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Experience based co-design reduces formal complaints on an acute mental health ward

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Abstract

An acute mental health triage ward at Oxleas NHS Foundation Trust was attracting high levels of formal service user and family complaints. The Trust used experience based co-design to examine the issues and redesign procedures. This resulted in an immediate eradication of formal complaints for a period of 23 months. This paper describes two outcomes: firstly, the successful adaptations made to the experience based co-design methodology from its origins in physical care, in order to ensure it was safe and effective in an acute mental health setting; and, secondly, the changes made to the ward as a result of this quality improvement intervention.

Problem

Studies consistently show that, while there are pockets of good practice, acute mental health wards are often frightening places to be for service users, and stressful for staff.[1,2] Acute wards are often people's first point of contact with secondary mental health services, and experiences there can shape the nature of future engagements with a service. Acute ward staff experience high levels of violence and complaints, with 49% reaching the threshold of burnout or emotional exhaustion, resulting in sickness and retention problems.[3]

Oxleas NHS Foundation Trust provides secondary mental health and community services in south east London. In 2011 there was concern that a particular acute mental health ward (Betts), which offered triage for its two neighboring wards (Goddington and Norman), was attracting high levels of formal complaints from service users and families. Triage aimed to assign patients according to need, offering an approach which assessed patients quickly in order to form an accurate care plan, involving either discharge to community based treatments, or transfer onto neighboring wards for an inpatient stay.

As is typical of complaints made in acute ward contexts, many concerned problems deriving from staff attitudes and communication. Investigations using the Oxleas Patient Experience Questionnaire offered a more detailed view of patient experience in the study setting.[4] Positive comments were received in the study, with many staff being described as friendly and helpful; the attention given to patient safety was valued by many respondents. Conversely, where there were problems, the main themes were:

- A need for more one to one time with staff

- An overwhelming focus on medication

- A need for more psychotherapy

- Service users should be able to go out on their own after a week

- A dislike of being locked out of bathrooms

- A lack of communication from staff to family following admission.

Background

The collection of data in and of itself is not sufficient to deliver improvements in the quality of care.[5] The Trust had implemented a number of management interventions to address the issues outlined above, but these had achieved minimal impact. At the end of 2011, the Trust became aware of positive evidence relating to an approach to quality improvement called experience based co-design (EBCD). EBCD is an approach to improving healthcare services that combines participatory and user experience design tools and processes to bring about quality improvements in healthcare organisations. Through a "co-design" process, the approach involves staff, patients, and carers reflecting on their experiences of a service, working together to identify improvement priorities, devising and implementing changes, and then jointly reflecting on their achievements.[6] As explained elsewhere,[7] four overlapping strands of thought have contributed to the development of the EBCD approach, namely:

1. Participatory action research
2. User centred design
3. Learning theory, and
4. Narrative based approaches to change.

User centred design offers two particular contributions to quality improvement thinking in the healthcare sector: a new "lens," or frame of mind, through which to think about approaches to improving patient experiences of healthcare, and methods, tools, and techniques (such as modelling and prototyping) that were little used in healthcare improvement work until recently.

The EBCD cycle is divided into six stages: (a) setting up the project; (b) gathering staff experiences through observational fieldwork and in depth interviews; (c) gathering patient and carer experiences through observation and 12 to 15 filmed, narrative based interviews;

(d) bringing staff, patients and carers together in a first co-design event to share, prompted by an edited 20 to 30 minute "trigger" film of patient narratives on their experiences of a service, and identify priorities for change; (e) sustained co-design work in small groups formed around those priorities (typically c-e); and (f) a celebration and review event.[8] By the summer of 2013 at least 59 EBCD projects had been completed or were being implemented in six countries: UK, Australia, New Zealand, Canada, Sweden, and the Netherlands. The projects had been undertaken in a range of clinical services, but these were predominantly related to physical health rather than mental health. Approximately 90% of respondents to an online survey stated a strength of their EBCD project(s) was that it "really engaged patients."[6]

Oxleas was interested in applying EBCD on the ward which was attracting high levels of complaints. However, the involvement of service users in mental health has some defining features which differentiate it from the physical health domain. These indicated that additional processes might be needed, to make the EBCD process safe and effective in an acute mental health setting. Firstly, EBCD asks for user perceptions of events. Repper and Perkins summarised that the mental health service user voice had traditionally been neglected in research and policy, due to an assumption of “lack of insight.”[9] Notably, most long term mental health studies had not used outcomes valued by service users.[10] Secondly, EBCD requires some equality between professionals and service users when they are brought together. However, the power differentials in mental health are highly complex in this respect. For example, mental health practices uniquely have impacted on civil liberties. Regarding user professional power relations, it is hard to imagine other branches of health which have organised movements defining themselves as surviving the treatment offered to them, as opposed to the condition they present with. EBCD uses patient stories to create change, but patients in Canada have reflected on the "appropriation" and over-reliance on the psychiatric patient “personal story” by professionals, raising ethical concerns about how the emotional power of people’s life stories can be harnessed in the service of professional interests.[11] Therefore, while Oxleas was keen to use EBCD to improve the ward experience, the Trust was also aware several aspects of the approach would need to be adapted if the project was to deliver not only positive service outcomes, but also a good experience for participants.

Fortunately, Oxleas had previously established a co-production research network called ResearchNet. This involved a network of linked groups where professionals and services users could consider how lived experience might improve mental health services.[12] ResearchNet had become a core aspect of the Trust’s approach to the patient experience component of the quality "tripod". Co-production requires different parties to work together with equality, while still retaining the breadth of perspectives each party brings.[13] ResearchNet offered some insight into the navigation of these sensitive issues for the EBCD intervention on the acute ward.

An initial ResearchNet study focused on the experience of one member who, while working professionally as an art therapist, had required an admission to the mental health ward that was being considered for EBCD.[14] This earlier study offered some indication about how difficult, yet ultimately essential, it is for staff, when constructing their treatment response, to have an understanding of the importance of what happens to a person when they experience a mental health crisis. While the experience of the crisis was emotionally vivid, it was difficult for the individual to recall in a narrative form, and very challenging to move beyond a sense of shame (similarly painful emotions were encountered several times in the later EBCD project), as described by the service user: “Imagine finding yourself on an acute ward when you’re at your most vulnerable, distressed and completely disempowered. Wherever you are you can’t be there, yet you need a place of safety. You are there because of you, the person. We talk about finding the person in the patient, but in acute mental health the person is the patient: the very things that make you who you are, are in chaos. Your feelings are overwhelming. You can’t communicate in the way you are used to. You’ve essentially lost who you are, but worst of all, you are aware of it which is horrendous. Then you come to the ward where staff are in a powerful position. You’re in a locked ward; personal items are taken from you for your safety and the safety of others. This is a highly challenging environment where staff are in constant demand, and you feel a useless burden. It is a trauma upon trauma upon trauma. No wonder none of us had spoken about it, and when we did it was so upsetting at first.”

In this earlier study, Woods and Springham overcome these issues by holding several preparatory meetings, using a timeline to structure an interview. This, and the fact the narrative interview was conduced within an established relationship, was central in overcoming the profoundly "silencing" difficulties described above, indicating some new procedures which could be added into the implementation of EBCD in an acute mental health setting.

Summary of problem

Problems between staff and service users were mounting on a particular ward, but previous quality improvement interventions had had little impact. A combination of EBCD and ResearchNet offered the potential for a viable intervention. However, the adaptation of EBCD to the acute mental health setting required consideration, primarily because service user experience had not typically been used to co-design acute mental health services. In addition, service users could experience fear and shame in offering their experience, posing a risk to their mental well being.

Baseline measurement

The baseline measures used were the formal complaints featured in figure 1.

Design

The Oxleas project used all phases of EBCD, as described in the free to use toolkit available on the Kings Fund website (http://www.kingsfund.org.uk/projects/ebcd, accessed 13 July 2015). An important early adaptation to the approach was to build in

additional preparation time for service users who consented to being filmed while telling their personal stories. The team decided to only recruit from within ResearchNet members who had left the ward at least 18 months previously, allowing the group to support people pre- and post-interview. ResearchNet members also had control of all aspects of the filmed interviews, including devising consent forms, data protection protocols, and reaching agreement on the editing of the films. The films were categorised into emotional "touch points" in four subject areas:

1. Admission
2. Applying "blanket" rules (such as removing personal items)
3. Establishing the basic needs of users of the ward
4. Tackling conflict between service users and staff.

A very high level of support was needed in ResearchNet to prepare for the joint event, as service users were worried about adverse reactions being triggered by meeting staff, and a fear they might need to be readmitted to the ward at some point in the future. At the joint event staff were deeply moved by the films, and some were in tears. It quickly became apparent that service users had prioritised basic needs differently from staff. Where staff had prioritised making sure new admissions to the ward had received a care plan, diagnosis, and medication, for example, service users all prioritised communication with staff as the most important first intervention. Some staff admitted the constant demands made on them through the repetitive processes involved in acute wards had obscured their value as people, to patients. Revealing how devalued both some staff and service users had come to feel due to the ward procedures gave both managers and clinicians material to reflect upon. The trigger film had a high impact in terms of improving the tone of the meeting between the two distinct groups of service users and ward staff, and undoubtedly increased cooperation in discussing these issues.

The joint event led to the decision that any future co-design of the ward environment and processes would need to foreground human communication, which had perhaps been taken for granted in routine procedures such as admission, or application of "blanket" ward rules.

Strategy

Key work streams

EBCD allowed service users' identified priorities to have parity with professional priorities. While triage had allowed professionals to thoroughly assess, and then allocate service users to appropriate treatment destinations, that two stage process added additional stress to service users who, at their most vulnerable moments, were required to communicate and build relationships with what was effectively two sets of professional strangers. In addition, the triage model grouped service users together at their most disturbed, which added to the anxiety and fear of those newly admitted, and to the stress on staff. The clarity of the service user perspective gained through EBCD convinced managers and clinicians that their identified needs would not be met by the existing triage system, and so this was abandoned.

A work stream instigated by the ward manager involved daily community patient experience meetings on the ward, which specifically asked about the emotional "touch points" highlighted in the films. Feedback received from service users was taken up in individual staff supervision sessions. This highly sensitive local feedback loop had the effect of helping staff to see how their behaviors and attitudes were being perceived by patients before matters escalated, potentially to a formal complaint. It is important to note that this feedback and these supervision sessions also included compliments from service users, which impacted positively on how staff rated the effectiveness of their communication as part of their clinical intervention.

In addition, ResearchNet and ward staff co-produced a "welcome to the ward" DVD. This involved complicated negotiations between providers and professionals about content at scripting levels, and how issues would be depicted. Staff described the process as “eye opening” in terms of seeing a new side to patients whom they had only previously met at their worst, ie in crisis. Service users described how enjoyable it was to encounter a more human and less distant "professional" side of the staff they had met on the ward. The making of the DVD also defined important details of what service users specifically valued in terms of communication from staff, when introducing them to the sometimes complex, and often frightening environment of the ward.

The EBCD process was continuous throughout the project, resulting in the action review cycle being undertaken numerous times. Complaints were reviewed each month at the Trust's patient experience meeting, and regular ResearchNet and ward staff meetings reviewed progress and decided on any further action that needed to be taken.

Results

Figure 1 shows formal complaints by month, for three neighboring wards over a period of four years. The red letters indicate the standard stages of the EBCD process as described above. Betts ward was attracting higher complaints than its neighbours, up to the point of the EBCD joint staff-user event where the films were first shown in July 2012. Betts ward then experienced 23 continuous months without any formal complaints following the EBCD intervention, which is a longer period than the two neighboring wards, Goddington and Norman, though they also experienced some reduction. Active EBCD work streams ended in March 2014.

As noted above, EBCD played an important part in abandoning the pre-existing triage system, and this clearly had an impact on complaint levels. However, figure 1 shows that the improvements in complaints achieved through EBCD did not merely return the ward to the standard of its two neighboring non-triage based wards, but actually resulted in the ward having the longest run without complaints of any of the three wards. It could be argued that the improvements should not be solely attributed to removing the triage system, but indicate broader improvements in the treatment approach as a result of implementing EBCD on the ward. The ward manager, Edward Kanu, described how although he initially felt skeptical about yet another quality improvement initiative being

implemented on the ward, the EBCD films and the co-production with ResearchNet were profoundly moving on a personal level; he attributed significant and lasting changes in his own practice resulting from this involvement with EBCD.[15]

See supplementary file: ds6064.png - “Figure 1”

Lessons and limitations

Key learning

Additional attention to the care and support of service user participants was needed in a mental health setting: a consistent support group for the duration of such projects would appear to be essential.

The pressures on ward staff and the quick turnover of patients meant many clinical procedures, particularly in admissions processes, had become overly routinised. Staff described this contributing to losing sight of the significance of their individual interactions with patients; the value that patients placed on this negatively affected morale. Service user feedback was central in restoring a more balanced sense of staff effectiveness, by reinforcing the importance of the relational aspects of their work. This created a virtuous cycle, where more effective interactions increased staff morale, which then further impacted on improving patient care.

Prioritising communication and relational aspects of care as defined by users resulted in no complaints on an acute mental health ward for 23 consecutive months. It can reasonably be inferred that formal complaints represent many problems at a lower level, and which were likely to have been similarly improved. In future studies we would recommend looking beyond formal complaints as a sole measure of impact. In this regard, it should be noted that an ongoing stepped wedge randomised controlled trial is currently evaluating the impact of EBCD on a range of validated measures in the community mental health setting.[16]

A limitation of our project was that complaints began to slowly rise as ResearchNet and the ward ceased actively co-designing, indicating that close, ongoing collaboration between recovered service users and ward staff may need to be a permanent feature on the ward. However, as is the case with most acute mental health wards, staff turnover is high, and so new staff did not have experience of the EBCD project, or contact with ResearchNet. Effectiveness of the EBCD approach appears to not only rest on the specific design solutions it produces, but also on significant levels of experiential learning for staff to implement those solutions competently. Some of the co-designed solutions were disseminated to staff from all three wards, though this did not result in as high impact or as lasting changes as on the target ward, which focused on implementing the full EBCD process. While the approach does seem to positively affect the culture of specific workplaces more than other quality improvement interventions which had been attempted in the study setting, it does require high commitment of staff time at all levels of the organisation.

Another limitation of our approach was that the project appeared to confer benefit only on those who took part; our study did not attempt to capture this systematically. The use of participatory co-design is unusual for clinicians in the NHS. It took time for staff to accept that EBCD was a design project and so was about the future, rather than an investigation seeking to apportion blame about the past. When the design process was embraced, it was enjoyed. The fact it was so different to normal ways of managing complaints seemed to allow staff to engage more creatively. Likewise, as many service users described, experience of acute mental health conditions which had so often made them feel like a problem were reframed by EBCD as a solution, and this had important implications for self worth and recovery. Given the relative novelty of co-design approaches in mental health settings, a better understanding of such mechanisms and potential risks may offer important parameters for increasing the likelihood of success in future EBCD projects for those who participate.[17,18]

Conclusion

The present study indicates that EBCD can improve the quality of care in acute mental health settings. However, to make the EBCD methodology safe and effective, it required adaptations from its typical use in physical care settings, specifically in terms of support for service user participants through an ongoing peer group. When these supports are in place, as in this case study, the experience can be very rewarding for both service users and staff alike.

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Declaration of interests

GR is one of the original developers of EBCD, and has been involved in the evolution and adaptation of the approach since the initial pilot project in 2005, which was funded by the NHS Institute for Innovation and Improvement. The Point of Care Foundation in London provides training in the EBCD approach, and both NS and GR contribute to this training.

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Ethical approval

The present study was exempt from ethical approval, as it was undertaken as a quality improvement design project. It used the experience of ResearchNet, did not involve changes to patient treatment, and was not a study on human subjects.