‘All the world’s a stage’: Accounting for the dementia experience – insights from the IDEAL programme

Should we rethink the way interviews work in dementia research?

We need to include the voices of people with dementia in research. This can be difficult to do well. Researchers need to design their research process carefully.

Researchers use interviews to learn more about people with dementia’s experiences. Interview questions often ask you to follow a structure. Researchers have sometimes assumed that interviews can reveal someone’s inner feelings.

It is not helpful to see interviews with people with dementia this way. Some people with dementia struggle to answer questions in an organised way. However, what they say and how they say it tells us a lot about their identity.

We looked at interviews with people with dementia and their carers. We wanted to understand how people with dementia talk about themselves and their lives.

We talk about ourselves and our lives in different ways. People with dementia are no different. We found that they:

- tell stories
- share some things and not others
- talk about what ‘society’ thinks about dementia

We should pay attention to how a person with dementia talks about themselves in an interview. We can learn more by accepting what is said rather than seeing inconsistencies. Researchers should think differently about how people with dementia express themselves and pay attention to how their stories are told.

This is a summary of a research article which appeared in the Qualitative Research journal in December 2019.