

People with dementia, contributing to learning and teaching in higher education: Innovative practice

Dementia

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journals.sagepub.com/home/dem**Christopher William Russell**

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Abstract

Patients and service users have a well-established role in teaching and learning on professional qualifying programmes such as social work and nursing. However, the role of people with dementia in contributing to educational initiatives at higher educational level remains under explored. Four people with dementia were recruited as Expert by Lived Experience Tutors for the Foundation Degree in Dementia Studies at a University in the United Kingdom. They met students regularly to support their learning. We were interested in researching whether and how this enhanced the ability of students to enable people to live well with dementia. However, we also discovered that the initiative gave insight into psychosocial aspects of dementia, and a new opportunity to explore personhood, co-production and social citizenship. That is the focus of this article.

Keywords

people with dementia, education, personhood, agency, social citizenship, co-production, professional qualifying programmes

Introduction

This paper reports on a project that explored the experiences of four people with dementia employed as ‘expert by lived experience tutors’ on the Foundation Degree Course in Dementia Studies at a University in the United Kingdom. They contributed to the students’ induction and then to a class in both Semesters of the year. Additionally, the expert by lived experience tutors worked alongside the Course Leader and academic colleagues to assess a poster assignment exploring the theoretical basis for understanding the experience of dementia. Their feedback was provided to students, who were then

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encouraged to incorporate this into their learning. They also provided advice and support upon related topics to students throughout the year via email contact.

This project was undertaken in two phases. Phase One provided an overview of the reasons and aspirations for tutors' participation, and has been reported in detail elsewhere. This article reports on the second phase which examined the experiences of the tutors and the outcomes they perceived at the end of the academic year.

The rationale for the project was two-fold. Firstly, it aimed to provide students with a genuine opportunity to learn in a manner congruent with person centred values (Brooker & Latham, 2016; Kitwood, 1997); i.e. through understanding the experience of living with dementia directly from people with dementia. Secondly, the desire to promote social justice; in other words, it was envisaged that the project could play a valuable role in challenging discrimination, recognising diversity and enhancing inclusion (British Association of Social Workers, 2014).

Whilst service user/ patient experience in a generic sense has been enlisted to contribute to programmes of study, in particular to professional courses such as social work and nursing (Tremayne, Russell, & Allman, 2014), there is a minimal literature about people with dementia contributing to educational initiatives at higher educational level (Innes, Barker, Board, Fenge, & Heaslip, 2012). This project aimed to explore how people with dementia could contribute to improving educational initiatives about dementia. It also provided insight into the experience of dementia, specifically in relation to – personhood and its maintenance; the biopsychosocial context of dementia; citizenship and social justice; and learning about new approaches to self-advocacy and coproduced initiatives with people with dementia.

Method

A qualitative approach was taken to the design of the research. The project was on a small scale and it was felt that this would best enable relevant material to be gathered from each tutor. Following consultation with people with dementia and family carers, four tutors were recruited from local groups facilitated by the Alzheimer's Society and the Dementia Engagement and Empowerment Project. The decisive factor in the decision to recruit in this way was that the people with dementia, with whom design of the teaching was discussed, were clear that there was a risk that people would be disappointed if they found they were unable to perform well in the role. The advice was that peer selection from existing groups would best address this risk.

The study had an exploratory focus. Thus, a semi-structured approach to interviews was adopted. This allowed specific information relating to participants' motivation for involvement in teaching, and their subsequent experiences to be explored. It also enabled additional themes to be covered as they arose. An interview was conducted with each participant before the teaching initiative began in the summer of 2014, and at the conclusion of the academic year in June 2015. Each participant was accompanied at their request by their partner. Consent for participation and for tape recording was sought at the beginning of each interview, and confirmed at its conclusion. Interviews lasted between 15 and 40 minutes. Ethical approval was granted through the university ethics committee.

Audio recordings were transcribed and listened to by the researcher. Thematic analysis was conducted upon each account, to enable themes and patterns to be identified within the context of a small qualitatively based study (Braun & Clarke, 2006).

Findings

The first phase of research

This explored the motivation of tutors for involvement in the educational initiative, and the features they considered would be most important to their contribution.

Themes relating to motivation for participation were the:

- ambitious Capital? positive contribution to society.
- Aspiration to share knowledge about their own experience of dementia so students could learn.
- Opportunity to enhance their own confidence, which had diminished following diagnosis.
- Chance to improve personal learning about dementia, and to reflect upon their experience of dementia.

In terms of the value their contribution would bring, the theme to emerge most strongly was that participants' own experience of dementia would permeate and inform every contact with students. For example the:

- Sense of loss that dementia had brought; loss arising from having to cease once familiar activities, and from losing the ability to complete well-known tasks.
- Necessity to make changes in one's life. An example, the period of recuperation following episodes of mental activity, unnecessary in times before the impact of dementia.
- Feeling it is necessary to show competence in daily activities in order to maintain one's sense of self-esteem.
- Value of support from both family carers and peer groups.

The second phase of research

The second phase of research examined the experiences of the tutors and the outcomes they perceived at the end of the academic year. Three themes were identified from their responses:

1. Enjoyment/satisfaction levels of tutors, and the reasons for their view.

The four participants consistently expressed that they had found the initiative rewarding, enjoyable, and interesting. This was reassuring in light of their ambition to continue both to make a positive contribution to society and to use their participation as an opportunity to enhance feelings of self-confidence.

This outcome appeared to be closely linked with the approach taken in class by students, where the emphasis was placed upon use of accessible language, with interactions founded upon empathy and respect (Scottish Dementia Working Group, 2014). For example,

Participant: 'Students were so interested and they put things clearly.'

Participant: 'They haven't patronised... you don't really need patronising'.

2. The merits of different teaching styles

The second finding concerned comparison by the four participants of the merits of different approaches to teaching within the class room. No consensus was reached upon a single approach within these responses. However, they were highly useful in planning future teaching sessions.

Two approaches found most favour, one-to-one work, and the use of a panel involving all four tutors.

Participant (One to one is preferable): 'I think it's easier... because if there's lots of people around, I think it's a bit more difficult to talk around them.'

Participant (Panel worked best): '... because (otherwise) it's all very – it's way too easy to get confused.'

There was agreement that direct questions from students worked best, but that this must be coupled by the effective establishment of rapport. This had links to the first finding within phase 2 (above), for example:

Participant: 'I think there was a lot of empathy. People were not pushed around. You know, sometimes you just feel people are really not taking any notice or that I'm not doing something that they think I should or anything like that.'

3. The challenges identified within the role

Participants identified a range of challenges to their involvement as tutors. Three particular themes emerged from responses.

(i) Lack of experience in the role.

Participant: '... it's still a big learning curve because it's something we've not done before.'

(ii) It's not challenging enough

Participant: '... so the more challenging it gets then the more we'll find out what our limits are.'

Participant: '... I'll take anything you throw at me.'

This contradicted 3i. (above), but appeared to relate to the participants' ambitions, set out within phase 1, to understand more about their own experience of dementia, and the feeling it was necessary to continue to demonstrate competence in daily activities.

(iii) The progressive nature of dementia.

Participants related that they were keen to be as much help as quickly as possible, fearing that the progressive nature of dementia would increasingly challenge their ability to effectively support student learning.

Participant: '... make use of us while we're still capable.'

Conclusions

This was a small-scale research project, exploring an apparently niche topic, i.e. the contribution of people with dementia to higher education. Its findings therefore must be approached cautiously. However, it provided valuable insight into educational initiatives involving people with dementia that can inform future projects. The project is judged to be successful and will form part of the ongoing educational provision on the Foundation Degree in dementia Studies. Learning gathered from the research will inform this. It also contributed to learning about matters of contemporary relevance to the wider dementia context, for example:

Personhood, and maintenance of personhood

The sense of self, and of remaining an active part of society is a key component of living well with dementia (Bryden, 2005; Kitwood, 1997). Findings from this initiative support the view that contributing to programmes at higher education level can boost feelings of confidence (Cleminson & Moseby, 2013), and appear to represent the first published example of these approaches being utilised alongside people with dementia. This study suggests that involvement in educational interventions can assist in promoting and supporting personhood for people living with dementia.

Challenging and moving beyond the standard paradigm of dementia

The standard paradigm of dementia views people with dementia from an exclusively medicalised perspective, as a collection of symptoms (Kitwood, 1997). The findings of this project not only challenge this, they promote and support a biopsychosocial context for understanding the experience of dementia which extends beyond into important contemporary contexts such as citizenship and co-production.

Feedback from students indicated that the value of the initiative to them was the importance and significance of the tutor role in redressing power imbalances and reversing traditional roles. They commented upon the value this had in highlighting and making real the shift in how people with dementia are perceived.

Feedback such as this, and the findings from the tutors themselves cannot be understood through an anachronistic, exclusively medicalised prism. Instead, this project was an innovative way of keeping people with dementia engaged with things that matter, in a manner that is useful. This placed it in direct contradiction to those traditional perceptions of dementia, and malignant social psychology. Recently the term 'prescribed disengagement' has been developed to illustrate how, following a diagnosis, people with dementia can be advised and encouraged to retreat from the activities and roles they previously pursued and held (Swaffer, 2016). In a small and relatively specific way this study is offered as an example through which such prescribed disengagement can be faced and overcome. It offers an example of the alternative; here an opportunity for the four participants to engage as active social agents within the context of genuine social citizenship (Bartlett & O'Connor, 2010). A new paradigm of co-production is provided in this example of co-producing learning.

Declaration of Conflicting Interests

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Author Biography

Chris Russell, is a registered social worker, and PhD Student at the University of Worcester. His forthcoming research will explore Sport, Identity & Dementia. Previously, Chris was a Senior Lecturer and Course Leader for the Foundation Degree in Dementia Studies.