Patient perspectives on compulsion and treatment of eating disorders

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Abstract

Introduction: Formal compulsion and other forms of suasion are widely used in the treatment of eating disorders. As they represent a restriction of liberty, it is important that we use such tools carefully and considerately. In order to do this it is important to examine the experience from the patient perspective. This project looked at the experience of involuntary treatment of anorexia nervosa.
Methods: Nine patients were interviewed using a semi-structured topic guide with 3 main areas of focus; the experience of legal compulsion, that of informal compulsion, and that of de facto detention. The patients were all current inpatients or recent inpatients who had graduated to the day program. The interviews were voice recorded and transcribed and will in the future be analysed using qualitative methods.
Results: Patients were very receptive to the project and gave open reports of their experiences. Preliminary results indicate that there is a variety of experience, with all patients having experienced compulsion or coercion at some point. Gentle persuasion from tangibly caring staff members was generally interpreted as both more supportive and more effective, whilst more domineering approaches were felt to be coercive and unhelpful in most, but not all participants. Furthermore, being involved in treatment decisions was less coercive than being simply told what to do.
Conclusions: This highlights the fact that therapeutic relationships and attitudes are important and should be tailored to individuals. Endeavouring to involve people in their own care as far as possible also results in a more positive perception of treatment. Future analysis will examine the transcripts more closely to pick up further themes and solidify these early results.

Introduction

Anorexia nervosa is a devastating and often debilitating illness. By its nature it frequently causes treatment resistance, which may lead to the compulsory treatment of the most severely ill patients.[1-5] In addition to legal compulsion, other means of suasion may be used to encourage or enforce treatment.[6,7] These include coercion and de facto detention.

Whilst the ethics of compulsion have been discussed at great length previously, there is less work on patients' experience of involuntary treatment, particularly by informal means.[3,5-8] If we are to know how to treat patients compassionately and without causing undue distress, it is vital that we understand their experiences. Coercion in itself is a subjective term and what to a clinician is explanation and reasoning may to a patient be coercive and threatening.[6,8] Previous work has found that the experience of coercion in patients with anorexia nervosa is mediated not so much by the level of restriction imposed but by their relationships with carers.[6]

This project aimed to gain a deeper understanding of what different forms of involuntary treatment are like for a person with anorexia nervosa, and how treating clinicians might use this understanding to minimize their patients' distress.

Objectives and Methodology

The objectives of this project were to understand what was experienced as coercion in the treatment of eating disorders and what was experienced as support. The secondary objective was to understand which of these experiences were perceived as helpful and harmful.

A topic guide was constructed, focusing on 3 main areas:

- The experience of legal compulsion
- The experience of de facto compulsion
- The experience of informal compulsion

Each of these areas were explored in terms of the feelings evoked at the time and retrospectively, where applicable. Patients were asked which experiences they felt were helpful and which were not and encouraged to elaborate on their reasons. Neutral language was used, with each interview beginning with open questions to minimise bias. Interviews took place on the ward in a private setting and were voice recorded before being transcribed and anonymised.

There were a total of 9 participants, aged 18 to 32. They all had a primary diagnosis of Anorexia Nervosa, with varying duration. All were either current inpatients or recent graduates to the day program. The interviews referred to all experiences in the course of the illness, including in the community, previous hospital stays, and current admission. The accounts are not divided by setting.

Information leaflets and consent forms for both the project itself and the voice recording element were provided a minimum of 24 hours before the interview, with opportunity to ask questions of both the researcher and an independent professional. The next steps will be to qualitatively analyse the transcripts for emerging themes using grounded theory.

Preliminary Results

While the transcripts have not yet been formally analysed, some patterns and themes were subjectively apparent during both the initial interviews and the subsequent transcribing.

Legal Compulsion

Of the 9 patients, 4 discussed being formally detained. Detention was seen as both a positive and a negative experience. People felt protected by the Mental Health Act and understood the reasons for it. They were able to challenge and discuss things through advocacy, but also often felt they had no choice and were being forced which was unpleasant and isolating.

- *"I didn't feel like I could trust them and I felt just helpless and like I was really alone and that I, I was powerless if I don't want this it didn't matter because I was getting it one way or another."*
- *"I feel like they're forcing me but, I think they have to because if they didn't force me I wouldn't do it."*
- *"Knowing that I'm under the community treatment order, that in order to enjoy the freedom that I've worked hard for in recovery I need to keep myself well otherwise I could be called back in to hospital. Like knowing, having that in the back of my mind does help."*
- *"So we spoke a lot to advocacy because we felt like it wasn't fair that they were doing that to us. And then eventually they got a lock put on the front door so eh, so they didn't need the corridor locked anymore because it was safe enough to be going about the unit."*
- *"At the moment I would say probably being detained is a little bit better because I do have access to, like I know my rights sort of thing whereas before things you know were a bit blurred."*

De Facto Detention

4 patients described clear de facto detention. These patients did not feel they had truly had a choice about being in hospital, despite being voluntary patients.

- *"So, I was forced. It was a "either you can go or you can be detained and you can go". So it was like, I was going anyway, whether I liked it or not. So that time was definitely not voluntary."*
- *"I kind of felt like I was stuck between a rock and a hard place. Like I felt like even if I wanted to go I couldn't because they were gonna get me here anyway."*
- *"When I got detained they were like "you either agree to stay here or we'll detain you" so I was like well I don't really have an option, I have to stay here anyway, so, yeah. So I feel like, if anything (sigh) even if I was an informal patient, I feel like at any moment they could be like "oh you're detained"."*

Informal Compulsion

Participants tended to have the most to say about this area and as such the main bulk of interview time tended to focus on informal suasion. A few key themes which became apparent early on are discussed below.

Involvement

Patients generally felt more forced in the early days of their treatment. They described this as being due to their own inability to believe they were ill, but also due to failure of clinicians to explain and involve them in treatment plans and make them feel listened to, cared for or understood. Later in the course of treatment, patients frequently began to feel more heard and involved in their own treatment, which reduced the feelings of coercion, improved their ability to comply, and increased their perception of supportive rather than coercive relationships.

- *"And I feel like it's easier to accept decisions and go along with treatment when you feel like you've been involved in the process. And I know that doesn't always mean it going your way."*
- *"I feel like if people are putting a little bit of trust in me, listening to me, looking at my personal circumstance, my personality, my – the history of my illness, then if they're taking all that into account then I'm more likely to trust them and to like to accept what they're saying and their advice and their suggestions."*
- *"The staff take the time to sit down and explain why it's beneficial to you and that, for someone with anorexia makes eating far more easier to reason."*
- *"If people don't listen to you, they don't really know what's going on. And then they make up their own assumptions."*

Approaches & Attitudes

Most participants reported finding it easier to comply with treatment when a gentle, encouraging approach was used. They perceived this as supportive, as opposed to coercive. However, this was not universal. A few needed more firm instruction.

- *"I feel like I'm forced to eat and forced to not exercise and not purge, but it's exactly what I need. So while it's so difficult and I wish it wasn't happening it's absolutely the right thing for me. "*
- *"I feel like they should help me, and if I'm still not getting then yes, having consequences and being blunt."*
- *"Sometimes it did feel like they were, like being nasty towards me or threatening or intimidating me and that didn't help. But then like I say some other times you would get staff who were calmer, who I felt knew me, and took a slightly different approach, more encouraging."*
- *"They do it in a much better way, they're like "come on", they're more encouraging instead of domineering is the best way to put it."*
- *"Like there are some staff that are really good and they'll speak to you and they'll be all like "aw come on like, you can do it" and they'll like give you all the motivation whereas some staff are like "you have to finish that, you have to eat that, you haven't done this" and you just kinda feeling like they're pushing you into it"*

Conclusions

Compulsory treatment, as expected, was an invariably difficult experience for patients. However, it appeared to be well used with reasons which were clear to both the interviewer and the patients. De facto detention was contentious, as there exists a fine line between a clinician being transparent about the possible course of events should a patient refuse treatment and threatening them with detention should they not comply. This line may differ between patient and clinician.
It is clear that although many patients perceive firmer approaches as being coercive and unsupportive, a select few admit that this is necessary for their recovery. This highlights the need for a tailored approach not only in treatment but also in the way that it is encouraged or enforced, as different patients will respond to different techniques.
Finally, it can be very helpful to involve patients in the planning of their own treatment. This will facilitate mutual decision making, which is perceived as more supportive than being simply told what to do. As with the rest of medical practice, perhaps it is time to move away from the paternalistic approach. Future analysis will look to further evaluate these and other conclusions in order to take steps towards improving the experience of eating disorder treatment.

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