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Patient choice as a means of empowerment in opioid substitution treatment: a case from Sweden

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ABSTRACT
Patient choice of treatment provider was introduced within opioid substitution treatment in the southern Swedish county of Skåne in 2014. Substitution treatment has often been criticised for being strict, rule-based, and driven by an ethos of discipline. This study explores the patients’ views and experiences of patient choice, particularly as a potential means of empowerment. The study is based on semi-structured interviews with 33 patients at six substitution treatment clinics in two cities. Patient choice within substitution treatment has empowered the patients in that many are able to choose their treatment provider and transfer to another provider. The interviewees appreciated the possibility to choose and transfer, and felt that they had gained more influence on their treatment. Experiences of poor staff conduct and the new clinic’s policies and practice on prescribing benzodiazepines were important reasons for choosing and transferring between clinics. In particular, the patients stressed the importance of the possibility to leave a clinic they felt offered substandard treatment, and the psychologically important feeling of knowing that they could transfer to another facility. However, patient choice in addiction treatment is very rare in Sweden, and the demographic structure limits the development of patient choice within substitution treatment.

Introduction
Skåne Regional Council (Region Skåne), representing the third largest health care district in Sweden, introduced patient choice for opioid substitution treatment in April 2014. This means that all treatment providers, public and private alike, which meet the accreditation requirements, have the right to provide substitution treatment with county-level funding, and that residents of Skåne (English: Scania) who are dependent on opioids may freely choose between these treatment providers. Patient choice in substitution treatment was instituted as part of an ideological effort to bring more choice into specialist health care, and was advocated by the right-wing political majority in Skåne Regional Council. Another motive for the implementation was the right-wing majority’s wish to expand the private, for-profit, provision of health care, based on a belief that competition leads to cost-efficiency. The reform sought to increase the availability of substitution treatment, to improve the way in which patients were looked after, to strengthen the patients’ own influence over their treatment, and to create more diversification among the treatment providers. The last goal was intended to lead to increased options for patients to choose from.

Patient choice is grounded in the Act on System of Choice in the Public Sector (2008:962), where the main competitive tool is intended to be quality rather than price. The costs to the patients are the same regardless of which treatment provider they choose. The providers are obliged without delay to see those patients that have exercised their right to choose the clinic, provided that the patients fulfil the criteria laid down for substitution treatment by The National Board of Health and Welfare (NBHW; Socialstyrelsen in Swedish), the authority that regulates substitution treatment in Sweden. The patients are allowed to switch from one treatment provider to another once in six months at the most (Region Skåne, 2015). Patient choice is outlined in more detail in a note.1

From a Swedish perspective (and probably also from an international perspective), such freedom of choice is unique. No other public health authority has previously tried out publicly funded patient choice within substitution treatment. In Sweden, patients who would like to receive substitution treatment are normally referred to a specialist clinic based on their place of residence. Until recently, the queues were long, and the patients had to wait for months, sometimes even years.

This article aims to explore the patients’ views and experiences of patient choice. We examine how the patients have exercised their right to choose a treatment provider and switch from one provider to another, and the possibilities and limitations of this freedom of choice. We focus expressly on patient choice as a potential means of increased empowerment.

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It is important to examine what freedom of choice has meant for patients. Substitution treatment is a branch of health care where the patients typically have long-standing and frequent contacts with the clinics. The treatment has often been criticised for being potentially oppressive and for resorting to rules and demands to discipline the patients. Neale (2013) argues that social-scientific studies on the problematics of substitution treatment have reached a saturation point, and would rather see research go one step beyond and study the practical and organisational endeavours to counter the problems that have been identified. This makes the southern Swedish case of patient choice especially intriguing, as it so manifestly aims to increase the patients’ influence over their treatment. Patient choice enables the patients to leave clinics which are felt not to deliver. This entails a power shift from the staff to the patients, which could help to curtail the disciplinary elements of the treatment.

Another reason to study patient choice is the potential risks associated with increased freedom of choice. Before the introduction of patient choice, there were fears that the clinics might start competing with one another by prescribing benzodiazepines or other pharmaceuticals generally sought after by patients with drug problems. Benzodiazepines can be used to amplify the intoxicating effects of other drugs, and they are often involved in polysubstance dependence. This is a particular threat, because the simultaneous use of benzodiazepines and opioids increases the risk of intoxication.  

We have delimited the scope of the article by choosing not to focus on the aspects of availability within the patient choice. The availability of different treatment providers to choose from is a prerequisite for any substantial freedom of choice. It should, therefore, be mentioned that the availability of substitution treatment has increased significantly in Skåne since the introduction of patient choice, both in terms of municipalities and clinics offering the treatment and in terms of the number of treatment places.

**Background**

**Patient choice in health care: arguments and criticism**

During the two last decades of the 20th century, a development towards increased market orientation and privatisation of the welfare sphere began in many Western countries (Beresford & Croft, 2001; Fotaki, 2011; Kettl, 2006; Petersen & Hjelmar, 2014). Within Swedish health care, this trend started in the midst of the 1990s recession and public cutbacks. An increased focus on market solutions seemed like a possible way of reducing government spending (Bevan, Helderman, & Wilsford, 2010; Fredriksson, Blomqvist, & Winblad, 2013).

Increased market orientation within the welfare sphere can more generally be seen as a part of a wider societal change driven by the liberalisation, internationalisation, and globalisation of politics and policies in the rich Western countries (Beresford & Croft, 2001; Erlandsson, Storm, Strantz, Szebehely, & Trydegård, 2013). This development has run parallel to the advent of New Public Management (NPM), which has brought steering and organisational models from business life into the public sector in order to achieve increased efficiency. In Sweden, the development towards privatisation and for-provit involvement in the welfare sphere has been dramatic, and has included the area of addiction treatment (Fredriksson et al., 2013; Storbjörk & Stenius, 2018).

Patient choice and other choice models are grounded in the idea that people should act as self-governing subjects that take responsibility for their actions and make their own decisions in such spheres as health care, social services, and education. Users of welfare services will thus be redefined to a certain extent, turning them from individual citizens with differing needs into customers and clients on the welfare market (Fotaki, 2011; Nordgren, 2008). This will ideally be accompanied by improved service quality and productivity when the customers ‘vote with their feet’ and abandon service providers that fail to deliver. Such providers will then be phased out from the market (Bevan et al., 2010; Erlandsson et al., 2013; Schlesinger, 2010).

In reality, the situation is rather more complex. It is often hard for ‘customers’ to assess the quality of a particular health care service, for example, which can lead to the users’ not choosing the best option (of the highest quality), or even the option which would best meet their needs (such as a service closest to where they live) (Blomqvist, 2004; White, 2008).

Another constraint can emerge if the users lack the required ability or autonomy to leave if they are unhappy with a service (Blomqvist, 2004; Vamstad & Stenius, 2015). Many welfare services are based on long-term relationships between the users and the professionals, which may further complicate a decision to leave a provider that does not make the grade (Vamstad & Stenius, 2015; White, 2008).

Patient choice has also been justified from an empowerment perspective and has been described as an organisational tool which can strengthen the users’ position within health care. This is an unresearched area in the addiction treatment field, at least considering the aspect of patient choice. Some studies have focussed on empowerment in addiction treatment (Frank & Bjerne, 2011; Kolind, 2007). Kolind (2007) stresses the importance of making the actual drug-treatment users’ voices heard in substitution treatment, in order to involve the users in the development and implementation of policy on substitution treatment.

In Sweden, the introduction of market models in the welfare sphere has often been linked with a discourse of patient rights. Market-oriented concepts such as ‘choice’ and ‘customers’ have been incorporated into the vocabulary of health care, focussing on increased involvement and rights for patients. Empowerment through reforms of freedom of choice is motivated by the idea that the overall relation on this new health care market will be more equal when the power shifts from politicians, authorities, and care providers to the users. What is crucial in this power shift is the users’ actual ability to become involved in the process by means of making rational choices (Nordgren, 2008; Rönning, 2007; Vamstad & Stenius, 2015). To speak of users as active and capable may disguise the fact that the patients are in practice in a disadvantaged position in relation to health care—it
is not a relationship on equal terms (Fotaki, 2011; 2013; Nordgren, 2008; Rönning, 2007; Vamstad & Stenius, 2015).

Another common argument against patient choice maintains that freedom of choice is sometimes seen as a goal above all others, regardless of what actual choice is offered. In a system where there are no major differences in the contents and quality of the care providers’ services, or where there are very few alternatives to choose from, freedom of choice becomes a mere illusion (Bavetta, 2004; Storbjörk & Samuelsson, 2018; Vamstad & Stenius, 2015; White, 2008, Fotaki, 2013).

**Substitution treatment**

Substitution treatment with methadone or buprenorphine is the most widely used treatment for heroin or other opioid dependence. Medical research shows that substitution treatment leads to decreased morbidity and mortality, reduced illicit drug use, and decreased transmission of HIV and other blood infections (Amato, Mineozi, Davoli, & Vecchi, 2011; MacArthur et al., 2012; Mattick, Breen, Kimber, & Davoli, 2009; Mattick, Breen, Kimber, & Davoli, 2014). Many patients also find that the treatment helps them to improve their social circumstances through less exposure to crime and prostitution, for example (Bukten et al., 2012; Strain & Stitzer, 2006). Still, many patients continue to have drug problems. For some, it is a question of temporary or periodical relapses, while others have more long-standing and complex problems. Psychiatric comorbidity and other medical or social problems are similarly common (Strain & Stitzer, 2006).

Social science research, as mentioned above, has typically viewed substitution treatment from a critical perspective. This research has often focussed on the control and disciplining aspects which the treatment may raise, and on the drug stigma that may make it harder for the patients to find their place in society.

Substitution treatment has sometimes been referred to as ‘liquid handcuffs’ (Rosenblum, Magura & Joseph, 1991), a medicalised system to control and discipline individuals with dependence problems (Conrad & Schneider, 1992; Petersson, 2013). Many patients consider the treatment a life saver, while a discontinued treatment cycle can lead to severe abstinence symptoms. The medication is a powerful tool in the hands of the clinics and can be used to steer the patients’ behaviour in the desired direction. In a therapeutic alliance characterised by trust, this is not necessarily a problem (Lilly, Quirk, Rhodes, & Stimson, 2000), but if the treatment practice is pervaded by moralising or disciplining attitudes, the power tools can be used to oppress and deselect undesirable patients. Several social-scientific studies have found that dosing routines and supervision can be employed to control, discipline, and punish patients (Bourgois, 2000, Friedman & Alica, 2001; Dahl, 2007; Fraser & Valentine, 2008; Lander, 2016; Petersson, 2013).

The practice of conducting supervised urine tests to monitor the patients’ drug use has been raised as a particularly demeaning measure within substitution treatment (Friedman & Alica, 2001; Lander, 2016; Petersson, 2013). In Sweden, these tests used to be linked to the discharge rules issued by the NBHW, which stipulated that repeated relapses would lead to a discontinuation of treatment (Johnson, 2013, Llander, 2016). This resulted in a great many users being involuntarily discharged and almost always returning to illicit opioid use (Svensson & Andersson, 2012).

The use of benzodiazepines concomitant with substitution treatment constitutes a more complex addiction problem and has an increased risk of negative treatment outcome (Brands et al., 2008; Laqueille, Launay, Dervaux, & Kanit, 2009). In Sweden, most doctors qualified to treat opioid dependence are reluctant to prescribe benzodiazepines to patients in substitution treatment. At the same time, many patients have sought prescriptions for these pharmaceuticals, since non-prescribed intake (or even intake from prescriptions issued elsewhere than at the treatment clinic) has been regarded as rule-breaking (Petersson, 2013). Repeated use of non-prescribed benzodiazepines has traditionally been the main reason for involuntary discharge. Consequently, there has been a major focus on benzodiazepines in substitution treatment in Sweden for many years.

In the 2010s Sweden has gradually adopted a less restrictive approach so that patients who exhibit dependence symptoms—such as relapsing into illicit or prohibited drug use, drinking too much alcohol, cheating on urine tests, or breaking the clinics’ code of conduct—no longer face consequences such as involuntary discharge or other sanctions to the same extent as previously (Johnson, Richert & Svensson, 2017; Monwell, 2019). This change in practice towards harm reduction rather than abstinence as the principal treatment goal preceded the official change in this direction, set in the revised directives of the NBHW in February 2016 (HSLF-FS 2016:1). The discharging rules were officially removed from the directives in this revision.

Controlling measures are necessary for substitution treatment, partly for reasons of patient safety and partly to minimise the risk of pharmaceuticals being resold on the illegal market. If these measures are not guided by an ethical approach, the patients run the risk of maintaining a deviant identity, which will counteract their rehabilitation (Gourlay, Ricciardelli, & Ridge, 2005; Johnson & Richert, 2015).

**Theoretical framework**

The article is primarily an empirical study concerning patients’ views and experiences of the introduction of patient choice in substitution treatment. Below we briefly introduce the concept of empowerment and the three options for action that, according to Hirschman (1970), service users may choose to act from when they are dissatisfied with the quality of a service.

**Empowerment**

As Frank and Bjerge (2011) mention, empowerment is a widely used and somewhat ‘fuzzy’ concept that is not always easy to define. Beresford and Croft (2001; Croft & Beresford, 1995) state that the practical implications of empowerment
in welfare services have mainly been defined in a top-down manner, by professionals. Thus, there may be a difference in views between professionals and service users concerning how to achieve increased empowerment. Professionals and organisations often wish to engage service users to participate as experts in order to improve user involvement in the organisation. This, they believe, would lead to increased empowerment in terms of user impact. For the individual service user, however, such commitment tends not to give much personal reward. It does not necessarily lead to individual empowerment that can enable a change in the power balance towards the service organisation (Beresford & Croft, 2001).

In this study, we view empowerment essentially as being about enabling persons in a powerless or vulnerable situation to find the strength that gives them the opportunity to change that situation and gain more influence over their lives. Empowerment is a major goal in such areas as social work, health care, and public health to help service users to take ownership of their lives (Adams, 2008). However, as we have already pointed out, such enabling measures—including substitution treatment—can have a strangulating and disciplining impact, largely due to the asymmetrical power relationship which exists between those who provide help and support (typically representatives of a professional group) and those who seek it (service users).

The asymmetrical power relation stems partly from differing levels of knowledge and different positions in the institution where this relation exists (Hasenfeld, 2010). The professionals will look into the need for help, decide whether a person is entitled to receive help and other resources, and they can also decide if that aid should in some circumstances be discontinued. The service users enter into a power relation because they feel that they need help and want something from an institution. This puts them in a less favourable position. Empowerment can happen, if the users are given (or take on) roles other than that of someone seeking help—if they can act, for example, as customers and make choices about their treatment (Beresford & Croft, 2001; Eriksson, 2015; Fotaki, 2011). If the help-seekers feel that the staff treat them in a professional and respectful manner, this may lead to a shift in the balance of power and contribute to the service users’ further empowerment (Adams, 2008; Kolind, 2007; Lee & Hudson, 2017). However, this power shift and focus on increased empowerment may be particularly hard to achieve in a practice ruled by control measures such as substitution treatment (Frank & Bjerge, 2011).

A distinction is sometimes made between horizontal and vertical empowerment. Horizontal empowerment refers to a collective mobilisation of equal actors, as in the case of establishing advocacy groups for various service users, while vertical empowerment deals with actors gaining a stronger foothold in relation to superior groups (Andersen & Bilfeldt, 2016). For individuals, vertical empowerment means that they can have real influence over areas that matter in their lives. According to Lee and Hudson (2017), such influence comes with three dimensions: stronger self-esteem to realise that it is conceivable to have more influence; increased competences and a capacity to critically reflect over various courses of action; and access to resources and strategies to make the most of a given situation. In the case of substitution treatment, this means that the patients are able to influence an institution which has a central and at times even a dominating role in their everyday lives.

Exit, voice, and loyalty: What to do if one is dissatisfied

The concepts exit, voice, and loyalty by Hirschman (1970) were originally coined for the economic sphere, to describe the customers’ choices when businesses try to sell products of a lesser quality. However, the concepts have been used in many other contexts, such as to analyse service users’ choices of action in relation to different welfare institutions. The concepts are useful in reasoning about freedom of choice in relation to the introduction of patient choice in substitution treatment in southern Sweden.

According to Hirschman, service users who are not happy about the way they are treated or about the quality of a service have basically three options. Loyalty entails that the users do not take any measures at all but rather accept or adapt to the prevailing situation. This is the most likely option if there is only a limited amount of dissatisfaction, if there are both advantages and drawbacks in the relationship, or if the costs of other options are high. Service users can also use the option voice, for example by making their criticism known to a representative of the organisation or by voicing their dissatisfaction publicly. The third option is exit: the service users will leave the organisation. If the dissatisfaction grows keeping and if it is easy to transfer to another organisation, the exit option is all the more likely.

In Swedish substitution treatment, the option of loyalty has been boosted by the contemporary structure of incentives. Using the option of exit by switching to another treatment provider used to be a costly option; this typically required that one moved to a new place of residence within the catchment area of the desired treatment provider. Protesting (voice) had its own risks and could lead to sanctions (Lalander, 2016; Petersson, 2013). Established service users’ forums, which can convey patients’ collective views, are still rare. What patient choice means—theoretically at least—is that the options of voice and exit become significantly less expensive.

Method

Sample and recruitment

The article draws on semi-structured interviews with 33 patients in substitution treatment (29 individual interviews and two in pairs). The interviews were conducted over seven weeks in autumn 2015 and spring 2016.

The interviewees were recruited at six clinics in two cities, which we selected because the patient choice was readily available for those who wished to make use of it. There were at the time 17 clinics in seven municipalities in Skåne, five each in the cities that we visited. Among the providers were both clinics that were in operation before as well as those that had started after the introduction of patient choice.
Table 1: Characteristics of the 33 interviewees.

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In the results section, we have not identified which interviewees are linked to particular quotes, in order to exclude the possibility of identification. However, the interviewees who appear in quotes are marked with asterisks in the gender column in Table 1.

Samples that rely on the interviewees’ interest and engagement always include a risk of bias. In our case, it is conceivable that the recruitment may have led to an underrepresentation of certain patient groups, such as those who at the time were negatively disposed towards their clinic or treatment, patients who were feeling bad at the time of the interviews, or patients who wanted to keep a low profile at the clinic. The recruitment may also have led to an overrepresentation of patients who visited the clinic frequently (mainly new patients and those having a relapse) and of patients who wanted to talk about what they had been through at their previous clinic.

We also interviewed the chairperson of the local drug users’ union (Skånes Brukarförening), which has a membership of drug users and patients in substitution treatment. The chairperson, who himself is a methadone patient, often comes into contact with patients with problems or staff conflicts in their treatment. He was interviewed in his capacity as representative of the drug users’ union, and not as a methadone patient. We felt that it was important not only to interview patients who wanted to be involved but also to consult somebody with an overview of ongoing dissatisfaction and problems within substitution treatment in Skåne.
**How the interviews were conducted**

Two weeks before our visits, posters were put up at the clinics with information in the waiting room about the study. Interviewees were recruited in the waiting rooms during the visits, and the interviews were conducted individually in separate rooms. The chairperson of the drug users’ union was interviewed at a cafe. All interviews were performed by the first author.

The interviews were guided by a semi-structured interview guide with the following focus areas: (a) personal background, (b) previous treatment experiences, (c) overall views on patient choice, including the goals of availability, patients’ influence over their treatment, differentiation between clinics, contents of treatment, and staff conduct with the patients, (d) opinions about the patient registration process and the requirements for participation in substitution treatment, (e) motives and thoughts behind transferring to another clinic, (f) the actual treatment situation, (g) views about control and support measures in substitution treatment, (h) the staff–patient relation, (i) benzodiazepines, diversion of medication, and other risks of substitution treatment, (j) thoughts about the future.

The interviews lasted from 30 to 60 minutes each. They were recorded digitally and subsequently transcribed word for word.

**Analysis**

We analysed the transcribed interviews in three steps using manual qualitative text analysis. The material was, first of all, read through several times, and the main arguments (that kept emerging from the interviews) were sorted and coded broadly. The initial coding reflected the focus areas of the interview guide, but we were also alert to key arguments that appeared outside the framework of the interview guide. For this article, views on autonomy, freedom of choice, staff–patient relations, and control have been of special interest. In the second phase, the material was coded in more detail in order to identify patterns and categories in relation to the main arguments. In the third phase, the texts were read once more for illustrative citations (Jacobsen, 2007; Rennstam & Wästerfors, 2015). The analysis was made by the first author with continuous input from the second author.

**Ethics**

The research project that this study is a part of has been approved by the Regional Ethical Review Board in Lund (dnr 2014/547). Prior to the interviews, the interviewees were informed orally and in writing about the project and the conditions of their participation (voluntariness, confidentiality, consent, and the way in which the material would be used). The interviewees then signed a written consent to participation.

**Results**

In the results section, we begin by addressing the patients’ views of empowerment and their thoughts about choosing and transferring between clinics. Thereafter, we approach the relationship between patient and staff. The significance of the lack of differentiation between treatment providers is also covered, as well as the role of benzodiazepines in relation to choosing clinic.

**Increased empowerment and possibility to choose**

Many interviewees found that substitution treatment patients were a weak group with poor cohesion. ‘We fall because of our [poor] cohesion’ (female, private clinic). Problematic drug use is often accompanied by social, economic, and emotional problems, and in some cases also by cognitive difficulties, which makes it harder to build any organised action. There is a drug users’ union in Skåne, but few patients are involved. Attempts to launch drug users’ forums at various clinics—both before and after the introduction of patient choice—have not proved to be tenable. ‘Often someone is active for six months, and then nothing else happens. I’ve been there once when things have fallen apart, I don’t want to be there again, I can’t take it. You have to think about yourself’ (male, private clinic). It seems therefore that the kind of empowerment that Andersen and Bilfeldt (2016) call horizontal does not exist in any great measure, and has not been impacted by patient choice.

Another form of service user impact pertains to the individuals’ opportunities to influence their own situation, to be able to attain a stronger position through vertical empowerment (Andersen & Bilfeldt, 2016). The interviews show that patient choice has brought with it a clear positive change: instead of being referred to a certain clinic, the patients can choose according to the criteria which they feel are important. This was expressed by the chairperson of the drug users’ union, summarising his impressions of how patients he had been in contact with felt about the reform. ‘In that way, patient choice was great, because it did away with this position of dependence [in relation to individual clinics]. That dependence is gone, now you can, like, we’re customers now [laughs]’ (chairperson of the drug users’ union in Skåne).

All interviewees were aware of patient choice, and everybody felt that it was good that substitution treatment patients too could choose their service providers. The consensus is illustrated by the following quote. ‘I remember what it was like when patient choice first came, people thought that it was really good that you could choose your clinic. They said: ‘Have you heard that you can make a choice about your clinic’, everybody talked about it and I know some who’ve switched clinics. […] I think that everybody really likes it. It’s good to be able to decide for yourself’ (female, public clinic). To be able to choose, and deselect, treatment providers is a new form of service user influence for patients in this sector of health care.

The interviewees cited several reasons for why they would choose a particular clinic or transfer to a new clinic. Many felt that they had been treated badly at their former clinic,
both in terms of the staff–patient relation and medication. Quite a few said that they had not got along with the staff: ‘Interviewee: At [the former clinic] they would talk about something that they don’t know anything about. Lisa: Is it different here? Interviewee: Yes, I think so, they are less arrogant, the doctors listen more to what you have to say. You get treated like a human being, there [at the former clinic] you get treated like a junkie, like you have only yourself to blame’ (male, private clinic). Some of those who had switched clinics because they were unhappy about the service had made their way to a clinic with a more liberal approach to prescribing benzodiazepines. We will come to this later.

We found that many patients had doubts about transferring to a new clinic. While they may not have been entirely happy about their present clinic, they hesitated about the change. To have to start building relations with new staff was a commonly cited reason: ‘Tearing everything apart again and beginning with new faces and all that’ (male, private clinic). Some were also uncertain whether it would really be better at another clinic.

Many of those who had a long history of substitution treatment at large, public clinics and who had switched to a new clinic once patient choice was introduced described their previous treatment experiences as marked by an atmosphere of suspicion and lack of trust. Some had felt that past injustices ‘stuck like mud’ and they had therefore elected to leave the public institutions, not reflecting much over the possibility that these clinics also might have changed recently. Some interviewees had been treated at a given clinic for a very long time and felt relieved that they could transfer and ‘start again’. ‘I think it’s great that you can change clinics. It really is, it worked for me, I felt that I needed to get away, start again where nobody knows who I am’ (female, private clinic).

Poor staff–patient relations are opted out

The relations to health care professionals appeared as very important to many interviewees, who described their clinic as a central part of their lives. There were also those—a smaller group—who saw their clinic as a medical institution where they get their medication from and have their tests done, but no more than that.

Several patients mentioned significant differences in how they had been treated at their previous clinic, before patient choice, and the one they were attending at the time of the interview. They had chosen to leave behind poor treatment when given the opportunity to do so. ‘There’s so much more energy and life here, and the [person-to-person] treatment, when you come here, the staff will greet you with a smile, that’s a huge difference to [the previous clinic]’ (male, private clinic). A patient compared her experiences with the staff at the two clinics she had attended. At her previous clinic, ‘the staff were really keen on jargon’, while she felt that the treatment was considerably better at the clinic which she had chosen to switch to. ‘I get respect here and almost feel that I’m equal with the staff members’ (female, private clinic). This quote also shows how being treated differently can be associated with increased vertical empowerment.

Other patients did not feel that there had been a major change in staff–patient relations or possibilities to impact on their treatment. This mostly applied to patients who had decided to keep receiving treatment at their old clinic. ‘I’m always well-treated here and I suppose I’m one of the few who can maybe do as they please around here, because I’ve shown that I can hack it’ (female, public clinic).

Many interviewees emphasised that they wanted cooperation between themselves and the clinic, and that this required honesty and trust in a therapeutic alliance (Lilly et al., 2000). ‘It’s in our interests as patients to be honest; if we’re not able to do that, we’re forced into a role where we again start to manipulate. To cheat. And lie. And this is such an easy role to take, it’s right there’ (male, private clinic).

In a recurring story, interviewees said that the staff would respond to them differently depending on the outcome of the treatment. For example, one interviewee said that the contact person at his previous clinic had behaved differently towards him when his urine test was positive rather than negative. He felt that the staff were more supportive at the new clinic and encouraged him to be honest and tell them in advance if the urine test would come back positive.

Possibilities of choice limited by lacking differentiation

Patient choice was partly motivated by offering patients better possibilities to influence their treatment than previously; the clinics were envisioned to specialise in different treatment modes. As a whole, the interviewees had not reflected very much on the clinics’ differing treatment approaches, but rather commented on freedom of choice as such. This is exemplified by the next statement: ‘This is the only clinic I’ve attended, so I can’t say very much about any differences. I appreciate the idea [of different orientations], and think it’s a good idea. […] That there can be differences. And that patients have freedom of choice themselves, it’s only positive when you’re about to choose your clinic’ (male, private clinic). The only clear difference that most had noticed was the clinics’ approach to prescribing benzodiazepines, which will be discussed in more detail in the next section. Few interviewees had ideas or suggestions about the clinics’ desired orientations.

One difference that came up in some interviews was the varying approach to patients’ spending time and pursuing social activities at the clinic following their appointment. One of the clinics where patients were interviewed encouraged them to spend time there. Many of the patients who had chosen to be treated at this clinic were older and had a long history of drug problems; few were employed. Several interviewees were happy about the possibility to spend time at the clinic with staff and other patients. ‘It doesn’t work as well at the other clinics: I know some who are patients at other clinics, but they only go there to get their medication and then go home and are happy with this. It’s different here, we [patients and staff] spend time together talking, and they help you in so many different ways’ (male, private clinic).
The premises in many clinics were such that the patients did not have much opportunity to spend time there. At one clinic, the waiting room was open but the doors to the other rooms were locked. The patients were seen one at a time, and they left the clinic immediately after the appointment. Many patients at this clinic wanted ‘to take care of themselves’ and did not ask to spend time together to the same extent as at the above clinic. Some expressly said that they did not want to see other patients any more than was necessary: ‘I think that you should spend as little time as possible with people that have the same problems as you, it’s been crucial for me’ (male, private clinic). This attitude (that can also be interpreted as exemplifying the difficulty of building horizontal empowerment) was most common among patients who had a long treatment history and were treated in public clinics.

**Benzodiazepines as a motive to choose a clinic**

As we have already mentioned, politicians and medical professionals were concerned before the introduction of patient choice that private, profit-seeking clinics might try and ‘lure’ patients by letting them have too much say over the prescription of medication. Most of all, there was concern over the prescribing of benzodiazepines and other sedatives, which may present an increased risk of intoxication during substitution treatment.

Regardless if the interviewed patients were prescribed them or not, benzodiazepines became a central topic in the interviews, mentioned spontaneously by many before we had asked their opinion. Several interviewees were ambivalent about these drugs, both in terms of their own use and about the fact that some clinics do prescribe them. Most of the interviewees had taken benzodiazepines while trying to deal with sleeping problems, anxiety, or nervousness, and many had also had dependence problems with these pharmaceuticals. Some said that they should not be prescribed at all within substitution treatment, but most commonly the interviewees felt that benzodiazepines should be prescribed to those patients who really needed them. ‘Of course, if I have anxiety problems and need benzodiazepines, I wouldn’t decide on the basis of location only [on choosing a clinic] but would also look into places where they’re ok. [...] I can agree that they’re a good thing sometimes, some people may need them, but, well, I’m very restrictive’ (male, public clinic).

A majority of the interviewees said that they did not want to be prescribed benzodiazepines. Many had made a conscious choice not to ask for benzodiazepines, and had stayed at or made their way to a clinic which did not approve of such use. This emerged especially clearly among patients being treated at public clinics. ‘I need clear rules to keep myself drug-free. […] They’re super tough at this place and they’re strict about everything. I thought that this is the way it must be for me, otherwise I won’t manage, I can’t be cut any slack… The others talk about clinics, ‘in that place it’s easy to get hold of stuff’, but then you’re hooked, I mean, to get hold of stuff, that’s not why I’m having treatment’ (male, public clinic).

Two of the 17 clinics were known for their liberal views on benzodiazepines (we visited both). One of them provided a long-term withdrawal scheme and the other offered in practice maintenance treatment with benzodiazepines, too (typically diazepam). Several interviewees at the latter clinic indicated that the possibility to be prescribed such drugs had been one of the reasons behind the choice to start treatment there. ‘I’ve had a lot of help here, I’ve switched from another clinic to this programme. It’s the only programme with (long-term) withdrawal, it’s meant for people like us who also have underlying misuse. It (benzodiazepines) is worse [quitting] than heroin’ (male, private clinic).

**Discussion**

**Increased empowerment and possibilities to exit and voice**

Patient choice is in theory about a change where some of the power over treatment shifts onto the patients—or customers. They get to choose in a market with many competing treatment providers and are thereby given the opportunity not to choose providers that they see as lacking in one way or another (Erlandsson et al., 2013; Fotaki, 2011; Nordgren, 2008). Our interviews show that this is how patient choice has, by and large, worked for patients in substitution treatment. What emerges from their accounts is that the possibility to choose one’s clinic is a decisive change. It has transferred the power relations of substitution treatment in favour of the patients—something that we previously referred to as vertical empowerment (Andersen & Bilfeldt, 2016). The patients felt that this form of empowerment could be seen in the improved staff conduct and staff–patient relations. By contrast, increased patient influence through collective organisation—horizontal empowerment—is still hard to attain.

Many interviewees stressed the psychological value of knowing that one is able to change clinics if needed, even if they were currently happy with their present clinic. The patients felt they had been ‘upgraded’ and were now on more equal terms with the treatment staff. In terms of the three dimensions of empowerment by Lee and Hudson (2017), it is safe to conclude that patient choice contributed to two of these: it strengthened the patients’ self-esteem by giving them the possibility to have influence (the first dimension) and it also gave them access to resources and strategies to make use of that influence through the possibility to transfer from one clinic to another (the third dimension).

Many interviewees had changed clinics, often as a result of unhappiness about the medical or personal treatment they had received. To return to Hirschman’s (1970) terminology of exit, voice, and loyalty, we argue that patient choice has greatly improved the patients’ possibility to leave a service they find unsatisfactory. Changing one’s treatment provider is today relatively simple, at least for the majority of patients living in a city with more than one clinic, which at the end of 2017 applied to almost 90% of the patients (Andersson & Johnson, 2018).
Protesting, too, appears to have become a less costly option for patients unhappy with their treatment provider. Previous research on substitution treatment in Sweden has suggested that it may be risky to protest and give voice to the complaint, at least if it is done in a dogged and pressing manner. Patients who are seen as troublesome may face retaliation, in the worst case involuntary discharge (Lalander, 2016; Petersson, 2013). Accounts of repression and disciplinary measures also appeared in our material, but almost exclusively in relation to how the interviewees had experienced the situation before patient choice. It should be noted that the changes in the national directives regarding substitution treatment in 2016 also supported a less restrictive approach. However, when the patients now have become customers, a mutual dependence has emerged between them and the clinics. The competition seems to have forced the clinics to improve, both in terms of the staff–patient relationship and the service they provide to the patients. This was also apparent in interviews performed with other stakeholders, such as clinic managers and collaboration partners, carried out as part of an evaluation of the implementation of patient choice in substitution treatment in Skåne (Andersson & Johnson, 2018).

It should be noted that, when the patient choice system has been implemented for a longer time and the adjustments in the national directives are consolidated, patients’ decisions regarding changing treatment provider may look different.

**Limitations of freedom of choice**

Patient choice is commonly objected to because patients, especially those in specialist medical care, do not have enough knowledge and information to be able to assess the differential quality provided by the treatment providers (Blomqvist, 2004). In order for the patient choice to drive issues of quality, it is crucial that the unsatisfactory healthcare providers are opted out when patients choose their treatment provider, and that patients mainly apply criteria that have to do with quality (Erlandsson et al., 2013; Fotaki, 2011). Substitution treatment is normally a long-term treatment relationship where the patients have many frequent contacts with the clinic. This gives the patients relatively good chances to evaluate at least certain aspects of the quality of care, not only in terms of the staff–patient relationship but also as regards how suited the medical and other treatment measures are for them.

When they talked about the clinics they had experience of, the interviewees, on the whole, gave the impression that they had reflected on their treatment. Some patients kept themselves informed about the developments at nearby clinics, even if they did not intend to switch to a new clinic just then. As a rule, however, the patients knew relatively little about the clinics which they had no experiences of.

Such issues are linked to the second dimension of empowerment as discussed by Lee and Hudson (2017), that is, an individual’s knowledge and ability to reflect upon different avenues of action. Drawing on the interviews, we found that patient choice had to a certain degree strengthened the patients in this respect, but not as much as was the case with the two other dimensions.

Another conceivable limitation for freedom of choice is insufficient differentiation. This is what happens when the possibilities of choice are not that different in reality (Bavetta, 2004; Fotaki, 2013; White, 2008). Poor differentiation risks making freedom of choice into an illusion, as we argued before. The possibility of being prescribed benzodiazepines at certain clinics was often mentioned by the patients, which we discuss further below. Apart from that, the interviewees had not detected any major differences in what their nearby clinics offered.

Aside from differences of size, the clinics appeared relatively similar. A difference that nevertheless appeared to matter to several interviewees was whether patients were allowed to spend time at the clinic—to socialise—after they had collected their medication and had their tests done. The clinics that we visited had differing policies, and the patients that raised the issue appreciated this regardless of the type of clinic they attended.

A limitation to the prospect of expanding patient choice as a model for substitution treatment in Sweden, is the country’s demographic structure. Outside of the three densely populated areas, one of which is Region Skåne, the market would be too small for treatment providers to be able to profit from a reform such as patient choice (Storbjörk & Samuelsson, 2018).

**Benzodiazepines: the risks of counterproductive choices**

There is a wide consensus among Swedish doctors qualified to treat opioid dependence that benzodiazepines should only be prescribed to patients in substitution treatment in exceptional cases (Andersson & Johnson, 2018; Nilsson, 2017). As we have already pointed out, the increased prescribing of this medication was seen as perhaps the biggest risk of the patient choice reform: both doctors and other representatives of dependence treatment feared that some clinics could attract patients by prescribing benzodiazepines. This might lead to alarm and rumours spreading, and was also viewed as competition on unfair grounds.

As shown in Table 1, about one-third of the interviewed patients had benzodiazepines prescribed by their clinic. The patients with prescriptions of benzodiazepines all had chosen to change treatment provider or, in one case, had selected a new clinic since the onset of the patient choice reform. They make up the main part of the interviewees who chose to change clinics. The interviews showed that the interviewed patients had broadly similar views on the prescribing of benzodiazepines, irrespective of the clinic and whether they were on such medication themselves. With some exceptions, the interviewees felt that benzodiazepines might sometimes be needed, and that it ought to be possible to obtain them in such cases. Nevertheless, most interviewees emphasised that they did not want to be prescribed these drugs themselves, many because they had a history of dependence on benzodiazepines. Some of these patients found it
problematic that it was possible to choose a clinic with a liberal approach to benzodiazepines.

This is an intriguing aspect of freedom of choice: should it be possible to choose something that may not be good for you? Many patients in substitution treatment are used to trying to solve their problems with medical or illicit drugs; they have what is known as ‘the medical mind’ (Lalander, 2003). Ultimately, it is the doctor’s decision what medication to prescribe, but treatment measures should be taken in joint consultation with the patient, and patients in substitution treatment often show a great interest in their medication (Lalander, 2016). Should the patients’ right to freedom of choice be valued more highly than how the treatment should be fashioned according to research and experience-based practice?

Also, it should be mentioned here that there is no scientific consensus on benzodiazepines in substitution treatment. While we do know that the use of benzodiazepines is often associated with complex problems and an increased risk of negative treatment outcomes (Brands et al., 2008; Laqueille et al., 2009), the kind of help that ought to be offered to patients dependent on benzodiazepines is not self-evident. In Sweden, it is typical to offer patients abstinence treatment or a short withdrawal cycle at the beginning of the treatment or if there is recurring substantial use of benzodiazepines. Internationally, though, there are examples of patients being offered more long-term withdrawal treatment or continual maintenance treatment with benzodiazepines (Weizman, Gelkopf, Melamed, Adelson, & Bleich, 2003; Bakker & Streel, 2017). The research on the impact and risks of such practice is so far insufficient (Abrahamsson, Berge, Öjehagen, & Håkansson, 2017).

The significance of control and increased tolerance

In social science research, control measures have often been seen as disciplinary and potentially oppressing actions in substitution treatment, as we mentioned in the introduction. However, our interviewees did not cite these measures when they were asked why they would choose a particular clinic or change from one institution to another. This may be because the controlling elements are clearly regulated in both the NBHW’s directives on substitution treatment and in the regional accreditation requirements. The clinics thus apply control measures in a similar manner, and the patients felt that rules and controls were unavoidable and necessary elements of substitution treatment. Some patients also said that the clinics’ control measures partially compensated for the lack of control they experienced as a result of their dependence problems. Several patients, however, found the supervised urine tests—widely used to test for drugs—offensive, which accords with previous research (Friedman & Alicea, 2001; Lalander, 2016; Monwell, Bülow, & Johnson, 2018; Petersson, 2013). Since we conducted the patient interviews the situation has somewhat changed, as a handful of clinics now offer saliva testing as an alternative.

We mentioned in the Background section that Swedish substitution treatment has become less restrictive in recent years. The admission criteria of the national directives have been gradually liberalised, and patients with various dependence problems—such as the use of illicit or prohibited drugs—are no longer subject to involuntary discharge to the same extent as previously (Johnson, 2013; Socialstyrelsen, 2015). The increasingly tolerant approach to patients who exhibit dependence symptoms became national policy in 2016, when the discharge rules were removed from the NBHW’s directives (HSLF-FS 2016:1).

In the Skåne area, there has been a clear trend towards increased tolerance well before the introduction of patient choice, which our interviewees were well aware of. The clinics’ approach to benzodiazepines can be seen as a part of this trend, but apart from this, none of the interviewees cited increased tolerance as a reason to choose or transfer to a particular clinic. It cannot, therefore, be specifically linked with patient choice.

Conclusion

Patient choice within substitution treatment has led to increased empowerment for the patients: it is now possible for them to choose and change their treatment provider. They can leave the clinic that they are unhappy with and be treated at another clinic, whereas they used to be stuck with the clinic they attended. Previously, the ‘exit’ option led (with few exceptions) to relapse (Svensson & Andersson, 2012).

The patients were emphatic about the psychological benefit of knowing that one could change clinics. As the clinic is often a central part of their lives for patients in substitution treatment, it is crucial that the staff–patient relations and the treatment relationship work well. Here, patient choice has led to an improvement through increased empowerment, which has resulted in a more equal balance of power between patients and treatment providers. What emerges from the interviews is the impression that the patients felt ‘upgraded’ in relation to the staff. The control measures used by the clinics were generally accepted by the patients, and were applied in a similar way in the various clinics.

One of the goals behind the introduction of patient choice was that there might arise differentiation between clinics of different specialisations. This has not happened to any major degree, and freedom of choice can thus be viewed as limited. However, the patients did not feel that this was particularly important. It is not the clinics’ specialisation that matters most to the patients, it is the freedom of choice in itself—the very possibility to choose and change clinics.

Lastly, we should mention the limitation regarding patient choice in substitution treatment to expand in Sweden due to the country’s demographic structure and, hence, the obstacles tied to a possible market for such choice reforms. Patient choice in substitution treatment demands a sufficient number of patients to operate; otherwise the market is too small for competition to exist. In Sweden, there are only three urban areas with enough population to make ground for such reforms (Stockholm, Gothenburg and Skåne).
Notes

1. Patient choice means that substitution treatment in Skåne is pursued in accordance with national legislation, that is, according to the Act on System of Choice in the Public Sector (2008:962). Under the Act, the pursuit of treatment is predicated upon competition between treatment providers, public and private alike, so that service contracts are continually made with all treatment providers that meet the accreditation requirements (Konkurrensvetket, 2014). Swedish substitution treatment is regulated by directives issued by The National Board of Health and Welfare. These directives determine, for example, who may be offered treatment. According to the current directives (HSLF-FS 2016:1), substitution treatment patients shall be at least 20 years old and have at least a one-year history of opioid dependence. The current directives came into force in February 2016, replacing the directives (SOSFS 2009:27) which were in force when patient choice was launched in April 2014. In addition to what is laid down in the national directives, the accreditation criteria decree on such matters as staffing and staff competences required at a substitution treatment clinic and what kind of services the clinics shall offer. A patient fulfilling the admission criteria must not be denied treatment.

The Act on System of Choice relies on a remuneration system based on treatment appointments and performance. The appointments are registered (differently with different kinds of appointments), which generates a predetermined sum in compensation. The clinics are not guaranteed any patients; the compensation is always based on the patients’ decision to choose a given clinic. Also, the treatment takes place without competition on price, as the Act on Choice of System works on the premiss that competition is based on quality and availability, and that the patients ought to be able to choose the treatment provider that will best meet their needs and requirements. The remuneration system of the patient choice for substitution treatment was designed to put a premium on work with challenging patients, to promote high patient retention, and to prevent patients from being discharged from treatment (KEFU 2015). Patients are allowed to change clinics every six months at the most. Patient transfer shall be preceded by joint planning between the old and the new clinic. It is the responsibility of the new clinic to make contact with the old clinic and to obtain the patient records (Region Skåne 2016). The treatment is financed through county taxation and is in principle free of charge to the patients. The treatment providers are allowed to charge patient fees, but there is an upper limit of SEK 1100 annually payable by the patients themselves. When this amount is reached, the patients are entitled to receive outpatient care free of charge in the entire region.

2. Benzodiazepines are generally the most sought after prescription drug among patients in substitution treatment. By other pharmaceuticals, we primarily mean the so-called z-drugs (e.g., zopiclone and zolpidem). The majority of deadly overdoses in Sweden are polydrug intoxications where opioids have been taken together with other drugs, most of all benzodiazepines. Such deaths also occur among patients in substitution treatment, but are so far rare in Sweden (Fugelstad, Johansson & Thiblin, 2010; Leifman, 2016; Ledberg, 2017).

3. The average waiting time from application to the beginning of treatment has been almost halved from 46 days at the end of 2013 to 25 days at the end of 2017 (Andersson & Johnson 2018). According to evaluations, the increased number of patients (an increase of more than 50 percent in four years) has been a result of private treatment providers’ freedom of establishment, combined with a backlog of demand among people with opioid dependence (KEFU 2015; Andersson & Johnson 2018).

4. Previous treatment experiences were not an inclusion criterion, but our aim was that the majority of the interviewees would have a history of substitution treatment both before and after the introduction of patient choice. Eight of the interviewees had received treatment for under two years in total, five interviewees for two to five years, 14 persons had been in treatment for a total of five to ten years, and six persons for more than ten years in all. There were no big differences between the clinics regarding treatment experiences. The patients interviewed at the private clinics with a restrictive view on prescribing benzodiazepines, had a somewhat shorter total period of treatment experience. The mean age of the interviewees based on clinics, following how the clinics are presented in Table 1 from top to bottom, were 39, 42, 47, 36, 35 and 46 years.

5. This clinic changed ownership in 2017, and the current aim is to wean patients off prescribed benzodiazepines.

6. No, it should not, said Region Skåne. The two private clinics that prescribed the most benzodiazepines were monitored and inspected on several occasions during 2015–2017, both by the county and the Health and Social Care Inspectorate, the authority in charge of supervising the Swedish health care services. Both clinics were required to take measures and have since scaled down their prescriptions.

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Author contributions

BJ planned the original project. LA and BJ designed the study and developed the interview questionnaire. LA did all of the interviews, conducted most of the analysis and wrote the first draft. Revisions were made jointly by LA and BJ. Both authors read and approved the final manuscript.

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