Edinburgh Research Explorer

Am I there yet?

Am I there yet? The views of people with learning disability on forensic community rehabilitation

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Abstract:

Purpose

– Previously, diversion from the criminal justice system for people with learning disability (LD) and serious forensic needs in Scotland meant hospitalisation. More recently new legislation has meant that community-based rehabilitation is possible for this group. The purpose of this paper is to qualitatively explore the views of people with LD subject to these legal orders. This is both a chance to work in partnership to improve services and also to make the voices of this potentially vulnerable group heard.

Design/methodology/approach

– Semi-structured interviews were conducted with ten participants subject to a community-based order. All participants were male. Ages, index behaviour, and time spent on order varied. The data was transcribed and analysed using interpretative phenomenological analysis.

Findings

– The main themes which emerged from the data were a taste of freedom, not being in control, getting control back, loneliness, and feeling like a service user. Participants described positives about community-based rehabilitation but also a number of negatives.

Practical implications

– Participant accounts suggest that the current community rehabilitation model has some shortcomings which need to be addressed. Suggestions are made for improvements to the current model relating to: achieving clarity over the role of support staff and pathways out of the system; increasing opportunities for service users to voice concerns; empowering staff teams via

extensive training and supervision; and directly addressing internalised stigma to promote community integration.

Originality/value

– This is the first piece of work evaluating compulsory community forensic care for people with LD from the perspective of service users. It highlights difficulties with the system which could lead to helpful ways to evolve this model.

Article

Introduction

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Although exact numbers are difficult to determine, people with learning disabilities (LD) make up a small but distinct proportion of the offending population. Estimates vary but authors report LD in up to a quarter of criminal justice samples (Barron *et al.*, 2002). This is a significant proportion, considering people with LD make up only around 2 per cent of the UK population (National Health Service, 2015).

There is UK consensus that mentally disordered offenders (MDOs, a term referring to offenders with serious mental health problems and/or LD) should be diverted from criminal justice systems into rehabilitation via health and social care (Department of Health, 2009). For such people, prison is

highly unsuitable due to difficulties navigating and accessing parts of the system, as well as their vulnerability when compared with other prisoners (Department of Health/Home Office, 1992; Scottish Executive, 2004). Previously the sole alternative for those with LD considered to present an ongoing risk to the public was long-term hospitalisation within secure or LD units. This has changed in the face of mass deinstitutionalization within generic LD services (Emerson and Hatton, 1994). Over the last two decades moves to community care have resulted in a significant reduction in inpatient beds in Scotland, meaning that hospitalisation for most people with LD and forensic needs is no longer a viable option.

A report by the Scottish Executive (2004) (*Home at Last*?) recommended that agencies should work with care providers to ensure appropriate community services were available for those leaving hospital, in particular those with more complex needs, including the forensic population. Mental health reform has also shaped this process. The Mental Health (Care and Treatment) (Scotland) Act (MHA) (2003) recommended that those detained under the Act, such as MDOs, should be subject to the least restrictive alternative, using community provisions where possible.

Designing community services

In designing a model of community-based care for serious offenders with LD in Scotland, a major challenge was to construct services which allowed for the autonomy and inclusion outlined in government policy (Scottish Executive, 2004; MHA, 2003) whilst still maintaining public safety. In 1999 the NHS Management Executive (Scotland) outlined its policy on MDOs (NHS Management Executive, 1999). The paper was clear that, although public safety was important, the ethos of community care should be focused on meeting the needs of individuals and giving them the best chance of being rehabilitated within society. The forensic managed care network set up a working group in 2005, who were asked to establish guidance on how services for forensic LD clients across Scotland should be set up. The recommendations are shown in Box 1.

The legal framework for compulsory community care was provided by the MHA (2003), which introduced compulsory treatment orders (CTOs), and amended existing legislation to allow similar orders (compulsion orders or COs) to be used where formal criminal charges had been brought. Both types of order allow an individual to be returned to the community under a number of conditions which may include: where they live; the professionals they must allow to visit them in their home; and the treatment they must receive. In practice "treatment" is broadened beyond medical intervention to include psychological interventions and acceptance of, often high, levels of staff support.

Benefits of community-based rehabilitation

Community rehabilitation theoretically fits well with modern "strengths-based" approaches within the field of forensic care (Purvis *et al.*, 2011). One example of this is The Good Lives Model (GLM), which advocates reducing recidivism indirectly by increasing an individual's access to more prosocial pathways to meet their needs (Ward and Brown, 2004). Community living, with its increased social and vocational opportunities would be expected to allow individuals much more opportunity for skills development and increased access to peers and activities. According to the

GLM this should lead to an increase in prosocial opportunities and a resulting reduction in antisocial behaviour.

Although the GLM was not designed with people with LD in mind, it fits well this client group, who often have skills deficits and lack of access to normal opportunities, leading to blocking of prosocial pathways (Aust, 2010). Impoverished social networks in particular have been found to be a key predictor of offending behaviour in individuals with LD (Wheeler *et al.*, 2013). Lindsay (2009) argues that engagement with societal values, and alternative positive interactions with the public, are key in challenging some cognitive distortions which promote antisocial behaviour in people with LD. At face value it appears that community living could be extremely helpful in tackling such systemic risk factors.

Difficulties in accessing community benefits

Policy initiatives tend to give little practical guidance on how best to apply principles of maximising choice and empowerment for people with LD and forensic backgrounds (Beacock, 2005). Although community orders, such as CTOs, were created according to the "least restrictive alternative" principle (MHA, 2003), the conditions to which the individual must adhere have led some to question whether this amounts to an infringement of human rights (Snow and Austin, 2009). This model of rehabilitation has been described as both "therapeutic stalking" and "professional paternalism" (Lawton-Smith *et al.*, 2008, p. 97; Graham, 2006, p. 41).

There are likely to be a number of barriers for people with LD and forensic needs attempting to access all the benefits community integration can offer. Cummins and Lau (2003) discuss the subtleties of "community integration" as opposed to mere "community exposure" (p. 145), alluding to the fact that the task may not be as simple as placing these individuals within a community setting. Individuals with LD who require some form of secure care are also likely to have complex backgrounds, and significant mental health needs (Myers, 2004; Hobson and Rose, 2008). This means that, even when presented with rehabilitative opportunities, for example, chances to build social capital, such individuals are likely to struggle (Steptoe *et al.*, 2006).

Support and supervision provided within community-based services for people with LD and forensic needs is delivered on a day-to-day basis by teams of specialist social care staff. There is an abundance of research within the field of forensic nursing which suggests that balancing the dual role of supporting and supervising an individual presents a significant challenge (Schafer and Peternelj-Taylor, 2003; Hinsby and Baker, 2004). Staff within these settings can resort to more rigid and controlling measures due to the consequences they perceive if risk is not adequately managed (Gildberg *et al.*, 2010; Hinsby and Baker, 2004). These findings have obvious consequences for the ability to maintain therapeutic relationships and the rehabilitative benefit of this support model. For example, McNally *et al.* (2007) interviewed a group of LD service users subject to detention under the Mental Health Act in England. They found participants had a negative experience overall, with feelings of powerlessness and vulnerability recurring in participants.

Gaining service user perspectives

The forensic community care model has been in operation since implementation of the MHA in 2005, however, there is, as yet, a lack of understanding of the experiences of individuals subject to

such orders. The current study seeks to explore service user views of their experiences of compulsory community rehabilitation. This is necessary in order to understand and develop services, promoting the culture of service-user partnership as envisioned by the Scottish government (Scottish Executive, 2000b; Scottish Executive, 2001). Those who become subject to compulsory powers are a potentially vulnerable group; and people with compromised communication skills, due to their LD, even more so. This is a much-needed opportunity to hear the voices of this group.

Method

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Participants

Ten male participants were recruited from two health boards in Scotland (NHS Tayside and NHS Fife). The single sex is a reflection of the lack of female presence within these services rather than purposive sampling. Inclusion criteria stipulated that participants were adults within LD services; had a forensic history; and were subject to a legal order obligating them to accept high levels of supervision due to the risk they presented to the public (for full participant characteristics see Table I). All participants were deemed able to give informed consent, as judged by their Responsible Medical Officer; and had sufficient receptive and expressive language ability to participate in a semi-structured interview, even if additional support (visual prompts or further language simplification) would be required. Criteria were intended to be as inclusive as possible. Recruiters were asked to exclude only individuals who would be unable to concentrate for more than a short period of time, or who were currently experiencing mental ill health which would greatly interfere with their participation, or may exacerbate their condition. Only one potential participant who was approached to take part declined. He did not state a reason for declining and was not asked to explain.

Home environments of participants varied slightly, but they all had their own tenancy and received support and supervision from social care staff as a requirement of their legal order.

Procedure

A contact clinician in each health board drew up a list of clients who fulfilled criteria, and, for those who agreed, a meeting was arranged with the interviewer to take them through the participant information sheet. This included details of the research rationale; what would happen during their participation; how their data would be used; and how they would receive feedback (the interviewer met with each participant to give general feedback on the study following its completion). Those who consented were given an additional week to consider participation before being recontacted. Where consent was gained, a "shadowing" session was arranged, during which the interviewer joined participants in their normal routine for a half-day to a full day. During these sessions each participant received a camera and was encouraged to take photographs of anything in his environment he considered important. If needed, these pictures were used as prompts during interview to facilitate conversation. For example, one participant had taken a picture of his daily

timetable, and this was used to enquire further about what activities he engaged in throughout the week, and the level of choice he had in deciding on these activities.

Interviews took place approximately one week after the shadowing session, at each participant's home, except in the case of the pilot participant, who had been readmitted to hospital and was interviewed in a private room. According to the tenets of interpretative phenomenological analysis (IPA) (Smith *et al.*, 2009) the interview schedule was employed flexibly to allow participants to direct the conversation as much as possible. The interviewer was the lead author, a 30-year-old white woman who had previously worked for four years as a clinician with an LD forensic client group, many of whom were subject to legal orders in the community. She was therefore known to some of the participants, which may have affected their responses: an unavoidable difficulty, due to the small population being accessed. The interviewer sought to minimise such effects by dressing more casually during the study, meeting with participants outside of working hours, and explaining to them the distinction between her roles as researcher and clinician.

The interview guide consisted of a number of open-ended questions related to participants' current living arrangements; comparison with previous living arrangements; daily routines; how participants understood and viewed the staff support they received; and their hopes for the future. Structured prompts were available in order to clarify or extend answers as recommended in Smith *et al.* (2009). An example of part of the interview schedule is provided in Box 2. The interview was piloted on one participant and was not changed significantly following this. The pilot participant's data is therefore included as part of the sample.

Interview length ranged between 25 and 90 minutes, with most lasting between 40 and 60 minutes. All interviews were recorded on a digital device. This was downloaded onto a secure laptop, and transcribed by the interviewer.

Ethical issues

Several important ethical issues, such as gaining informed consent, were raised by the study. Government guidance emphasises consent as a process, rather than a single event, which may take time to establish Scottish Executive (2006). The participant information sheet and consent form were designed in accordance with principles of accessible information (CHANGE, 2010), and were reviewed by a speech-and-language therapist in an effort to communicate clearly what the study involved. The researcher also presented these documents on two occasions to a patient focus and public involvement group of LD service users, modifying them according to feedback from this group. Care was taken to make absolutely clear that there was no pressure on individuals to participate, and that the support they received would not be affected in any way if they declined. This was particularly important in the current study, where individuals were being asked to comment on the care they received. Deliberate intervals were placed between the potential participant's consenting to meet the researcher; meeting the researcher to discuss the study further; and signing the full consent form. This was to allow individuals as much time as possible to discuss with others and consider participation fully. A witness was also asked to countersign the consent form as verification that the participant understood and had consented freely.

Studies involving people with LD tend to show that participants can focus too heavily on pleasing the researcher (Goldsmith et al., 2008). In order to encourage participants to express their true views, efforts were made to build a relationship with the interviewer before the interview took place (e.g. the "shadowing" session). In order to help them feel more at ease, all participants, bar one recently hospitalised, were interviewed in their homes.

Maintaining confidentiality in such a small and closely supervised population was also a significant difficulty. Support staff work intensively with these clients. It is possible that certain details in the interview data, although anonymous to the general public, may still be identifiable to staff members who have worked with, or are familiar with, a client. These issues were difficult to overcome, but were countered wherever possible. Where anonymity could not be guaranteed, the researcher made these limitations transparent to allow individuals to make the most informed decision possible about participation. For example, the client was made aware from the outset of the study that support staff would need to be aware of the researcher's visits, be present during the shadowing episode, and be given some information on the study, as these were necessary aspects of the process.

Alongside this went difficulties of creating private space, where participants felt able to comment on the care they received, whilst adhering to risk protocols. Efforts were made to maximise privacy during interview. Support staff were asked to leave enough distance, so that participants could feel confident their comments would not be overheard. Participants were informed that, following transcription, data would be fully anonymised, with any identifiable details extracted. All non-pertinent interview details were removed or altered to safeguard participants' identities.

Efforts had also been made prior to recruitment, to communicate with care providers regarding purposes of the research, in order to be as open and transparent as possible. Letters were sent to seniors and managers of the care provider organisations within the recruitment pool, outlining the nature of the research and its aims, and the reasons why staff opinions did not form part of the study. The purpose here was to alleviate possible concerns of specific organisations regarding the discussion of practice methods, as there was a risk this could filter down to staff and impact upon their treatment of clients. It was acknowledged that the topic area of this investigation was a sensitive one. In theory, participants were being asked to comment on the experience of community rehabilitation. In practice, since much of this was based on care staff support and supervision, participants illustrated this with examples of the practices of individual staff members, some of whom were still a part of their team.

Analysis

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Interviews were transcribed verbatim. As IPA is concerned with semantics, transcription includes all words spoken, plus false starts, laughs, pauses, and so on (Smith and Osborn, 2003). A slightly modified version of the coding system recommended by King and Horrocks (2010) was therefore used for all transcripts.

Each transcript was individually read and re-read a number of times. Line by line coding was then completed according to IPA principles (Smith *et al.*, 2009). Data were transferred into a three-column table, which allowed notations to be documented in a second column, and emerging themes in a third. Initial notes were made line by line in the second column, noting aspects which were: frequently mentioned; appeared to evoke emotionality in the participant; were considered relevant due to pauses or omissions; or were interesting in terms of the individual's overall narrative. These themes were clustered into main themes and subthemes (see Table II).

Transcripts were analysed sequentially, with ideas from previous transcripts "bracketed" as much as possible, to reduce bias and make room for unique themes from each participant to become evident. Following this, the researcher looked across transcripts to identify themes which appeared for multiple participants. These were then regrouped through a process of abstraction, subsumption, and polarisation to produce main themes for the sample as whole and subordinate themes which branched from these. Findings were then interpreted within parameters of the researcher's knowledge and the empirical context.

Quality assurance checks

Smith *et al.* (2009) cite Yardley's (2000) work as a basis for quality checking qualitative research. One of the core principles cited within this is transparency.

Transparency alludes to the idea of auditability, meaning that a third party could repeat the processes carried out by the researcher, and understand their interpretation, even if they would not come to the same interpretation themselves. Qualitative transparency can be more difficult to achieve than quantitative, since its conclusions are integrally linked to the influence and interpretation of the researcher. Keeping further aids, such as memos, which effectively serve as a reflective journal, and field notes, documenting thoughts following each encounter with a participant, can add lucidity to the links between each stage of the research (Holloway, 1997; Strauss, 1987). Both memos and field notes were recorded throughout the study.

The current project was subject to individual audit by the academic supervisor, employing two transcripts. An audit trail was also established. This refers to all documentation involved in a research project: for example notes from discussions with colleagues; ethics approval documentation; annotated transcripts and report drafts. These are the documents that theoretically allow an independent individual to audit the pathway of a project, following each step to its conclusion (Smith *et al.*, 2009).

Results

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Five main themes emerged from the data: A taste of freedom; Having no control and the interconnected theme of Getting control back; Loneliness; and Feeling like a service user. Each theme is discussed below, with participant extracts which capture the theme or an aspect of it. Within quotes "P" here refers to participant and "I" to interviewer. In a number of quotes additional

details, such as exact activities, dates and so on, which are not directly relevant, have been concealed in an effort to retain the anonymity of participants (as previously discussed within the method section).

Theme 1: A taste of freedom

Trying new things

Most participants felt there was an opportunity within their community order to try new things: for example joining classes and groups, and enjoying holidays:

P: Well, it's easier from my, it's easier for me, eh? It just […] makes it a lot easier for me as well to, to go out and do things that I've never dreamt of doing.

I: Right. What kinds of stuff can you do now that you couldn't do before?

P: Well, I do a lot of painting, eh? Ar, art stuff. I was never into that before (Participant 7: line 454).

Having my own space

Not only were there opportunities for engaging with new activities, but participants described a more general sense of personal space which was afforded by this way of living, usually as compared to hospital:

You've got your […] your own space (Participant 5: line 321).

Doing my own thing

Participants also expressed a sense of autonomy and choice in their daily lives, which they viewed very positively:

I: […] so when you go to the discos are you with staff?

P: No, no I'll go there myself so I will (Participant 9: line 363).

P: […] my weekly planner day – every Sunday.

I: Mmhmm.

P: For the whole week.

I: And who kinda decides what goes on the planner?

P: Me.

I: You? So […] have you got a free choice about what you put on there?

P: I […] normally take […] if I miss […] my ironing, know, I put it to the next day (Participant 5: line 44).

Freedom within limits

Frustration was expressed by some that the freedom was not all it could have been, and that limitations remained:

P: Yeah, that's what […] that's what it was in hospital time I was there. Soon as I moved from the hospital into here, in […] the community, I says hopefully I will get the same thing.

I: Yeah.

P: Hopefully I'll get my freedom – to just to go to the shop myself, or to go down the town myself, but no, eh, eh, it didn't work 'cause staff have […] eh, staff have to come with me and make sure they keep me safe from […].

I: Right. And what does that feel like then?

P: Eh, I felt like […] I says to myself, this is rotten – I can't do what I used to do when I was in the [*hospital*] (Participant 3: line 2077).

That means you're bringing a wage onto the hoose. You're, you're getting stuff like furniture for the hoose, tables, chairs, everything like that. You'd be like bringing stuff into the hoose to help her. […] Used to have a wage in my pocket and anytime I was stuck my mother used to help me [interviewer name] you know? Never short. But noo I feel like when I've got the support workers I've gotta ha' them all the rest of my life (Pilot participant: line 424).

Some participants reminisced about their time in hospital, with close living quarters and shared social events breeding a sense of community, which appeared relatively lacking within an actual community setting.

Theme 2: Not having control

The second subordinate theme was related to a sense participants described of not having control over their situation. The majority described, or alluded to, a large degree of external control in their lives, similar to themes emergent in McNally *et al.* (2007). These were analysed under two subthemes.

A. Not knowing what the rules are

This was partly based on a lack of clarity around a number of different aspects of their care. Participants expressed uncertainty over why they were subject to staff support:

P: Not sure because you need to see staff about that because I dunnae ken why.

I: That's fine. Yeah. So you're not sure why?

P: No.

I: OK. What would happen if you went out? Without staff?

P: Because I might disappear or anything like that.

I: You might disappear?

P: Aye.

I: Right (Participant 4: line 348).

There was also uncertainty over the role of the staff team. Most participants identified the main role of staff members as giving support with household tasks:

[…] I used to clean the house on a Sunday and he let me do it all myself. Eh […] get the hoover out on a Sunday, clear my room and that, and he let me do it, all myself you know? I mean I ken I'm old

enough to do it like, but he wouldn't even brush a […] wouldn't even brush the toilet or […] he wouldn't do nothing for me, you know? (Pilot participant: line 148)

P: […] I'm cleaning the hoose. Why don't they just come in and help? No.

I: No?

P: No, no, no, no, they will not come in and help me to clean the hoose.

I: Right.

P: I find that actually wrong actually […] (Participant 2: line 1491).

Although the staff team may be clearer that their role expands beyond practical help to promoting independent living and risk management, these roles may be less obvious to the individuals themselves. This perception that staff members are sitting back while the participant is putting work in (coupled with the implication in these extracts that the participant felt unable to raise this with the staff themselves) seems to have created frustration. Participants may thus begin to view staff as distant overseers rather than actively involved partners in their rehabilitation.

The fact that information is perceived to be held and understood only by others gives a sense of powerlessness to these participants, and exacerbates the pre-existing power imbalance within these client-staff relationships. Without this understanding of why certain restrictions are in place it would also be very difficult for these individuals to question or challenge any of them, which again leaves them in a vulnerable position.

There is a consistent feeling throughout participant responses that they had not ever had the chance to consider and reflect on some aspects of their care:

I: And do you […] do you have any free time, or time when you don't have staff at the minute?

P: What do you mean?

I: Do you have any time kind of on your own – when staff aren't here?

P: [4 sec pause] No (Participant 5: line 232).

I: And do you tell staff you don't like it?

P: No 'cause I hadn't thought aboot it 'til you asked, ken, I never thought aboot 'til I said it (Participant 2: line 531).

This lack of reflection by participants raises a concern about the lack of an adequate forum for participants to think about and explore these issues. One exception was participant 7 who clearly stated the use of an advocacy group as a means of doing this.

B. Staff having too much control

Participants also spoke about the lack of control they felt due to their home becoming a staff workplace and issues managing the power balance within relationships with support staff:

P: She doesn't do her dishes some mornings and she doesn't do dishes. She gets her tea at night, she doesn't do her dishes. She does them in the morning. I have to live with that all night.

I: Right.

P: And if she treats it like that, I wouldnae be cleaning. I would just leave mine too, eh.

I: And are you able to say to her that you don't like […].

P: Na, cause I like the person.

I: Yeah.

P: And that's the hard – cannae get round that one (Participant 2: line 1564).

Because he […] he had went and got his papers and his own cigarettes if he needed them, and he says "Come out now". I said to him, "I want to have a fag myself" and he says, "No, I'll have a fag with you" (Participant 9: line 1049).

This illustrates the difficulty of maintaining professional boundaries whilst co-habiting, as well as maintaining awareness of the power imbalance inherent in these relationships.

Theme 3: Getting control back

Participants attempted to regain control in a number of ways: proactively, through advocacy groups or via their lawyers; by more passive-aggressive behaviours such as "sneaking" extras, refusing to engage, or employing a "keep your head down" approach; or finally, by giving up and ceasing to try:

Ah, it's basically […] helps, helps some of the members tae, to look at different points of how […] how they're feeling, how things are, eh? And just basically, em, just talk about things that are important to them and how they, how they feel and stuff. So, that's basically what [advocacy group] is all about (Participant 7: line 248).

[…] I'm keep on nowadays progressing with my independent living. I'm not giving any of these professional people any excuses or any cases to argue (Participant 9: line 871).

I just don't wannae go to eh […] meetings and, nothing gets done like. Go to a meeting and ho- I be building my hopes up, right? I'm gonna get this, I'm gonna get this. It doesnae happen, you get telt to go away and come back in about a month's time. Go away, come back with another staff -- I dunnae want to build my hopes up like that (Participant 2: line 1802).

Theme 4: Loneliness

A fourth prevailing theme was that of loneliness. Participants described extremely limited social networks and difficult family relationships, leaving them feeling isolated and lonely:

[…] I'm on websites like Facebook, I'm trying to find pals cause I no get very many, I just […] I lied, I did say earlier that I didnae want pals, but I'm trying to find friends (Participant 2: line 1588).

[…] my brother's always sadly let me down when every time he's been at a CPA meeting – eh, he's always had some sort of, this and the next thing, of problems he cannae make […] I think I packed in the swimming at the [*place name*] 'cause I […] my original plan was to go and see my mum after that, but that all fell through – she had her own problems, she couldnae see me (Participant 9: line 811).

Participants described difficulties in maintaining the relationships they did have, due to staff presence:

We were in […] we were at the [*restaurant*] about a fortnight ago, eh […] she sits on her own again, she asked the staff to move on because she's trying to talk to me privately, about the family and everything, and it's really ridiculous, I cannae get time to speak to her. It's really scandalous like, we cannae get time to speak (Pilot participant: line 296).

P: Aye – ha'ing staff. I got to lie. But the second time you go and meet them with someb'dy else, 'who's that?'. 'Oh aye, that's my brother'. You cannae, you cannae win that way eh?

I: Yeah.

P: I think about it, I think it's just better to just keep myself to myself (Participant 2: line 1614).

For many participants, staff became like friends due to shared activities, contact over time, and lack of others in their lives. As a result, despite expressing a desire to move on and a frustration with their current situation, the prospect of not having staff with them all the time was difficult to consider:

P: I don't know if it'd be […] I'll be really honest, I think I'd be lost.

I: You think you'd be lost? Right.

P: If it was during the day anyway I'd probably just, I'd be lost, honest I would

I: Tell me a bit --

P: 'Til you get used to it, 'til I get used to being alone again eh? (Participant 2: line 557).

It is however important to note that not everyone reported loneliness; and some reported feeling that family relationships were actually eased by the presence of a third party.

Theme 5: Feeling like a service user

The final theme captured that perceived stigma associated with having a disability was a significant issue for this group. Interestingly, participants appeared to experience more shame associated with needing help to care for themselves than with being seen as a risk to the public:

[…] cause people […] the people will see, they'll see me as […] they'll maybe,people see me as […] that I can't look after myself […] They'll say, "Oh, look at him, a'him or her or him", eh? I dunnae get any reaction it's just that sometimes people see maybe […] staff, eh? But they dunnae ken […] they dunnae ken why I need the staff, eh? So […] (Participant 7: line 371).

This brings into focus that having someone alongside you at all times may bring unknown reactions from the public; either the stigma of needing support with daily living or concerns about risk to the public, making disclosure around this topic difficult.

The theme "Feeling like a service user" divided participants. Some accepted their need for support, reacting well to being aided in developing new skills and being open to social integration with others in the same situation:

I: So do you see the other service users sometimes?

P: Yeah.

I: How often is that?

P: Eh, once a week or something. All at different times and that. Em, I don't see [*name*] very often. 'Cause he's in his house all the time.

I: Right. Are there some that you're quite friendly with?

P: Yeah (Participant 8: line 270).

I: And did you write it out [shopping list] or who wrote it out?

P: Eh, I got somebody to write it out, em […] and somebody wrote it out and I did it on the computer, eh, got them to check it before I printed it off (Participant 7: line 45).

Others wanted to see themselves as self-sufficient with no need for support. Ironically this seemed to continue their need, as it became a barrier to developing some of the independent living skills which would have aided them:

P: Just […] I'll be honest with you, I can do anything, I can do everything. Only thing I cannae do is read my bills, and read my letters.

I: Right.

P: And I don't want to learn to read and write. If I do, I'm learning on the computer myself, I'm no wantin' someone to come along and do it for me.

I: Right.

P: Cause I willnae I'm just not interested, I'll no be interested, and it's me, that's just me (Participant 2: line 1276).

Internalised stigma also seemed to result in some participants becoming socially somewhat stranded, rejecting a potential peer group and striving for another they seemed unable to access:

P: I no want that noo, cause I'm no wanting people like[…], I just don't want them pushing, cramping all round me cause I'm no wantin' nothing to do with anybody else

I: Right so you want to stay separate.

P: I want.

I: […] from the other clients?

P: I'm wantin' to be kept a secret (Participant 2: line 371).

Overall an ambivalence regarding support seemed to permeate the data:

It's just […] sometimes I feel like eh […] I could do without them, and other days I'm no wantin' them, and other days I do want them. And some days I feel like I've just done enough time, being in prison and all this crap ya ken? I've just done enough time, being in here and […] I just feel like I've done enough (Pilot participant: line 824).

This quote captures the frustration most participants seemed to feel regarding the compulsory care they received. Although they recognised that they could not in many ways do without it, it was

nonetheless a difficult to manage and unwanted presence in their lives, which was hard for them to see a route out of.

Discussion

Section: i17 i17_i41 i41

Several important themes emerged regarding experiences of forensic community rehabilitation for service users with LD. A taste of freedom related to the experience of increased independence and opportunity which emerged from community living. Most participants felt they did achieve some positive benefits from living in this less restricted environment, which is encouraging. These are important aspects in terms of individuals increasing their ability to self-manage, and developing a new self-narrative and identity, away from their offending (Haaven *et al.*, 1990).

Results replicate tensions experienced between care and control in forensic settings previously discussed in the literature (e.g. Hinsby and Baker, 2004). "Not having control" described the sense of a lack of autonomy participants felt over their environment, their care, and their plan for progression. Partly this came from a lack of clarity about how to begin to self-manage and reduce staff input; and partly from lack of confidence in their ability to do this. Participant descriptions emphasised externalised control, where, until the point that all risky thoughts could be extinguished, risk management was often equated with staff supervision. The same sense of externalised control was noted within McNally *et al.*'s (2007) sample, although the authors described this as more of a general feature, also relating to participants' accounts of why they had been detained. It may be that this sense of external control is to some extent a general characteristic of people with LD, reflected in the subjects here discussed.

Participants described a lack of control in relation to their care plan, feeling that their progress was dependent solely on the subjective judgement of others. This perceived lack of self-determination may lead clients to employ a "head down" approach, learning to conceal anything that could hinder their progress. This form of subtle non-compliance, or "playing the game", has also been noted in another study of service user views of compulsory treatment in the community (Gault, 2009, p. 509). If participants respond in this way to restrictions they may increase their risk, as early warning signs of potential recidivism may be missed (Pithers *et al.*, 1983).

Loneliness was described as a major issue for participants, who felt that true community integration was very difficult to achieve. They reported social isolation due to already poor social networks being further limited due to the presence of support staff, echoing findings of Ellem *et al.* (2012). This resulted in a growing dependence on support staff as companions, and a self-perpetuating cycle of dependency on care. Considering the accepted importance of social bonding in terms of both quality of life and links with offending (Wheeler *et al.*, 2013), this is an important issue to address within current practice.

Stigma was another prominent theme within the category "Feeling like a service user". Participants appeared split between those who felt able to access support more fully and develop links with others in the service; and those who felt too stigmatised to do so. This internalised stigma has been

noted within other studies, reported by service users as a barrier to integration and accessing support within other LD forensic populations (Gerber *et al.*, 2003; Ellem *et al.*, 2012).

Support appeared to be viewed by participants as simultaneously protective and restrictive. As participants described this need for protection, it was welcomed at times, but appeared to lead to a vicious cycle of dependency on support, both practically and emotionally. This style of support also resulted in a lack of opportunity to develop self-management skills, maintaining a pattern of dependency, and leaving participants feeling disempowered. As a consequence, many participants failed to appreciate the rehabilitative aspects of supported living; and instead experienced staff support as a form of prison.

Implications and future directions

Although there were advantages which were valued by participants, for the majority, community integration appears to have lost some of its way in the road from ideal to implementation. This may mean that benefits, in terms of both feelings of improved quality of life and accessing prosocial pathways, are unlikely to follow.

The principles of care and control are acknowledged as difficult to manage: but they can be successfully married within a strengths-based approach, such as the GLM (Ward, 2014). This allows for clear, shared goals and positive risk-taking in the context of solid risk management planning. This in turn can only be delivered with appropriate training and support for staff who are delivering this model on the ground.

Improving the model

Achieving clarity

Part of the disempowerment participants expressed in the current study was related to a lack of understanding about various aspects of the system they inhabited, including the roles of the support team around them, and what to do in order to have their legal order removed. It may be that more work needs to be done in clarifying these points for service users during open and ongoing discussions with them. Meetings involving service users, for example those facilitated by the care programme approach (CPA) (Scottish Government, 2013), may be an ideal forum for this.

Role clarification is an important task within the forensic field as responsibilities often combine support and supervision (Trotter and Evans, 2010). This may be helpful in promoting clarity and transparency, not only for clients, but for staff teams about their dual roles of support and public safety. These are complex roles, needing regular discussion of related issues and ongoing support.

Clear care pathways, which outline individual goals and time frames for gradual progression on a community order, should also be shared with clients. This is to make clear what is required of the individual in order to progress, as well as how to achieve this. This process would reveal achievable goals as tangible realities, enhancing hope for the future. This is not, of course, to say that everyone will be able to "move on" in the sense of achieving independent living. Both their disability, and their ability to make choices that will not put themselves or others at risk, may mean they will always be subject to support. For these individuals, transparency will be important in explaining that they will be helped to have as meaningful a life as possible within these restrictions.

Providing the necessary support

Reciprocity, one of the ten principles on which the new MHA (2003) is based, states that, where individuals are subject to compulsory care by law, there is a duty to provide them with appropriate rehabilitation opportunities. This raises the need to determine whether or not this form of care is providing people with the support they need to progress. This issue is raised in the work of Cummins and Lau (2003) on difficulties caused by attempting to achieve community inclusion without essential planning and support needed to facilitate a genuine societal engagement. In their study of LD prisoners, Ellem *et al.* (2012) also emphasise this important consideration:

[…] containment on its own did not adequately address participants' offending behaviour or make a positive difference to their already impoverished lives. The systems often failed to adapt to the needs people had arising from their impairment and the difficulties they experienced in community living remained, often exacerbated by their experiences of institutionalisation (p. 405).

Empirically, typical individuals with LD and forensic needs will present with significant mental health issues, insecure attachment patterns, communication difficulties, high acquiescence, and low assertiveness (Lindsay, 2002; Myers, 2004; Hobson and Rose, 2008). Significant levels of support and treatment are needed in order to help them begin learning self-management skills. As well as providing a therapeutic environment, well-validated psychological therapies are needed as standard to address such complex needs (Barron *et al.*, 2002) participants described feeling empowered when there was a clear way of raising concerns; for example through the CPA or independent advocacy services. Advocacy groups, in particular, seem an important area to build on. Goodley (2005) describes the functions of such groups as multi-faceted, since they promote "friendship-making (interpersonal), rule-challenging (social), and label-checking (political)" skills (p. 338). A related issue concerns whether it is realistic to expect the majority of individuals with such complex needs to possess the motivation and understanding needed to take advantage of such opportunities.

There is also a suggestion from the results that directly tackling internalised stigma may benefit this group. Since stigma is associated with shame and hidden deficits (Matthews and Harrington, 2000), exploring these issues with clients more directly and explicitly could help reduce their impact. There is scope for improvement via professionals who can feed into feelings of stigma by avoiding bringing up difficulties for fear of embarrassing the individual or causing feelings of inadequacy (Craig *et al.*, 2002). If those around the client can be more open about the individual's difficulties, this may encourage them to do similarly.

Empowering support staff

Relationships with support staff are vital to the delivery of rehabilitation within this model (Campbell *et al.*, 2006). How such relationships are perceived has a huge impact on the foundations of the care package, which directly affects feelings of stability and readiness for change (Breckon *et al.*, 2013). Support and clinical supervision are essential within forensic fields (Campbell *et al.*, 2006) and supervision is a forum where the challenges of dual roles should be explicitly addressed and discussed.

When forensic nursing staff are provided with additional training on psycho-educational and psycho-social principles, their levels of stress decrease, and they have a more positive orientation towards

the client (Ewers *et al.*, 2002). Ongoing supervision and space to reflect as a team may also be helpful. Shared formulation meetings, like those set up within other complex or challenging LD services, may be useful (Ingham *et al.*, 2008; Ingham, 2011). Such meetings encourage teams to reach a shared understanding of the client, in terms of psychological factors which may drive his/her behaviour and resulting needs. This can assist in clarifying goals and coordinating care, with improvement of outcomes both in staff attitudes and client response (Ingham, 2011).

Therapeutic use of environmental control could also improve staff-client relationships, by gradually decreasing one-to-one contact, reducing interpersonal tensions, and decreasing the burden placed on staff as the main source of managing risk. Participants did not mention constraints in their environment (e.g. alarmed doors) as a source of difficulty. It may be that a more physically controlled environment actually leads to feelings of greater freedom. Such indications are tentative; but they suggest that options of increased physical restriction and technological monitoring may be worth exploring. Alternatively, shared group residences may reduce the intensity of 1:1 support and alleviate some of the feelings of exclusion and loneliness described.

Limitations of the study

Participants did have difficulties with expression, comprehension, and speech, emphasising general difficulties with communication for this group. Participants' impairments may also affect their understanding of the support service they are being offered although this should not detract from the feelings described.

Generalisability of qualitative studies is always limited due to the small number of participants. The present findings, however, provide useful indicators that broaden our understanding of some of the issues possibly affecting other mentally disordered offenders and mental health patients in compulsory care, as well as generic LD populations experiencing high levels of support.

Future research

There is a wealth of future research that would be useful within this area. Suggestions have been made here for improving the system but it would be useful to explore from a staff perspective what the difficulties may be in applying these suggestions. It would also be useful to identify what social care staff themselves believe are the difficulties within the current system and what would help them within their role. Quantitative research could be employed to look at how many clients in Scotland, and perhaps across the UK, with LD and forensic needs are subject to community-based orders, how long individuals are generally subject to this type of order, and what they move on to. This may help us to understand what is realistic and achievable for this group.

Studies such as this one give us the chance to draw out some of these issues in order to explore solutions. It is hoped that through dissemination of these findings the voice of these service users can be translated into clinical practice.
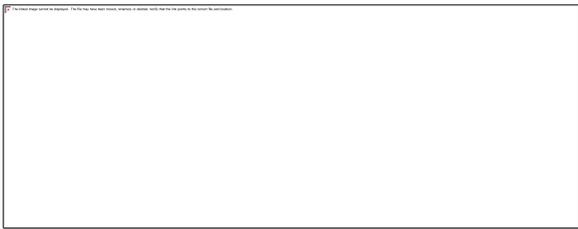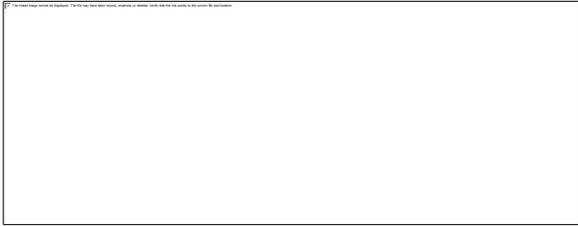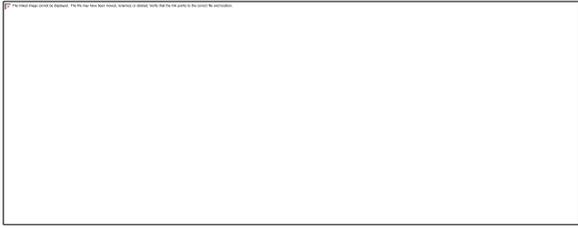
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