Stigma, treatment beliefs, and substance abuse treatment use in historically disadvantaged communities

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Abstract

Objective: Access to substance abuse treatment among historically disadvantaged communities (HDCs) in Cape Town, South Africa is limited, despite a growing demand for services. Although research has reported on structural barriers to treatment access, nonstructural factors remain largely unexplored. The aim of this paper is to describe two nonstructural influences on the use of substance abuse treatment services for people from HDCs: stigma and negative beliefs about treatment. **Method:** Findings from the qualitative component of a multi-method study are reported. In-depth interviews were conducted with 20 key informants, all of whom worked or lived in HDCs in the greater Cape Town area. Content and thematic techniques were used to analyse data. **Results:** According to key informants (i) stigma towards individuals with substance use disorders was prevalent in HDCs and negatively impacted on attempts to access services; (ii) negative beliefs about the quality and effectiveness of treatment were commonplace and acted as barriers to the use of existing services; and (iii) several factors contributed to these nonstructural barriers including media representations of both individuals with substance use disorders and treatment facilities for these disorders. **Conclusion:** This paper moves beyond the description of structural barriers to treatment to describe how two nonstructural factors, stigma and negative beliefs about treatment, hinder treatment seeking for substance use disorders. Recommendations for addressing these barriers include efforts to (i) shift discourses about substance abuse treatment, (ii) improve service quality, and (iii) address myths and misconceptions about treatment.

Keywords: Substance abuse; Treatment beliefs; Stigma; Historically disadvantaged communities

Introduction

Despite the increased demand for substance abuse treatment, access to treatment remains limited in the Cape Town metropole; particularly for poor Black/African and Coloured South Africans who were historically disadvantaged during the apartheid era.[1-2] According to recent findings from the South African Community Epidemiology Network on Alcohol and Drug Abuse (SACENDU) project[1-2], the race profile of clients at treatment facilities still does not reflect the demographic composition of the general population[3]; with black persons remaining underrepresented. This is cause for concern as high levels of substance-related problems within black communities suggest that this profile reflects limited access to treatment rather than lower levels of substance use within these population subgroups.[1-2]

While attempts to understand and improve access to treatment have focused on structural barriers to substance abuse treatment use (such as service availability)[4], current understandings of access also highlight how individual and community influences inform decisions to use health services.[5] Stigma and negative beliefs about treatment are two such influences. Previous research has identified perceived stigma towards substance users as a significant barrier to treatment use, with individuals who need help tending to deny or hide their condition for fear of being negatively labeled.[6-8] This may be

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especially true for women with substance use disorders (SUDs), due to the negative associations between female intoxication and sexual availability.[9] Negative beliefs about the treatment process also seem to act as barriers to substance abuse treatment use.[10-13] For example, several studies have identified concerns about the effectiveness and confidentiality of substance abuse treatment as barriers to seeking treatment for SUDs.[10-14] Representations of substance users and treatment services in the media may entrench these barriers to treatment use.[15-16] As the media is a space where meanings regarding illness and treatment are constructed and negotiated[17], it has the potential to shape and perpetuate beliefs about SUDs and their treatment. Through their reproduction of stigma and negative beliefs about treatment, media images of substance use may contribute to substance users' failure to seek and poor adherence to treatment.[15-17]

Although stigma and negative beliefs about treatment are potentially important influences on substance abuse treatment use, these non-structural factors are poorly understood in the South African context. This paper aims to address this gap by describing the way in which stigma towards substance users and negative beliefs about treatment influence the use of substance abuse treatment services by people from HDCs in the Cape Town metropole.

Method

Findings are presented from the qualitative component of a large multi-method study of access to substance abuse treatment in the Cape Town metropole. The qualitative case study examined individual, contextual and structural influences on access to treatment. A sample frame was constructed from the contact list of the Western Cape Drug Forum. The final sample consisted of 20 key informants from the community development, treatment and social welfare sectors of the substance abuse system including representatives from community based local drug action committees (LDACs), non-profit treatment service providers (TSPs), substance abuse co-ordinators (SACs) from the six district social service offices in the metropole, and policy makers. LDACs consist of community representatives concerned with substance abuse problems as well as substance abuse agencies operating in specified communities, such as Mitchell's Plain, Khayelitsha and Gugulethu. Several key informants had multiple roles: 7 were TSPs, 4 were involved in LDACs, 5 contributed to substance abuse policy and 5 were SACs. Key informants were purposefully selected according to their knowledge and experience of substance abuse treatment delivery within HDCs in Cape Town.

Semi-structured in-depth interviews were conducted to explore key informants' perceptions of influences on substance abuse treatment use. These interviews took approximately 90 minutes to complete, with data collection continuing until saturation of themes occurred. Each interview was audio-taped and transcribed verbatim. Qualitative data were analysed using content and thematic analysis techniques[18], aided by the Analysis Software for Word-Based Records programme, version 6.4.[19] While several themes emerged, this paper reports only on how stigma and negative perceptions about treatment influence substance abuse treatment use.

Ethical approval for this study was granted by the Ethics Review Board of the Faculty of Humanities at the University of Cape Town.

Results

The major findings were that (i) stigma towards individuals with SUDs was present in HDCs with the result that SUDs remained hidden; (ii) negative perceptions of the quality of existing services hampered treatment use; and (iii) negative images of individuals with and treatment for SUDs in the media reinforced stigma and negative perceptions of services.

(i) Stigma

Perceptions of addicts as mad, bad and dangerous to know

According to key informants, as substance use is normalised in many HDCs, stigma is not attached to substance use per se but only to individuals with substance-related problems. Respondents observed that substance-related problems indicative of a need for treatment (such as loss of control over drug use, theft to fund drug use, and drug-related mental health problems) were associated with being an "addict." They thought that HDCs hold negative perceptions of "addicts" that include notions that "addicts" are "weak", "lack self-control", and are "mad." Respondents believed that individuals with substance-related problems were reluctant to seek treatment due to the stigma attached to and the ostracism that accompanies the "addict" label:

> *"First of all it's when you're an addict you lose control, and addicts are mad…So if you're in our clique and you go to a rehab, you're like a sissy. I'm in control of my drugs, but you're not…So what are you going to do? Not go to rehab. I'm in control of my drugs… I smoke the drugs, the drugs don't smoke me… When you go to rehab it means the drugs are smoking you."* [TSP 2]

> *"The stigma is basically you are a junkie. It is socially acceptable (to use) but it is not socially acceptable being in rehab with your problem. It is almost like you have been defeated by your problem and I would assume they don't want to be defeated. Because every drug addict says 'no I control my bad habit'."* [TSP 5]

Stigma, family shame, and service use

Our respondents also commented that stigma towards "addicts" hindered families from seeking help for family members with substance-related problems. They reflected that families internalised drug-related stigma and were often ashamed of the problem within their family structures. This shame seems related to fears of ostracism should the drug problem become common knowledge.

> *"And then there's the mom that said if I send my son to rehab, the neighbours are going to know. Even if the neighbours knew long before I got to know my son is an addict. Then of course, if I send my son to rehab, what's the rest of the family going to think? So I've got to keep it all under wraps. Even when my whole house is being carried out, I can't let my sister know that my child is on drugs. What are they going to think of me?"* [TSP 3]

Moral discourses around substance use perpetuates stigma
Key informants understood these negative perceptions of ''addicts'' to be underpinned by moral discourses on drug use. According to participants, these moral discourses represent ''addicts'' and their substance-related behaviour as ''evil'', ''deviant'' and ''bad.'' Moral discourses seem particularly salient for women with substance-related problems compared to their male counterparts. For example, almost all respondents suggested that HDCs believe ''these are good women gone bad'' and that ''when a woman drinks then her morals slide out the window.'' For female ''addicts'', these discourses are defined against commonly-held discourses about what it means to be a ''good woman.'' Key informants thought female ''addicts'' were stereotypically perceived as engaging in deviant sexual behaviour and being unable to fulfill traditional gender roles, such as parenting:

> *''When women use (drugs), there is a misconception that you will sell your body.''* [TSP 1]

> *''I think it lowers their (women's) value in terms of tradition as they won't be able to look after their families.''* [SAC 4]

Key informants believed that moral discourses around substance use not only perpetuated stigma towards ''addicts'' but limited their use of treatment services. They thought that ''addicts'' and their families might avoid treatment in an attempt to maintain a positive self and social image, especially as going to treatment would be ''… like saying to the community, 'I'm not good'.''

> *''I think that's one of the biggest barriers to treatment, is that it's viewed as a moral issue. And they do everything they can do to fix it (themselves) before it becomes insupportable.''* [LDAC 2]

(ii) Negative perceptions about treatment
According to our respondents, negative perceptions about treatment, specifically that treatment is (i) ineffective and (ii) punitive in nature, restricts help-seeking for substance use disorders.

Community perceptions that treatment is ineffective
According to all respondents, HDCs believe that substance abuse treatment is ineffective and that ''it doesn't really help to go to rehab.'' This perception appears to hamper treatment seeking. As one treatment provider stated: ''When people hear that you are going to rehab they say 'Why do you want to go, rehabs don't work'.''

Key informants noted that limited knowledge of SUDs within HDCs contributed to perceptions that treatment is ineffective. HDCs commonly believe that a single treatment episode should ''cure'' the ''addict''. In this view, treatment is seen as a ''quick-fix'' and relapse after a single treatment episode indicative of treatment failure:

> *''People don't understand inpatient treatment because it's like if you are going for treatment you will be fixed. So people still look at treatment as 'quick fixes'.''* [TSP 5]

> *''They really don't understand about treatment… people think like you just go in and come right.''* [TSP 6]

Treatment as punishment
Respondents also reflected upon another commonly held belief about treatment in HDCs - that treatment is punitive. As one treatment provider noted:

> *''They feel like it's a punishment…One (client) said to me, people said that in the treatment centres that thing is painful because alcohol is drained from your blood.''*
> [TSP 3]

According to our informants, concerns about a lack of choice, loss of freedom, physical safety and well-being contributed to the perception that treatment is a form of punishment. For example, treatment providers remarked on clients' fears ''about a lack of control over yourself and what's going to happen to you once men in white coats take over the whole process'', that ''it's a jail and you cannot go out'', that they were going ''to be controlled, these people (were) going to hit me'', and that ''rehabilitation centre equals madhouse, where people get put in padded cells and people in white coats walk around.'' Our respondents thought that this perception of treatment as punishment increased reluctance to seek substance abuse treatment.

(iii) The impact of the media on stigma and treatment beliefs
Key informants reflected that the media's representation of substance abuse treatment facilities as predominantly authoritarian and punitive in nature contributed to perceptions that treatment is a form of punishment and should be feared. According to key informants, the media's predominantly negative and sensationalist representations of treatment facilities fed into community concerns about treatment, and consequently hampered the use of existing treatment facilities by people from HDCs:

> *''Government is not bringing the whole drugs issue out into the open. It's the newspapers; it's the media that needs to do that. And media on the other hand sensationalise it. They do not deal with facts. If it is some kid dying of an overdose, they will jump on that bandwagon and write about this for weeks. We do not give people the facts. We do not educate people, we sensationalise. And that's the problem with the media.''*
> [TSP 4]

Despite this concern, respondents noted that the media has a potentially positive role to play in facilitating help-seeking for SUDs. They thought that responsible reporting could facilitate help-seeking by disseminating accurate information about SUDs and by increasing awareness of when help is needed, where to seek assistance, and of appropriate treatment options. Some key informants reported actively using the media to increase community awareness of substance abuse services:

*''We did a lot of advertising in the community
newspaper regarding tik (methamphetamine)
and what to look out for and whatever. So
whenever I talk to clients or the mothers and ask
'How did you know the child was on tik or
whatever?' They say, 'No I read it in the
newspaper that these were the signs.' So they are
obviously made aware by the community
newspapers.''* [SAC 1]

Discussion

Findings suggest that even in a context of numerous structural
barriers to substance abuse treatment use[4], individual and
community level factors inform decisions about whether to use
existing services or not. This study examined two non-
structural influences on the use of substance abuse treatment
services: stigma towards individuals with SUDs and negative
perceptions of treatment. Findings clearly depict how these
two factors act as barriers to the use of treatment services by
people from HDCs in the greater Cape Town area.

Results indicate that stigma towards individuals with SUDs
hampers treatment-seeking. We found that negative
representations of individuals with SUDs are underpinned by
moral discourses; with these individuals constructed as mad,
bad, and socially deviant. While these representations may
serve as a deterrent against the initiation of drug use in HDCs,
an unintended consequence is that they hinder treatment-
seeking. According to our respondents, individuals with SUDs
and their families, in an attempt to maintain positive personal
and social identities, not only keep the problem hidden from
others by avoiding treatment, but also deny the extent of the
problem and the need for treatment. This is cause for concern
given the negative associations between low problem
recognition and substance abuse treatment use.[20-22]

Related to this, our findings suggest that women with SUDs
are more negatively perceived than their male counterparts.
This mirrors findings from studies conducted in other
settings.[7-9] One reason for this may lie in the finding that moral
discourses around substance use and intoxication are
particularly salient for women, compared to men; with female
substance abuse generally associated with sexual availability
and an inability to fulfill traditional gender roles. These
representations may hinder treatment-seeking for women, as
they may deny or hide their condition for fear of being
labeled, for fear of having their children removed from their
care, and for fear that treatment providers will be judgmental.
This last concern may arise from previous experiences of
punitive responses on entry into the treatment system. Support
for this explanation emerges from findings of negative
perceptions towards women who use substances by health
professionals and community-based organisations in South
Africa.[22-23]

Findings also suggest that negative perceptions of
treatment, such as beliefs that treatment is ineffective and
punitive, hamper the use of existing services. More
specifically, fears about treatment and beliefs that treatment
does not work seem to increase reluctance to seek substance
abuse treatment. This parallels findings from prior research
conducted in the U.S.A.[10-12,20] In part, beliefs that treatment is
ineffective are shaped by treatment myths, including the faulty
notion that a single treatment episode is sufficient to cure

substance dependence. This is worrisome as recovery from
substance dependence often requires several treatment
episodes and is a lifelong process.[14] One recommendation for
debunking these myths is a public awareness and education
campaign that focuses on providing clear messages and
accurate information on when and where to seek treatment as
well as on the process and expected outcomes of treatment.
Findings from this study suggest that the media could be a
powerful tool for educating individuals, families and
communities about what constitutes effective and appropriate
treatment.

On the other hand, negative beliefs about the effectiveness
of treatment also are informed by real concerns about the
quality of services available to individuals from HDCs.
Previous studies have noted several structural factors that
impact on service quality including high caseloads of staff
responsible for treatment service delivery, the proliferation of
unregistered and unregulated treatment facilities in the private
sector, the limited use of evidence-based treatment models,
the use of unskilled and untrained staff to deliver treatment
services, and limited capacity to provide a comprehensive
range of treatment services.[2,4] While the presence of some or
all of these factors in the settings that serve clients from HDCs
raises important questions about service quality and
effectiveness, such questions are impossible to address
without a systematic evaluation of the substance abuse
treatment system. Service quality and effectiveness probably
vary considerably from service provider to service provider. A
systematic evaluation of the substance abuse treatment system
would provide insight into the factors associated with better
treatment outcomes, where quality improvement initiatives
should be concentrated, and how current services could be
improved. The use of evaluation findings to drive quality
improvement initiatives might go some way to addressing
negative perceptions about treatment.

In addition, findings suggest that media representations of
treatment facilities contribute to negative perceptions about
existing substance abuse services. Key informants noted that
the media focuses on sensationalistic and newsworthy items
and, as such, rarely represents treatment facilities in a positive
light. In some cases these representations are not unfounded.
In recent years several private treatment facilities serving
HDCs have been closed due to human rights violations and
concerns about patient safety. Despite this, current media
representations of treatment provide the general public with a
skewed picture of the substance abuse treatment system.
Although a significant proportion of treatment facilities are
professionally-run and adhere to ethical guidelines, this is not
reflected in the media. Even though these media
representations may serve an advocacy function by
highlighting patient rights and the need to regulate substance
abuse services, they also entrench negative perceptions of
treatment and consequently barriers to substance abuse
treatment use.

Given that the media is a powerful tool for influencing
perceptions of treatment; health professionals have an
advocacy role to play in helping the media understand and
redress the deleterious effects of media representations of
drug users and treatment facilities. This can be accomplished
through careful communication of substance-related
information and research findings (to avoid misinterpretation

of findings) and through educating the media about responsible reporting on substance-related issues. Education about responsible reporting should address any myths about substance abuse treatment, provide information on how stigmatising representations can be avoided, and encourage balanced portrayals of treatment facilities that depict treatment successes and not just failures.

Although we gathered rich data that gave us insight into how stigma and negative perceptions of treatment hamper the use of substance abuse treatment services, this study has one main limitation. We recognise that interviews of individuals with substance-related problems in HDCs would have enriched our understanding of the stigmatising experiences of individuals who require treatment as well as their perceptions of treatment services. Consequently, this study does not speak to the lived experience of individuals with SUDs in HDCs in the greater Cape Town area. As such, future research should attempt to directly explore experiences of stigma, perceptions of treatment and treatment-seeking among a sample of substance users in need of treatment.

Conclusion

Despite study limitations, findings from this study reflect how stigma and negative perceptions about treatment, two nonstructural factors, are barriers to substance abuse treatment use for people from HDCs in the greater Cape Town area. Several factors contribute to negative perceptions about treatment including structural barriers within the treatment system, myths about treatment, and media representations of treatment services. This study makes several recommendations for addressing these factors, including a systematic evaluation of the substance abuse treatment system and the introduction of quality improvement initiatives, a public awareness campaign to address stigma as well as myths and misconceptions about treatment, and educating the media about responsible reporting on substance-related issues.

Acknowledgements

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