

Live Symposia

101 - THE APPLICATION OF MASS OBSERVATION DATA IN THE UNDERSTANDING OF AGEING, DEMENTIA AND END OF LIFE CARE

This symposium brings together insights from a wide range of disciplines to explore the utility of Mass Observation Data (<http://www.massobs.org.uk/>) in the field of gerontology and mental health. The Mass Observation Project, established in 1937, documents the lives of ordinary people living in the UK, and explores a wide range of health and social issues. The symposium comprises four separate papers.

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Personal Narratives of Ageing

Personal Narratives of Ageing: This paper presents personal narratives reflecting on the ageing process, and growing older in the UK.

This presentation reflects on self-written narratives from 170 respondents to a mass observation directive, focusing on the experiences of growing older. Narrative methods are theoretically and methodologically diverse, and are helpful in social research to understand events or happenings in human lives. This data presents accounts from a heterogeneous sample in the form of self-penned responses. These experience-centred narratives bring stories of personal understanding into being by means of the first-person description of past, present, future or imaginary experiences of later life. This presentation will focus on the findings with reference to mental and physical and impacts, both real and anticipated to the ageing experience. We will also explore themes arising from the data including gender differences, age-cohort effects and stigma.

The data should be utilised to inform Health and Social Care education and practice, particularly in co-producing appropriate person-centred services with older people.

The Health Impact of Financial Fraud: 'Scams'

The Health Impact of financial fraud: This presentation will offer new and alternative insights into fraud and the health effects on older people, using data from the mass observation directive. The term utilised for such crimes in the UK is 'Scam'.

The paper reports data captured from a Mass Observation Project "Directive" focusing on 'scams' (see the UK definition of 'scam' below) and the impact on individuals. One hundred and forty-four 'Observers' responded to the 'Directive'. Narratives indicate that victimisation to a scam may have negative impacts on individuals' mental wellbeing, self-esteem, and relationships with others. Furthermore, data analysis identified that fear of victimisation can also affect individuals, resulting in worry, anxiety, and maladaptive coping strategies.

Offering further understanding of the health impacts of 'scams' highlights the necessity to legitimise the issue as a public health concern.

A scam is interpreted to be: a misleading or deceptive business practice where you receive an unsolicited or uninvited contact (for example by email, letter, phone or ad) and false promises are made to con you out of money (Office of Fair Trading 2006).

Perceptions of Dementia

Perceptions of Dementia: This paper (Exploring public perceptions and understanding of dementia: Analysing narratives from the Mass Observation Project, (Olsen et al 2019) presents a perspective on the public knowledge and understanding about dementia not previously considered, where respondents have written openly about their own experiences, and reflected on their perception of the wider public's knowledge and understanding about dementia.

This paper considers narratives of 143 respondents ("Observers") to a Mass Observation Project Directive exploring individuals' perceptions of dementia. Perceptions of dementia held by "Observers" with experience of dementia and those without differed sharply. "Observers" with experience of dementia offered insight into living with, and caring for, a person with dementia; including the impact this had on their lives and personal relationships. Whereas, "Observers" with no direct experience of dementia focused more on common disease symptoms, such as memory loss and reflected idealised views of care. "Observers" often feared being diagnosed with dementia themselves. This suggests education to facilitate care planning and ameliorate fears held by the public is required.

Previously, perceptions of dementia have been captured utilising traditional research methods and samples drawn mainly from professionals. This new approach identifies public understanding of dementia, highlighting areas concern, and supplements the existing UK

Olsen, V., Taylor, L., Whitely, K., Ellerton, A., Kingston, P. & Bailey, J. Exploring public perceptions and understanding of dementia: Analysing narratives from the Mass Observation Project. *Dementia: The International Journal of Social Research and Practice*. <https://doi.org/10.1177/1471301219861468>.

End of life care

This paper considers narratives from two Mass Observation Directives exploring individuals' perceptions of dementia (n=143) and personal narratives of ageing (n=170). 'End of Life Care' has, in a UK context, focused on care and support for individuals in the last months or years of their life. Care planning and management of this stage in the life course usually incorporates symptom management and emotional support for the individual, the family and carers. Whilst patient choice, involvement and co-production of the care plan is widely advocated to promote a dignified death, responses to the mass observation directives also reflect the need to revisit the options for individuals with a diagnosis of dementia and other life limiting illness. There was, in particular, a renewed call to return to the 'euthanasia' debate and to encourage discussion and end of life decisions to be undertaken earlier in the life course, prior to any diagnosis of a life limiting illness. As people's attitudes and behaviours towards end of life care planning change, it is imperative to ascertain current perspectives to inform and guide future direction of social policy and services.