Title: English vs Dutch high secure hospitals: Service user perspectives

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Abstract

Purpose

The aim of this paper is to describe service users' perspectives on the difference between high secure long-stay forensic psychiatric services in the Netherlands and high secure forensic psychiatric care in England. These perspectives are relevant in considering the benefits of a similar long-stay service in England.

Method

A current in-patient detained in a high secure hospital in England and other mental health service users and carers with experience in forensic-psychiatric settings were asked to watch a documentary on a Dutch high secure long-stay service. Then they were invited to make comparisons between this service and high-secure care in England. These perspectives were gained in the context of their membership of the Service User Reference Group of an externally funded study on long-stay in forensic-psychiatric settings in England.

Findings

Our small group of participants highlighted the importance of relational security, meaningful occupation, autonomy, positive therapeutic relationships with staff and a homely environment for those with lengthy admissions and perceived these to be better met in the Dutch service. These factors might contribute to improved quality of life that services should strive to achieve, especially for those with prolonged admissions.

Practical Implications

Perspectives of service users with lived experience of long-stay in forensic settings are important in informing service developments. Lessons can be learnt from initiatives to improve the quality of life of long-stay services in other countries and consideration be given on how to best manage this unique group.

Originality/Value

To our knowledge this is the first study asking service users about their view on forensic services in other countries. Our findings suggest that service users have valuable contributions to make to aid service developments and should be involved in similar such exercises in the future.

Introduction

Detention in a secure forensic psychiatric setting can be expensive for society and highly restrictive for patients (Adshead, 2000; Centre For Mental Health, 2011; Farnworth, Nikitin & Fossey, 2004), particularly those experiencing long-term care. In this paper we discuss the views of five mental health service users, including one currently residing in a high secure hospital in England and a carer for someone who has spent time in such setting, to whom we showed a DVD entitled 'Long-stay forensic care in the Netherlands: A film by Maria Mok and Meral Uslu' (https://www.youtube.com/watch?v=iCMt7ynK9jg). Participants were asked to make comparisons between the high secure long-stay hospital in the Netherlands and their experience of high secure care in England.

There are important differences in the structure of forensic services between the Netherlands and England. In England services are organised according to three levels of security: high, medium and low. Most hospitals provide services at one security level only. As each hospital has its own referral system and gatekeeping process, transfers between hospitals and step-down through security levels can be problematic, resulting in waiting lists and delays in treatment (De Boer & Gerrits, 2007). In contrast, forensic psychiatric services in the Netherlands incorporate all levels of security in one institution, including community services (Mcinerny, 2000). This provides greater continuity as the same clinical team maintains contact with the patient throughout their time in services, whereas in England a patient will often come into contact with many different clinical teams as they are transferred between different wards and hospitals (De Boer, Whyte & Maden, 2008).

In the Netherlands, there is a separate high secure service for patients deemed to need long-term forensic psychiatric care. This service will be the comparator for the exercise presented here. Admission criteria for this service are that an individual has been an inpatient at two separate forensic psychiatric hospitals for 6 years or more in total, that they have completed relevant treatment programmes but with little progress and no expected reduction in risk from further treatment. These individuals can be transferred to a long-stay facility following review by an independent national panel (De Boer & Gerrits, 2007). There, the aim of treatment is no longer to reduce risk but to stabilise the patient's mental state, offer them as much autonomy as possible and an optimal quality of life (Braun, 2010). These services aim to provide the least restrictive internal environment using the minimum amount of security measures necessary, whilst still providing substantial external and perimeter security (Pompestichting, 2008). It is the therapeutic relationship between patients and staff and an in-depth knowledge of patients' needs and risks that is relied upon to create a secure environment. In addition, there is a recognition that the forensic service is effectively the patient's home and that fostering a sense of belonging and meaning contributes to improved social control and security (Braun, 2010). This is further reflected in the use of language whereby 'patients' are referred to as 'inhabitants' who go to 'work' rather than receive 'therapy'.

Few direct comparisons have been made between services in the two different countries of interest here. De Boer & Gerrits (2007) argued that high secure care in England relies more

upon physical and procedural internal and external security than the Dutch model (). Some authors have contended that English high secure hospitals place responsibility onto the patient's *responsible* clinician while Dutch services emphasise patients' responsibility for their own behaviour (De Boer & Gerrits, 2007; Maden, 2007). While these observations are now quite dated, more recent writings have also referred to English forensic services as highly restrictive, in particular in comparison with other European countries. E.g. it has been noted that the UK is amongst the most restrictive with regards to sexual expression (Tiwana, McDonald & Völlm, 2016), that patients stay in secure settings for long periods of time (Sampson, Edworthy & Völlm, 2016) and aspirations to optimise quality of life, particularly for long-stay patients, are not always successful (McDonald, Furtado & Völlm, 2016). The restrictive nature of UK high secure services is also reflected in the High Secure Service Directions (Department of Health, 2011) which stipulate, amongst other things, restrictions with regards to the amount of personal belongings allowed, visiting rights and procedures for searches monitoring. It is further of note that the most recent report by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment made a number of critical observations of UK secure services, including with regards to increasing numbers of patients detained in such settings, delayed discharges, night-time confinement, long-term segregation, the general living conditions, the "overwhelming use of force" during restraint procedures, safeguards around consent to treatment and the limited powers of Mental Health Tribunals (Council of Europe, 2017).

Research in England in the 1990ies has suggested that some patients spend too long in environments that are too restrictive for their needs (Pierzchniak et al., 1999; Thomas et al., 2004)) – it is these patients who may arguably benefit from a long-stay service similar to that of the Netherlands. The accelerated discharge programme in England has attempted to combat long-stay in high security. However, recent research (Völlm et al., 2017) has again identified that a significant proportion of patients in high secure settings who stay there for excessive periods of time. Those who do move on, usually move to medium secure services that still impose significant restrictions. Recommendations have therefore been made for specific policy development and service design to focus on provisions for longer term patients (Royal College of Psychiatrists, 2003).

Despite apparent differences in treatment philosophy, services in England and in the Netherlands have one mutual aim for their patients – recovery. Recovery from mental illness has been defined as a personal journey taken in pursuit of unique life-goals in the presence or absence of continuing symptoms (Drennan & Wooldridge, 2014). Recovery goals should be largely formulated by patients themselves and professionals need to understand what recovery means to individual patients and how it can be implemented (Shepherd, Boardman & Slade, 2008). Repper & Perkins (2003) have identified three key principles services should follow in order to support recovery: hope (maintaining the belief that a person is still able to pursue their life's goals), control ((re)gaining a sense of control over their life and symptoms), and opportunity (being able to live a life 'beyond illness' and become part of a community with access to the same opportunities as others)

While the value of a recovery focused approach in general mental health services is widely recognised, the evidence is weaker for forensic services. A number of authors have noted that the recovery approach might be difficult to apply in forensic settings, e.g. as service users in such settings are detained against their will, are detained for long periods of time and because the approach to therapy may be more confrontational compared to other settings (e.g. Mezey et al., 2010). Nevertheless, Drennan & Wooldridge (2014) have identified five key areas that contribute to the creation of an environment where recovery can be nurtured in forensic settings, including supporting recovery along the care pathway, quality of relationships, risk and safety, meaningful occupation and peer support (Drennan & Wooldridge, 2014).

Some have argued that, whilst recovering, it is important that patients are offered a standard of living which is at least as good as what they would expect if they weren't detained in hospital (Swinton, Carlisle & Oliver, 2001). This becomes even more pertinent when patients are staying in secure services for lengthy periods of time, when treatment is no longer aimed primarily at returning the patient to the community but at ongoing care, acceptance of stay and optimising quality of life (QoL) (Schel, Bouman & Bulten, 2015). QoL has been found to be lower in forensic as opposed to general psychiatric patients (Schel, Bouman & Bulten, 2015); and for personality disordered patients Swinton, Carlisle and Oliver (2001) found evidence for superior QoL a Dutch compared to an English secure setting which the authors attributed to higher levels of therapeutic optimism in the Dutch system.

Both recovery and QoL based approaches to service delivery require a partnership approach between professionals and patients to enable an exchange of ideas and understanding of experience (Amering & Schmolke, 2009). International research has shown that genuine collaboration and involvement of patients and carers is vital to the development of legislation, policies and services for mental health patients (Wallcraft et al., 2011). However, relatively little is known of the experiences and perspectives of people who use forensic mental health services (Coffey, 2006) though there are some examples of positive and innovative practise in UK high secure care (e.g. Canning et al., 2009; Cromar-Hayes & Chandley, 2015).

This preliminary consultation therefore aimed to obtain the views of services users with experience in forensic care in England on long-stay forensic services in the Netherlands with a view to stimulate debate regarding the best way to care for patients detained in secure setting for lengthy periods of time.

Methods

Service users with experience in secure care who acted as members of the service user reference group (SURG) of a 3-year research project on long-stay in forensic settings in England, were asked to participate in this exercise. They included: A service user with lived experience of more than one high secure hospital (WT, not real initials), a parent-carer for someone currently in secure care (TG), a mental health service user and current volunteer at a high secure service (KL), a service user with previous experience of secure care (SJ), and an ex-offender and peer support worker within the criminal justice system (RS).

All service users watched the documentary on long-stay services in the Netherlands 'Long-stay forensic care in the Netherlands, A film by Maria Mok and Meral Uslu' (previously shown on mainstream Dutch television, https://www.youtube.com/watch?v=iCMt7ynK9jg) which documents the daily lives of patients in one of the long-stay forensic psychiatric hospital in the Netherlands. The documentary was produced in close consultation with staff within the service and, according to our personal contacts, accurately reflects the situation there. The member currently resident in high secure care was visited by a member of the research team on two occasions to view the documentary while the researcher was present; a member of ward staff was also present The other members of the SURG received a copy of the DVD to watch individually and were invited to discuss the film in a feedback session. Comments helped in the interpretation of findings of the overall study from a service user's perspective. All members of the group had had, as part of their role, wider exposure to the topic of service provision for long-stay patients in forensic care.

Initially participants were allowed to freely talk about their key observations, focusing on similarities and differences between the two services. Then, three direct questions were asked to aid discussions as shown in the Results section below.

Comprehensive notes were taken by the researcher throughout each session to document the observations accurately and thoroughly, but no audios were taken. Notes were read and subjected to thematic analysis (Braun, V. & Clarke, V., 2006). Key themes were identified deductively to organise the data which captured areas of service structure and provision participants choose to focus on in the unstructured part of the session. Within these themes key similarities and differences are reported via the explicit meaning of the data with no judgements imposed on the reported observations. Given the preliminary nature of our consultation, we only drew out a limited number of specific themes regarding key differences and similarities between the two services to avoid overinterpretation of our findings. In addition, answers to the specific questions posed are reported descriptively.

Except for one service user, who could not be located, all were shown a draft of this paper and consented to the publication of this manuscript.

Findings

Participants reported differences and similarities between the two services in the broad areas of staff-patient interactions, environment, procedural and legal, and patient experience. Within the theme of patient experience the sub-themes of responsibility, choice and privilege were identified.

1. Staff-patient interactions

Participants felt that this was less imposing and staffing numbers appeared lower in the Dutch service. WT reported that he was "still looking for staff" in the Dutch hospital throughout most of the documentary. He found it difficult to differentiate between staff and patients and highlighted that the number of staff needed for escorting appeared lower in the Dutch service.

TG also noted this difference, saying that staff seemed much less suspicious of patients including whilst on escorted leave. WT described how interactions between Dutch staff and patients seemed more relaxed and that staff spoke to patients in a very friendly manner, provoking a more friendly response from patients in return. He felt this promoted a better power balance, resulting in more positive therapeutic interactions. KL also commented on staff relationships with patients, observing that those in the Dutch service really seemed to get to know their patients on a personal level and this allowed them to build trust. TG highlighted an example of this, where a patient grabbed a staff member's arm and their response was more positive than she felt it would have been in an English high secure facility, where more punitive measures may have been taken in response.

2. Environment

WT observed that patients in the Dutch service appeared to have more freedom to move around the hospital grounds unescorted than patients in English high secure care, where unescorted ground leave was the exception and only available for short periods during the day in a constrained space within the hospital. He felt that the buildings were more open-plan than in England and as a result felt less enclosed and controlled. RS agreed with this, discussing how the communal areas felt like a family living environment and patients seemed to feel very safe and comfortable there. WT described how a level of control was still present in the Dutch hospital but not so much in physical form and he felt this would be less imposing and overpowering for patients. KL felt that the quality of patient relationships with staff contributed to this through increased trust and respect.

Some of the Dutch patients had access to power tools to do paid metal and woodwork within the hospital, which everyone found surprising but positive. WT could particularly see how this daily meaningful occupation would be beneficial to patients who are in secure services for lengthy periods of time and RS commented how having access to potentially dangerous tools demonstrated patients being given trust and responsibility, making them feel valued.

WT was surprised at how homely and comfortable Dutch long-stay service looked and thought it would feel like a "proper living room" for patients. He characterised this by saying it was "a hospital set up not to be a hospital". He felt this could have both a positive and negative impact on patient experience, in that they would feel more comfortable and settled but this may not encourage change or hope because they felt content. He felt that those in the Dutch facility didn't seem to be institutionalised because the hospital wasn't as institutional as the English high secure settings he had experienced.

3. Procedural and Legal

WT observed that the tribunal procedure for Dutch long-stay patients was more formal than the procedure in England as it takes place in a courtroom rather than in hospital. He identified some similarities in the processes – most notably that the index offence, sometimes committed a number of years ago, remained the key justification for continued detention. He could see how it might be difficult to shift this emphasis, particularly for violent and sexual offenders where the stigma and prejudice attached to their actions is amplified. However, he

felt that care should be taken in both services when considering the impact of this on future assessments.

Both WT and SJ found the difference in patients' leave astounding. Patients in the Dutch facility work towards different levels of leave, including escorted and eventually unescorted community leave [achieving such leave is incentivised for service providers]. WT reported that patients in English high secure care had previously been allowed community leave; however, this had since been stopped. He felt that such leave would be highly beneficial as it would be something to look forward to, acting as an incentive to motivate patients in completing treatment and behaving appropriately as well as providing a feeling of moving forward and inspiring hope. SJ agreed and felt that access to escorted community leave in the Dutch facility was excellent and highly beneficial for patients in terms of quality of life and being able to demonstrate and practice social skills.

During the documentary a patient is seen receiving a phone call from his partner. The handset is brought to the patient in his own room, where he takes the call while a member of staff stands in the doorway. WT felt this was a much less intrusive way of monitoring phone calls, especially as only the patient's side of the conversation is listened to, allowing the patient more privacy and respect. Similarly KL observed how two male patients were allowed to get married and live together in the Dutch facility and commented on how well this was managed in terms of respect for them and the other patients, as well as positive risk management.

4. Patient Experience

The differences in patient experience highlighted can be broken down into three key factors – responsibility, choice and privilege. Participants felt that patients in the Dutch facility were given significantly more of all three of these.

Examples given with regards to responsibility includedpatients in the Dutch facility being able to enter the staff room at any time without asking permission. Another example, highlighted by WT and TG, was that patients were allowed to show visitors round the hospital as the primary tour guide rather than as an "accessory". Further examples included being able to enter other patients' bedrooms and having access to metal cutlery. Participants felt that these examples showed that there was more trust in patients by staff.

With regards to *choice*, in the Dutch long-stay facility patients can choose whether they stay in their rooms or not and whether they want the door open or closed. Other examples related to *responsibility* and *choice* were access to paid work at the Dutch hospital and the possibility to purchase personal items for their rooms, such as televisions and stereos, with the money earned. All participants felt this would be highly beneficial for patients in secure care for long periods of time as it would give them a respectable occupation to be proud of and a sense of achievement at having earned money to purchase some of their possessions. Patients in the Dutch facility are also allowed to keep pets in their room and WT felt this would give patients a real sense of purpose as well as pleasure. All participants commented on how having more *responsibility* would lead to patients being allowed more *privileges* as the

documentary showed patients getting tattoos, having access to their own finances, personal mobile phones, computers and televisions in their rooms.

The film also showed clinicians discussing the possibility of providing opportunities for sexual expression for long-stay patients, which WT found "shocking". He commented that this wouldn't even be discussed in English high secure care and as a result he felt some patients do "very silly things" (for example self-harm) because they are sexually frustrated. He thought this area would be worth exploring further in England, as long as the correct precautions and risk assessments were undertaken.

It is important to note that WT also highlighted two noticeable similarities between the services. The first of these was the night-time confinement of patients to their rooms. This is practiced in both settings and he noted how this could be distressing for some patients and emphasised that wards must remain appropriately staffed during this time. Another similarity was that the Dutch facility felt to him like a "life sentence in disguise", which he said secure care in England can also feel like. He felt that in both settings patients didn't seem to have much hope of moving on. However, he identified that patients in the Dutch facility appeared to have accepted their stay and were prepared to make the best of what they had, made easier by the service being designed to be as homely as possible with a specific focus on quality of life. Despite this, he struggled with the fact that there was little or no hope – "Shouldn't there always be hope?".

At the end of the documentary, all participants were asked three direct questions displayed below along with a summary of the main aspects in their responses.

1. <u>How do you think the quality of life differs between patients at the Dutch high secure long-stay facility and patients at your current / in a high secure hospital in England?</u>

Participants were unanimous in their view that the Dutch service provided a better quality of life to residents. WT in particular highlighted that patients needing life-long secure care deserve a much better quality of life than what is currently offered. He felt quality of life was better in the Dutch facility and highlighted more access of technology and less intrusive security as reasons for his perception. He felt that in the English service one is made to feel very small due to having to ask permission for "every little thing" and given no responsibility.

He felt that life in the English service was very monotonous with no opportunity to practice what patients had learnt in treatment. Having a more homely environment would increase patients' quality of life and overall well-being. Others agreed and highlighted more normality and freedoms, e.g. being able to have plants and pets and personalise their own rooms resulting in a better quality of life. More discrete application of rules and regulations and the more trusting and cooperative relationship between staff and patients were further reasons given for the perception of a better QoL in the Dutch service.

2. <u>Would patients be accepting of a similar long-stay service here in England?</u>

WT felt that patients would be more accepting of being told they'll be in secure care for, say, 7-10 years if they were given a more homely environment. He said he would have been happier with this scenario himself and more co-operative with treatment. He felt, however, that the rest of society may not accept a similar separate long-stay facility – which was also echoed by other service users - but that long-stay wards within current hospitals might be an alternative. TG felt that if patients could see an example of what it's practically like and be part of the planning and design, they would be accepting. He also highlighted the importance of an honest opinion on their diagnosis and risk and support in accepting their situation for such a service to be successful.

3. Do you think there is a need for a long-stay service in England?

All participants felt there was a need for a long-stay service in England. WT felt such service might benefit particularly those in secure care for 20-30 years. TG commented that forensic services needed to decide whether they're punishing or treating people. Both RS and SJ noted the need for a shift in attitude and culture around risk and quality of life and the need for senior management and governmental support.

Discussion

This small study aimed to gain the perspectives of service users on a Dutch forensic-psychiatric long-stay service, in comparison to high secure care in England. In order to avoid overinterpretation of the findings presented here, a number of limitations need to be highlighted. Firstly, we consulted a small group of self-selected service users; as such it cannot be claimed that their views are representative of those of service users on the whole. Service users volunteering to serve on a SURG to a research project might be those with particularly critical views about service provision. On the other hand, the advantage of the group consulted here was that they had already had the opportunity to engage with the topic in an in-depth way by virtue of their role. While some 'bias' might nevertheless be present in the views expressed (identified, e.g., in observations which might not be 'objectively' correct), the ethos of service user involvement, in the view of the research team, is to take seriously the views expressed, albeit subjective. It would be informative to supplement the preliminary findings presented here with an 'objective' comparison of policies in both settings but, in our view, both such approaches are necessary and should be seen as complimentary in gaining a balanced view on the topic. Another limitation pertains to the method chosen, namely the watching of a DVD; the material might itself be limited and biased and, obviously, this way of representing a service is different from lived experience. However, such lived experience would be nearly impossible to achieve. In addition, as part of the wider research project we facilitated an actual visit of a service user as well as staff to the Dutch long stay service, and the SURG had been exposed to discussions about these exchanges.

Despite these limitations, some relevant conclusions can be drawn with regards to the care for long-stay patients in forensic settings. Service users highlighted important elements of such services and identified several differences between the Dutch and English provision. While clearly the perspectives of this small group of participants are highly subjective, it is

nevertheless noteworthy that they highlighted a number of positive aspects in the Dutch setting and felt that the QoL of service users was enhanced compared to high secure care in England. Reasons put forward for these observations included positive, relaxed and trusting staff-patient relationships, environmental features, less intrusive and restrictive security measures and improved opportunities for exercising responsibility and choice in the Dutch setting. As a result service users felt that those detained in the Dutch facility were less institutionalised compared to those in high secure hospitals in England. It is noteworthy that these perceived positive aspects of service provision match with the declared aims of the Dutch long-stay service, namely the provision of a homely, as close as possible to 'normal', environment, focusing on individual responsibility and quality of life. In order for patients to move towards recovery, the importance of responsibility and regaining control over certain aspects of their lives has previously been emphasised (Braun, 2010; Repper & Perkins, 2003). This may at times be difficult when trying to manage risk within a potentially volatile patient group; however, it should remain a priority for forensic psychiatric services. Other factors related to promoting recovery were noticeably present in the Dutch facility, including clear incentives for movement along the care pathway (e.g. escorted community leave), individualised security policies (including the use of personal mobile phones and computers) and increased access to meaningful occupation (including in paid work).

The concept of hope is also highlighted in the literature as being an aid to recovery (Repper & Perkins, 2003), yet participants in this consultation thought that patients in both settings seemed to have little or no hope of moving on. As a key principle for recovery, it is important that staff continue to instil a sense of hope for patients in both short and long-term goals. It is also important to remember that the future will look different for each patient and therefore their sense of hope should also be individualised (Shepherd et al., 2008). Interestingly, Mezey et al. (2010) noted that some central recovery themes may be more problematic in forensic service users, at least in the UK, including hope, self-acceptance and autonomy. This is as service users in their study believed that, even if they did well in treatment, due to the double stigmatisation as a mentally disordered offender they will not be given the chance to be accepted back into society. It is possible that societal attitudes play a role in the differences in service provision between the UK and other European countries.

An important aspect also highlighted in this consultation was that of 'acceptance'. The Dutch services placed emphasize on helping patients to accept their life situation as a resident in a long-stay care facility while aiming to optimise their quality of life. Service users felt that it would be easier for patients to accept a long-stay facility if communication about their prognosis was honest. It is of note that between 2010-2014, 38% of patients in the Dutch Long-term Forensic Psychiatric Care facility of the Pompefoundation were discharged, with many moving to lower levels of security and back to mainstream care. This figure demonstrates that hope and the option of moving on still remains for these patients (Bulten, personal communication). Hope and recovery as key principles were emphasized by our service users while still supporting the introduction of a type of service where the hope of discharge might be denied. This potential contradiction represents the ethical dilemmas

inherent in the concept of long-term care (and to some extent in forensic services – care of custody – more generally).

Implications for practice

Our preliminary findings highlighted some key elements of service provision for long-stay patients in forensic settings. The service users consulted here indicated that it might be worthwhile exploring the development of specific long-stay services, similar to those provided in the Netherlands, either as a stand-alone service or as part of current high and/or medium secure provisions. This should have a particular focus on quality of life and patient autonomy within a 'normalised' living environment. Such service might be more acceptable to patients if enhanced QoL was achieved and if staff communicated openly with them about the nature of such service and helped them to accept their particular life situation. It has also become apparent that long-stay patients may require a different approach from staff; therefore additional staff training on working with this population would also be crucial.

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