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Title

Exploring Irish Travellers' experiences of Opioid Agonist Treatment: A Phenomenological Study

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Abstract

Background: The Irish Travelling community are identified “as a people with shared history, culture and traditions including, historically, a nomadic way of life”. The core of Travelling culture is strong family bonds which support resilience, however changing social circumstances and dislocation have contributed to significant mental and physical health issues accompanied by a steep rise in substance abuse and addiction.

Aim: To explore and describe Irish Travellers’ experiences of drug use and opioid agonist treatment (OAT), with a view to improving service delivery and expanding the limited research base.

Materials and Methods: A phenomenological approach using semi-structured interviews was conducted with seven opioid dependent Irish Travellers (two females/five males) currently on OAT at an outpatient clinic in Dublin, Ireland.

Results: All participants described the complexities arising from drug use, with significant life events often accompanied by depression and drug use (street, prescribed and over the counter) as a means of self-medication. Barriers to accessing treatment included shame and stigma, fears around being shunned by the community, and a negative attitude towards OAT. All participants and particularly women reported that stigma related physical violence came from community elders if suspected of drug use or association with drug users. Despite initial strong reservations about OAT, experiences were largely positive with acceptance by and support from staff viewed as instrumental.

Conclusions: The development of culturally appropriate, gender sensitive and integrated OAT and mental health support services, designed with input from addiction and mental health specialists, alongside community members is warranted.

Key Words

Travellers, drugs, OAT, cultural approaches

Introduction

Ireland's indigenous nomadic people known as the Travellers ('gypsies', 'tinkers') are documented in Irish history as far back as the twelfth century, and are a minority ethnic group with a long shared history, nomadic way of life and value system comprising of language, traditions and culture [21]. The most recent Irish Census reported that the number of Travellers in Ireland is 29,573, and represents 0.6% of the total population [4]. As of the 1st of March 2017, Travellers have been recognised by the Irish government as a distinct ethnic group with the President of Ireland commenting that this will help in "*ensuring respect for Travellers' distinct identity within the fabric of Irish society*" [26]. Whilst some acceptance of Traveller identity is reported in the past three decades, assimilationist policies and social changes in Ireland since the 1950s have led to Traveller displacement from a transient existence on the road into urban marginalised areas, which has been accompanied by a loss of traditional income generation (trade and craftwork) and their inherent nomadic way of life [30]. Despite governmental efforts to provide culturally specific housing and other social supports, Traveller communities in Ireland experience a multiplicity of socio-economic disadvantage [17, 22, 28, 29, 30, 38]. Irish Travellers fare poorly on every indicator used to measure disadvantage including unemployment, poverty, social exclusion, literacy, education and gender equality [5, 20]. The disparity between the sedentary (or settled) population and Irish Traveller culture, values and norms also underpins public discriminatory attitudes and behaviours directed towards this ethnic minority [10, 24].

Major sociological changes due to assimilationist government policies and public discrimination have contributed to disillusionment, identity conflict and cultural anomie (dissolution of group traditions) within the Travelling community, resulting in high vulnerability to mental ill-health, suicide and other risks such as drug use [22, 29, 32, 37-38]. Social and cultural upheaval through the dislocation of Traveller families and the dilution of

the traditional religious and patriarchal cultural values (that promoted stringent anti-drug norms protecting members from self-medicating or intoxicating behaviours) has resulted in a steep rise in substance abuse and addiction with associated mental health and social problems. [23,29,32,33,35-36,38]. The All Ireland Traveller Health Study (AITHS) [1] reported that Travellers are inordinately burdened with the issue of mental ill-health, and estimated that Traveller male suicide is 6.6 times higher than the general population. Twenty years ago, illicit drug use was not a reported issue for Irish Travellers, who by virtue of their separation from sedentary society were largely distanced from illicit drug use activity [22,24,29,31,32,34,35]. In 1995, the Report of The Task Force on the Travelling Community did not mention illicit drug use among Irish Travellers [29]. More recently the AITHS [1] reported that 66% of Travellers said that illicit drugs were a recent and concerning problem in their community. Increasing concerns are evident around the issue of substance abuse and addiction to both licit and illicit drugs affecting Traveller families and their communities [9, 22, 24, 29, 32, 33, 38]. Factors stimulating the rise in substance abuse and addiction include high rates of male incarceration, loss of male economic independence, enforced housing within anti-social and marginalised areas (with high rates of drug dealing and abuse), and the diversification of Travellers themselves into drug activities (use, dealing and violence) within these areas [1, 6, 17, 24, 29-36, 38].

Estimations of numbers of Travellers using drugs are difficult to quantify given the inherent stigma of addiction within the Traveller community, and potential for undercounting of ethnicity in treatment services [29]. Travellers commonly employ denial with regard to addiction issues, due to feelings of personal and familial shame and often attempt to self-manage the problem (home detoxification, faith healing) [9]. Uptake of drug treatment services by the Travelling community tends to occur once addiction pathologies are chronic and increasingly difficult to treat due to the stigma of addiction in the community [22, 29, 33,

36]. Current indicators of the extent of the issue within the Irish Traveller community are at present restricted to the number of cases of Travellers accessing national treatment services [3] and those attending prison based treatment services [1, 6, 17]. At present there is no individual identifier despite calls from the AITHS [1] and the Health Research Board (HRB) [3]. Recent treatment data reports that incidence of treated problem substance use among Travellers is three times that compared to the general population in 2010 (523 per hundred versus 173 per 100,000) [3]. Most common problem substances are alcohol, followed by opiates (street and prescribed), benzodiazepines and cannabis [3]. In this most recent data set, the number of cases of Travellers accessing opioid agonist treatment (OAT) in Ireland rose by 291% in the timeframe 2007-2010 and is 8% higher than the number of cases presenting from the general population. OAT in Ireland can be accessed by self-referral or referral by a third party, and treatment location is determined by place of residence [12]. Patients with a dual diagnosis (addiction and significant mental illness) are recommended to be prioritised for OAT upon referral [13]. Current Irish OAT guidelines [13] are mainstream and do not refer specifically to the cultural considerations of ethnic minorities such as Travellers. In contrast, health service strategies in recent years have responded to Traveller needs by enhancing cultural competencies of staff involved in key service provision and care planning [2, 22-24, 29, 33, 38]. Given the issues with Traveller literacy, and in order to better understand and describe Travellers' experiences of drug use and OAT with a view to improving service delivery and expanding the very limited research in this area, this study aimed to explore and describe Irish Travellers' experiences of drug use and OAT, and describe the impact of opioid dependence on the Traveller community.

Material and Methods

Approach

The study was conducted at a large Health Service Executive (HSE) addiction treatment clinic in the north inner city area of Dublin, Ireland. The clinic provides outpatient OAT to

230 patients from a defined geographical catchment area. A phenomenological research design using interviews was chosen by the research team in order to describe Traveller experiences of drug use and OAT. Phenomenological research approaches suspend or “bracket” any presuppositions about the normality or abnormality of phenomena under investigation [7, 27]. An interview guide was created based on extant literature, prior research team experience with Traveller drug use [31-36], and team consultations around access and approach. The guide consisted of three areas of investigation namely 1) the context of the research in terms of drug use, Traveller culture and participant life circumstances; 2) exploration of their experiences and attitudes of family, peers and participants towards drug use, addiction and OAT; and 3) participant reflection on these experiences, personal, peer and familial attitudes and associated feelings or emotions. Techniques applied (by author one who undertook all interviews) within the phenomenological design were in line with Jasper’s recommendations [15] and centred on the use of reflection, clarification, requests for examples and descriptions, and the conveyance of interest through listening techniques.

Sampling

Seven Travellers attending the clinic were recruited using convenience sampling with a gender breakdown of five males and two females. This represents the breakdown of the total number of cases presenting for treatment reported by Carew and colleagues [3]. Participants were aged between 30 and 44 years, and were prescribed methadone (n=6) and buprenorphine (n=1).

Ethical and Study Procedures

Ethical approval was granted in 2017 by the School of Psychology Ethics Committee, Trinity College Dublin and the OAT clinic in 2016. Participants were recruited by author one, with support from the clinic’s gatekeeper (author two). Potential participants were asked if they

would like to take part in the study as a member of the Travelling community. Generally, the response was positive, with some concerns expressed around assurances of confidentiality. Subsequently, times were arranged for participants to attend the clinic for interview. Interviews took place in a private room at the centre, with all participants provided with information around the study's aims and objectives, and with written and verbal consent procedures explained to all participants. All participants gave permission for audio recording of interviews, which lasted between 19 and 68 minutes. Interviews concluded with provision of a debriefing sheet with referral and support information.

Data Analysis

Each audio file was fully transcribed by author one in order to become familiar with the data. Phenomenological analysis of data commenced with the generation of specific "meaning units"[15, 27], followed by the identification of a number of categories. Categories were then placed into themes. Three themes emerged from the data; Mental Health; Drug use and Blacklisting, and Service Access, Experiences and Treatment Modalities.

Results

Mental Health

All participants reported experiencing aspects of depression, anxiety or both. Periods of depression/anxiety were usually triggered by significant life experiences, with subsequent drug use employed as a coping mechanism and means of self-medication.

"I just left home, I got fed up, I couldn't. I just couldn't cope... I never used so I got myself strung out in less than a week." Traveller female

"I had a bad car accident a couple of years back... all injured...(friends) said 'that will help you with the pain' (heroin)... I wasn't in my right mind... I went downhill and I never got back up and I'm trying so hard to get back up." Traveller male

“I suffer from anxiety and depression... that started when I got banned off the road... big effect on my life... I couldn’t work anymore (describes prescribed benzodiazepine abuse and needing a detox)”. Traveller male

Problems with diverted, prescription and over the counter opioids and other sedative type drugs were described.

"I can tell you what drugs is rising... is tablets... rapidly hitting Travellers." Traveller male

"I have a few (relatives) who take tablets, one of them was rushed down to hospital a few days ago." Traveller female

Issues of self-medication using these medications as well as illicit forms of drug use (cannabis, heroin) as a coping mechanism were mentioned.

"I had to take them to be normal." Traveller male

"I was going through a hard time, I got into tablets at that time as well." Traveller male

"I did overdose...my mother called me a load of names this one day...the names that she called me were hurtful... I took all my father’s strong... painkillers." Traveller female

One male participant with a history of prescription opioid dependence offered a possible explanation for why prescription medication abuse was increasing within his network.

“I can walk into your house and pull out my (prescribed medication) and say, “look my doctor gave me these”, and you won’t bat an eyelid because it has my name written on the box ...but if I walked into a person’s house smoking hash or smell a hash off me I’d be more embarrassed” Traveller male

Over 10 cases of Traveller suicide related to drug use were reported by participants in their Traveller networks. The impact of these fatalities was severe for them and their communities.

“He ended up on drugs as well... hung himself after that” Traveller female

“Hung himself out of the trailer...He was depressed out of his head...It was drug related.”

Traveller male

Three out of the seven participants reported recent and/or past suicidal ideation.

“I was 100% mentally unstable... I went in and I said I’m gonna kill myself and I genuinely and truly meant it.” Traveller male

“I got so upset... I was gonna through myself out in front of a bus.” Traveller female

Drug use and Blacklisting

Both genders acknowledged a difference in how male and female Travellers are treated with regard to drug use and abuse within their own Traveller communities and networks. Participants described the protective effect of strong Traveller families, and their attempts to protect children from drug use. Travelling families were described as opposed to their children associating with drug users due to fears around suspected drug initiation, stigma by association and a wider community impact.

“The way any Travelling man thinks... If one person is on drugs and his son is talking to him. Word gets around. They automatically think that he is on drugs” Traveller male

“If her mother... if she knew... (that her daughter was) hanging around with myself... there’d be blue murder” Traveller male

“Put it this way nobody wants no drugs around their kids.” Traveller male

However, participants described that a more normative attitude toward drugs such as cannabis has emerged in recent times especially amongst younger Travellers and within their younger peer networks.

“I’m going back years, when I was smoking cannabis you were classed as a junkie then...now they’ve accepted cannabis and I think they’re kind of accepting heroin, they can

see there is a lot of Travellers improving, getting off it, changing their lives". Traveller male

Participants described a fear of being "**blacklisted**" or ostracised from the community which was described as highly likely if a Traveller was suspected of using drugs and associating with known drug users, despite treatment seeking efforts.

"Put it this way if anyone was ever ever seen one time... They'd be ran out." Traveller male

"You are outcasted, when you are on drugs and that is a promise." Traveller male

In particular, the concern was mainly if an elder Traveller found out, and the ensuing repercussions.

"The elders in the Travelling community would... cut your hand off if they caught you taking drugs, without a doubt." Traveller male

"It's the likes of the older generation of Travellers that's stopping the younger ones from coming to centres." Traveller male

Other reasons include the potential for physical and verbal abuse from family members.

"I would actually hide it... cause my family... oh god... I'd get a serious severe beating and that would be that." Traveller male

"He was trying to lock me into a press, when he first found out... he was saying all these hurtful words" Traveller female

Attitudes to a male Traveller drug user appeared more lenient within the Traveller community.

"Ah well, that's up to them. The lads are the lads, you know what I mean, if they want to do it let them ruin their lives... It's up to them". Traveller male

“(He) hates him doing (drugs) but still he’s a boy you know what I mean. He’s a fella. Whereas if (a) girl... if she took it... he’d kill her” Traveller female

Female Travellers appeared to experience greater shame and stigma around drug use, and potential for ostracisation and physical violence from elders, than males from the community.

“Well Travellers say a girl should have more respect than to do things like that.” Traveller female

“I’m a Traveller. And I see another female Traveller taking drugs. Oh that’s a no go.” Traveller male

One of the female participants explained the physical and emotional abuse received from family members. She further described the negative impact *“the hurtful words”* had on her before speaking generally that *“a girl would be getting more giving out to than a boy.”* Traveller mothers suspected or found to be using drugs were described by participants as most at risk of being ostracised by the community, and at risk of losing their children.

“They’d say that’s a disgrace, she’s out of her head and she has kids...” Traveller male

“The children would be automatically taken... by her mother or father... the woman who owns the children, she’d be shunned.” Traveller male

“They’d be asked to leave the site... they should have more respect for themselves especially for their children.” Traveller female

Service Access, Experiences and Treatment Modalities

The majority of participants experienced difficulties in accessing treatment due to a fear of confidentiality, and the repercussions from the community. There was a high level of concern that if a Traveller was seen by members of the community going to an OAT clinic, it would

lead to stigma, discrimination and being shunned by other Travellers including family and friends.

“You will get some Travellers on treatment programmes and you'll get some not... because you'd be probably embarrassed if another Traveller seen you coming down ... and the word got around.” Traveller male

“So I had to go around the other way and come in the back way... I was afraid of my life they were going to catch me coming in.” Traveller female

“...sneak out to get to their clinic... say daddy I'm going shopping, jump into the van and... down to the clinic and back.” Traveller male

Some frustrations with the system of accessing OAT services in Dublin were described by participants and included the necessity of producing documents required to start treatment and personal impatience with waiting times and not receiving the immediate required care.

“They've to run here they have to run there, there under this doctor, get that form, get this form, that form, photos...There's other Travellers screaming to start treatment.” Traveller male

“I'm asking the last while, ages, to go to (a detoxification centre) ... I had a worker upstairs (councillor)... and I just got fed up... I filled everything out... I did all my weeks with (the councillor) ... but nothing was happening.” Traveller female

Participants described a negative initial perception of OAT and particularly methadone as therapeutic agent, in favour of drug detoxification. This view was reversed once OAT commenced. The one participant treated with buprenorphine described a positive experience with this therapeutic agent.

“Like they wanted to put me on Methadone. I swear on the Bible I'd never go on that to my (partner).” Traveller male

“I didn’t think I needed treatment, because I was gonna go through the detox myself...I was very very against methadone.” Traveller male

Despite initial strong reservations about OAT in favour of drug detoxification, the experience of participants was largely positive with initial concerns and fears outweighed by the positive changes in their lives. Mixed views around service experiences were voiced. The efficiency and freedom of being an outpatient was far more suited to some, whilst caused frustration to others.

“When I’m here, its relaxed, you can come in get your script and leave and then go down, get your methadone and be with your partner and child.” Traveller male

“I think it’s bad... all they are doing is giving the prescription and taking the urine.” Traveller female

Acceptance by and support from service providers was instrumental throughout these experiences. Participants were unanimous in their appreciation for how they were treated by staff.

“This is the first place I’ve ever gone for treatment really and I’ve been treated very well.” Traveller male

“Anything they done for me only helped me.” Traveller male

“The people treat everybody here, like, equally... no one treats me any differently.” Traveller female

“I’m 8 months without taking (drug of choice) ... and the only reason I’m like that is because of the people that’s around me, that’s helped me (mentions the names of people from the addiction services).” Traveller male

Participants reported positive mental health, social and family interactions associated with their attendance of OAT.

“I'm stable here and I'm happy here.” Traveller male

“Like sometimes you'd go down, like a few people (from the clinic) would go down, they'd have a cup of tea, cup of coffee.” Traveller male

“Things are starting to change in life for me now... with my family, my partner and my child.” Traveller male

“I'm coming back to myself...my (partner) she's delighted... I had the rope in the shed now I have my punch bag in the shed.” Traveller male

Discussion

This study is one of the first to explore the experiences of Irish Travellers of OAT within national treatment systems. Uptake of support and treatment services by the Traveller community generally takes place when chronic addiction occurs, and given the life circumstance of Travellers becomes complex and difficult to treat [22, 29, 31-36, 38]. Travellers in this study described the complexities around drug use, significant life events (SLE) and experiences of depression, with drug use (street, prescribed and over the counter) often used as a means of self-medication. Walker [37] suggested that the presence of so many social pressures in the lives of Travellers place them in a state of crisis with further SLEs putting them at significant risk of suicide. In the past Travellers employed a coping strategy known as ‘*shifting*’ which meant leaving an area if they were being discriminated [37]. This coping strategy may not be a viable option anymore due to the reduction of available sites for caravans and the recent housing crisis in Ireland. Walker [37] described how frustrations associated with social exclusion and discrimination can contribute to some Travellers adopting drug- or alcohol-use as a coping mechanism for psychological distress. The high

rates of poor mental health and suicide [1] and drug use [1, 3] among Travellers when compared to the general population signify the complexities in those Travellers presenting to OAT services.

Within the Travelling community there is stigma attached to mental health problems which impact on Traveller help-seeking behaviour [1, 24]. Lack of awareness and visibility of support and treatment services, as well as concerns around literacy, waiting times, being seen by members of the community and need for culturally appropriate interventions represent barriers for Travellers to accessing and engaging with addiction services [29]. Travellers and their families struggle to deal with drug use, addiction and associated behaviours within their communities and addiction [1-2, 9, 22-24, 29, 35]. We report here on similar barriers but with shame and stigma of drug use (real and by association), of addiction and a significant threat of being '*blacklisted*' from the Traveller community representing the lived realities of Travellers seeking help, most particularly Traveller women. Violence, stigmatisation and being ostracised by their family and wider community were reported to be the repercussions for Travellers who use drugs, so to be seen attending a treatment centre poses a significant risk for the individuals and also their family/friends (stigma-by-association) [11, 16]. Efforts to alleviate this barrier could centre on changing the system of assigning patients to clinics based on their place of residence, and developing gender sensitive pathways [13, 25]. Despite initial strong reservations about OAT and challenges in navigating the system itself, experiences within the OAT system were largely positive with acceptance by service providers viewed as instrumental [1, 2, 25].

The positioning of Travellers in Irish society continues to reflect the country's struggle to effectively promote pluralism [18]. If the potential benefits of the recent recognition of the ethnic status of Travellers in Ireland is to work its way through to improved access to and provision of health and welfare services, then there must be

initiatives to revise the relevant policies to make them more equitable; in other words, to ensure that adequate resources are provided to travellers to counteract their marginalization and allow them to expect similar health and welfare outcomes, as are enjoyed by mainstream society. Inevitably this requires social structural change, along with greater resources and effective treatment [19].

Conclusion

On the 1st of March 2017, the Irish government recognised Travellers as a distinct ethnic group which had previously been hoped to be a platform for service enhancement in addressing substance-abuse within the Traveller community [39]. The Joint Oireachtas Committee on Justice, Equality and Defence [14] in Ireland have underscored that ethnic recognition carries considerable benefit in ensuring respect for the cultural identity of Travellers in the context of targeted health services. Continued research efforts on drug use and mental health, on Travellers living traditional nomadic lifestyles in halting sites and on those who are settled in rural areas must accompany this piece to garner a true and accurate picture of the situation. Our study underscores the need for continued efforts in policy and practice, and in particular in providing OAT and drug treatment services to Travellers and other ethnic minorities in Ireland. We recommend the following key changes to be targeted by policy makers and service providers. Given the high rates of poor mental health and drug abuse, the promotion of integrated mental health and substance abuse treatment services that do not assign clinic location purely on location along with the development of specific cultural and gender sensitive OAT guidelines on the Travelling community is warranted. Outreach services which foster the development of trust between the community and addiction and mental health services [1, 8] should be designed in conjunction with Traveller

organisations such as Pavee Point (the National Traveller Centre) to enhance treatment seeking behaviours and reduce the stigma associated with addiction and mental health.

Contributors

All authors were involved in the study design, had full access to the survey data and analyses, and interpreted the data, critically reviewed the manuscript and had full control, including final responsibility for the decision to submit the paper for publication.

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Conflict of Interest

All authors declare no conflict of interest.

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