumer perceptions of what it is like to participate in the ORT program in these rural regions. It should be noted that the term ‘participant’ is used throughout this report to refer to the 16 consumers who consented to take part in the project and who were consumers of the ORT program at the time of the study. Their views and perspectives therefore relate directly to consumer experiences of the ORT program in the Grampians and Loddon Mallee Regions of Victoria.

Aim of the Project

The aim of this project was to identify the strengths, possibilities and challenges in the ORT program from a consumer perspective. Reflecting this aim, the following objectives were addressed:

1. Explore the Opioid Replacement Therapy (ORT) program from the perspective of the consumer in the context of rural communities.
2. Inform best practice guidelines that pay attention to consumers' voices while ensuring that the information gained can be transferable to other settings.
3. Generate knowledge about the consumers’ experience of participating in a rural ORT program that will inform health practitioners and encourage knowledge translation activities that facilitate evidence-informed practice.

The Research Team were focused on achieving the following project outcomes:

- To contribute to the knowledge and evidence required for a review of current policy, to help enable changes to processes used in delivery of ORT for regional ORT consumers.
- To develop a research collaboration between community health practitioners and researchers that will lead to longer term partnerships that are designed to foster evidence-informed practice.
Overview of the Pharmacotherapy Networks

Community-based ORT was introduced in the state of Victoria in the mid-1990s (State of Victoria, Department of Health and Human Services, 2016) as a move away from medical clinic-based operations. This aimed to increase the accessibility of opioid replacement to individuals in need. The shift in service provision has enabled designated medical practitioners and community pharmacies to be providers for the ORT program. It has helped in the integration of the treatment of opioid dependence with treatment of physical and mental health co-morbidities (King, Ritter & Berends, 2011; State of Victoria, Department of Health and Human Services, 2016).

Administration of the ORT program occurs through 995 accredited prescribers in Victoria, of which 977 are private medical practitioners and the other 18 are doctors geographically located in correctional facilities (Australian Institute of Health and Welfare 2015, p.13). The prescribers are usually located separately from the dispensing pharmacies and most operate within a small business medical clinic setting. There are many additional GPs who are not accredited methadone prescribers who are each able to prescribe Suboxone for up to five patients under the current Victorian Pharmacotherapy Guidelines.

In 2014, five area-based pharmacotherapy networks were established in Victoria to support localised approaches in connecting care, driving best practice and improving health and wellbeing outcomes for opioid dependent people. The main service objective of these networks is to support health professionals (GPs, Pharmacists, Nurses and Allied Health clinicians) to prevent, identify and treat opioid dependence throughout the state.

One of the five-area based networks is the Orticare Pharmacotherapy Network that comprises the Grampians and Loddon-Mallee geographic areas situated in the north western region of the State of Victoria. The main aims of this network as described in the Orticare Pharmacotherapy Network Action Plan Year Four, 2017-2018, are to:

1. Develop sustainable, joined-up, local and catchment-wide pharmacotherapy service systems.
2. Facilitate a well-supported pharmacotherapy workforce equipped with up-to-date knowledge of best treatment and support options for clients.
3. Change attitudes and build communities that are inclusive and respectful of people requiring pharmacotherapy services, no matter what the reason.
4. Provide a sustainable, collaborative leadership platform to underpin and maintain the group achievements.

A statistical snapshot of ORT consumers in Victoria
In Victoria in 2012 more than 14,000 clients were receiving pharmacotherapy maintenance for opioid dependence (State of Victoria, Department of Health and Human Services, 2016, p.5). Taking a closer look at 2014 figures, the number of ORT clients per 10,000 population in Victoria was 24 (Australian Institute of Health and Welfare, 2015, p.5). The opioid drugs of addiction used by clients in Victoria were estimated as follows:

- Approximately 50% of opioid dependence is reported by heroin users
- 5% on morphine
- 10% on methadone
- 3% buprenorphine
- 2% on Codeine
- 4% on Oxycodone and
- Others, not stated.

During 2014, a statistical snapshot of ORT program attendees was taken. This revealed that the percentages of clients receiving different forms of ORT on a day-to-day basis varied, with approximately 65% of the clients accessing methadone; 5% buprenorphine; and, 30% buprenorphine-naloxone (Australian Institute of Health and Welfare, 2015, p.7).

**Literature Review**

Following a review of the literature the following four broad themes emerged:

- Historical perspective on establishment of ORT treatment and policy in Australia.
- Pharmacological and cost benefits of opioid maintenance treatments and clients’ perceptions of treatment impact.
- Consumer perspectives and/or perceptions of ORT programs, and
- Role of community pharmacies in ORT.

We describe these below.

**Establishment of ORT treatment and Australian policy**

Internationally, the use of ORT began in 1962 at the Rockefeller Institute, USA. Studies conducted by Dole and Nyswander (1965) paved the way for illegal substance abuse to be treated as an illness, thus medicalizing addiction (or substance use disorders as is the current accepted terminology). These authors identified that methadone was able to reduce withdrawals and cravings for people addicted to heroin. At that time, the benefits of methadone usage included the replacement of one opioid (heroin) with another long-acting opioid (methadone) without the associated euphoria experienced by the user. It was believed that by removing the euphoria, opioid dependent users could maintain a normal life. Since then many studies have shown ORT is effective in treating opioid dependency (Gowing, et al., 2014).

Methadone was introduced in Australia in 1972, whilst buprenorphine was approved in 2000
and suboxone in 2005 (King, Ritter, & Berends, 2010). In Australia, current policy guidelines suggest that opioid dependency should be treated in the same way as diabetes or other chronic illnesses requiring pharmacotherapy (Department of Health and Human Services, 2016). Victorian policy provisions surrounding ORT are applied within the Quality of Medicines framework. These principles as expressed by the National Medicines Policy and outlined in the Policy for Maintenance Pharmacotherapy for Opioid Dependence include:

- Establishing the best possible management for a patient/client.
- Considering whether a medicine is necessary for treatment (and undertaking a risk versus benefit appraisal).
- Maintaining a commitment to a treatment plan that comprises ongoing evaluation of medication safety and efficacy.

This policy has resulted in increased accessibility to treatment across the state for people with opioid dependence. Policy provisions in Victoria include specialist pharmacotherapy services that help support community-based delivery through consultations and recommendations for managing complex clients. However, these services are limited to certain areas of metropolitan Melbourne. The Drug and Alcohol Clinical Advisory Service is a 24-hour telephone advice line for health professionals. The Royal Australian College of General Practitioners (Victorian Branch), delivers training for prospective prescribers in Victoria and the Pharmaceutical Society of Australia (Victorian branch) provides equivalent training for pharmacies in order to dispense ORT. The Pharmacotherapy, Advocacy, Mediation and Support Services (PAMS) helps ORT consumers to maintain engagement with, or else access to, a treatment provider; they mediate disputes and provide advice, referral and support in circumstances of hardship (Department of Health and Human Services, 2016).

To receive ORT a person must be diagnosed with an opioid dependence in accordance with the Diagnostic and Statistical Manual V criteria for a substance use disorder (Health and Human Services, 2016). Simply having an increased tolerance to escalating doses and use of opioids does not warrant a diagnosis of opioid dependence. For example, a person with chronic pain due to cancer or other ailment may be taking opioids regularly with increasing doses due to tolerance (or increased pain) and may also suffer withdrawal upon cessation (neuro-adaptation). The National Guidelines indicate that for a medical practitioner to assess a person for prescribing ORT, they must meet the criteria “consistent with diminished control over opioid use, such as multiple dose escalation, unsanctioned routes of administration, use for reasons other than pain and difficulties in reducing opioid use” (Gowing, et al., 2014, p.12). National guidelines (Gowing, et al., 2014) also note that treatment should be influenced by:
- Physical condition (e.g. chronic non-malignant pain, liver, cardiovascular, injecting-related infections, endocrine)
- Psychiatric conditions (e.g. anxiety, depression, cognition)
- Social problems (e.g. unemployment, housing, financial, relationships)
- High risk behaviours (e.g. overdose, self-harm, child protection and domestic violence issues)

The Australian Federal Government covers the cost of opioid maintenance drugs in the treatment of opioid dependence under Section 100 of the National Health Act, which includes the cost of the medication itself via the national Pharmaceutical Benefits Scheme (PBS) (Victorian Pharmacotherapy Area Based Networks, 2016). The cost of dispensing is not covered, and the client is expected to pay for the provision or dispensing of the medication. The Victorian Department of Health and Human Services, however, covers the cost of pharmacy dispensing service fees for some clients, such as individuals under 19 years of age and those on youth justice community orders. The Victorian Department of Justice and Regulation pays pharmacy service fees for incarcerated clients for up to 30 days post release from prison (Lord, et al., 2014). PAMS offers limited assistance in certain circumstances to people experiencing hardship may also contact, which can.

Chalmers and Ritter (2012, p.912) report that 43% of opioid maintenance costs are paid by State and Territory Governments, 33% by clients, and 24% by the Commonwealth Government. The average daily fee for methadone dispensing is reported to range from $1.93 to $10 (with the mean at $4.65). The lack of assistance with dispensing fees for ORT clients is controversial, because for most other medications the dispensing fee is included within the PBS medication provision. Chalmers and Ritter (2012) also noted that the Commonwealth Government provides $11.73 million per month towards fees associated with ORT. This includes: the cost of methadone covered at 50 cents per dose, the cost of the GP prescribing at $3.74 per day, and the State Government also covers the expense of prescribing ($14.58 per day) with a contribution of $1.05 (private) and $5 (public), and $10 (correctional). The dispensing fees for the typical outside high-risk group person on ORT is estimated to cost an average of $31 a week (Chaar, et al., 2011). Australian research shows that the co-payment is the major factor leading to people discontinuing therapy (Shepherd, et al., 2014).

A review by the Pennington Institute (2015, p. 13-14) suggests that a co-payment model requires two amendments, namely:
1. That the recording/dispensing fee, handling fee, counselling and pharmaceutical care costs that Pharmacists incur per patient are covered through the payment of a monthly fee.

2. Consumers are required to make a monthly patient contribution. This would be $6.00 per month for those on a Health Care Card and $36.90 for those without.

Similarly, other studies of best practice funding models (Doran, et al., 2006; Ritter & Chalmers, 2009; Shepherd, et al., 2014) argue that the elimination of the stress of co-payment results in favourable outcomes not just for retention of clients within therapy, but also on the wellbeing of Pharmacists because they no longer need to ‘chase’ clients for outstanding debt (The Pharmacy Guild of Australia, 2007).

Pharmacological benefits to clients and cost effectiveness of opioid maintenance treatments

ORT as a treatment for opioid dependence has been well researched and has received endorsement from World Health Organisation (2009). The majority of studies (Lawrinson, et al., 2011; Burns, et al., 2009, 2015; Horynik, et al., 2011; Gisev, et al., 2015) analyse the impact of ORT treatment by examining issues related to retention, prevalence, diversion and cost effectiveness of a multitude of opioid treatments. Studies such as Ward, et al. (1998; 1999) and Mattick, et al. (2004) report that some clinical trials have demonstrated that opioids, including methadone and buprenorphine are relatively effective treatments for opioid addiction.

Moore, et al. (2007) and Doran, et al. (2006) compared methadone treatment to other regimes such as detoxification and residential rehabilitation. These authors suggested that methadone reduces heroin use, correlates with a fall in criminal behaviour and improves psychosocial functioning. Burns, et al. (2015) compared ORT client retention rates in Buprenorphine and methadone treatment programs for the first time between 2001 and 2010. Their study reported that 46% of clients used buprenorphine, whereas 54% commenced with methadone. The retention rate for the population using buprenorphine was poorer, as clients switched between medications more frequently and they had more subsequent treatment episodes. Similarly, Winstock, et al. (2010) examined the prevalence and frequency of diversion rates with injectable methadone and buprenorphine. They concluded that the rates of diversion in the preceding 12 months were over three times higher for participants receiving buprenorphine as opposed to methadone.

Degenhardt, et al. (2009) in their study of clients in a state-wide opioid pharmacotherapy program in New South Wales over 20 years, suggest that despite elevated risks at different points in time, there was 29% reduction in mortality rates. Winstock, et al. (2008) assessed the effectiveness of methadone and buprenorphine on consumers’ general health and...
identified that consumers sought help for dental problems (29.9%), sweating (26.4%), constipation (25%), headache (24%) and reduced sexual enjoyment (24.2%). They concluded that users of ORT have considerable unmet healthcare needs.

Other studies (Horyniak, et al., 2011; Winstock, et al., 2010; Larance, et al., 2011) analysed the emerging health issues clients experience with diversion among injecting drug users. Digiusto, et al. (2006) sampled 997 heroin users and 300 methadone users in Australia and noted that there was no significant difference between the relative effects of methadone, buprenorphine and buprenorphine-naloxone treatments, and participation in criminal behaviour and illicit drug use.

Horyniak, et al. (2011) sampled 440 clients from three different jurisdictions in Australia using a mixed methods approach (interviews and quantitative analysis). The authors claimed that in states of Victoria and New South Wales clients were significantly less likely to have ever inhaled buprenorphine than those in South Australia. They reported that participants identified seven key physical and psychological motivations for injecting buprenorphine. These included dislike of other treatments, elimination of negative behaviour associated with illicit drug use, convenience of buprenorphine due to low price and ready availability, desire to self-medicate, and the practicalities of injecting. The authors noted, too, that participants felt empowered and were able to mitigate negative perceptions and stigma associated with illicit drugs.

In another study Larance, et al. (2011) surveyed perceptions of prescribers of the ORT program on diversion and/or injection of methadone, buprenorphine and buprenorphine-naloxone. They claimed that while prescribers perceive most clients do adhere to the ORT program, systemic inconsistencies in assessing and responding to risk from diversion/injection do influence clinical decisions and create complexities for prescribers. Other studies (Holliday, et al., 2013; Longman, et al., 2012) examined the barriers GPs face in becoming prescribers of ORT. They argue there is shortage of GPs registered as prescribers of ORT in Australia because of the psychological, social and behavioural challenges associated with the management of clients with a dependency.

Increasingly, the benefit of the treatment is being analysed within the framework of cost effectiveness (Darke & Ross, 1997; Moore, et al., 2007; Ross, et al., 2005; Gisev, et al., 2015). Moore, et al. (2007) suggests that methadone and buprenorphine are not only effective treatments, but are also cost-effective. Studies (Ross, et al., 2005; Darke & Ross, 1997; Gisev, et al., 2015) have also examined the cost effectiveness of methadone and other opioid treatments by taking into consideration the diversity of the clients. Ross, et al. (2005) chose to include participants based on their demographics, drug use, mental and physical
health. They then compared the included participants with the characteristics of heroin users currently not seeking treatment. They argued that the majority of the treatment-seeking clients had a history of heroin overdose, health problems, and high degrees of psychiatric co-morbidity in comparison to users not seeking treatments. The study concluded that the similarities between the non-treatment and treatment modalities in terms of lifetime poly-drug use, needle sharing, physical and other related health and suicide history, were alike. What is interesting, however, is that both groups were similar whether they were treated as having a lifelong condition requiring ORT or if they continued using drugs of addiction without treatment interrupting the person’s patterns of behaviour.

Gisev, et al. (2015) examined the cost-effectiveness of OST for individuals released from prison. The study demonstrated the incremental cost-effectiveness ratio for a period of 6 months, concluding that the final average costs were lower for the group that was on ORT after their release. The cost effectiveness of ORT post-release per life year saved was significant, however there was a cost to clients of $500. There is also other research (Ross, et al., 2005) which cautioned against these similarities by suggesting that heroin users tend to be involved in more cycles of dependence and active use, voluntary abstinence and incarceration in comparison to other drug users.

In looking at the cost effectiveness from the fee for prescribing and dispensing medications point of view between Commonwealth and State Governments, Chalmers and Ritter (2012) analysed the expenditure incurred by both governments if the dispensing fees for methadone were subsidised. They argued that if Governments participate in cost sharing, the flow-on of psychosocial impacts to the consumers’ health status would offset the increased social and economic burdens from ‘failed’ methadone treatments.

In summary, studies that have examined the benefits of pharmacological treatments are primarily interested in the relationship between cost effectiveness and opioid dependence treatment. Other studies examined the prevalence, frequency, and causes of diversion as some of the emerging issues found among users of opioid substitution treatments. The main perspectives considered are either the pharmacological impact or the prescribers’ and dispensers’ points of view. There is little discussion about the service users’ (consumer) perspectives in these studies.

Consumer perspectives and/or perceptions of ORT
There are few studies that explore the perspectives of consumers, that is, the experience of being a participant in an ORT program. In the limited studies available, Treloar, et al. (2007, 2011), Shepherd, et al. (2014), Lea, et al. (2008), and McCraty, et al. (2010) have examined the impacts of dispensing of ORT medicines ‘on’ clients. Shepherd, et al. (2014) using a
mixed method survey noted that the majority of respondents stated that dispensing fees had a significant effect on clients’ finances and lifestyle. Dispensing charges were likely to have a negative impact on ORT’s users’ compliance with therapy and their retention in the program. Similarly, other studies (Muhleisen, et al., 2005; Ritter & Chalmer, 2009) noted that dispensing fees contributed to cost burdens and social exclusion among clients. Muhleisen (2005) and Rowe (2008), pointed to the variability of dispensing prices in different jurisdictions imposing financial burdens on many clients. Chalmers and Ritter (2012) argued that if governments provide dispensing fee relief for methadone maintenance clients, it would be a costly exercise. However, these costs would be offset by the clients’ improved social and health dispositions gained from the methadone maintenance program. Crawford (2013) has argued that the impact of the ORT program has been to further increase the discriminatory experience felt by service users, perhaps because of the medicalization of addiction and coinciding consequences of this shift.

In summary, analysis of consumer perspectives and perceptions are dominated by discussions about cost effectiveness, affordability and accessibility. There is scant literature that examines the everyday experiences of participants in an ORT program.

Role of community pharmacies in ORT
The literature on community pharmacies is focused on examining Pharmacists’ experiences of participating in the ORT program. A number of studies (Lea, et al., 2008; Berends, et al., 2015; Le & Hotham, 2008) have shared the experiences of community Pharmacists in the ORT program. These studies suggest that Pharmacists are required to address a number of issues related to inappropriate behaviour, missed doses, expired prescriptions, provision of credit for dispensing fees, termination of treatment, managing problems experienced by clients and lack of communication between prescribers and dispensers. They conclude that community Pharmacists have a number of complex challenges to address, and that they need to be better supported.

Other studies, for example one by Le and Hotham (2008), who conducted a survey of rural community Pharmacists in South Australia, argued that access to allied health client support services in regional areas needs to be better coordinated with increased financial incentives. Similarly, Berends, et al. (2015) claim there is less capacity to provide services between prescribers and community Pharmacists in rural and remote settings in comparison to their counterparts in urban areas. The authors noted that due to gaps in program delivery there is a need to establish more financial incentives for GPs as prescribers and better resources for Pharmacists. A survey of community Pharmacists in South Australia (Lawrinson, et al., 2008) claimed that respondents indicated high levels of support for ORT programs plus their willingness to take on more clients. This study, contrary to other research, suggests
Pharmacists are open to dispensing ORT. Lea, et al. (2008) analysed consumer satisfaction with opioid treatment services at community pharmacies and argued that 61% of participants expressed satisfaction with their treatment and also reported high levels of satisfaction with most aspects of ORT delivery at their pharmacy. These authors noted that consumers were mainly concerned with lack of privacy and the high cost of treatment, although a minority of consumers felt they were being treated differently to other customers. These studies broadly note the barriers to community Pharmacists as dispensers of ORT in rural/remote settings. Furthermore, the design of programs and service delivery was the primary focus, and recommendations were made to improve service provision and increase incentives for Pharmacists and GPs to participate in ORT programs. The service users’ perspectives were more peripheral to the discussion and the impact on consumers was primarily a third-party view from the perspective of the Pharmacists.

Gaps Identified in current practice
ORT as a community-based model in other jurisdictions of Australia and in Victoria is well studied. The pharmacological/clinical benefits of methadone, buprenorphine and buprenorphine-naloxone treatments have been extensively researched. Furthermore, studies that have analysed the benefits of ORT have also examined prevalence, retention and diversion rates. They have primarily argued that ORT regimes are beneficial to consumers as the program reduces diversion and decreases mortality.

The other dominant area that has been studied is accessibility and affordability of ORT regimes. While studies have noted the financial, psychological and social burdens to clients because of the cost of medications, they are primarily written or analysed from the dispensers’ or prescribers’ standpoints. An analysis of the everyday experience of consumers combined with societal attitudes are important. However, these aspects are missing in much of the literature. This is the major finding of this literature review.

The gap in the literature has implications for improving program delivery. As noted previously, most of the prescribers and dispensers are advocating for improvements and more efficient programs that can be driven by incentive for ORT delivery in Australia, with the objective of program provision and delivery remaining central. However, one of the key elements to improving program delivery is to bring the voices of consumers to the centre of the delivery debate. A model that includes the input of consumers, prescribers and dispensers will assist in bridging gaps in service provision and assist with developing best practice guidelines for program delivery.
RESEARCH METHODS

The study used phenomenology as the methodology (Hammond, et al., 1991). Phenomenology is described as the search for particular phenomena regarding, in this instance, that noticed by individuals participating in the study (Williams, 2010). Interpretative phenomenology acknowledges one’s Being but goes further to locate the perceived experience of one’s Being in the broader historical and spatial contexts of one’s everyday world(s) (Mackey, 2004). Using an interpretative phenomenological approach has enabled the research team to explore participants’ everyday experiences (Darbyshire, et al., 1999); their perceptions of Being a consumer of the ORT program. Using an interpretive approach in this research has enabled the conceptualisation of meanings participants attribute to the phenomena of being ‘service users’ of ORT. The advantage of conducting an interpretative analysis allows us to locate participants’ meanings as they apply to broader social contexts in which they situate themselves.

As a qualitative methodology, interpretive phenomenology draws upon the rich descriptions (Geertz, 1973) of participants to enable the research team to establish the phenomena participants perceive as part of their day-to-day experience. Voice as an expression of their experience is a critical component to understanding the nature and extent of the phenomena under study. Given the depth and breadth of the conversations with participants, Connelly (2010) argues sample sizes are usually small and purposeful. Thus the phenomena are explored with fewer participants, however the approach relies on more detail and fuller commentary. The advantage of this approach lies in the potential for elaboration, reflection and ‘reflexivity [through] shared human competencies of communication’ (Kelly, 2010, p.11). The number of participants is not as important, rather, it is the depth of the data collected that is crucial (Schneider, et al., 2007). Instead of large number as can be seen in quantitative studies, this methodology and coinciding methods rely on data saturation, the repetition of information provided by participants (Kelly, 2010). As a rule of thumb, and depending on the nature of the study, approximately 15 to 24 participants is considered to be about the number necessary for saturation.

Procedures

Ethics approval was received through Federation University Human Ethics Committee prior to commencement of the project. The following processes took place.

Establishment of a Reference Group

A Reference Group of stakeholders was established and it included a general practitioner, community Pharmacist, Pharmacotherapy Advocacy Mediation Service (PAMS) representative and two consumers of the ORT program. This group provided advice to the research team on areas such as the recruitment processes that would work for this
population, the wording of the open-ended questions to glean the participants’ perceptions of their everyday experience, and the appropriate guidance to be made available in the event that difficulties arose. Three meetings took place.

Recruitment
A formal agreement with the participating Central Highlands and Grampians community Pharmacists was established. Currently, there are a limited number of pharmacies dispensing ORT medications in the Grampians region. Pharmacists in five selected sites (three in Ballarat, two in Bendigo, one in Stawell, one in Ararat and one in Maryborough) participating in the ORT program were asked to act as recruitment sites for the study. An advertisement was given to these network pharmacies to advise potential participants about the study and invite them to contact one of the researchers to discuss the project. Pharmacists also handed out these advertisements to potential participants over the age of 18 years. Through a combination of purposive sampling and snowball technique (Kelly, 2010; Kumar, 2010) we were able to recruit 16 participants out of the 28 who expressed interest.

While a representative sample from each location was attempted, there were issues with recruitment. Not only were the desired numbers not achieved in each location, the majority of participants were from the Central Highlands. Prior to being interviewed, each individual expressing interest was sent a plain language statement, the demographic data collection form and a consent form. Individuals were asked to bring the latter two forms to the interview. Many interviews were arranged (often with the same individual once or twice) and yet despite interest, some individuals did not attend. On these occasions, a follow-up telephone call was made. Most participants signed the consent form and completed the demographic form at the time of interview. In some instances, interviews took place in dyads rather than on an individual basis. On these occasions, the research team member checked with both participants that they were in agreement that they were comfortable with the presence of the other person. All interviews were held in a public location that was easily accessible to the participant - such as the municipal library, McDonald’s restaurant, a café, or a public park. Four telephone interviews were conducted due to difficulties with, for example, accessing the participant(s), availability of transport, and illness.

Many of the interviews were conducted in the presence of two research team members. To maintain consistency and reliability of the data and interviewing techniques, researchers de-briefed and discussed issues that may have arisen during the process. Most of the interviews were 25 to 45 minutes duration. Each participant was given a small monetary token in the form of a supermarket voucher in an acknowledgement of their contribution. Interview transcription was conducted by an independent contractor who is a widely known commercial provider.
Participant demographics

Of the 16 participants who were interviewed, 12 were men and four were women. This sampling technique enabled us to speak to service users who were currently in the ORT program although it excluded previous users. Participants’ ages ranged between 30-55 years. Of the 16, four were in full-time employment whereas others depended on social support via Centrelink, or disability pensions. Regarding education, six did not complete year 12, whereas the remaining 6 did finish year 12; four went to university but did not finish their course. Six reported a history of childhood abuse which included physical, emotional and/or sexual abuse, whereas two reported they had been neglected.

Data Analysis

Interview data were transcribed verbatim. Each transcription was independently reviewed by two members of the research team. Coding of the data occurred with the clustering of ideas reflecting participants’ meanings. Backwards and forward movements with the data enabled the identification of sub-themes. Searching for the phenomena experienced by participants was helped with the classification of experience subthemes into themes. These themes, with their coinciding subthemes, revealed a sense of resonance and there were correspondences between consumers, which then added credibility (Denzin & Lincoln, 2011). Moreover, as two researchers examined the data independently, when they compared their themes and subthemes, they found they were able to establish the veracity of the thematic analysis. Moreover, the themes and subthemes were further verified by using NVivo. NVivo is a software analysis program used for managing large amounts of data, but can also contribute to clustering ideas. Outcomes of the use of NVivo added strength to the findings and provided a very rich picture of participants’ every day experience.

In addition to the transcribed material, the researchers kept a personal log or journal of their own experiences. This information also helped to contextualize and document the processes used during the research, along with impressions and ideas emerging from the researchers’ reflexivity.

RESULTS

The main theme and sub-themes across the interviews are identified based on content analysis of the data. Many participants provided rich and in-depth responses that illustrated the multi-layered aspects of the ORT program and treatment. The narratives spanned from discussing reasons for joining (pathway into) the program, the physiological and psychological impacts of specific treatment regimes, and the vexed issues of participating in a legal program to maintain their addiction and the stigma/exclusion associated with it.

Furthermore, participants described the advantages and challenges of being in the program and made a number of suggestions for how the program can be enhanced. The main themes
have been broadly characterized into the following four areas and predominantly flow from
the interview questions.

Theme 1: Experience of participants on ORT treatment
Theme 2: Engagement between Pharmacists and consumers
Theme 3: Psychosocial impacts and lived experience
Theme 4: Consumer suggestions to improve the program.

Within these themes there are a number of sub-themes which will be discussed in the
sections below.

Theme 1: Experience of participants on ORT treatment
In response to the question *tell us about your experience of ORT treatment*, the following sub-
themes emerged:

- Pathways into substance use
- Current treatment (methadone and buprenorphine)
- Leading a “normal” life
- Cost of medications and takeaways.

Pathways into substance use
Participants’ experience of pathways into substance and/or drug use were diverse. The
majority reported a difficult upbringing, or poverty, social and economic disadvantage, being
homeless and ‘on the streets’ as examples. Experiencing mental health issues or having
been sexually and/or physically abused were common. A few participants reported they took
up substance/drug use for recreational purposes or to manage chronic pain. In describing
their pathways many identified themselves as “morphine drug addict”, “heroin-addict”, and/or
“addict”. To illustrate this, one participant stated, “*Oh okay. Well, myself- [name] I was a
morphine addict-drug addict all my life*. Other participants identified themselves as addicts,
recounting in matter-of–fact-terms how social and economic disadvantage and poverty had
affected their lives.

The following excerpts reflect the experiences that led to substance and/or drug use:

*I was a morphine addict-drug addict all my life. It’s a comorbid addiction due to early
childhood sexual abuse. So I’ve been a drug addict since I was 14, 15 years old. So
opiates I started taking when I was 17. Then just – yeah, that, that’s been my favourite
drug just to be able to deal with life and the world. So I find - found – I was a
methadone addict - morphine addict for about eight years.*

*Well yeah, I’ve got an extensive history. I was using [unclear] probably from the age of
21. I’m 38 now. I had a pretty rough lifestyle… I ended up on the streets and it was the
one day that I, yeah, decided I couldn’t find a bed, ended up sleeping in the street.
Rainy night, and that was it.*
I got abused physically; every day I got bashed and – because I had a thick [country of origin] accent. I was the smallest kid in boarding school, and I just got picked on, and picked on, and picked on. This has led to a lot of … using illicit substances and drinking; that’s what’s sparked it if at all, that is where I started.

When - I was dirt - we were dirt poor, and I wore Salvation Army clothes. You could tell [they] were Salvation Army clothes, and I’m going to school with kids that are wearing JAG and Country Road… that’s one of the reasons I got picked on.

I have an alcoholic father, so I grew up in youth hostels and places like that. So its inevitable life wasn’t going to be too good.

I have been [abused] in certain ways, yes. Physically, mentally, emotionally, from her past, a relationship she had. Familiar stuff… I come from a broken home so to speak and all that sort of stuff.

A few of the participants talked about the impact of chronic pain as a pathway into drug use. One noted:

Eleven years ago I had a major addiction to the pain killer codeine. I was starting to use the codeine again and I also had hip pain and I couldn’t really have Panadol so I was having suboxone.

In summary, while the majority of participants talked about structural disadvantages that influenced the choices they made, a few participants nominated chronic pain and social networks that introduced them to recreational drugs as reasons for pathways into drug use.

Current treatment (methadone and buprenorphine)

Of the 16 participants, nine were on buprenorphine (Suboxone/Subutex) whereas seven were on methadone treatment. Most had been on either methadone or variants of buprenorphine for more than five years. Participant responses ranged from describing their experiences of being on methadone or buprenorphine treatments to changing and experimenting with different treatment regimes, testing which suited their needs best and helped their goal to reduce dosages. Most participants used commercial names to describe the drugs they were taking, such as, ‘Suboxone, Subutex, or methadone’, whereas a few described them as ‘films’ or ‘liquids’.

The following excerpts highlight the way participants described their current treatments:

It’s the same as the Suboxone which I had as Subutex in the old days. I have only just used that up.

[We] are both on Suboxone [and have] no trouble [with it].

[I’m] on methadone. Well, I initially – I had - I was on it for 10 years. Then I got off it, Death in the family, relapsed, and I’ve been back on it now for 12 months.

I’ve been on methadone now for about five months. No, four months. I get - I pick up on Mondays, Wednesdays, and Fridays.
Many participants made references to trying different treatments (methadone and buprenorphine) because of the way they reacted to the drugs. Some argued that either methadone or buprenorphine suited them better because of other co-morbidities, whereas others felt Suboxone was more effective. A few participants also noted the challenges they felt with taking methadone and the withdrawal symptoms they experienced.

The following responses illustrate the diverse ways in which participants settled on either methadone, buprenorphine or Suboxone treatment:

_I tried Suboxone for 18 months and was doing Uni at the time. But I found it was really toxic once they made – like, I've had just straight buprenorphine before - and that I found worked really, really well. But no-one will prescribe that now. It's all the Suboxone which has got Naltrexone [in] ... which is counterproductive to the active nature of the drug, anyway. It's - and it just toxified me. I was waking up - I had to go to bed with a stack of towels every night because I'd wake up with night sweats three, four times a night. I was getting big pus boils all over my body. In the end my brain just broke. I couldn't - someone would start a sentence and by the time they finished it I didn't know what it was about. I seriously thought I'd lost my mind and that was from taking too much Naltrexone in the Suboxone - I believe - because it was the only thing I can contribute it to. I've just come out of the same stupor - gone from Suboxone to methadone because the Suboxone was making me seriously ill._

_Then I went from methadone to Suboxone because I found the methadone to be actually toxic, I suppose… because I was on a pretty high dose I suppose. So I'd gone from that to Suboxone back on to the methadone. I find the methadone probably a little bit more variable._

_I know how to manage [Suboxone] withdrawal whereas the methadone is quite an extended withdrawal… extended withdrawal, it's terrible. It's a really high maintenance detox._

The other area a majority of the participants discussed were the diverse impacts the levels of dosage had on their symptoms. Many participants mentioned the symptoms they experienced when they had high or low-level dosages and had disclosed this during consultation with their GP. Participants illustrated the point by citing their varying experiences:

_But every second day, they'd get to - instead of 16 a day, they'd give me 32, which is a fairly high dose. Back then, it was around the highest, but then I heard of people who have been on higher. But anyway, that was Subutex, which was different to the Suboxone._

_Yeah and that's much of the problem. The doctor says “No, you've got to do it real slow. You've got to do it 2.5 each week” and that's it._

_Oh just getting down slower and yeah, the way you feel and you've always got to be careful, if you start feeling too sick then you've got to go slower and stuff like that. Mentally, the fact that you just want to hurry up and get off it and get it all done, but you can't hurry and you've got to slow yourself, pace yourself down. Otherwise you'll start feeling too sick and go too quick and then I won't be able to handle it. Exactly, because they know how quick you can start feeling sick and then, yeah, it's not good. Then you_
start withdrawing and, yeah, that means you're falling too fast and you should have stayed on the dose you were on.

As I said earlier, it could be from the Valium. Not having any Valium in my body, it probably went into shock and stuff like that. Yeah, since then I've always been on top of my medication, I make sure I have the medication.

I’m on 6 milligrams of Suboxone and three Valium per day. My doctor’s trying to cut me back on the Valium and that, so we’re head butting each other at the moment because I don’t want it to go any lower than three a day.

Taking a closer look at comments, many participants reported how their lives were affected from methadone or buprenorphine treatments, the dosages they took and the steps they are taking to regulate their levels in consultation with their GP and Pharmacist. Despite a few misconceptions about what were the chemical compositions in Suboxone, participants had a good understanding of the symptoms and the need to experiment between methadone and/or buprenorphine or Suboxone treatments to manage physical and psychological concerns.

Cost of medications and takeaways

Participants described aspects related to the medications, namely, the number of takeaway doses they were allowed, the cost of medications, the variation in prices between pharmacies in the same regional centre and between regional and urban areas. Many participants voiced challenges experienced with the small number of takeaways allowed and the costs for medications, versus financially managing their everyday lives. (We return to this issue later). The majority of participants had three to four takeaways a week and they incurred expenses that varied between $35 and $50. Very few participants were permitted to have six takeaways, although this marginally reduced the dispensing costs. Some participants also mentioned the cost of other medications necessary for pre-existing morbidities.

The following excerpts illustrate the views of many participants on the weekly costs of medication and the number of takeaways:

…yes absolutely. Five dollars a day. That's your daily dose. So it's $5 a day or $35 a week.

Yes, it was. I did notice that. It was, some of them were $10 a day or $40 a week, so it does vary. I get the cost of it, like the $5 a day and all that, because with your takeaway they've got to provide bottles for you and they've got to take the time out to do it.

So that's about $100 fortnightly then if it's $5 a dose.

Yeah … it's $30 for the week.

It's costing $100 a fortnight to dose ourselves at the moment.
But up here’s a lot different than Cranbourne that you can pay your $30 for your seven doses. Up here they like to charge $30 a week regardless. So there’s no incentive to go later up here…

Other participants discussed the variation in pricing between pharmacies in Melbourne and those in regional areas, such as Bendigo, Ballarat, Ararat and Maryborough, in Victoria. One participant who compared prices between pharmacies noted:

About $105, I pay here, where it was $85 in the [name of pharmacy omitted] where I just was, or it’s $60 a fortnight in [name omitted], so it’s only half price in […], compared to what I’m paying here. Well, it’s $15… Well, I mean $60 a fortnight is the cheapest - $85 at one chemist and $105 at the chemist here.

Another participant described the cost differences in dispensing medications to consumers in Melbourne and in one of the research sites. The participant noted:

Yes, it’s like $52.50, whereas in Melbourne we were paying $35 but there was a place where we could get it for $20 a week, so it’s a lot cheaper compared to here. Here it’s like an extra $35 or something a week, $70 a fortnight extra compared to what we were paying. So it’s quite a bit of a difference.

Participants were very clear about inconsistencies in the costs of medication between pharmacies as well as between urban and regional areas. Many noted how the cost of medications affected their psychosocial wellbeing. What added to their distress was trying to deal with other regular expenses in their everyday life such as rent, water, electricity, gas, food, and travel costs.

Leading a “normal life”

Most of the participants were long-term consumers in the ORT program and most talked about significant changes the program brought to their lives. To characterise these changes participants used terms such as “being stable”, “leading a normal life”, “legal” and “functioning as a normal human being”. Some spoke about the emotional, financial and social stability they experienced due to being able to move away from the old social networks where it was tempting to engage in illicit drug dealings and fall back into past activities. The following quotes provide an insight into participants’ observations about the benefits of the program:

Yeah. I think the program is great, because it’s stable and legal. You can be stabilised, because it’s monitored and it’s legal, yeah.

I wouldn’t be able to be the man I am now and have the life I do at home, you know, stable and hold down a job - I wasn’t, without that program I wouldn’t be able to function properly because I’d be still probably using, I would be. There’s no doubt about it.

Okay,… that it allows you the opportunity to function as a normal human being in society. With that dose there you’re not having to worry when you wake up ‘where I am I going to get 50, 100 dollars’ or whatever … when you’re on drugs.
Maintaining sobriety means not bumping into certain people.

Stability… emotionally, lifestyle, financial [and not] waking…[in] the morning and wonder where the next drug is coming from…

Clearly, the ORT program has played a significant role in helping participants establish and where possible to maintain a ‘normal life’, finding new stability. It is interesting to note some participants specifically highlighted the difference the program has made in terms of rebuilding new social and community networks which are not part of illicit drug use.

In summary, despite many of the participants experiencing social and economic disadvantage (such as social exclusion and poverty), the majority highlight the substantial benefits of ORT. Another interesting finding is the vexed identities of participants who felt that although there is stigma and exclusion, there is also safety and stability in their lives in undertaking a legal addiction maintenance program.

Theme 2: Engagement between Pharmacists and Consumers

In response to the question *tell us about your experience of using local pharmacies*, the following sub-themes emerged:

- Engagement between Pharmacists and consumers
- Pharmacists are like a ‘small community’
- Stigma in the pharmacy setting.

Engagement between Pharmacists and consumers

Participants had varied responses to the types of relationships they had with Pharmacists. Because of the stigma they felt by being on the program, many of the participants respectful engagement was the basis of a positive experience in the pharmacy. One participant noted that, “You do feel a bit like the damned, kind of thing, lining up there and - but they [pharmacists] do treat you really well, they don't treat you like a Leper. … I've never had a problem with any of the people doing it.” Furthermore, most participants described positive experiences with Pharmacists such as, “non-judgemental”, “respectful”, “nice”, “caring”, and “understanding”. Participants used the same basis to compare and contrast difficult experiences they had with a few Pharmacists.

The following descriptions illustrate the aforementioned:

*The Pharmacists and that, they're all great in there. They're wonderful people, nice and kind, nice and polite …*

*They're generally pretty courteous.*

*The Pharmacists are wonderful people…*

*They (pharmacists) do not pass judgement or anything …*
We have a good relationship with our chemist. He would ring us now and then and see how we were going.

Yeah. It's really nice, this pharmacy… wonderful. Oh, they're beautiful - consistently like it, too. They're bubbly.

I think we're really bloody lucky to have [name of pharmacy anonymised] … the best pharmacy I've ever been to …

Honestly, they - it's very efficient. They're very organised. The staff themselves. So that they can manage the extra workload and they are very helpful if it comes to running out of a script or something like that - you know, they will really do their best to make sure that you can at least get dosed that day.

A few of the participants compared the working styles of different Pharmacists. The emphasis was mostly on the way a Pharmacist engaged with consumers and in other cases it was about the time it took to dispense their prescription. One participant noted:

You can wait up to half an hour to 45 minutes sometimes, to get your dose. Because he is just - he's smart and he's academic and everything - but he seems to be slow at doing everything - very, very slow.

A few participants used personal attributes to contrast working styles.

Yep. I find this chemist I go to now - it's fantastic. It is the best chemist I've ever been to actually, whereas another person stated, ‘But it's that other guy that … Yeah, he's just rude.

There's a couple of really cold Pharmacists around too. You don't want that to get back to them, though … It's an attitude.

Despite these negative experiences mentioned by a few participants, overwhelmingly many talked about the respectful, empathetic and person-centred engagement with their Pharmacist.

Pharmacists are like a ‘small community’

Participants talked positively about some Pharmacists who were able to administer the medication judiciously and discreetly because they understood the constraints of living in a small community. One of the participants noted,

[Because we live in a small community] we do not want the neighbours to see, or no one … to know. They (pharmacy) certainly helped us. I like going to this pharmacy because they know [my situation] and serve me quickly.

Others pointed to the relational aspects of living in a small community and the role the pharmacy plays. One of the participants stated, “They are really caring. It's a family pharmacy. They understand addiction. They don't judge and they're efficient in their service of people.”

Another participant explained:

We still keep in contact with our previous pharmacy, he would ring us every now and then and say “How are you going?” Yeah, he's a really good guy. Yeah, he bought his
own pharmacy in [name of place anonymised]. He still rings up now and then and we have a chat.

Other participants talked about the understanding and person-centred care they receive from their local pharmacy. To illustrate:

I'm in a position due to my anxiety where I'm getting six takeaways a week so I only have to go to the chemist one day a week. I just have to get out and go, you know? But they usually have my takeaways made up for me … all ready and I just walk in and walk out. They're aware of my anxiety and they've worked with me. They're great down there. Yeah, always.

Stigma in the pharmacy setting

Whilst most participants were positive about the care they received from Pharmacists, the majority talked about the stigma they felt because of the physical settings or the special positioning of the dispensing area as the primary cause of stigma. Very few participants mentioned the attitude of the Pharmacists as the primary cause of stigma. In describing the physical settings participants used terms, such as “open area”, “open glass door”, “no private space” and “hallway”. One participant explained their feeling of stigma that arose from the organisation of the physical space in these terms:

The only problem I found … is - they had their window … where you go for the program - it was separate - a bit more hidden. It was a hallway as well, so you’d have people going in and out behind you all the time - quite often - so you keep moving forward, keep … So that was kind of uncomfortable. So if they - my experience is that any chemist that can do that would benefit, well it would benefit those who take the dose to have a more private area.

Similarly, other participants talked about how the physical settings of the dispensary situation extenuate the stigma they feel:

It's not a good look for the chemist, but it also attracts attention, the people's attention, if you get what I mean.

Sitting at the chair, waiting, and whatnot, and they're off they're head going nod. It's not a good look and then you're tarred with the same brush because you're doing the same.

Here [at the pharmacy] there is an area there, but everyone can see you, where you sit. Sometimes you feel a little bit uncomfortable.

They say - and give you - you've got to put it in your mouth in front of them … I've seen it many times, people standing there. What are you - I tell them, what are you doing? I feel a little bit degraded, if I could say that word. Degrading. Yeah. But it's being seen by...

Interestingly, a few of the participants also identified the ways some Pharmacists acted that caused them to feel stigmatised. A participant noted, “Just various subtle little ways, like whether it's just speaking down to you or making you wait excessive amounts. Yeah, separating you from not from every - from the other customers, things like that”. Similarly,
another participant talked about one particular pharmacist who they felt “had extremely personal issues ... with junkies”.

Other ways in which consumers felt uncomfortable was the fear of ‘bumping into’ people they knew in the community. One participant stated, “I found the biggest stigma is that people know what you’re there for …”

In summary, the majority of participants appreciated the person-centred, empathetic and understanding care given by their local pharmacies. The other major finding is that most of the participants nominated the physical setting of the dispensing area of the pharmacy as the primary basis of exclusion and their feeling uncomfortable and stigmatised. There were also a few instances where participants felt judged and were subject to discriminating actions and attitudes of Pharmacists and pharmacy staff, and in some instances by the general public who attended the pharmacies in question.

**Theme 3: Psycho-social impacts and lived experience**

In response to a number of questions related to describing being on ORT, using local pharmacies, barriers and strengths of ORT treatment and local pharmacies, the following sub-themes emerged from participants’ responses:

- Social impacts of the treatment
- Community supports and a sense of belonging
- Systemic barriers and challenges.

**Social impacts of the treatment**

Participants provided detailed and in-depth insights into the social impacts of their treatment. Responses varied from discussing the barriers to family life, to the emotional and social challenges of being on ORT and at the same time being “safe”. The financial drain was also a strong area of concern. Reference to the number of takeaways allowed remained an issue, particularly where access to easy and readily available public transport to get to the prescriber and/or the dispenser was a factor that added to the cost of medications. Some expressed the subtle and clearly blatant ways in which they faced social stigma and exclusion.

In describing the familiar challenges associated with the ORT regime one participant highlighted the multifaceted cost it has had on his family life. Since there were restrictions on the number of takeaways he noted that taking holidays with his family was restricted. He mentioned, “my stepdaughter asked if I wanted to go camping this year at Christmas. I said ‘look, I can only come for three to four days at the moment’. She’s going for just under two weeks, so I can't go”. Similarly, others noted:
Yeah, that would be really good if they could do that, instead of you’ve got to put all your holidays off because you’ve got to come back every couple of - every three, four days. My holiday [unclear] every three, four days. Not really - not much, nothing you can do 200 kilometres away.

You get tired of it (the program). I don’t like the program. You can’t do anything, you can’t go anywhere … [not] interstate, or overseas …

Yeah, in that sense you can’t really go any further [away]. You’re only allowed the two on the weekend and two during the week, so you’re only allowed that many and yeah you can’t really go any further than more than a couple of days without needing more. So, yeah, in that sort sense you’re sort of stuck with being limited within the area, having to go to the chemist.

One participant mentioned that he did not want his grandkids to “see him taking [his] medications” and the lack of privacy in the pharmacy setting made it very difficult due to his/her sense of being visible to others in the pharmacy. This is particularly so in smaller communities where there are less dispensaries available.

Other social challenges related to managing the symptoms of the medications and not wanting other family members (specifically grandchildren) to know about the maintenance program. One participant noted:

… a week before and after my seizure. I can’t even remember being at my granddaughter’s house. She rang the ambulance and rang a few next-door neighbours to come and check on me. They found me passed out on the floor. My grandson and granddaughter were really upset.

Participants talked about the anxiety of attending social events. To illustrate:

I’m fighting it real hard inside not to cry about it. Yeah, so, I ‘don’t – I just stop, lean forward for a couple of seconds and try to [forget], but it is embarrassing … I could be at a mate’s house, or whatever, a friend’s house. And something sad comes on and I just cry. I can’t help it.

I don’t know, it’s changed me. I’m not the person I used to be. I don’t enjoy anything anymore. I don’t go anywhere. I don’t see anybody. It’s sort of turned me into a recluse and also one with a bit of an attitude, now, because of the way everything has been going down …

Other difficulties participants raised were regarding social friendships, friends coming to the house or apartment and keeping the takeaways in a safe place. Some participants spoke about avoiding having too many friends because of the pressure to “share their takeaways.” One person said, “For me - the only issue for me is that I'll run into someone I don't want to see there - yeah. It's only contact with other people from my past life is the way I look at it - because they're no longer part of my life.” Concealment of being involved in the ORT program was palpable to most participants. It was noted that “When I'm out I don't generally take them out of my sight, you know, I don't. You just can't trust people. They'll always, say they'll cut your takeaways off if you get them stolen or lost or anything happens to them”.

Others were worried about their children not seeing their takeaway doses, or to have access
to them. For example - “I put them in my bedroom and lock my bedroom up”, while a not uncommon response was, “I store it in a high place so they [children] can't see it”.

Travel to and from the dispensary was frequently via public transport. Discussion around accessing public transport and having to make multiple trips per week to attend the pharmacy or the prescriber was regarded as a financial burden while they were trying to stretch their already tight budgets. The following excerpts illustrate the point:

> It’s hard as I spend so much time on the bus getting my doses, working out how to get to the pharmacy, how to get to Melbourne for the script. There’s only one dispensing pharmacy in this small community … there is no private dispensing area … I go to Melbourne …

> It's a big hassle. She (partner) doesn't like going in the car that long and it's very difficult for that reason. Sometimes if we don't want to drive back the same day, if he's too tired or something, we've got to stay overnight, and [are] stuck in Melbourne. It's difficult with that sort of stuff, because she really doesn't like travelling back and forth all over the place.

> It’s just going to the chemist every day; it's the cost. It's embarrassing being in the chemist every day at the same time … There are cameras trained on me there.

> So you go down every day. There's no common sense. I've gone in stable – always been stable on the program. Never jumped off it once. Never missed a dose. Now I've gone from that, to every day. Having to drive into town every day … and spending fuel money you can't afford.

> I can't come in on Sundays because there's only one bus. A lot of the times that's either late or early. Saturdays aren't so bad. There's only eight or nine buses on the Saturday, but yeah, during the weekdays they're every half an hour. Every half an hour, up until about one o'clock and they go hourly, which is not too bad.

> If they take my takeaways from me – you know, me going there once a week becomes going three times a week. So it's going to really put more strain on that system too and that's if they're under more strain it makes it - the whole situation [tough] …

Some of the participants talked about the discrimination embedded in the ORT regime. One participant pinpointed how the policies and regulations perpetuate discrimination even when the rules are being followed.

> It's just hard that there's - because I know so many people personally that do misuse their medication and do misuse their takeaways. And, it's like, I can understand it and I can see why these restrictions are being put on [you]. But you can't paint everyone with the same brush …

> That's only someone like me, that's been doing this for 10 years. There's a certain subset of us out there that are very regular, very consistent. It's just annoying. It's what we have to do. We hate it. It's like being addicted to cigarettes … [but] then there's the other people that do go and do that, and there's kids that sell it and do whatever else they do.

> It's funny these days. I want to tell - I tell my doctor the truth, and I get nothing. Twenty years ago when I was abusing the system, I got whatever I wanted. Now it's turned around. I'm a very light sleeper. He won't prescribe me no sleeping tablets, or nothing.
Wellbeing, community supports and sense of belonging

Many participants not only talked about the normality and stability brought to their lives and also the sense of belonging and safety the ORT regime brought to their worlds. A few mentioned their sense of improved emotional, community and financial wellbeing and the new networks they were able to establish by being on ORT. Others talked about improved wellbeing because of stable family relationships and being able to spend time with their children and/or family members. Participants used terms, such as “safety”, “trust”, “support” and “wellbeing” to describe their lived experiences. One of the participants noted:

Now I feel safe because no one knows where I live. And even if they do see me pick up those takeaways, I've got that taxi waiting out the front.

Another person was more direct in describing their feeling of safety, “maintaining sobriety means not bumping into certain people. Some people you bump into and you [think] its just a bad day … It is the security [that's important].” Other participants talked about the financial security they established by being able to hold on to a paid job.

It just gives you – I mean I know it's still, it's another addiction still, and it's a substance that's harder, probably harder to get off. But it gives you the ability to function during the day without having to spend a fortune to go out and try and make ends meet while you're out there spending how many hundreds a day [on illicit drugs].

Normal, you know working five days a week, sometimes six. Having, you know, paying the bills and making sure I'm providing a safe stable home for my children and partner. I've got 12 acres out there.

So all you need is $5 a day, you know you've got it – it's a security blanket and it stops the illness of, you know, your withdrawals and everything. Having that drink allowed me to feel like a normal person, that I could wake up in the morning, go to work and not be drug affected. Just to be, you know?

Some of the participants also noted the advantages of increased wellbeing because of improved family supports and a feeling of greater safety when they were away from their previous social networks, after relocating to live in a rural community in regional Victoria.

Oh my Mum is here and some of my family. If I didn’t have them I would probably be dead like so many of my friends – dead due to overdose, bad stuff or hep C… Coming here has saved my life – if you don’t have the connection you may as well be dead. I now live here in rural Victoria having moved from Melbourne to get away from the scene. It was pretty bad there. I was really sick and had to get away so I could make a new start. Here you avoid going to the pharmacy when there are people there I might know.

Now I just smoke a bit of dope when I meet up with old friends in Melbourne every 6 months or so but there are hardly any of them left. They don’t know I am on [the] program otherwise they would want my stuff. That’s it, really.

It is just not bumping into inappropriate people.
Socially, the importance of family connections, feeling safe and being able to financially meet one’s social responsibilities while on the ORT program seemed to have had a significant impact for a number of the participants. Avoiding the cultural landscapes of their pasts, remaining out of contact with previous friends and networks and finding an environment where they felt a sense of belonging has enabled participants to lead what they understand to be a ‘normal’ life.

**Systemic barriers and challenges**

Participants discussed a range of systemic barriers they faced while on the ORT program. The barriers ranged from managing the costs of medication, to Centrelink payments, to accessing help regarding other health issues. In addition they found the lack of coordination among various services such as Centrelink, the prescriber, the dispenser, the GP and allied health services, frustrating. Many participants mentioned managing a number of comorbidities while on ORT. For instance, one participant on methadone described the lack of holistic understanding when he/she was hospitalised:

> Well, I've been off and on it for over 20 years, the methadone. So I've seen every single thing, seen them shoot it up and stuff like that. But some of the staff make you do it [in front of them]. They don't understand how sick [you can] be when you haven't got your methadone and you're meant to have it. The staff if they understood for half a second, the pain and whatever that we go through if we miss a dose. Like, I know some nurses up here, [say] it's like “you'll be right. It won't kill you. Just get it tomorrow”, or whatever. I'm like, “No”.

The challenges of navigating and managing parole conditions and the expectations of health practitioners, namely the prescribers, were also a concern. One participant explained in detail how lack of coordination and knowledge about ORT by these agencies created a misunderstanding of the participant’s situation. This led to unrealistic expectations.

> What made it difficult was the amount of time – at times, when I had to wait at least 30 to 45 minutes, that was hard. Here in [name of the pharmacy anonymised], there’s two main doctors who see – I said to my corrections officer … my job agency boss, that with the methadone program, there’s only so many doctors. He said, “I find that hard to believe. Any doctor should be able to write it up”. That's his attitude.

> I've gone from having one job agency person, right?, that was just blasé and didn't care, to one that's over-the-top and cocky – “Oh, I can do this for you, do that for you.” I can do anything. Well, I'm not putting all my cards and hopes in him! He says he's going to do this and do that, like a politician. He's so excited, but I doubt it – if it happens, it's a bonus … because [I've had] too much of it and I've been let down every single time.

The coordination between government agencies, namely Centrelink and the job agency was poor when one participant’s Centrelink payments were cut. The participant who had severe ‘atrophy of muscles’ and had developed arthritis, was expected to do a farm job. When he
informed the farm owner that he could not undertake the job due to health reasons, he discovered that his Centrelink payments would be stopped.

[I] wasn't going to be paid for eight weeks, because I turned down a job that [according to Centrelink] I should be able to do. But the thing was, they put me in the wrong stream and I told her (Centrelink employee) that. She said, “no you're in the right stream. You can do da, de, da, de, da”. I thought, excuse me – plus, what I've just been through. I couldn't believe it!

The lack of coordination among government and their allied healthcare agencies was not uncommon and it added to the structural barriers consumers involved in the ORT program faced.

A further example of the lack of communication between agencies and thus system failure was revealed when one of the researchers spoke with a participant who was unable to attend a face-to-face interview due to ill health. This consumer was clearly very unwell and required significant support through the health services, palliative care, and council home help assistance. Living such a distance from his primary care provider, a lack of co-ordination between services had resulted in the absence of support for any health or home care needs. This situation highlights important failures and the subsequent distress experienced by the ORT consumer who did need urgent medical and psycho-social help.

In summary, while the benefits of the ORT program improved the emotional, financial and family wellbeing of consumers, there were a number of system wide barriers that accentuated participants’ sense of social exclusion and stigma. In terms of the provision of the number of takeaways permitted in the ORT regime and the cost of medications, all added to the financial distress for many of the participants. The pharmacy setting (often lacking privacy) and treatment by some dispensers affected participants in different ways. In the main, where a participant felt accepted as an individual their experience was positive. On the other hand, where the person felt unsafe or felt judged and stigmatised, their experience was one of significant discomfort. Other systemic barriers such as the lack of coordination between a number of government agencies appeared to negatively influence the psycho-social wellbeing of participants.

**Theme 4: Consumer suggestions to improve the program**

In response to questions related to improving the pharmacy setting and ORT experiences in general, participants’ responses fell into the following sub themes:

- Reducing costs and increasing the number of takeaways
- Privacy for consumers
- Enhancing communication between prescribers/dispensers and better resourcing
• Education supports for ORT consumers.

Reducing costs and increasing the number of takeaways
Most of the participants to whom the research team spoke, mentioned that costs incurred for the medication could be reduced by increasing the number of takeaways. Additionally, the cost of travel to the pharmacy when added to the amount paid for dispensing made access to the program more expensive, particularly for unemployed participants.

I think the program could be cheaper. Lower the cost of takeaways.

If you can prove you are stable I think being able to ask for 2 weeks of takeaways would be reasonable. Then people could travel [for holidays].

Fortnightly pick-ups would be just amazing … I’ve got to come in once a fortnight either way, for Centrelink. [to] come in on a day that I come to Centrelink, would be just great.

I just think there should be basically one of two rules for methadone patients. If you’re trustworthy and you’ve proved yourself, you get takeaways. If not, you get none. Not this ‘one a week’ - and there’s no difference.

The dilemmas facing the prescribers (who determine a patient’s eligibility for take-away doses) are reflected in government policy that dictates current requirements for all those on ORT and fails to take into account individual situations and participants’ everyday world(s) in terms of a ‘normalised’ life.

Privacy for consumers
Enhancing the privacy of people on the ORT program in rural and regional areas was an important consideration, particularly for those in smaller communities where there might be one or two pharmacies that dispense. Suggestions to facilitate privacy to avoid public scrutiny were made. In part, this was to avoid derogatory treatment and stigma, but it was also to avoid others knowing they were involved in the program.

I suppose if they had some sort of screenage there, or in other – another area. But, there’s a pretty small bit [of space] around there. Just a screen or something so when people are in there, they [have some privacy], because I guarantee I wouldn’t be the only [one] I’m sure.

Yeah, so just a screen or just another way of doing it so we’re not in the public eye. I suppose it’s up to the owner of the pharmacy, if he (sic) wants to do it.

Where people who are on medication are out of the public eye, if they want to be. I know people that don’t care, and stuff like that. There are times where I’ve had to go

---

1 The increased restrictions of the policy came about in 2016 as a safety measure, following repeated pressure by the Victorian Coroner on the Department of Health and Human Services owing to the demonstrated increase in Victorian deaths due to consumption of Methadone take-away doses (State of Victoria, Department of Health and Human Services, 2016).
without my medications. I've had the grandkids, and I don't want them to [find out] - they know I'm on medication, but I don't want them to see me taking it.

Enhancing communication between prescribers/dispensers and better resourcing

An increase in the number of medical practitioners who are able to prescribe ORT was a common suggestion; a situation that would ameliorate some of the difficulties experienced by participants having to travel long distances (some going to Melbourne or to a larger centre to get a script for ORT). Reiterating the earlier comment:

The amount of doctors and how many hours they're actually open a week. That's the main problem. Here [at the clinic], there's two main doctors who [you] see. I said to my corrections officer – my job agency boss, that with the methadone program, there's only so many doctors [who can prescribe]. He said, “I find that hard to believe. Any doctor should be able to write it up.” That's his attitude.

Thus, knowledge of other government services is wanting, perpetuating assumptions about other agencies and the availability of medical practitioners able to prescribe ORT.

Yeah, we've got - that's actually something that would benefit small towns. That's probably, no it's probably overall, that more GPs are prescribers, because there's not a lot … and the fact that I, even in Melbourne, I found that I had to ring around a lot of doctors, GPs, to try and get somebody that would prescribe [ORT] for me because they were overwhelmed. They had so many clients that you're just hopping around trying to find one.

Complicating matters, however, is that many GPs are unable to address the person's other healthcare needs if they are their prescriber. As a result, medical conditions experienced by clients can be over looked, ignored, or dismissed as irrelevant.

So is that confusing? Is that confusing then, when you have to go to that other doctor? [a non-prescriber] …

The interesting thing too, which is really odd - and [it makes] everything uncomfortable with me … it says that he's a GP, but he can't see me for anything but to write methadone scripts – and that's it - full stop. So if I've got any physical problems for the GP or I'm about to die – so you can't see me. You're going to have to see a [another] GP.

… because I had a hyper-extension, which I knew. It doesn't move – a slight dislocation there. “I can see that” [the doctor says]. I know that already. Broken bones - I know those things - I told the doctor … that's the problem and [I've] used - because he was arrogant and of course, he thinks he knows better because he's the doctor. He said, “look mate - just take some Nurofen. It will go down and be fine.” It wasn't the case, so I went to my osteo[path] in the end and she said, “you should have got that looked at straight away … you'd never have had this problem.”

In [the doctor's] eyes, I'm fit enough to work. As he said, when I first seen him after my seizure, he doesn't want me to drive cars and doesn't want me to work. Yeah that's basically it. He won't fill out disability pension forms for me, even though Centrelink keep giving them to me. The last time they gave them to me, I said “I don't want it.” They said “why?” I said “well, because my doctor won't fill it out…”.
Having a pharmacist who could act as a prescriber as well as a dispenser would potentially alleviate client numbers that GP prescribers are seeing, helping OST participants to get the timely care they require.

*If it's just a [pharmacist] - it's a methadone or a Suboxone writer. That's it. He's not a GP. If I've got - my thumb problem that I had, I [finally] changed [my] doctors…*

Instead, pharmacist prescribers would enable opportunities for GPs to better serve their clients with an option to provide holistic care.

**Better education programs for consumers:**

There were many comments made about the importance of education, not only “for people just starting, to have some education in relapse prevention” but also to better prepare consumers for other aspects of their experience of ORT.

*I had to learn all this myself over a period of time. I’m lucky that I’m a studious … guy and I like reading books … I feel [better with education].*

A participant noted that, “counselling, where you can sit with a counsellor” would be beneficial. Having access to medical practitioners, Pharmacists, community health, allied health and social services including Centrelink would provide opportunities for the integration of multiple sectors to support a more holistic approach to clients’ care. Indeed, travel costs would be reduced, communication between services could be enhanced while advice on incomes, pensions and other social security questions might be effectively answered.

“Centrelink only let you earn so much … it is the disposable income when you think about the cost of the therapy and what you can afford.”

Despite the importance of education one participant stated:

*The bottom line, what I've found in my experience, what it comes down to, is you'll only benefit from the program if you want to. It's like, you know, the only barrier you would have is yourself, stopping yourself and using the system that's provided.*

**Discussion**

Consistent with the literature (for example, Amato et al., 2005; Moore, et al., 2007; Doran, et al., 2006), participants in this study felt that the ORT program has been critical in supporting them to live their everyday life in a normal fashion. Some mentioned that they had gone back to opioids at various points in time but returned to the program as this choice was better for them on a day-to-day basis than working out where to obtain illicit narcotics. The availability of ORT facilitated psycho-social well-being and this included the sense of having control over one’s life rather than being dependent on where one ‘scores’ next (Horyniak, et al., 2011; Larance, et al., 2011; Winstock, et al., 2010). The research team interviewed consumers who
participated in the ORT program on and off, over various lengths of time. Participants expressed that they could maintain a normal life despite the rigid requirements of the program that involved acquiring scripts, finding solutions to issues around dispensing, and accessing takeaways. A number reported they were able to have a family, where relevant to have a job, and had established new social networks to avoid engaging in previous addictive patterns of behaviour.

Similar to studies conducted by Connor, et al. (2009) and Mills, et al. (2005), we found that some participants reported forms of abuse and/or neglect in earlier life. Participants in this study reported that they had suffered traumatic experiences such as assault, bullying, sexual assault, or other psychological trauma. One-third mentioned that they had had been abused in their early lives. Despite a number of studies (Conoro, et al., 2009; George, et al., 2018) linking ORT and the presence of significant mental health concerns, participants did not report having continuous and regular mental health assistance. This calls for a shift from a medical model of ‘management’ to a social model of health that focusses on the socio-emotional wellbeing of the individual along with medical interventions that may be required. Further research that explores integrated approaches to the psycho-social and medical dimensions of care is needed. It may also serve to better equip communities to support people with opioid addiction in facilitating their everyday life, by creating a sense of belonging and place in community.

In addition, in regard to participants’ general health, we noted that there are a few studies that analyse the link between the impact of ORT treatments and other co-morbidities, particularly those related to psychiatric and physiological illness (Ross, et al., 2005; George, et al., 2018; McCance-Katz, et al., 2010; Kidorf et al., 2015). Similar to these studies, many participants reported that they had experienced significant mental and physical changes to their body, such as muscle wastage, weight loss and cardio-vascular and respiratory problems. They also spoke about diversion, criminality and coping with social and economic circumstances as challenges in terms of participating in ORT. Some of the participants reported that the prescriber was not their regular GP and hence they had difficulties in seeking medical assistance to manage other co-morbidities. Additionally, many participants experienced agitation, anxiety, depression, or mood and sleep disorders. However, there is limited research/literature that analyses the psychosocial supports that can be provided for consumers on ORT. That is, looking into an alternative approach to care may facilitate the coordination of consumer support across a number of services, including counselling.

There are a number of scholars (Berends, et al., 2015; Wakeman, et al., 2009; Hotham, et al., 2005) who have highlighted the need to increase access and create financial incentives to attract more prescribers in rural and remoter geographic regions. For instance, Berends, et
al. (2015), like the experience of the participants in this study, reported a multitude of challenges in terms of access to prescribers, dispensers and other medical services in rural and remote settings. Not dissimilar to the findings of Berends, et al. (2015) and Hotham, et al., (2005) our participants also reported that sometimes they had access to only one medical practitioner who in some cases had high workloads or did not have the time to discuss comorbidities and other health issues. The inability to act in these circumstances illustrates the tenuous social, economic, and health circumstances of this group of consumers. The views of the participants concur with the study conducted by Longman, et al. (2012) who argued that there are not only service provision and service delivery barriers but also negative attitudes, experiences and stigma associated with addiction that adds to the shortage of prescribers in rural and remote areas. While more opportunities are needed to educate medical personnel in caring for people with addictions, so too is further education warranted for those on the ORT program especially in areas such as the impact and side effects of replacement drugs, for example, methadone, or buprenorphine.

Participants talked about stigma and the discrimination they felt when in the pharmacy setting. Fraser (2006) in her interview with consumers on methadone substitution treatments highlighted how participants felt stigmatised by what she calls ‘the space-time manifold’ and the ‘chronotone queue’. Interestingly, several participants in our study mentioned the physical setting and dosing in a pharmacy environment was a productive site that helped, ‘materialise particular methadone subjects—often the very kinds considered undesirable; that is, the “unproductive” the “disorderly”, the “illicit” ‘ (Fraser, 2006, p.193). Similar to the interviews Fraser conducted with consumers, several participants in this study found the pharmacy setting distressing because they felt scrutinised.

The issue of privacy is widely documented in literature (Lea, T., et al., 2008; Fraser, 2006; Lea, P., et al., 2008). Some participants raised issues of visibility, lack of privacy and confidentiality particularly when receiving ORT in pharmacies within small communities. Our participants commonly reported anxiety and stress of ‘being seen by other addicts’, ‘bumping into the wrong crowd’ or being ‘seen by others’ while they tried to avoid connecting with people they knew. They felt it made them anxious that other members of the family and/or employers might become aware of their situation. Some participants suggested that wherever possible, pharmacies should have a private area where they could get their treatment, even if the area is screened off.

Many participants noted that community Pharmacists were in the main helpful, caring, and listened actively to their everyday experiences. They noted the vital role community Pharmacists play in providing this service to clients. Several participants commented on how helpful they were and how they would take a personal interest in the consumer, a situation
also reflected in the literature. Lea, T., et al. (2008) surveyed 508 clients and concluded that 61% of the clients were satisfied with most aspects of the program delivery. Further studies undertaken by Lawrinson, et al. (2008) and Lea, P., et al. (2008) raised issues that a few of our participants referenced, such as occasional difficulties with dispensers and Pharmacists over scripts, a lack of payment and less access to pharmacies in rural and remote areas. A minority of the participants compared working styles of Pharmacists and noted the difference in the way Pharmacists treated them. A few participants commented upon subtle ways in which Pharmacists ignored them by making them wait longer or by speaking disrespectfully. In a recent survey of Pharmacists administered by Etcheverrigaray, et al. (2016), it was noted that while ORT as a pharmacological intervention had overwhelming support from Pharmacists; when it came to Pharmacist attitudes towards consumers, 49.1% considered ORT consumers as ‘different’ and ‘feared’ they (consumers) could cause problems. Despite concerns from a few of our consumers, in the main most of them valued their relationship with the community Pharmacist and wished they had access to more pharmacies in rural/remote areas.

Limitations of the research

It is important to note that the challenges the research team faced in recruiting participants for this study is indicative of the psycho-social issues that consumers of ORT face. There were many occasions that interviews were arranged and a participant did not show up for their appointment. Difficulties with public transport and mobile phone credit were cited as impacting on participation, as well as chronic ill health. Participants tended to organise their appointments around their pharmacy visits, indicating that accessing medications remained central to their everyday lives. While the number of participants was 16, the strength of the study lies in the in-depth descriptions participants were willing to share with the researchers. Their voices therefore reflect their experiences, telling what it is like for them in terms of their everyday lives in being involved in the ORT program in a regional/rural setting.

Recommendations

Based on the findings and discussion, our key recommendations are:

Health Policy Provisions:

1. Review the cost of dispensing fees incurred by consumers, with the aim of reducing cost and ensuring equity.
2. Review restrictions on supervision and take-home doses, based on risk.
3. To increase the number of prescribers and General Practitioners in rural areas.
Service Provision:

4. Offer optional case management models based on psycho-social principles of caring for, and working with, ORT consumers. Connect key services such as GPs, prescribers, Pharmacists, community health, hospitals, Centrelink and other social services for program optimization.

5. Improve access to social services including social housing, training/education/employment and financial management.

6. Improve access to counselling services for consumers through community based allied services.

Improving community attitudes and reducing stigma:

7. Explore opportunities to engage prescribers, medical practitioners, Pharmacists and other health professionals in discussion about educational opportunities about how they might improve consumer experience of ORT programs.

8. Explore different strategies to reduce stigma and improve privacy in the pharmacy setting.

9. Provide information campaigns in the broader community about the benefits of ORT and the reduction of stigma associated with drug use.

Conclusion

This study aimed to fill a gap in the literature in terms of putting forth consumer experiences of an Opioid Replacement Program in regional and rural areas in Victoria and more broadly, in Australia. Based on information gathered using a rigorous approach to research, we make recommendations in three main areas: Health Policy, Service Provision and also Improving Community Attitudes/Reducing Stigma.

While the experiences of the participants in this study are widely represented in the literature, this study is significant because it updates prior research and is specific to ORT consumers who live outside the large cities, in rural Victoria. We suggest there is a pressing need for review of current policy in several areas, including in regard to variability in the cost of dispensing fees and restrictions on medical supervision and takeaway doses.
References


