

Nicky Taylor

Whose narrative? People with dementia and creative co-production in theatre



Full Time study (2017 – 2020)

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Background

Dementia is a major world health concern and is the current leading cause of death in the UK. In the absence of a medical cure for dementia there is growing interest in research that explores methods of engaging people with dementia to improve their quality of life. Some people live with the condition for 20 years or more, therefore it is vital that interventions offer meaningful engagement and hope to those affected. There is much evidence to suggest that creative activities such as drama, music and art have a positive impact on wellbeing and quality of life for people living with dementia.

Co-production is a process of professionals working together with interested citizens to steer and enhance services. A key element of co-production is seeing people who use services as assets, and successful co-production can have a transformative effect on individuals, professionals and services.

Historically, people living with dementia have rarely been invited to actively contribute to developing services that impact their lives. A lack of meaningful involvement may affect the ability of people with dementia to live independently and could lead to greater reliance on health or social care services or family members for care and support. Conversely if people with

dementia were invited to engage in hopeful and purposeful activity after diagnosis, isolation and loss of confidence may be lessened, and people may find empowerment through involvement in planning their own daily activities. Recognising the importance of direct involvement, charities and policy makers are now involving people with dementia as collaborators at events and on reference panels.

Creative participatory arts approaches regularly acknowledge that each person involved in a project has something unique to offer, which the artist or facilitator draws out and connects with other offerings from the group. Creative methods of sharing power between professional artists and participants can be referred to as co-creation or shared authorship. It is these processes I am interested in interrogating through my research based in a live creative participatory arts context.

This PhD study explores the experiences and processes of creative co-production in a theatre setting with a group of people living with dementia and their supporters - family members, dementia care professionals and professional artists. The study focuses on the process of planning, programming and creating artistic content for a theatre festival on the theme of dementia at West Yorkshire Playhouse, a major producing theatre in Leeds.

My background as a creative arts professional with over 20 years' experience in this field, including 12 years based at West Yorkshire Playhouse, places me in a unique position to link practical research to academic investigation.

Aims and objectives of the PhD

1) To conduct a study to explore the experiences and processes of co-production of a theatre festival with people with dementia, specifically in relation to:

a) the short and longer term impact of engaging in creative co-production on people with dementia, including benefits and barriers

b) the impact of creative co-production on artists' professional practice

c) the potential for, and experience of, people with dementia acting as evaluators of the theatre festival, to assess and disseminate its success, impact and gain feedback for future events

2) To establish a suitable definition of creative co-production with people with dementia. From this definition, to create a set of guidelines or reflective questions to inform methods of creative co-production involving people with dementia in planning and realising arts activity.

Study design and methods

The research project will adopt a qualitative approach in the form of ethnographic participant observation supported by semi-structured interviews, allowing me to explore individual lived experience, values and beliefs during a co-production process through working with a long-term group of collaborators.

Data collection will include:

- 1) Audio-recording, photography and documentation of Curators and Co-authors meetings, including any notes, emails or creative tasks completed.
- 2) Semi-structured interviews with Curators and Co-authors –to include people living with dementia, their partners/supporters and professional writers. It is likely that ad hoc conversations will also be included as evidence, to allow people with dementia the flexibility to respond to and query parts of the process as it develops. There will also be regular checking-in conversations with professionals to highlight any challenges during the process.
- 3) My observations as participant observer and my field notes in my reflective diary during the curating and co-authorship processes.
- 4) The Festival events programme produced by Curators, final play scripts produced by Co-author partnerships, and works in progress as they develop.

What the contribution to knowledge will be

There is growing interest in people with dementia telling their own stories, but the prevailing narrative is still one of burden and loss for caregivers, rather than the lived experience of people with a diagnosis. By offering supportive conditions for people with dementia to confidently share their experiences, there is potential for building resilience and finding peer support amongst others affected. The process of this research could offer innovations in gathering and sharing stories directly from people with dementia, through co-production of creative processes and people with dementia acting as co-researchers to carry out peer to peer interviews.

An initial literature search has indicated that the field of co-production and dementia is an emerging field, with a growing level of interest, and that there are only a few published examples of such studies in the creative arts. There is potential for this study to innovate a new definition and guidelines of co-production and dementia in the arts thereby filling a gap in this area of research.

There is also potential for this PhD to have a direct impact on practice within the wider arts community. The findings could provide guidance and develop confidence in the sector to share respectful and balanced messages about dementia that are rooted in lived experience, informed by the voices of people with dementia. This may encourage more theatres and arts organisations to plan events or festivals that celebrate the creativity of people with dementia and appeal to the general public, including people with dementia and their supporters as collaborators and audience members.

Plan for dissemination of the PhD

In keeping with the co-production ethos of the research, the findings will be disseminated in conjunction with people living with dementia. Together we will prioritise events or publications which may be interested in featuring findings from the study, and where possible the methods of sharing findings will also be co-produced or co-delivered. This could be in dementia or arts-focused academic journals, conferences and events by organisations such as UK Dementia Congress, Alzheimer's Society, Creative Dementia Arts Network, and through practice-based guidance published or created in partnership with West Yorkshire Playhouse to inform and guide the wider theatre sector.

I am interested in working with people living with dementia to find the most accessible routes to share findings in order to support practice development in the creative sector, as well as contributing to evidence in the academic sector. This could involve using methods such as film, social media or blogs, as well as more formal routes.

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