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RESEARCH

'Slow co-production' for deeper patient involvement in health care

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SUMMARY

"Slow co-production", achieved by involving patients in in-depth research, can help deepen patient involvement in health care. Using our participatory qualitative research project, *This Sickle Cell Life,* as a case study, we describe how slow co-production offers a specific and mutually beneficial form of patient and public involvement and engagement (PPI/E). As well as generating in-depth qualitative data for researchers, slow co-production can generate high-quality, patient-centred knowledge to inform service improvement and to allow examination and reflection on the co-production processes and relationships themselves. All of these outcomes can deliver benefits for patients, their parents and carers, and health services.

Key Words

Patient involvement; co-design; co-production; qualitative research; quality improvement

ABSTRACT

Background

Co-production and co-design are increasingly popular terms in health care, policymaking, and research. During these processes, essential, patient-centred knowledge can be co-produced.

Aims

We discuss how "slow co-production" is an underused but valuable tool for co-production in healthcare design.

Method

We present our research project, *This Sickle Cell Life,* as a case study. This project is an ongoing qualitative exploration of healthcare transitions for young people with sickle cell disease. The research is co-produced with affected young people, their parents and carers, and other stakeholders.

Conclusion

Slow co-production, which entails involving patients in qualitative, in-depth research from the start and throughout the project, can deepen patient involvement processes within health care. A powerful, currently underused technique, slow co-production reveals the nuances of the specific setting and context of health experiences, and develops transferable patient-centred knowledge that can be applied elsewhere.

BACKGROUND

"Co-production" and "co-design" are increasingly popular terms in health care, policymaking, and research. We have previously defined co-production as an "exploratory space that brings together different values and social relations";[1] co-production can generate meaningful ways of shaping and taking part in health care.[2,3] Co-production and co-design have a central role in National Health Service (NHS) service reform in the United Kingdom, with the revised mission statement of the health service emphasising "patient-centred" care.[4,5]

Similarly, co-design is defined by the NHS as a form of "shared decision making",[6] providing a way to realise the "full potential" of patients in healthcare settings, with the aim of making "patient-centred services a reality".[7] What co-producing knowledge in the context of patient and public involvement means in reality, however, is less certain; this paper offers some insights into how it might be practised.

Healthcare service planning is often based on survey data and supposition about what the target group needs,

rather than in-depth understanding of the wider factors influencing health and health behaviours.[8] Further, patients, particularly children and young people, are often "only given a passive role with staff making all the decisions" in terms of how to improve services,[7] and meaningful involvement at earlier stages such as study design is even less embedded. Where top-down planning models dominate and where there is a strong emphasis on quantitative data—the situation in most healthcare service delivery settings—there is little scope for patient voices or patient participation in service planning or priority setting. Children and young people may be particularly excluded, and we focus on their needs here because of our work with this group.

We propose what we term a "slow co-production" approach to help address this problem. We see slow co-production as a process of in-depth qualitative research that involves the patient from the earliest planning stages such as project proposal development and funding applications, through data gathering and analysis, to practical and policy outcomes. Presently, it is not typical to consider this type of qualitative research as a way of practising co-design, and we would argue that this should change. Borrowing from the terminology of the "slow science" movement, a "slow co-production" approach helps emphasise participatory thinking and practice[9] and generates knowledge that is deeper and more responsive to the wider social context and the changing temporalities of children's and young people's health and lives. The 'slow' approach is particularly important given that a condition like sickle cell receives markedly less attention than other long-term health disorders.

The deeper knowledge that is generated through slow co-production can in turn help researchers and clinicians to design child and youth-centred health services and health promotion strategies, and help us make progress towards better, human-centred design in healthcare.[10] A slow co-production approach can help to develop more sustained and personalised engagements, and improve understanding of how children and young people experience health care over time. From this deeper engagement, such an approach can involve children and young people in dynamic processes that go beyond shallow or "lip service" involvement.

In previous research, we have examined some of the differences between tokenistic involvement and more valuable forms of co-production.[1,11–14] The notion of co-production of value and services in health care "cannot be dissociated from the values and implications of co-producing knowledge or the meanings of participation as a social and political process".[1] We examined what co-production actually means and what exactly it is that is being coproduced.[1] Here we build on that work in order to attend specifically to the new forms of knowledge that emerge out of co-production processes through "slow", in-depth and participatory qualitative research with young people with a long-term health condition. The different dimensions within this knowledge—embodied, affective, and experiential—contrast with the traditional large-scale, quantitative survey knowledge more often used in researching health conditions. In our in-depth qualitative research project, it is health-related knowledge that is being co-produced. To illustrate this point, we will discuss a specific slow co-production project, *This Sickle Cell Life*, in which we explore young people's experiences of living with sickle cell and of transitioning from child to adult health services.

METHOD

We use as a case study our UK-based, National Institute for Health Research (NIHR)-funded, patient co-designed project, *This Sickle Cell Life*, to illustrate how slow co-production is being built into our work with young people. There is little research on how social context mediates transitions between children's and adults' healthcare services for sickle cell. This lack of information hinders delivery of quality health care for young people. *This Sickle Cell Life* aims to increase knowledge around the "neglected area"[15] of transition care by conducting an in-depth examination of young people's experiences of moving from child to adult services. The project explores the experiences of children and young adults aged 13–21 with sickle cell as they transition from child to adult NHS services, taking a holistic approach in order to examine how these experiences are integrated into their whole lives beyond the clinical setting.

This Sickle Cell Life was conceptualised and designed with the patients and patient representatives we encountered during an investigation into patient involvement in sickle cell healthcare improvement, part of our work with the NIHR Collaboration for Leadership in Applied Health

Research and Care (CLAHRC) for Northwest London. We collaboratively designed *This Sickle Cell Life* with people with sickle cell and their carers from the earliest proposal and planning stages. Forty-eight young people in London and another large UK city participated in the research. The study was approved by the appropriate London School of Hygiene & Tropical Medicine and NHS research ethics committees; participant transcripts were anonymized; and we provided young people involved in the study with information on referral agencies should they need help with issues raised in an interview.

Our in-depth, qualitative research includes repeated interviews (80 in total) and participant diaries (completed between interviews) with young people with sickle cell, to facilitate prolonged, contextual, and more personalised engagements with participants. We also interviewed healthcare providers across paediatric, transitional, and adult services for young people with sickle cell. During this process of co-producing knowledge via in-depth qualitative research, patient and carer representatives continued to participate, from helping to design research tools, to analysing and interpreting findings. We are working with them and with other stakeholders (patient charities, clinicians, service improvement experts) to co-produce support resources based on our study findings.

RESULTS

Our work on *This Sickle Cell Life* shows how co-production can support and shape qualitative research. Co-producing research "slowly" allowed conceptual space for deeper reflection and analysis, as well as time to build the relationships necessary to engage patients in knowledge co-production. Taking time to analyse the different elements of the interview account, such as reported speech or participant non-verbal behaviours, has helped us to generate broader observations about the social processes, contexts, and relationships that underlie people's accounts. Conducting in-depth interviews on young people's "home turf" and adopting an open approach that allowed them to elaborate on issues that were important to them, has also produced highly contextualised insights with all the additional depth that doing so allows us to capture. Repeated interviews helped us capture changes over time, including deeper insights into the fluctuating nature of participants' condition.

Our "slow" co-production involved more than just qualitative interviewing. Interpreting findings, dissemination, and non-academic outcomes of this project are all co-produced with stakeholders. Patients and patient representatives actively participate in *This Sickle Cell Life* in deciding how best to translate and communicate co-produced knowledge into resources for service improvement. The co-production model has the advantage of producing detailed findings that help amplify patients' concerns by involving them both as active research participants and as patient representatives within the patient and public involvement (PPI) environments that are becoming more popular in healthcare settings. In the process of slow co-production, we "create knowledge in ways that differ from currently valued modes of research" that tend to favour "information acquisition" over "knowledge production".[9] We do this not only by prioritising in-depth approaches to understand patient experience, but by involving healthcare users and carers as research partners in thinking about service improvement. Certainly, the longer timeframe involved and the specialist expertise required in a "slow" approach is useful in amplifying young people's voices, and in creating an enabling environment for young people to act as experts in their own conditions, bodies, and lives.

Slow co-production can bring challenges, particularly because it is not always compatible with traditional academic research and funding models, with their emphasis on metrics and the standard academic outputs required within the university system.[16,17] For instance, research funding deadlines caused problems for us by disrupting the patient involvement process at the grant proposal stage—turnaround times to respond to reviewer comments were too short for us to ensure all parties had a say and our deadline extension request was refused. Some relationships may not be fully established at the time the research funding is sought, and so key scoping work can become compressed.

Flexibility in our approach was important for us to engage in successful co-production. For instance, regular meetings were not always possible to organise with all stakeholders at once. We replaced them with other spaces for dialogue that better responded to participants' needs and preferences, such as smaller meetings or alternative activities. Activities involving both researchers and non-

researcher participants must meet the needs and preferences of both parties; in this project, workshop days or informal collaborative discussions such as coffee shop meetings with different stakeholders proved helpful in sharing ideas and shaping the direction of the research. Reflecting on our own roles in the research process and how they shape our work has helped us critique our own assumptions, as well as larger conventional epistemologies in healthcare research about how research knowledge (or "evidence") is produced.[18]

DISCUSSION

In *This Sickle Cell Life*, we do not conceptualise healthcare transition as a purely clinical experience; rather, we see healthcare transitions as a set of evolving processes. We situate these processes within patients' broader social contexts and their whole lives, including for instance, their experiences in education and relationships. The co-produced knowledge resulting from the in-depth and long-term engagement with patients captures some of the temporalities of sickle cell and of larger health transitions more generally. For example, individuals with sickle cell experience fluctuating pain. At one point a patient may feel healthy and report a wellness narrative in an interview, but in a later interview they may narrate a recent sickle cell crisis. By adopting an in-depth and long-term approach to patient engagement, the project is well positioned to inform and improve care pathways into adult services.

Slow co-production as we conceptualise it here is, of course, more onerous than some of the more established methodologies for co-production such as workshops, which may be quicker but likely lack depth. The nature of in-depth, one-on-one interviews means that using these methodologies can be time-consuming and expensive. In-depth research also requires specialists, as well as responsiveness to participants' needs and preferences. High-quality research interviews require a higher level of training and selection than for survey questionnaires where the interviewer can simply read the questions to the respondent. A qualitative interview requires the interviewer to know the topic area, to be able to elicit rich narratives on difficult topics, and to ask clarifying questions in appropriate ways should interviewees seem to contradict themselves or make vague statements. Participants might prefer to be interviewed in their homes and local communities, which also increases the time needed for data collection. All these considerations require time, resources, and reflection from researchers and participants alike.

In fact, the time-consuming and highly complex nature of in-depth qualitative analysis on work that includes such a rich range of co-produced data is what allows slow-co-production to lead to high-quality outputs. As Adams et al. argue,[9] slow science is not about "doing less over time", but about "working with an ethic or set of values and strategies that valorise different things from the emergent norms". Descriptive qualitative studies yield simple reports of interviews or focus group discussions but may not have wider relevance, whereas the slow co-production we are experimenting with helps capture details of the wider context of health experiences, and how these interact with services and experiences of health care. Increased depth allows better transferability of the findings to other settings.

Further, a slow co-production approach recognises that patient involvement can be messy. There are complex power dynamics at play[7,19] that must be recognised and navigated, such as who is in charge of budgets, who is ultimately answerable to the funder, and who drives the dissemination of co-produced knowledge. Involving patient and carer representatives as collaborators also required resources to support their time on the project. We had specifically requested these costs from the funder in our grant proposal for the study, and were fortunate that our funder supported us in this endeavour.

It is important to illuminate co-production "messiness" and encourage continuous reflection throughout the co-production process to help improve understanding of how a co-production approach can be implemented and improved.

CONCLUSION

In-depth, qualitative research offers one way to improve participatory approaches in healthcare research; slow co-production can help amplify patient voice and centre patient experience. We would argue that co-production of knowledge related to health care (e.g., about experiences of using services and living with a chronic condition, in this scenario sickle cell) should be viewed as a key aspect of service co-design. This form of co-design improves understanding of local health contexts and the

temporalities of health experiences, and generates patient-centred knowledge for healthcare improvement. It also helps us to capture the specificities of the wider social context of patients' health experiences, and how this wider context affects (and is affected by) healthcare service provision and uptake. While we can capture the nuance of a specific setting, the depth of the analysis in this approach helps yield findings that are transferrable to other contexts. In the case of *This Sickle Cell Life*, for instance, it helps build wider knowledge about transitions between child and adult care, relevant to sickle cell, but also pertinent to other health conditions.

To achieve the highest level of co-production and co-designed work with patients, sufficient resources and time must be allocated to allow in-depth participatory processes to develop, including through dedicated qualitative research. A slow co-production approach allows time, place, and pace for quality relationships to develop, enhancing dialogue between researchers and patients and by doing so, amplifying patient voice. It holds the promise of producing patient-centred knowledge that a simpler or quicker approach cannot deliver, and works to make patient-centred services a reality.

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PEER REVIEW

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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ETHICS COMMITTEE APPROVAL

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