


Wandering the Wards: An Ethnography of Hospital Care and its Consequences for People Living with Dementia

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Authors note: Jane M. Mullins' dementia nursing experience spans memory clinics, care homes, hospital and care in the community. Her PhD, *a Suitcase of Memories*, involved co-producing research with people living with dementia and their partners, to explore multisensory ways of communication and embodiment. Here, she adopted sensory ethnography as a methodology to overcome some of the challenges associated with cognitive decline and examined in-depth ethical ways of undertaking research with people who have dementia. She is the author of *Finding the Light in Dementia, a Guide for Families, Friends and Caregivers* and is currently exploring sensory spaces, communication and dementia at the Awen Institute, Swansea University, which brings together researchers, older people and the creative industries to co-produce products, services and environments for an ageing population through research and development.

Wandering the Wards is an emotive in-depth account of Featherstone and Northcott's ethnographic study of hospital care for people living with dementia. The title, in itself, is a tongue-in-cheek declaration of the general lack of understanding of how dementia affects a person, especially within hospital settings where conformity to rules is expected. There is no doubt about the breadth of their work, depth of analysis and emotional impact resulting from these encounters that are informed by over 330 days of observations in eight hospitals across England and Wales. The value of their study is also in the ongoing public consultation with people who have dementia, their families and carers at all stages of the research and whose experience sadly echoes their findings. In the spirit of reflexivity, it too resonates with my hospital nursing experience, taking me back to a time when I was deeply troubled about how I did not have the resources or support to help me care for older and often vulnerable patients, resulting in my own burnout and profound sense of letting people down. This book is not for the faint hearted and I found myself having to read it in stages as the ethnographic descriptions at times were very vivid and powerful. I can only begin to imagine how the crisis of the COVID-19 pandemic has since impacted the people and environments in this study further.

This book is a stark reminder that despite all the work of the Dementia Engagement and Empowerment Programme and the Dementia Friends movement, there is still much to do to educate about dementia; the different conditions that the term embraces, how it can affect people (not just focussing on memory) and how health- and social-care staff can support them whilst in hospital. Featherstone and Northcott's observations clearly show how people living with dementia, their

families and the staff who care for them are grossly let down by archaic institutional practices. The reader is frequently taken back to ethnographies from the 1950s, 60s and 70s where the authors depressingly find little change in the organisational structures and ward cultures where hierarchies of staff and patient roles command the knowing of one's place and having to fit into the rhythms of the system. The hidden language of uniform and ways of belonging are inaccessible to those from the outside, thereby creating a feeling of alienation for the patient. Here, I was saddened to read an extract where the likes of Sir Lancelot Spratt (a character from the 1950s series of "Doctor" films that highlighted the power of the medical consultant) still exist! Where on one occasion, a consultant chastised the only person (a healthcare assistant) engaged in meaningful communication with three patients who had dementia, to help them feel safe and calm, because the patients were not obediently waiting at their bedside. Further analysis showed that often the grade of staff allocated to 'special' patients (provide 1:1 care for close observation, as deemed at risk of harm to themselves or others) were unqualified or from an agency, where no continuity of care was observed and the value of these skills was not recognised. This book highlights the organisational cultures where the 'badge of honour' still goes to those who work in the more 'glamorous' acute areas! and where older adult nursing is still a Cinderella service.

The authors examine the complexity of ascertaining differential diagnoses in great detail (usually undertaken by a specialist clinician in a calm controlled environment), but their observations found the frequent labelling of a generic 'dementia patient' by ward staff following basic memory testing with little cultural, temporal and environmental considerations or awareness of how acute conditions impact cognition. Furthermore, they observed that once a label of dementia applied (with or without formal diagnosis), more dehumanising labels of 'bed blockers, feeders, absconders and climbers' were attached to the person and risk averse practices to prevent people falling (often a predictor of quality of care!) or 'absconding' lead to containment and restraint. Here, paradoxically, I was horrified to read about the invisibility of patients who tried to express their needs and their privileges taken away. This included standard practice of not helping people go to the toilet because they wore a pad and they would be safer not to get up and walk! Wandering the wards sadly but successfully shows that these undignified practices actually contribute to the decline of a person's condition, (let alone, their personhood) withdrawal or escalation of their stress, which in turn perpetuates the view that those living with dementia are agitated and aggressive. The authors' use of metaphor where the person living with dementia is an 'island existing in isolation within the wards' shows the degree of disconnect that the staff have with the patients, and this was observed across all sites within the study. Descriptions show how justifiable patients' responses are and resonate with [Campbell's \(2019\)](#) research where environments are viewed as 'restorative' or 'resistive'. It is through reading this book that I recognise how staff would gain great insights if they undertook such observational work, similar with [Kitwood's \(1997\)](#) dementia care mapping. To my surprise, this study found old task-based rituals, criticised as long ago as the 1980s ([Walsh and Ford, 1989](#)) still embedded in ward practices. Despite the changes in nursing education and the advent of person-centred care, of which there is much rhetoric, this is not available for patients who have dementia (diagnosed or not).

By adopting the lens of medical sociology, the authors observed profound stress and anxiety experienced by staff, where surveillance and fear of judgements of not fulfilling timetables or getting things 'done' were endemic; something I remember all too well when working as a nurse in the acute ward setting. Here, they identify that care, such as sitting with a patient to support their emotional needs (whose responses are not irrational given the 'imprisonment' they feel), is frowned upon and cannot be quantified or recorded.

Featherstone and Northcott had to muddy their roles as ethnographers at times, when, in the enviable position of observers and not workers, they sometimes had to intervene and help both

patients and staff. Envious, I say, with my tongue firmly placed in my cheek; the emotional toll on the researchers cannot be ignored here. This is undeniably the most important evidence to inform healthcare policy and practice for people living with dementia and it needs to be responded to urgently. My only criticism of the book is that I would like to have read more about where the authors go from here, as I know they are deeply passionate in supporting change for people living with dementia (as am I) and making sure that their study is not relegated to the archives like previous ethnographies. I recommend all people involved in the health- and social-care of people who have dementia read this book to open up their empathy and humanity for hospital patients (people) and to become agents of change.

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