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Participatory video and situated ethics: a pilot study involving people with dementia

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Capstick A: *Participatory video and situated ethics: a pilot study involving people with dementia (panel presentation)*

Abstract

It might be argued that visual methods are particularly appropriate in research involving participants whose ability to express themselves verbally (eg by means of formal interviews) is compromised for some reason. One such group of participants is people with dementia, a condition often characterised by fluctuations in memory, concentration, comprehension and speech. Whilst increased research into the subjective experience of people with dementia is vital, this can often be hampered by the difficulties of ascertaining participants' capacity to give informed consent. Ideally, also, research should go beyond non-maleficence, and offer real benefits to those involved. People with dementia are all too often subjected to social exclusion and narrative dispossession (Baldwin 2006), so research practice should reverse these trends as far as possible.

Participatory video, with its commitment to including the voices of those on the margins and breaking down power differentials between the observers and the 'observed' (High 2008) may thus be a particularly apt visual method for ethnographic research on dementia. This presentation will report on a pilot study in progress, funded by West Yorkshire and the Humberside Strategic Health Authority (WY-SHA) using participatory video with people with dementia in community settings. The intention is for participants to exercise choice over what is filmed, which side of the camera they prefer to be on, and final editing. Central to this will be the establishment of ongoing, negotiated, process consent. Film clips to demonstrate the indicators of such consent will form part of the presentation.