Reflections on Co-production, Lived Experience and the Shared Learning Environment within the Development and Early Delivery of a Recovery College

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KEYWORDS

Co-production, Lived experience, Recovery College

Abstract

Objective: This study sought to explore and value the experiences of the service users, staff, carers, and volunteers who were involved in the development and early establishment of a recovery college in a large mental health Trust in the United Kingdom. **Research Design and Methods**: This qualitative study used Interpretative Phenomenological Analysis (IPA) to explore the experiences of 25 participants who were involved in the design, development, and early delivery phases of the recovery college. Data were collected using face-to-face semi-structured interviews. **Results**: The findings discuss a number of key features relating to participants' experiences of the development of the recovery college, with the central themes of 1) co-production; 2) lived experience; and 3) the shared learning environment. **Conclusions**: Key recommendations for those seeking to develop their own recovery college include: i) co-production is essential, but there are both philosophical and practical considerations; ii) lived experience is *valuable*, but it needs to be *valued* and supported within both the recovery college and the host organization; and iii) the shared learning environment and educational approach of the college is vital and needs equity of opportunity between the service users, staff, carers, and volunteers involved.

Introduction

The development of recovery colleges can complement existing mental health services, using an educational model to support self-directed recovery and learning opportunities for those experiencing mental ill-health.[1] Although recovery colleges in

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the United Kingdom (UK) were initially developed in 2010,[2] the idea of 'recovery education' predates this initiative.[3] Over the past decade, the increasing number of new recovery colleges (that are often idiosyncratic and shaped by local contexts) has somewhat outpaced the limited but growing evidence base, with the important development and early establishment phase an aspect that remains under-explored.[4] The paper by Meddings et al.[5] is an exception, though their paper focussed more on the importance of co-production during the development process rather than a more holistic study. Building on that paper, the centrality of co-production for recovery colleges, along with the interrelated elements of valuing lived experience and creating shared learning environments. form the basis of this empirical paper.

Lived experience differs from clinical expertise as it refers to those individuals who have used services or have personal experiences of mental illness.[6] Within the mental health space, an individual's personal experiences of illness can benefit others[7] and be understood as including "the belief of people who have faced, endured, and who have overcome adversity, can offer useful support, encouragement, hope and perhaps mentorship to others facing similar situations."[8] In this context, lived experience refers primarily to someone's experience(s) of distress that is labelled mental illness, but can also include volunteers or experts by experience, peer support coaches,[9] carers' and family members' personal experiences.[10] Although it is widely accepted that lived experience can aid in promoting mental health recovery, there still needs to be a maturity developed in the evidence base;[11] therefore, debates remain around whether or not lived experience roles should be adopted within mental health services and recovery colleges, and in what ways.[12] Despite the slow pace of integration of lived experience roles into health services, the use of lived experiences is evident via co-production of certain interventions and activities, which includes recovery colleges.[13]

Co-production

Co-production in this context should mean those with lived experience are involved in all elements of a recovery college as experts by experience, including curriculum development, delivery, and quality assurance.[14] In a traditional treatment relationship, as defined within a clinical model of recovery,[15] the power and control remains with the mental health practitioner with the assumption that this individual knows what is best,[16] and the service user is disempowered.[17] Co-production is fundamental to recovery colleges[18], which requires active participation from all recipients enabling an environment where skills and experiences can be exchanged, as well as building on existing capabilities.[19] Recovery colleges often employ a small team of peer workers (who commonly have lived experience of mental illness) and mental health practitioners, with a larger group of peer trainers and practitioner trainers from mental health services and community agencies who deliver aspects of the curriculum.[20]

Co-production, like recovery,[21] is a contested term because of its 'definitional ambiguity.'[22] This vagueness in the definition is problematic, and there have been calls for greater clarity in forming a universal theoretical definition due to the concept being over-used and over-stretched.[23] Nabatchi et al.[24] listed thirteen different definitions of

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co-production within studies published between 1980 and 2016, but helpfully developed typologies for recognizing some of the important differences to consider. Firstly, the diversity when considering co-production at an individual level (e.g., a service user and practitioner working together on a care plan), group level (e.g., service users, staff, carers, and volunteers working together on a project, potentially developing a recovery college), and collective level (e.g., changing culture at a macro-level, such as working to embed co-production across a large mental health Trust). Furthermore, co-production can be conceptualized and practised at different stages of a process, for instance, when co-commissioning, co-designing, co-delivering, or co-assessing.[25] A criticism of co-production is the lack of a clear and consistent understanding of co-production processes, and how they are implemented into service delivery; nevertheless, it has been found that many organizations lacked both structure and procedures to facilitate genuine co-production.[26] Depending on the specific context, the highly flexible nature of co-production could be viewed as a strength or a weakness,[27] although advocates of co-production would argue conceptually and practically it has the potential to transform the way services are delivered and systems are structured.[28]

Given the challenge to enable co-production across large organizations, it could be argued that recovery colleges are a specific site within the broader system where co-production can be undertaken, to facilitate the acquisition of knowledge to enable culture change towards shared learning opportunities.[29] Establishing co-production and a shared learning environment should be the first aspects to focus on when developing a recovery college.[30] An empowering environment and shared learning have been found to be key mechanisms for action for recovery college learners to gain positive outcomes.[31] Learning in a shared environment should allow learners to be themselves, rather than wearing a label of mental distress,[32] and contributes to addressing stigma and discrimination.[33]

Research Design and Methods

In recognition of the values of co-production and lived experiences, this study sought to explore and value[34] the experiences of the service users, staff, carers, and volunteers (volunteers were individuals outside of the Trust who gave their time in the advisory group to help set up the recovery college) who were involved in the development and early establishment of a recovery college in a large mental health Trust in the UK. This inclusive basis for the study aimed to value the contributions of the different participants equally, especially as, for instance, carers are often not listened to or involved in mental health treatment or practice.[35] In order to explore the in-depth experiences of those involved in this particular phenomenon, an Interpretative Phenomenological Analysis (IPA) was undertaken. The aim of IPA is to focus upon people's experiences and to develop an interpretation of their perspective and understanding of a particular phenomenon[36], in this case the recovery college. Semi-structured interviews are considered a common approach to qualitative data collection and have been used successfully in a significant number of mental health-related studies[37], and so were considered a suitable method to employ. For the analysis during this study, IPA guidelines as outlined by Smith, Flowers and Larkin[38] were

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adopted and used flexibly, as the generalizability of existing literature on IPA analysis does not prescribe a single method for working with the data.

All participants for this study were recruited via purposive sampling[39] through the Recovery College Advisory Group (i.e., the group acted as a gatekeeper to advise who might be suitable for an interview). Aside from having to be over the age of eighteen, there were no specific inclusion or exclusion criteria relating to gender or other demographic factors, only that they were involved as either staff, carers, family members, volunteers, or service users in the development of the recovery college. In total, 25 individuals were interviewed during this study, of which four identified as service users, four described themselves as having a dual role as both service user and member of staff, two participants were carers who also had a role within the Trust, two participants were third sector partners and considered themselves volunteers, and the remaining participants identified as staff within the Trust.

In the early research design phase, the research team met with the SureSearch group of service users (suresearch.org.uk) to discuss the proposed study and gain feedback and suggestions from the service users (and carers and Trust governors) prior to seeking ethical approval. This helped to ensure the project valued the (potentially) different experiences of service users, carers, volunteers, experts by experience, and family members as well as the staff members; and to value actively listening to people and their stories. In addition to receiving ethical clearance from the University ethics committee, the study also received full ethical clearance from the National Health Service (NHS) Integrated Research Application System (IRAS) (project ID 226545). A distress protocol was provided within the participant information sheet in case a participant was distressed by any aspect of the process, and all interviews were conducted on an NHS site with clinical staff present in the building. Given the nature of the study, it was not envisaged that these precautionary steps would be utilized (which was, in fact, the case).

Results

Data analysis revealed a number of different over-arching themes; however, this paper focusses on three key themes: 1) co-production; 2) lived experience; and 3) shared learning environment, which shall be discussed in the following sections.

1) Co-Production

In general, all participants shared a similar narrative regarding their understanding of the term co-production, which is a key feature of the recovery college's approach. The following excerpt is indicative:

> "When we design or facilitate anything, we do it in partnership rather than in isolation with people who have a different experience or wear a different badge to our own. If we involve people from different experiences, whether that be gained from employment or life experience, when we co-work and co-design we take on a broader range of views that allow us to create and offer something

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> that is much more broad and encompassing of people's experience." (Participant 18)

Other participants similarly reported how "co-production is about having an expert by experience involved in and having an equal opportunity to develop and create a session" (Participant 20); and also, that "co-production or co-design, whatever you label it, as [it] entails equal representation from both parties from design stages to the delivery on a level playing field" (Participant 10).

Some participants commented on how they were unfamiliar with the term prior to becoming involved with the development of the college and hence had adopted the college's discourse of how the term was understood. One participant noted that "I didn't actually understand what co-production was until I become directly involved in the college" (Participant 11). This aspect perhaps demonstrates the potential for the broader benefit for the organization, as via development of the college the philosophy of co-production can be shared and discussed and thus can disperse across the organization. When asked about co-production and how it's implemented within the recovery college, participants shared mixed perspectives on the incorporation and facilitation of co-production:

> "I'd love to say that every session is created equally with two minds coming together to create something that is co-designed, [but] they just aren't. Red tape and deadlines often prevent true co-production from occurring." (Participant 8)

This highlights the barriers to changing services and culture in terms of co-production, and furthermore, it was highlighted how on occasions the co-production process is not well understood outside of those involved in the recovery college:

> "We definitely try to encourage co-production within all sessions delivered within our recovery college. However, I'd be lying if I said that happens every time. We're often approached by facilitators coming to us requesting an expert by experience once everything is done. This defeats the purpose of co-production." (Participant 3)

> "There are varying degrees in terms of co-production. Some people will be more vocal than others. I feel co-production doesn't have to be 50/50. It's the level of opportunity being offered that I would be more concerned about rather than saying that everything has to be unpicked and reproduced." (Participant 5)

These points raised by participants highlight the importance of the concept (or philosophy) of co-production, as well as the ambiguity in the precise definition (especially within differing contexts) as has been outlined previously.[40] The data also highlight the consideration needed of the practicalities required to integrate the approach for it to be more than 'just a token gesture,' which leads on to the further themes of lived experience and creating a shared learning environment.

2) Lived Experience

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A common theme discussed was lived experience, highlighting its significance within the recovery college framework, as "a mechanism that can not only enrich a learning experience but provide valuable insight that can't be gained from a textbook" (Participant 13). Other comments supported this perception:

> "At the heart of a recovery college is lived experience and this is what is used to assist learners in empowering and building hope and confidence." (Participant 11)

> "You need to be able to connect to your audience and provide personal insight, and showing your vulnerabilities is one way of doing this." (Participant 14)

> "Knowing that someone has experienced something similar to me is so empowering." (Participant 19).

> "Input from individuals with lived experience can assist in providing a platform for continual monitoring, as well as challenging discriminatory attitudes." (Participant 4).

It was evident throughout the data that lived experience aligned very well with the broader recovery college ethos and obviously can be viewed as being a central component of recovery-informed services or models (which can, and arguably should, be formalized into service practice via co-production). Several participants spoke positively on how peer support can complement the recovery college model:

> "It's nice for service users to come in and see a peer support worker who is able to relate and has been on that recovery journey themselves. Also, often they can pick up on signs that others may miss." (Participant 11).

One participant who has transitioned from service user to peer support worker expressed how peer support was

> "[a…] transformative experience that was being witnessed by my care team. People were learning from me and they were able to witness first-hand that the recovery-focussed practice promoted by the recovery college was changing and developing me." (Participant 13)

However, it is important to note that the data demonstrated challenges with incorporating those with lived experience into the recovery college during the delivery phases. It was also highlighted that recovery is very much unique to each individual and, although lived experience narratives enable hope and opportunity, they can inadvertently have a negative impact for some:

> "I've been in a session where it's obvious that the person with lived experience is unwell. How are they meant to help me when they are struggling themselves?" (Participant 2)

> "Just because they've made progress doesn't mean they have to rub it in my face. I felt I was being held to that standard." (Participant 20)

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> "As a carer, although lived experience gives me hope that everyone with mental health can recover, when I look at my own child and the lack of progress they make, I can become very enraged and bitter. I'm sorry my child can't be that poster child you've got on display at the front of the classroom." (Participant 25).

The data suggests that it remains a challenge to ensure that both the college and the individual sessions are socially inclusive and can meet the needs and expectations of a diverse group of people, and Thériault et al.[41] called for this to continue to be a focus for future research. The above findings highlight that those facilitating the involvement of individuals with lived experience need to be mindful that with the benefits comes the requirement to remain mindful and supportive within the shared learning environment.

3) Shared Learning Environment

> Participants' perceptions of the college environment were generally positive, and many commented on how it was evolving and adopting an educational practice identity in the early development phase. For example, one participant illustrated how "everyone present works together to create an environment of transformative change, as we are all on an equal footing" (Participant 8). Another described how the college creates "a collaborative working environment focusing on strengths and not weaknesses" (Participant 17).

Many participants highlighted advantages of the shared learning environment:

> "Lived experience is an amazing resource to provide insight and enable change in one's life, ideas are shared without fear of judgement, and this can combat addressing stigma linked to mental health." (Participant 5)

> "Some of the sessions I've attended have helped me regain my control, helped in breaking down stigma, and I feel that I'm able to contribute and that I'm more than just an illness." (Participant 22).

Another participant described how "I thought it was going to be a taught session, but this was a new kind of learning I've not experienced before" (Participant 24). One participant shared that

> "…after the session, I overheard one of the students talk about how what they learnt helped them become more informed and they were going to adopt a new way of working with patients….I didn't know until then that he was a nurse." (Participant 20)

The above comment in particular sheds light on the underpinning ethos of the early stages of the recovery college where as service-users, staff, carers, and volunteers attend sessions but without those 'labels,' so instead it is a room full of learners together focusing on a topic/workshop. Participants also commented on the evolving

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roles of staff and service users affiliated to the recovery college within the shared learning space:

> "I never saw myself as an educator. Suffering with mental health and the stigma associated to it, how could I possibly think that my story would be beneficial for others? It was only once I shared my story and was able to witness the transformation of minds and thought that I was able to make that connection." (Participant 10)

> "It's strange how my working environment, that was highly influenced by the clinical model is slowly evolving. Some days it feels more like a college environment than a mental health service. A shared learning space where everyone adapts to the role of both a learner and an educator." (Participant 1)

> "I really like how the college describes everyone as students. It doesn't matter what your role is outside of the college, when we're in the classroom everyone is a student, even the teacher. I'd even go as far as describing others as teachers too, as we all have lived experience that when shared could be beneficial in the right circumstances." (Participant 7)

Some participants shared some of the disadvantages of trying to create a more inclusive pedagogical environment where students and teachers learn together incorporating real life examples via the lived experience platform. One participant felt that "some students were using the sessions as a form of personal therapy, and this prevented others from engaging in sessions" (Participant 8). Another commented on how "some people can have very loud personalities and try to take control of a session when there isn't a strong control presence" (Participant 9). Whilst this could be true of any learning or educational environment, it is again important for facilitators to keep these aspects in mind in the development and delivery phases of establishing their college.

Conclusions

Co-production and learning were identified as foundational components of a recovery college,[42] and this study found that co-production was present from the start of the development process, facilitated by a co-produced advisory group (consisting of service users, staff, carers, and volunteers) to plan and design the college, who then continued as an advisory group through the delivery phase and beyond. The group met collectively each month and had a co-chair with lived experience, and the underpinning philosophy of co-production was discussed regularly in the meetings from the planning stages of the college onwards. Often in the meetings, there would be small-group workshop style activities that were designed to encourage shared discussions on how the philosophy of co-production could be manifested into the practicalities of the recovery college that was being designed. The data suggested that, when it came to co-producing the actual sessions, in the early stages there were limitations on how practicalities and bureaucracy restricted the co-production at times. This highlights the point that there are both philosophical and practical considerations

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for co-production when developing a college to consider at all stages, as co-production can be conceptualized and operationalized at different stages, when co-commissioning, co-designing, co-delivering, or co-assessing.[43]

From the data ,it appeared that having the initial advisory group (that then continued meeting once the early delivery phase had begun) enabled a space for ongoing discussions and concerns to be shared, and an opportunity to work together for group members when there was a clash in terms of the philosophy of co-production versus the practicalities of making it happen (such as time, specific expertise required, meeting availability, and resources, to name just a few of the potential hurdles to negotiate). Participants reflected on the challenges that emerged during the early stages of the co-delivery stage of co-production of the college. For example, although there exists an ethos of co-production within the college, it can be argued that, outside of the college (organizationally), the Trust lacked understanding of the processes required for achieving genuine co-production. Interviews highlighted some challenges in setting up this new co-production model, as participants shared how scheduling commitments, budget constraints, and the design processes made it difficult to keep to timescales in some instances. This data indicates that from an organizational perspective such shortcomings are a possible result of the lack of financial investment made and still needing a change of culture towards co-production at a macro-level.

From the outset, the findings are indicative that the college itself appeared to have achieved an understanding of the mechanisms related to co-production, as the data provided insight that most courses are collaboratively designed through a visible relationship between the co-facilitators. This suggests that the design and early delivery of the college demonstrated co-production at a 'group' level,[44] but there is still work to do to implement co-production at 'individual' and 'collective' levels of the organization, which supports previous work[45] that suggested that colleges could develop and operate somewhat separately from their host organization. However, when utilized 'correctly,' co-production can aid in creating skills and capabilities that can then be embedded back into communities and aiding in the transformation of mental health services, and so the initial embedding of co-production within the Trust (via the college) could potentially act as a catalyst to spread a co-produced approach across the organization over time, as many participants reported learning more about co-production from being involved in the college.

The co-production at the design phase of the college, as well as the early delivery phase, has demonstrated clear use and appreciation of lived experience, helping to demonstrate the value of equity between staff and those with lived experience,[46] further showing that individuals who access mental health provision are not 'drains on the system' but rather hidden resources. One of the ways this was frequently discussed by participants was through the sharing of lived experience narratives incorporated in many of the Recovery College's courses. As previous literature has shown, recovery for individuals suffering from mental illness does not occur in isolation[47] but rather recovery is closely associated with social inclusion where opportunities are provided to develop and create meaningful and satisfying social roles within local communities,[48] as opposed to in segregated services. The opportunity to

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consider different perspectives and hear lived experiences was highly valued by attendees and offered something unique. Hope is a central process for recovery[49] and can be enhanced by each person seeing how they can have more active control over their lives and by seeing how others have found a way forward. This learning experience could result in a positive impact personally for students, including, but not limited to, increasing confidence[50] or self-esteem,[51] creating opportunities for meaningful interactions[52] and challenging attitudes of (self-)stigma.[53]

A shared learning environment is not an easy thing to create, as the results highlighted the challenges of still having some of the power dynamics from the pervasive, historical clinical model approach of the health services, and managing expectations and some behaviours during the early delivery phase of the college. However, overall, participants were positive about the environment created, which was facilitated and informed by the values of co-production and valuing lived experiences.

Connectedness has also been highlighted as a key process for recovery[54] in various contexts,[55] [56] [57], and the data suggested that the recovery college did facilitate connectedness and people interacting and developing social networks,[58] regardless of whether they are service users, staff, carers, or volunteers. Nevertheless, for those seeking to create a recovery college, it is important to consider the cultural context of recovery and the interpretations of people, as what constitutes connectedness or hope for one person is not necessarily the same for another[59]. Managing expectations (for instance, as with the data relating to expectations being raised by listening to peers who might be at a different stage of their own personal journey) within a recovery college may be simultaneously challenging and beneficial across a particular group.

Overall, this study has contributed to the limited but growing literature related to recovery colleges,[60] especially relating to the early design and development phase, and has included and combined the experiences of the service users, staff, carers and volunteers involved in co-producing the design and early delivery phases. Future research in this area should seek to appreciate the nuances and idiosyncrasies of the different contexts and cultures that might fall under the umbrella term of recovery colleges, not just focus on fidelity[61] or what they have in common. There are three key recommendations for those seeking to develop their own recovery college i) co-production is essential, but there are both philosophical and practical considerations; ii) lived experience is *valuable*, but it needs to be *valued* and supported in both the recovery college and organizational context; and iii) the shared learning environment and educational approach of the college is vital and needs equity of opportunity between the service users, staff, carers and volunteers involved.

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