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“A lot of people call it liquid handcuffs” – barriers and enablers to the opioid replacement therapy in a rural area

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ABSTRACT

Introduction: Opioid dependence is a complex health condition often requiring long-term treatment. The main objectives of treatment are to reduce dependence and the associated morbidity and mortality. Opioid replacement therapy (ORT) is an effective pharmacological therapy for opioid dependence. The aims of this research were to explore barriers and enablers to ORT in rural areas of Australia.

Design and Methods: A qualitative study design incorporating semi-structured interviews was used to explore views of people in ORT. Interviews were analysed for emergent themes and issues.

Results: Barriers to ORT were restrictiveness, stigma, the medication and structure of the program. Enablers were structure of the program, access to takeaway doses, effect on drug use and the medication.

Discussion: To improve access and retention in ORT programs action is needed to facilitate programs meeting the needs of rural people, including reducing cost of medication, addressing the restrictiveness of programs and effect on employment opportunities, and stigma associated with drug use and addiction in communities.

Conclusions: Barriers and enablers to ORT programs exist in the rural areas studied. Geographical distance, inability to gain and maintain social connections including employment, and lack of community education addressing stigma are significant barriers to ORT in these areas.

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Opioid replacement therapy; opioid addiction; methadone; buprenorphine; qualitative research

Introduction

Opioid dependence is a complex health condition requiring lengthy treatment. (World Health Organization, 2009) Opioid replacement therapy (ORT) is the most effective pharmacological therapy for opioid dependence. (Amato et al., 2005) In Australia, ORT is provided for heroin dependence (Ritter & Chalmers, 2009) and increasingly for management of pharmaceutical opioid dependence. ORT is associated with significant reductions in illicit opioid use, criminal activity, overdose deaths and behaviours, which increase the risk of HIV transmission, while improving physical and mental health, and social functioning. (World Health Organization, 2004) ORT is an important component of community-based approaches, allowing treatment provision on an out-patient basis. It's associated with high rates of retention and enables individuals to tackle major health, psychological, social and legal issues. (World Health Organization, 2004)

The health of people in rural Australia is poorer than their urban counterparts with reduced access to medical treatment at a greater cost. (Strong & Strong, 1998) This includes drug and alcohol treatment and harm minimisation programs. Despite similarities in profile of drug users in urban and rural areas, access to services is significantly limited in the latter. (Day, Conroy, Lowe, Page, & Dolan, 2006) A 2009 report on the Australian ORT system identified that most associated problems were compounded in

rural or remote locations, including access to prescribers and dosing, travel costs, few service providers, stigma, discrimination and poor workforce support. (Ritter & Chalmers, 2009) The Victorian Pharmacotherapy Review and other studies identified costs as well as stigma and discrimination as barriers. (Digiusto & Treloar, 2007; King, Berends, & Ritter, 2013) A study conducted with health professionals in rural and remote Australia identified that despite ORT being “highly valuable to the community” it was not without problems. These health professionals suggested that travel time and costs, employment issues, opening hours of the GP clinic and pharmacy, GPs' time constraints and privacy were key barriers to accessing harm minimisation programs. (Peterson, Northeast, Jackson, & Fitzmaurice, 2007)

Whilst there is a plethora of research on ORT programmes, there is limited research on ORT delivery in rural Australia where geographic and social features of the environment complicate service delivery. Very few studies describe the delivery of ORT from a client perspective but rather focus on the views of prescribers, pharmacists and others involved in service delivery. Ensuring effective and equitable ORT access in regional and rural areas is essential and a qualitative approach provides a critical means to do this. This research investigates the perceived barriers and enablers from a client perspective to accessing and remaining in ORT treatment in rural communities in Victoria and New South Wales (NSW).

Methods

A qualitative narrative design with semi-structured interviews was employed. Two rural Australian communities (in Victoria & NSW), were selected. These farming communities are more than 100 km from a regional centre. In Victoria, the emphasis is on a community model of ORT. (Drugs and Poisons Regulation Branch, 2016) Provision of services is primarily through general practitioners (GPs) and community pharmacies with specialist services to treat more complex dependence problems. (King et al., 2013). In NSW, ORT is funded and managed through both public and private sectors. (New South Wales Department of Health, 2011) The NSW model has primary sites co-located within hospitals or community health. These sites generally provide assessment, prescribing, dispensing and limited case management. Most staff are trained nurses, while prescribers are visiting specialists or sessional GPs. There are minimal ORT provisions by community prescribers and dispensers. (Berends, Larner, & Lubman, 2015)

Adults over the age of 18, currently engaged in ORT in the studied rural communities, were recruited voluntarily. Service providers were supplied with information and asked to promote the research with ORT patients. Participants were asked to contact the chief investigator to arrange an interview if interested. Participants already enrolled were encouraged to disseminate information about the research to recruit further participants.

Twelve semi-structured interviews (6 in each community, 1 hour in length) were conducted with researchers (CO and PW), audio recorded and transcribed verbatim. For accuracy of data each transcript was sent to participants for authentication. Written informed consent was obtained before interviews. The interview (Appendix 1) was used to gain narratives from participants including their childhood experiences, impact that dependence had on their lives, and experiences with treatment, especially ORT. Recruitment continued until consistency in concepts and insights into lived experiences of opioid dependence and ORT emerged, without the presentation of new themes. (Fusch & Ness, 2015) Data were de-identified, coded and analysed for common emergent themes using NVivo data analysis software (11 for Windows). (Qrs International Pty Ltd, 2015) Data were analysed separately by researchers and compared for consistency.

Approval for this research was obtained from Human Research Ethics Committees (HREC), in each presiding jurisdiction: Goulburn Valley Health HREC 23/GVH/16 (Victoria), Murrumbidgee Local Health District (NSW) HREC 16/GWAHS/84 and La Trobe University.

Results

Demographics

Twelve participants in total, with equal representation from the two areas (Table 1).

Themes emerging from interviews were organised into barriers and enablers. Barriers to ORT were restrictiveness, stigma, medication and program structure. Enablers were organised into sub-themes including social, physical and mental enablers, program structure, including access to takeaway

Table 1. Patient demographics.

GENDER	Male 8	Female 4		
AGE	18–25 1	26–35 2	36–45 3	46–60 6
EMPLOYMENT STATUS	Employed	Unemployed		
REGION	0 Victoria	12 NSW		
DEPENDENCY	6 Heroin	6 Prescription/ pharmaceutical opioids	Both	Other
TREATMENT	3 Methadone	4 Suboxone	4	1
	9	3		

doses, the effect on drug use and medication. No barriers or enablers were unique to any particular location.

Barriers

Restrictiveness

A common barrier for the ORT program for participants was lack of freedom. If they had more freedom, engagement and satisfaction with programs would be greater, highlighted by one participant: “I would stay on the methadone if I had my freedom.” (Participant 12). The main issues restricting freedom included having to collect doses daily and not be given “takeaway” dose (doses that can be taken from the pharmacy and taken at a later time), and travel to a designated pharmacy or hospital. For those living out of town this was time consuming and expensive. Regular dose collection (daily or several times weekly) meant restrictions in seeing family or for recreation “...when you’re stuck in the one town, you start to get a bit edgy and that. It would be nice to go away for a couple of days or something.” (Participant 10).

These restrictions meant patients wanted to leave the program “I want off it, only for the simple fact is it’s - draining, you can’t live a normal life. I can’t wake up and be normal like everybody else.” (Participant 4). They likened the program to being incarcerated “they took my takeaways away – the Methadone doctor here - which has made my life now, back to liquid handcuffs, it’s worse than um, my corrections order.” (Participant 4).

Restrictiveness of having to be near a dosing pharmacy made it difficult to find employment in a rural area “...the painter that painted our house after we had the walls fixed - he gave me a job and I started painting - but I couldn’t keep it through the stupid chemist hours. ...it was a seven o’clock start to leave to come to XXXXX from all the way like half an hour - backwards, forwards. Yeah, he didn’t like it, so I just stopped working for him.” (Participant 9). Living in a rural area had limitations in range of work available to people who had used drugs or had histories of incarceration “...a lot of the people around my area know that I’ve been in gaol. Dairy farms all closed down. That’s the only thing I really know - in this area. I’ve got no training.” (Participant 5).

Stigma

Participants felt stigmatised by family, community, the pharmacist, pharmacy staff and prescriber. “I break out into a sweat just walking into town. I do. I get anxious. I’m still trying to pick up on being part of the community.” (Participant 5). A

number of participants felt classed as a “junkie” even if their dependence was prescription painkillers or they were using ORT to manage chronic pain as well as dependence. They felt this stigma caused them to lose friends and affected their capacity for employment. *“I hate the whole stigma that comes with it, the Chemist, the doctor’s appointments, the whole [crying] I feel like I haven’t got my life really back, but I have...”* (Participant 4). Anonymity was compromised in rural areas *“I don’t want to do it down the chemist because I’ll bump into people I know and I have a lot of respect for myself. I don’t want to have anyone know that I’m on it. I try to keep it a big secret.”* (Participant 7).

The medication

The medication presented as a barrier to some. Problems included issues with dose, interference with other medications and diet, developing tolerance to the medication, side effects (sleepiness and cardiac issues), being unable to consume alcohol and dependence on methadone in particular, with one participant resigned to lifelong treatment. *“Probably stay on it for the rest of my life because it’s hard to come off.”* (Participant 6).

The program

Structure of the program was also a barrier. Lack of social and mental health support and a focus on drug and alcohol counselling was raised *“... they sort of were only focused on drug and alcohol counselling. They didn’t really want anything to do with all the mental health and stuff like that.”* (Participant 3).

Cost of the program was a major issue particularly for participants from Victoria where the system is community based. The additional costs of travel added to the financial burden *“if you’re like me and you’re 50 kilometres out and you’ve got to do 70, 80 or 90 kilometres every day to pick it up and pay for it every day it becomes challenging, the money - financial side of it.”* (Participant 5). Some participants felt attending the pharmacy to collect doses was a barrier, as they did not like mixing with other dependant people and were sometimes harassed outside to sell their takeaway doses.

Other barriers included waiting to access the program, which can be longer in rural areas *“...they made an appointment for me ... at the clinic to get on methadone or Bupe, right, which is Suboxone, but there was a waiting list of a month.”* (Participant 11).

Enablers

Social

The majority of the enablers related to social factors. These included getting finances organised: *“Since I’ve been on the methadone, I went to a financial advisor, he helped me out and stabilised me. Now I’m virtually out of debt.”* (Participant 1), providing security, allowing them to attempt to mend broken relationships and regain a social life. *“Now I’m on the methadone I think a lot straighter. I go fishing, I can go camping. When I was on the other gear I didn’t want to do any of that sort of stuff.”* (Participant 1). Having a team and seeing someone regularly for assessment, particularly a drug and alcohol

counsellor, seemed to be important: *“You sort of do a lot better when you’ve got someone that you see regularly.”* (Participant 3). One participant felt they got more help in an ORT program than when they were taking painkillers. The program allowed people to get parole and prevent further incarceration as illustrated by participant 8, *“Ever since I’ve been on Suboxone I have not had one problem with the law and I am - I guess I’m more secure...”* The ORT program was seen as an alternative to residential rehabilitation programs, as it was cheaper and didn’t come with risk of losing housing, sometimes even supporting retention of housing. The birth of a child was a motivational factor for one participant to start ORT. *“I do have to stay on the methadone to just keep it all equal, going and I can do the best - be the best version of me that I possibly can be for the children...”* (Participant 7).

Physical

Motivation for starting and remaining on ORT was that it stopped people from dying. *“...it was either go on methadone or overdose and die.”* (Participant 10). Some found they received significant pain relief from methadone. *“I wish they gave me methadone when the accident happened because it’s so good for the pain”* (Participant 1).

Mental

There were perceived mental benefits of ORT. *“Yeah. I found once I went onto the methadone, total mood swing changed, thoughts changed, whole life changed because it was so easy to operate with.”* (Participant 1). Participants found using ORT made them feel normal again. They felt it kept them grounded and helped with coping skills and keeping clear thoughts and emotions under control. *“At first it was just a way of, I guess dealing with not being able to deal with the world straight.”* (Participant 8). Some participants felt the program was more successful if you were in the right mindset and if health professionals were gentle.

The program

Enabling structural features of the program included access to a pharmacy (especially one within walking distance), *“It’s a lot easier when I can walk, saves asking people for rides and that.”* (Participant 6); being confined to one dose a day and only having access to one medication (reducing temptation of using more). Awareness of available programs enabled people to get access to treatment and the ORT program was cited as being *“... a lot easier to go to the chemist than to go to a dealer...”* (Participant 8).

Most perceived access to takeaway doses as an enabler to remaining on the program. Despite this, a couple of participants found having to pick up doses every day as more beneficial for them *“I’m on daily pick-ups now. I quite like that anyway, because it keeps me up and having to go down the street every day.”* (Participant 3). Others felt that having takeaways was easier for them to travel and stay connected with families. Takeaways *“brings people closer to their family because they can go and visit.”* (Participant 2). Not having to go into the pharmacy daily saved participants from having to mix with others with dependency issues.

Drug use

Participants found the ORT program stopped them taking other drugs and blocked the effects of heroin. ORT stopped withdrawal effects and cravings for heroin. Heroin “... it just wouldn't do it for me. I don't know what it's done, whether it's fried the receptors or what, I just don't have any interest in it whatsoever. I could sit here and watch you do it, I could help you do it. I could help six other people do it and leave the room without breaking a sweat.” (Participant 9).

The medication

The medications themselves were enablers. Participants on buprenorphine/naloxone appreciated it was difficult to overdose on. Seeing ORT as a medication used for pain or maintenance made the program more acceptable and being able to dose daily was perceived as a benefit “...with my counsellor helping me find the right medications and stuff like that, it's been a really big help.” (Participant 3).

Discussion

ORT programs are effective in reducing inappropriate opioid use (Mattick, Breen, Kimber, & Davoli, 2009). However, treatment delivery strategies that improve patient outcomes such as frequent patient contact, observed dosing and limited takeaway doses, may decrease treatment availability, practicality, acceptability, enrolment, and retention for some in rural areas. The treatment paradigms most convenient for patients and prescribers (e.g. infrequent clinic visits, reduced oversight, providing longer-duration supplies of medication) may increase risk of medication diversion, misuse and undermine treatment outcomes. (Sigmon, 2014) This paradox poses significant barriers to widespread therapeutic delivery of effective medications to opioid-dependent patients, particularly in rural areas with fewer services and unmet need for treatment thus potentially needing a more individualised approach. (Sigmon, 2014)

This study identified barriers and enablers to both accessing and remaining in ORT programs in the rural communities of Victoria and NSW, where our study was located. No enablers appeared to be unique to rural areas and while many of the barriers were similar to those identified in other studies (Berends et al., 2015; Day et al., 2006; Digiusto & Treloar, 2007; Fraser, Valentine, Treloar, & Macmillan, 2007; King et al., 2013; Peterson et al., 2007; Ritter & Chalmers, 2009), they may be more pronounced in rural areas due to geographical distance and the lack of both anonymity and employment opportunities.

In rural areas considerable travel is required to access services, when they are available. (Berends et al., 2015) The main issues identified in this study included having to collect doses daily, involving travel to the pharmacy or hospital. For those living out of town this was time consuming and expensive. Costs of travel added to significant financial burden on patients receiving ORT in the private sector. Day et al. (2006) reported that for rural patients treatment was often accessible only by private car and some participants hitchhiked into town daily to receive ORT if they could not afford private travel. (Day et al., 2006) In rural America, the situation is

similar to rural Australia. Major barriers to ORT treatment included travel times of approximately 60 minutes per clinic visit with reported cost of \$48.84 USD per week for transportation. Many reported missing at least one clinic visit and medication dose due to transportation. Additionally, participants reported that travel time for their opioid treatment had interfered with their ability to maintain employment. (Sigmon, 2014)

Having to be near a dosing pharmacy was restrictive, and makes it hard to find employment for anybody on ORT programs, and in rural areas this is compounded by limitations on range of work available, especially for people with histories of drug use and/or incarceration. Not being able to travel for employment, to see family, friends or recreational purposes, impedes social recovery and is seen as a barrier for remaining in ORT. In rural areas, distances are often greater, public transport more limited therefore more time and resources are needed for travel thus the problem can appear magnified. A report from the National Centre in HIV Social Research identified that having takeaway doses contributed to finding and retaining employment, fulfilling family responsibilities, capacity to travel for work and leisure, self-esteem and a sense of progress in treatment, control over contact with other clients, confidentiality in treatment and cessation of illicit drug use. (Fraser et al., 2007) This needs to be balanced with safety. Recent changes to the ORT policy in Victoria were a result of coroners' findings that methadone takeaway doses had significantly contributed to deaths involving methadone overdose. The latest policy has reduced the number of recommended methadone takeaway doses. (Drugs and Poisons Regulation Branch, 2016) Due to its better safety profile in overdose, buprenorphine/naloxone has less stringent rules surrounding availability of takeaway doses. (Drugs and Poisons Regulation Branch, 2016) In view of these issues, there could be a trend toward buprenorphine/naloxone to overcome the barriers of lack of methadone takeaway doses but it is important to acknowledge that due to its different pharmacology buprenorphine/naloxone is not suitable for everyone. (Tanner, Bordon, Conroy, & Best, 2011)

Privacy was also a concern for people prescribed ORT. Participants in the Day et al study felt that drug use was particularly stigmatised in rural areas. Participants raised concerns about attitudes of employees of pharmacies where methadone was dispensed and of drug services including prescribers and GPs. [6] This was also a finding in this study. Participants identified stigma from the community, healthcare professionals and family as a significant barrier that was enhanced by living in a small town where anonymity was limited. Cooper and Nielsen (2017) identified that strategies to address generalised opioid-related stigma needed to be employed including education of the community and healthcare sector around opioid dependence being a medical condition. (Cooper and Nielsen, 2017)

Contemporary approaches to ORT might expand program reach and reduce demand for face-to-face visits. Approaches could include programs utilising sustained-release formulations of opioid agonist medications such as buprenorphine implants. (Sigmon, 2014) Other alternatives include the use of mobile health platforms providing customized content and

support via telephone offering benefits in cost, consistent delivery, access, privacy and convenience. Web-based platforms also hold potential for extending access to clinical support, education and monitoring to patients living far from clinics. (Sigmon, 2014) Roving dispensing buses between regional towns could be another option. (Ritter & Chalmers, 2009) Reductions in the number of visits would reduce the burdens of time and travel for patients, thereby making it easier for patients to participate in prosocial activities (e.g. employment, educational opportunities and family responsibilities). These novel approaches need to be balanced against degree of patient oversight to maximize treatment access and outcomes while minimizing risk of non-adherence and diversion. (Sigmon, 2014)

Limitations of this research include generalisability to all Australian rural areas. Each region is unique in attitudes and employment opportunities and may present its own challenges depending on attitudes and skills of health professionals and the models implemented. Depending on location and availability of services, people may need to travel further to access ORT. Not all participants in this study were initiated on ORT in a rural area and this may influence experiences of the program. Methadone was the predominant treatment for participants; therefore, barriers and enablers represent issues faced with methadone more than buprenorphine/naloxone.

The effective delivery of ORT for people with opioid dependence in rural Australia is an on-going challenge. There barriers to the ORT program, which are amplified in rural areas due to the size of the community, distance from services and family and social characteristics. Geographical distance, lack of anonymity, access to takeaway doses and the effect these factors have on employment opportunities are significant factors impeding participants staying in treatment in rural Victoria and NSW, highlighting deficits in a one size fits all model. There needs to be flexibility of options to increase retention and improve social and emotional health. Addressing stigma and improving access will be important for future success.

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APPENDIX

In-Depth Semi-Structured Interview Procedure

- Introduce Interviewer.
- Introduce Project.
- Discuss PLS and consent.
- Discuss confidentiality, voluntary participation, Pharmacotherapy Program clinicians not knowing who participates.

1. Tell me about yourself.
 - i. Where did you grow up
 - ii. Your family
 - iii. Your friends

- iv. When you began using opioids
2. Describe how your life began to change once using opioids.
 - i. When did you realise you were addicted
 - ii. Did your general health change
 - iii. Were you employed – did this change
 - iv. Were you in a relationship – did this change
 - v. Did you have your own home – did this change
 - vi. Were you close to your family – did this change
 - vii. Did your friend group change
 - viii. Sport and leisure activities – any change
 3. Describe the moment that you decided you wanted to enrol into a pharmacotherapy program, what happened at that time?
 - i. Where did you go for help
 - ii. Who provided help
 - iii. Did you believe the program would help
 - iv. Did you set goals that you believed you could achieve
 - v. Have these goals changed
 - vi. Has the program been easy
- vii. Have you dropped out and started again
 - viii. What caused you to drop out
 - ix. What led to starting again
4. Has pharmacotherapy changed your life in any way?
 - i. Family
 - ii. Friends
 - iii. Relationships
 - iv. Employment
 - v. Drug craving
 - vi. Drug seeking behaviour
 - vii. What aspects of the program have made a difference
 5. Where do you see yourself in five years time?
 - i. Is pharmacotherapy a part of your long term future
 - ii. Is the program supporting you to achieve your goals
- Is there anything else you would like to add?
Thank you for taking the time to be interviewed and for sharing your experiences with me.