

Cigarettes and Alcohol: An exploration of the tensions and challenges of qualitative research conducted by people with lived experience of substance use.

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Background

The Public Health Institute at Liverpool John Moores University runs an MSc in Public Health (Addictions) which attracts students from diverse backgrounds and experiences. As part of the degree students are required to undertake a dissertation project which is usually based on empirical research. As I have experience of drug and alcohol treatment services, both as a service user and member of staff, I was keen to undertake a project which involved this population. The organisation I work for was supportive of this project and my role as a student researcher. Despite knowing the public health risks, I, like many involved in drug or alcohol treatment services am a smoker. Having experienced the lack of cessation support and being aware of the high prevalence of tobacco use in this population, I chose to explore the use of tobacco in residential treatment services for substance use (Swithenbank, 2017). In this poster I will reflect on how personal experience can be a valuable tool in qualitative research, but can offer additional dilemmas and challenges for the researcher (particularly a student researcher), research participants and the organisation.



Advantages of personal experience:

- Participants were at ease with researcher, therefore more likely to have a positive experience and be more open and honest during the interviews, without the fear of judgment or prejudice. This adds to the validity of the research.
- The researcher was also at ease due to experience with this population and a prior relationship with the individuals who took part. This enabled more comprehensive data collection and a more thorough examination of the issue being explored.
- Shared experiences and values can help to reduce power imbalance and feelings of being judged. Participants are able to identify with peer researchers and feel less wary of sharing their thoughts.
- Participants were more honest when discussing smoking with a fellow smoker, in contrast to many interactions with professionals regarding tobacco use where they felt judged and pressured to respond in a certain way.
- Access to a potentially difficult to reach population. Management were happy to take part in the project as they already knew the researcher and were confident in their abilities. Relevant training and DBS checks were also completed and provided a protective factor.
- The researcher's knowledge of the service and substance use treatment made it easier to discuss the issues at hand rather than needing to explain terminology or interventions during the interviews.

Challenges and disadvantages:

- Potential for confusion of roles and lack of clarity in interviews due to assumptions that researcher already knows certain things about the participant. Some participants carried on previous conversations or referred to incidents or individuals that the researcher understood from their alternative roles, but an independent researcher would not have. At times, it was difficult to isolate the interview content.
- Participants may feel obliged to take part or to respond in a certain way, for example not to portray the organisation in a negative way. This did not appear to take place during this study, as participants were open about their feelings towards the organisation. Some were, however, reluctant to criticise members of staff.
- Researcher bias and prior knowledge may lead to distortion of meaning in analysis. It was necessary to focus on the participants' experiences and try not to project any personal opinions or assumptions on the part of the researcher.
- Researcher conflict due to knowledge that some information given by a participant was not true, and the dilemma of what to do with this information. It was decided that this was not significant in the findings of the project, and was possibly due to the participant trying to please the researcher by saying what they thought would be useful rather than the truth.
- Participants' knowledge of the researcher may have influenced their responses during interview, as non smokers were less likely to make judgemental or negative comments about staff smoking knowing that the researcher was a smoker.
- Stigma and potential for discrimination towards the researcher due to disclosure of tobacco and alcohol use and the appropriateness of their involvement in research.

Co-Production

Co-production involves researchers and others with a stake in the project: citizens, patients, health care providers, and/or health care decision and policymakers. There are different approaches and ways to involve stakeholders, for example some organisations hire staff or volunteers with lived experience; others include public and patient involvement in their studies. For some organisations, the concept of co-production is simply an advancement of the user involvement which already takes places, but successful co-production involves stakeholders at all levels and in all processes. It involves a shift in the power dynamics as hierarchies and traditional ideas about service user involvement are challenged (Pinfold, et al, 2015). Traditionally, it has often been assumed that those with lived experience have limited capabilities or relevance to the area of research and there is a noticeable gap between research, 2017), which has been fairly successful. This is hopefully contributing to a shift in how the world views those with lived experience of substance use and the expectations or beliefs about their abilities.



Student Research

Much co-produced research involves the academic researcher working with someone with lived experience, however in this research they were one and the same. This brought to light the conflicts between anonymity and transparency, as well as the challenge of 'coming out' to academic supervisors about my experiences. There is still a degree of stigma regarding substance use, and responses to this disclosure have been varied. However, I felt that it was important to the research and to the population I was studying that the project was as authentic and representative of their views as possible, and that my multiple roles and experience would help this to happen. I hope that my unique perspective can help to bridge the gap between academics and those with lived experience and encourage a more open discussion between these different social worlds, which will challenge the power dynamics in such relationships and ensure that the voices of people with lived experience are heard.

Conclusions

Further research is needed to better understand the complexities of these multiple roles in research and the benefits they may have on both the research project outcomes and on the experiences of the participants who take part. Understanding the perspectives of those with lived experience can be invaluable in research and the development of policy, and this method may present an opportunity to capture the voices of those with lived experience of substance use with more clarity. Drawing on multiple facets of the researcher's identity can give a unique insight into phenomena which can extend beyond substance use and treatment. It is also important to be aware of the challenges that such research may pose and the potential disadvantages to such studies for all parties involved. If done well, co-production and the involvement of researchers with lived experience could offer benefits for the quality of the research, but also contribute to the challenging of stigma and stereotyping of people with experience of substance use.

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