Original

Sharing control: user involvement in general practice based methadone maintenance

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Abstract

Objectives: **This study assessed patients' views of a methadone programme in a Dublin general practice including the degree to which the patients were 'involved in decisions about their treatment'.**

Method: **All patients receiving methadone were asked to participate. A face to face questionnaire, with open and closed questions, was administered. Interviews lasted approximately 30 minutes. Quantitative data were analysed using descriptive statistics and qualitative data were analysed using a thematic approach.**

Results: **Forty one (87%) of the 47 patients attending the general practice methadone service were interviewed. Of the 39 patients who had used heroin on admission, 69% had stopped and 31% reduced heroin use since starting methadone treatment. A total of 71% reported that the doctor either always involved (59%) or sometimes involved (12%) them in decisions about their treatment. Involvement was interpreted as 'being listened to' or 'having a say' in deciding methadone dose. Surprisingly those who reported that they were not involved in treatment decisions were more likely to have stopped heroin use (10/11). A significant majority of patients (81%) expressed the desire to stop taking methadone.**

Conclusion: **Most patients receiving methadone in general practice were listened to and had a say in deciding their methadone dose but did not have an opportunity to engage in more structured or contractual forms of involvement in treatment such as written care plans. In line with a patient centred approach, treatment providers should set their sights beyond the safe delivery of methadone, to provide a service which is centred on patient goals, expectations and choice.**

Key words: Consumer participation; Methadone; Primary health care; General Practice.

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Introduction

After decades of research, the effectiveness of methadone maintenance treatment in reducing heroin use and associated problems including involvement in crime and reduced transmission of blood-borne viruses is well established.[1-3] In Ireland legislative and administrative regulations to control the prescribing and dispensing of methadone have been in place since 1998.[4-6] Their purpose is to prevent the diversion of methadone onto the black market and reduce the risk of overdose deaths.

Regulations include registering each person who is prescribed methadone and restricting prescribing and dispensing to doctors and pharmacists who have undergone special training. Protocol regulations include restrictions on the number of patients a doctor and a pharmacist can prescribe and dispense to.

During treatment a patient's consumption of methadone is supervised either on a daily or weekly basis depending on the patient's level of non-prescribed drug use, which is assessed by means of urine testing. In Ireland one-third of patients on methadone maintenance therapy (MMT) attend a general practice for their treatment.[7]

As part of the general healthcare system, patients are encouraged to actively participate in decisions about their own treatment, as well as to provide input into policy decisions about the treatment service itself.[8] Though patient involvement is a characteristic of modern health systems it is not well supported in the context of addiction services.[9,10]

Our study explores patient involvement in treatment decisions and their views of the methadone programme.

Method

The study setting was a sizeable general practice in a deprived area of Dublin. Patients treated for heroin addiction were seen, separate to other patients, at one of two set times each week by one of two general practitioners. The practice manager attended the 'clinic' and general assistants were available to observe patients providing urine samples. This is common practice in drug treatment clinics and aims to ensure the sample the patient is providing is their own sample. Nursing and counselling services were available by appointment.

The study population included all patients in receipt of methadone treatment at the general practice. The interviewer administered questionnaire was developed in collaboration with the general practitioners and the drug user's forum, (Union for Improved Services Communication and Education, UISCE).

Interviews were conducted over a four week period during July and August 2006. Data on demographics, client history with the service, views of different aspects of the service, involvement in decisions about treatment, health status and

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drug use were collected. The questionnaire included open and closed questions and took approximately 30 minutes to administer. Answers to closed questions were coded and analysed using descriptive statistics. Bi-variate analysis was conducted using Fisher's exact tests. Answers to open questions were recorded verbatim. Quantitative and qualitative data were entered into SPSS 14. Some qualitative data were used to explain or expand on closed questions. All qualitative data were coded through eye balling and labelling individual units of meaning. These codes were then re-categorised according to emerging themes. Quotes illustrative of specific themes were selected for inclusion in this paper.

Service users attending the methadone services verified the analytical interpretation of the data.

Results

Forty-one (87%) of the 47 patients attending methadone treatment at the general practice were interviewed. One patient refused to participate, one was in prison, two were not in contact with the service during the study period and two did not attend the interview.

Demographics

At the time of the study, the patients' ages ranged from 21 to 53 years with a mean age of 34.5 years. Over one-third (37%) were 36 years and older. Patients were predominantly male (73%) unemployed (54%) and single (63%). A significant minority (44%) lived in private rental accommodation and over one-fifth (22%) lived with family members. Four patients (10%) lived in hostels.

Client history with the service

At the time of the study, 60% attended the service for over four years and 24% attended for less than one year. Most patients (95%) attended the service once per week. Patients were referred from a wide range of services with the largest single proportion (46%) being referred from drug treatment clinics.

Changes in drug use

Thirty-nine patients had been using heroin on admission to the practice. Of these, 69% had stopped using heroin and 31% reduced their heroin use. Nine of the 10 patients using amphetamines had also stopped. The numbers who had stopped or reduced their intake were relatively small *(see Figure 1)*. A number of patients reported continued use of heroin (12), amphetamines (1), cocaine (12), benzodiazepines (19), cannabis (21) and alcohol (14).

Involvement

A total of 71% said that the doctor either always involved (59%) or sometimes involved (12%) them in decisions about their treatment. Forty four per cent reported having an agreed plan with their doctor regarding 'where their treatment was going'. The remainder stated they did not have an agreed plan (51%) or did not know if they had one (5%). The majority of those with a treatment plan described it as 'verbal in nature' (78%) and subject to review.

A total of 61% stated that their doctor decided the amount of methadone they were prescribed while 34% stated that the doctor and client jointly decided the dose. Just under 50% said that they had a say in deciding the prescribed dose although some said this decision was within limits:

- *"I do have a say; but it's more up to the doctor" (Participant 21)*

Others felt their experience was being taken into account by the doctor;

- *"He'll ask me how I'm feeling, sleeping, eating, how things are going, he listens" (Participant 19)*
- *"You say it isn't holding you and you need extra" (Participant 41)*

Those who felt that they did not have a say (36%) commented that the decision-making power was with the doctor:

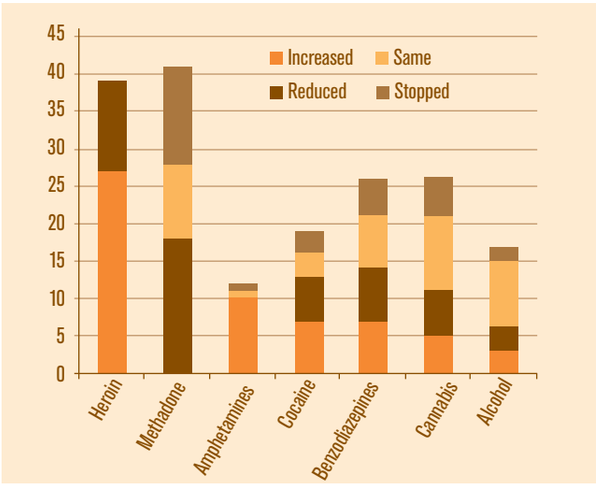
- *"He has the power... You take what's given" (Participant 20)*
- *"It looks like a partnership but at the end of the day the doctor decides. When they decide on your dose, that's it" (Participant 30)*

A total of 44% of responders said they would like to be more involved in decisions regarding their treatment. Improved dialogue was cited as the most appropriate means to greater involvement though some suggested group meetings may be helpful.

Table 1 presents a comparison between those who said they were involved in decisions about their treatment and those who said they were not involved. Those who said they felt involved in decisions about their treatment were more likely to feel the service was helping them, to have a treatment plan, and to have a say in deciding the dose of methadone. They were less likely to be stable in terms of illicit opiate use, to be in the service for more than a year and to want more involvement.

As lodging a complaint is one way for service users to influence service provision, patients were asked how they would go about making a complaint if they had one. Of the 35 who answered this question, 40% would go to a member of staff (usually the doctor), 26% said they would not make a complaint (as nothing would be done or it may be held against them), and 11% would go to the service users' forum or to the health authority.

Figure 1: Reported changes in drug use since starting with the service



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Almost one-quarter (23%) did not know how to make a complaint. Just over one-third (34%) made comments suggesting a lack of confidence in an internal complaints system.

- *"If I had a complaint I don't think I would make it.. the doctors are going to back the receptionists and vice-versa. They are not going to go against each other for an addict" (Participant 31).*

Patient's goals

Patients were asked about their long-term treatment goals. A total of 17% expressed a desire to continue methadone treatment into the future but the majority of patients stated that their long term goal was to stop taking methadone, either in the immediate future (59%) or eventually (22%).

Views of 'the service'

Of the patients 83% stated that the service was helping them to achieve their goals with three themes emerging: stabilisation, motivation and referral

i) Patients described the stabilising effect of being on methadone as making it possible to lead a normal life:
   - *"If I wasn't getting methadone I'd have to smoke everyday... it stabilizes you so you can go back to work" (Participant 41)*
   - *"It keeps you away from the street and other elements and to spend more time with the family... and if you want you can hold down a job" (Participant 36)*

ii) Some felt that the service providers motivated them to come off drugs:
   - *"I would have been on heroin if I wasn't here. It does push you now and again... Since I'm getting stable now I'll start to come off soon" (Participant 39)*
   - *"It pushes you, but sometimes I'm not ready" (Participant 1)*

iii) Others appreciated referral to other services, eg. counselling and inpatient detoxification:
   - *"(It's helping me) by letting me see the counsellor… she passed me on to other people who are giving me support" (Participant 3)*
   - *" (names doctor) is putting me down to go into treatment" (Participant 37)*

A minority felt the service was not helping them to reach their long-term goal:

- *"…it's the same thing every week. Throwing a mouthful of phy down me isn't going to help me" (Participant 31)*
- *"All I see is a doctor for five minutes here – I get all the other support I need at (names another service) from counsellors and in one to one sessions. It's daily support you get there" (Participant 15)*

While the majority felt the methadone service helped them to achieve long-term goals, they also identified other substantial requirements in order to recover from addiction. The most common requirements were a stable environment (away from temptation) and a sense of purpose (something to do each day).

- *"Get somewhere to go… to get away from everyone and then have somewhere safe to come out to" (Participant 25)*
- *"Permanent accommodation, not hanging around the streets all the time, getting a job and having take-aways. When you have a job you're occupied and kept away from it" (Participant 19)*

Table 1: Comparison of patients on the basis of feeling involved in treatment decisions

	Feels involved in treatment decisions (%)	Does not feel involved in treatment decisions (%)	p value (Fisher's exact test)
N	24	11	
Like more involvement (13)	3 (13)	10 (91)	< 0.001*
Defined treatment plan (17)	15 (63)	2 (18)	0.027*
Service helps (28)	22 (92)	6 (55)	0.021*
Say in dose prescribed (20)	19 (79)	1 (9)	< 0.001*
Doctor decides dose (19)	9 (38)	10 (91)	0.004*
Not using heroin (25)	15 (63)	10 (91)	0.112
Attending more than 1 year (25)	14 (58.3)	11 (100%)	< 0.02*

**Statistically significant results p < 0.05*

Supervised urine testing

Most (83%) felt that supervised urine testing (providing a urine sample under observation) was necessary and accepted it as part of the rules which must be adhered to when receiving methadone treatment. Among those who said it was necessary, there were those who indicated that they had 'no problem' with this practice (53%) and those who expressed they had some level of discomfort (41%) about it either in the past or currently.

Accepted urine testing without reservation:

- *"It's no problem. Its part of it" (Participant 12)*
- *"If it has to be done it has to be done. It's alright. I've no problem with it." (Participant 21)*

Accepted urine testing with some reservation:

- *"I don't mind but it's degrading" (Participant 10)*
- *"I feel a bit paranoid about it" (Participant 23).*

Another six per cent thought the practice was necessary but did so against their feelings of discomfort;

- *"I'm not comfortable with someone looking at me" (Participant 2)*
- *"I don't like it full stop. It's degrading" (Participant 7)*

Daily supervision of methadone consumption

A total of 61% felt that daily supervision of methadone consumption (drinking methadone in the pharmacy every day under observation), usually as a consequence of opiate positive urines, helped reduce their use of heroin. Amongst these there existed the view that it was either 'necessary' or 'fair', with several commenting that it served as an aid to abstinence:

- *"I think it's fair. You need some sort of consequences" (Participant 16)*
- *"That's the right thing to do because if I hadn't been thrown*

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off or supervised (daily) I would still be using" (Participant 39)

- *"Because it makes me think twice about using with the trouble of going to the chemist everyday" (Participant 37)*
- *"It's right... I'm on dailies since last year but it's my own fault" (Participant 35)*

A total of 34% felt that being put on daily supervision of methadone consumption did not act as a deterrent to heroin use and some suggested it may be counter productive because it increased exposure to illicit drug use:

- *"I think it helps you meet more people where drugs are available and it can be tempting" (Participant 13)*
- *It frustrates more than anything else. You just say f*ck and go and use... rebel against the punishment (Participant 17)*

Dissatisfaction was expressed regarding the practical inconvenience that it caused;

- *"It's ridiculous when you have three kids! You have to drag them all with you" (Participant 4)*
- *"If they're living local it's one thing, but for me living in (names area outside Dublin) it's really unfair" (Participant 14)*

Positive and negative attributes of the service

Thirty-three patients described what they considered as positive aspects of the services while 28 described negative aspects. Positive comments related to the service 'helping' and being 'good and fair'. They described the staff as being friendly and competent, particularly the doctors: Listening and understanding were appreciated attributes as well as 'respect' they were shown.

A total of 28 people described some negative aspects which described a service that was not user friendly in terms of timing of clinics and having to leave children outside. Negative comments relating to treatment of the person included examples of lack of trust and respect by some staff.

Discussion

The meaning of patient involvement remains ambiguous in the literature. It has been conceptualised broadly as patient-centeredness which relates to doctors adopting the biopsychosocial model in preference to a purely biological model along with a more equal rather than paternalistic doctor-patient relationship.[11-13] More focused interpretations concentrate on shared decision making with clinicians, health literacy and self-management of chronic conditions.[14] In our study respondents appeared to interpret involvement as having good dialogue, feeling they were being listened to and having a say in deciding their methadone dose. While good dialogue and being listened to may be precursors to involvement they do not necessarily imply it. Having a say in dosage implies a more equal relationship, though as some patients observed the power ultimately lies with the doctor.

It is good news that all patients had ceased or reduced illicit opiate use and that there was a high level of satisfaction expressed by service users who alluded to the presence of support from caring staff. However, high consumer satisfaction levels in drug or alcohol services are not a good predictor of service performance.[15-17] Some authors suggest that this is because drug and alcohol service users often perceive themselves as undeserving and have low expectations.[15,18] While some studies suggest a link between satisfaction levels with patient involvement in care planning,[19] others found that even where this is below standard from a programme perspective there continues to be a high level of satisfaction.[19] This echoes our finding of appreciative service users though none had involvement in formal care plans.

The poor link between satisfaction levels and programme characteristics means that patient views, though an important aspect of service evaluation, should not be taken as the definitive statement about the value of service provision.[18-20]

The comparison of those feeling 'involved' with those who did not feel in any way involved suggests an association between feeling uninvolved and being stable. Nearly all of those who did not feel involved said they were no longer using heroin. It is plausible that the sense of non involvement of those who are stabilised relates to the interpretation of involvement as centring on 'deciding the methadone dose'. Once stability is reached and the dose is set this involvement ceases. In fact, it was the view of the GP that there was little to be involved in once stability on methadone was achieved.

While 'stability' on methadone may be an end point and a marker of success from the service providers' point of view, this study suggests that service users do not share this perspective. Most, wanted to be drug free and did not want to be maintained indefinitely on methadone. Similarly, McKegeny found that though patients aspired towards abstinence they ended up maintained on methadone maintenance for years.[21,22] As such, drug service users' goals are more in line with an abstinence approach rather than the harm reduction model, which long-term maintenance supports. Though retention in treatment is reinforced by a strong evidence base, particularly in respect of social outcomes, it may not be in keeping with consumer choice.[9,23]

While there have been calls for the provision of user based choice and participation in shaping goals,[10,23] some authors suggest this is less straight forward in the context of addiction services; that `partnership with patients' reduces the ability to 'counter manipulations' by them.[9] While the treatment of heroin addiction has been likened to the treatment of people with chronic illness[24-26] some regulations are based on an assumption that service users can not be trusted (patients observed urinating to ensure they cannot provide false samples and observed drinking methadone to ensure they do not sell it). Can shared decision making and other markers of patient involvement in treatment decisions exist where such regulations are considered necessary?

The fact that a majority of patients in our study accepted these measures as necessary may suggest that they can. The acceptance of these rules may indicate that such a regime provides a reasonable incentive for patients to 'stay clean' and a disincentive to sell methadone on the black market. Bergschmidt provides another interpretation however, positing that patients may accept these checks due to a belief fostered by the system, that they had 'lost their entitlement to social existence'. Thus, due to a 'desire for normalisation' they accepted controls that would be unacceptable in other chronic medical conditions.[27] The difference between what patients find acceptable and what they find helpful can only really be assessed in the context of patient choice.

Our study highlights a gap between what patients said they wanted (abstinence) and what they were experiencing (maintenance). Reasons for this gap require further exploration.

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One possible explanation is the lack of adequate facilities, particularly residential and rehabilitative, to support the achievement of abstinence for those with this aim.[28] Another possible explanation which McKegeny offers for similar findings, is that the desire to become drug free is a long-term and ultimate objective, while maintenance may be more in line with an intermediate aim.[21] A third explanation is that the patient's view of an appropriate treatment path conflicts with the doctor's view which may be more influential in treatment decisions.[20,29] Whatever the reason for the gap between aspirations and experience, it is likely to be less extreme in the context of real choices made by patients.

Conclusion

Most patients receiving methadone in general practice were listened to and had a say in deciding their methadone dose but did not have an opportunity to engage in more structured or contractual forms of involvement in treatment such as written care plans.

Patients who have become stabilised and who wish to eventually stop taking methadone do not feel involved in their treatment; this may be due to disharmony between the patients' long-term aim (to be drug free) and the aim of methadone treatment 'to reduce or end heroin use and the harm associated with it'.

In line with a patient centred approach, treatment providers should set their sights beyond the safe delivery of medicine, in this case methadone, in order to provide a service which is centred on the patient goals and expectations. This undoubtedly requires a range of treatment options to be made available to patients and service providers including further training for GPs. Involvement in treatment decisions and care is likely to build patient confidence and their sense of responsibility for the management of their care. At the very least it is likely to narrow the gap between expressed goals and treatment goals. Patient choice on type of treatment experienced and how this is delivered should be made more explicit in the treatment of opiate addiction in Ireland.

Declaration of interest: None.

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