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How Could Co-production Principles Improve Mental Health Spiritual and Pastoral Care (Chaplaincy) Services?

Emily Wood¹, Julian Raffay², and Andrew Todd¹

¹ Cardiff Centre of Chaplaincy Studies, St Michael's College, 54 Cardiff Road, Llandaff, Cardiff. CF5 2YJ

²Corresponding author, Spiritual and Pastoral Care, Mersey Care NHS Trust, Indigo Building, Ashworth Hospital Parkbourn, Liverpool, L31 1HW

Abstract:

This report reflects on our experiences of using co-production in mental health chaplaincy research and how the lessons learnt can be applied both to research and to service design and delivery in the NHS. A panel of experts by experience was recruited to assist in planning and implementing a research project to explore service user views of NHS mental health chaplaincy (spiritual and pastoral care services). Both the panel and the interviewees provided clear insights into how services could be run in a more patient-centred manner, participants were thoughtful, usually realistic and considered in their suggestions. Recruitment was not difficult suggesting that mental health services users are keen to share their opinions on the spiritual care they receive. Eliciting views from service users in Trusts will show if our findings can be considered representative of the UK.

Keywords: Chaplaincy, co-production, spiritual and pastoral care, service user perspectives, mental health services

Background:

The UK Department of Health have made clear statements that 'it is not acceptable for organisations to see people as passive recipients of services; they must be seen as active partners' (Department of Health, 2001). However, there is a whole spectrum when it comes to levels of patient involvement in service design in the NHS (Slay and Stephens, 2013). They define co-production as 'A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities' . Researchers who have explored users' opinions of mental health staff report that they consider human qualities of warmth and sensitivity more important than specific therapeutic approaches (Chandley and Rouski, 2014, Forrest et al., 2000).

There are several reviews of the literature on co-production and service user involvement in mental health. Overall, they suggest it has the potential to lead to big improvements in patient experience. However they consider the evidence to be weak because of a lack of rigour in the studies reviewed (Doyle et al., 2013, Brett et al., 2012, Slay and Stephens, 2013). Slay and Stephen's (2013) work is the most relevant, specifically their 'doing with' approach which is the fullest form of co-production. They document both social outcomes and monetary impact of projects. Despite being an emerging area, they suggest the use of co-production in mental health can have a positive effect improving social networks and social inclusion, addressing stigma, improving skills, and employability. It may also prevent ill-health and improve mental and physical well-being outcomes. Unfortunately, they do not offer before-and-after comparisons that could evidence causation (Slay and Stephens, 2013).

The aim of our work was to explore how people who use mental health services would like to see spiritual and pastoral care/chaplaincy improved.

What we did:

As co-production is a key philosophy of the research team a public and patient involvement panel (the Panel) was recruited from the start. This consisted of six service users and carers from the NHS Trust, recruited by the Trust's Research User Carer Lead. The Panel was consulted and involved throughout the research process. They advised the interview questions, took part in pilots, decided which service user groups to recruit and offered insights for the analysis. The Panel met approximately monthly. Panel members were paid expenses when they attended.

The research was given a favourable ethical opinion by Haydock NHS Research Ethics committee.

What did not work as we hoped?

The findings of the research study itself have been described elsewhere (Raffay et al., in preparation), this paper is concerned with the experience of using co-production within the NHS and within research. One of the first obstacles the team found in having patients and public as key members of the research development team was with the research ethics committee. The Panel challenged the wording on the Consent Form suggesting auditors might have free access to the entirety of their records. This required returning to the ethics committee with a major amendment and explanation as to why we needed to change the standard wording.

The interview questions were originally developed with the Panel. However, as the constant comparative method (Charmaz, 2013) was used, the questions evolved over time with less input from the Panel. To follow the constant comparative method, a researcher must analyse the interview transcripts as soon as they are transcribed so that changes can be made to the interview questions for the next participants. This allows emerging issues which are important to the interviewees (but not necessarily recognised by the researchers) to be explored with other participants. Because the questions develop on the basis of the researcher's analysis of the data, involving the Panel would have been difficult. Analysing qualitative data is a complex task and requires training and access to patient data. A compromise was reached where the researchers presented their interpretations to the Panel. However, this meant that researchers' interpretation has already been imposed upon the data.

What we learnt:

It is possible, indeed advisable, to include service users and carers at all stages of research and of service design and delivery (NIHR, 2014). This can involve a Panel discussing service design or peer support workers subsequently delivering the service. As long as a proper training and support network is provided there is no reason why people with mental health issues cannot contribute to the services they receive. Although we recruited people for a funded research project, it does not need to occur in that setting. An existing group, such as a chaplaincy volunteer or a spirituality interest group, could be asked for their candid feedback and what they would like to see change (or importantly, remain unchanged).

All health care professions have theoretical debates about what their members should and should not be doing. Chaplains are no different from nurses or psychiatrists in this.

However, the answer can often be sought from the service users themselves. A simple example is whether ordained Christian chaplains should wear a clerical collar on wards. Our participants were clear that this was not only acceptable but actually preferred. They said it made the chaplain easy to identify but was also a symbol of trust and approachability. Although our participants were able to access regular Christian services weekly, many expressed the wish that this was on a Sunday, instead of Thursday or Monday. The quality of the service was not (generally) in question but the day of the week was. Some participants also wanted more ward staff on a Sunday morning to provide escorted leave to church. Individual chaplains will have little control over the last recommendation. They may be able to little more than advocate to nursing managers. Other wishes are well within a chaplains' ability to address and do not need additional resources. The full analysis of the interviews is described elsewhere (Raffay et al., in preparation).

Our participants highlighted both spiritual/religious and pastoral benefits of chaplain interventions (Raffay et al., in preparation). For example, the ability to talk openly to a critical friend was highly valued. Participants felt it was easier to talk to chaplains than other staff as chaplains did not have any 'ulterior motives'. However, the key message was that there was no healing without spiritual healing and that healing was a gift from God. Although other mental health professionals were respected for the work they did, the participants were clear that if their spiritual needs were not met, they would either heal much more slowly or not at all. This has led us to recommend the NHS adopt a more holistic bio-psycho-social-spiritual model care (Raffay et al., in preparation).

Lessons for the future:

Co-production has the potential to improve services by allowing services to be patient centred. Our participants described spiritual care as 'integral' to their treatment within the NHS. Due to the reluctance of Spiritual and Pastoral Care (SPC) departments to engage with research in the past, there is little that can be described as evidenced based research to sustain SPC funding. Indeed some have called for SPC funding to be withdrawn from NHS structures (NSS, 2012). Co-production gives a voice to under-represented mental health service users and provides a counter argument to the National Secular Society. For the participants SPC was an essential service and one that compliments other departments. As one remarked, psychologists might be able to teach you different ways of thinking and behaving but it is the Grace of God that gives you the motivation to actually do it. This corroborates American research that religious faith plays an important role in healing the whole person (Koenig and Al Zaben, 2013).

Co-production was not difficult or time-consuming. The difficulties we had encountered were mainly around IT approvals for research and would be less apparent in service design/evaluation situations. Our experience was situated within Mersey Care NHS Trust. Merseyside is not demographically representative of the rest of the UK, having higher than average levels of deprivation and Christian religious affiliation. Until this work is repeated in other Trusts, we cannot assume the views of our participants are the views of mental health service users nationally. This would not require a formal research study but could simply involve minuted conversations with service user volunteers.

Conclusions:

Service user suggestions for and comments on spiritual and pastoral care were thoughtful and considered. In the main they were realistic and reasonable. Participants were keen to

share their experiences and discuss what had been helpful to them, as well as insightful suggestions for improvements. Although some suggestions would require significant financial investment (such as extending chaplaincy to carers and community teams), others could be met within existing budgets (ensuring service users were given sufficient information about services and identifying chaplains more easily). The exercise gave evidence for the importance of spiritual care to a substantial proportion of service users.

Using co-production in service design and delivery is not difficult. It can lead to a better service, more focused on the needs of patients and carers. NHS policy (Department of Health, 2001) favours service user involvement and SPCs can be examples of good practice in this area as they are small departments which can be responsive to change.

When planning co-produced research, a longer time scale for analysis must be included. So too must research training for panel members. Some of our members found the research concepts difficult. This is not unique to our research group, nor is it surprising, research uses a range of jargon and specialist terms and methods that the non-researcher is not used to.

Author contributions:

JR conceived the study and lead on the co-production, interviewing, and study design. EW undertook some interviews, transcribed the interviews, analysed the data, and drafted the manuscript. AT took part in the study design, cross-checked data coding and analysis. All authors read and approved the final manuscript.

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