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Journal of Psychiatric and Mental Health Nursing

DOI:

<https://doi.org/10.1111/jpm.12763>

Published: 01/12/2021

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Page, S., Davies Abbott, I., & Jones, A. (2021). Dementia care from behind the mask? Maintaining well-being during COVID-19 pandemic restrictions: Observations from Dementia Care Mapping on NHS mental health hospital wards in Wales. *Journal of Psychiatric and Mental Health Nursing*, 28(6), 961-969. <https://doi.org/10.1111/jpm.12763>

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Dementia care from behind the mask? Maintaining well-being during Covid-19 pandemic restrictions; observations from Dementia Care Mapping on NHS mental health hospital wards in Wales

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Author contributions – all authors contributed equally to the paper. SP was one of the qualified DCM mappers who collected and analysed the data. IDA undertook a secondary analysis. All three authors jointly drafted the paper. SP addressed changes suggested by the editorial team.

Funding statement – there was no funding for this study.

Conflict of interests – all three authors assert that there are no conflicts of interest.

Abstract

Introduction - The effect of the novel coronavirus (Covid-19) on people living with dementia is potentially severe in terms of its clinical impacts. More widely, for this vulnerable group, the social restrictions that are imposed to limit the spread of infection are regarded as emotionally and psychologically damaging. Aim – To explore the impact of such restrictions on well-being for people with moderate to severe dementia in acute mental health inpatient hospital care. Method - ‘Dementia Care Mapping’ was the observational tool used to determine levels of well or ill-being. The observations were undertaken in two mental health hospital wards during a time of restrictions related to visiting, social distancing, periodic isolation and, the use of face masks and other protective equipment. Results - We report levels of group and individual well-being that are higher than might be expected (compared to historical rates for those inpatient areas), a change in the focus of psychological care delivered and, significantly high rates of mental health nursing interventions aimed at enhancing well-being. Discussion – We postulate that mental health nurses faced with an unprecedented challenge respond by changing practice to mitigate for infection prevention measures and to compensate for family absence. Implications for practice - We suggest that the desirable enhancing actions by nursing staff which raise well-being in these hospital settings are readily transferable to other settings that are aiming to maintain well-being but also practicing under Covid-19 restrictions.

Accessible summary

What is known on the subject? –

- Coronavirus disease 2019 (COVID-19) is a new infectious disease that has spread across the world and infected a large number of people many of whom have died.
- People with moderate to severe dementia are at very high risk of becoming infected as the disease mainly impacts on older people with other health problems and once infected the person with dementia is more likely to become seriously ill than other people.
- To prevent infection people are required to wear masks and isolate from contact with others. It is believed that these measures can reduce the quality of life and general well-being of people with moderate to severe dementia in hospital or social care. This belief has not yet been demonstrated by research.

What does this paper add to the existing knowledge? –

- We show that people with moderate to severe dementia receiving care on mental health hospital wards and subject to strict infection prevention measures can still achieve high levels of well-being.
- We show that mental health nurses alter the focus of their care to deliberately overcome the challenges and particularly the restrictions on visiting by families.

What are the implications for practice? –

- We believe that the changes in practice we observed can occur in other health and social care settings and that whilst restrictions remain in place care staff can protect and possibly enhance well-being for people with moderate to severe dementia.

Relevance Statement:

We demonstrate that within the context of the strict infection prevention measures, which the management of Covid-19 demands, mental health nurses can still provide care that enhances wellbeing for people with moderate to severe dementia. We observed that mental health nursing practice changed during the initial pandemic period. Those changes to practice refocused nursing attention on specific aspects of psychological needs and were at odds with the way those same nurses and teams have been seen to practice historically. As a consequence of this we report increased levels of patient well-being which may mitigate the potential negative aspects of infection prevention and control measures.

Introduction

Coronavirus disease 2019 (COVID-19) an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was first identified in December 2019 in Wuhan, the capital of China's Hubei province. The virus spread globally and reached the United Kingdom in late January 2020 where the subsequent rapid transmission rate was reflected in the outbreak being declared a world-wide pandemic by 11 March 2020 (World Health Organisation, 2020). By the 16th November 2020, the European Union and the United Kingdom have seen a combined total of 10,727 551 cases of COVID-19 which represents 19.7% of all global cases and; recorded 267,394 COVID-19 related deaths or 20.2% of the global total (European Centre for Disease Prevention and Control (ECDPC) 2020).

People that have a dementia are perhaps the most vulnerable COVID-19 patient group due to three factors. First their age, as the severity of illness increases older people are increasingly represented in age distribution models. 80% of those with severe Covid-19 symptoms were aged over fifty years whilst more than a third of critically ill males were aged over sixty years (Intensive Care National Audit and Research Centre, 2020). Mortality has been high in the UK for older people with severe/critical Covid-19 illness who accounted for 89% of deaths in hospital (Office for National Statistics, 2020), which was in line with the global pattern of multiple case fatalities (Oxford Martin Programme on Global Development 2020).

Second, the presence (and severity) of underlying health conditions is a factor in determining how seriously affected the person is by Covid-19. Such conditions identified as increasing the degree of risk include, heart disease, respiratory disease, and, diabetes (Centres for Disease Control and Prevention, 2020). These conditions also increase the risk of developing the more common types of dementia (Prynn and Kuper, 2019) and consequently people with moderate to severe dementia have, on average, one high risk co-morbid medical condition (Browne et al, 2017)

Third, dementia progressively impacts upon the cognitive ability to understand actions, such as self-isolation and social distancing, that are necessary to mitigate risks of Covid-19 (Ayalon et al, 2020) Failure to comply with these measures increases contact with others which increases the risk of transmission, however compliance increases the risk of social isolation and reduces contact with family and carers. In particular the cessation of family visiting to hospitals or care homes is a further factor suggested as impacting upon those with dementia, although it is acknowledged that primary data for this is lacking (Verbeek et al, 2020).

National and international recommendations regarding the care of people living with dementia in 24 hour care settings identify the risks observed in this cohort. Recommendations position the protection of people living with dementia in care services against the devastating physical effects of the virus as the overwhelming priority during the pandemic (Alzheimer's Disease International, 2020; Alzheimer Europe, 2020; British Geriatrics Society, 2020; Public Health England, 2020). Whilst protecting the lives of people with dementia is an undisputable priority, there also appears to be a risk that the overall dominance of the physical health narrative relegates the need to address the psychosocial care of people with moderate to severe dementia as less consequential during the pandemic. The Covid-19 pandemic therefore represents an unprecedented and multi-layered challenge to dementia care.

Aim

As Covid-19 will continue to present significant challenges to health and social care there is vital learning to be captured from clinical experience. We aimed to explore whether in the new reality of almost constant use of personal protective equipment, social distancing and severe restrictions on family visiting, clinical staff could still maintain a focus on the psycho-social aspects of care and facilitate well-being.

Ethical statement

This paper is built around observations of the care environment and interactions between those delivering care and those receiving care. There was no intervention involving either clinicians or patients and there is no data included that could identify any particular individual. The observations were made within the framework of 'Dementia Care Mapping' and as part of a quality improvement programme each of the wards cited had been mapped quarterly since 2013. Inclusion in the mapping exercise is supported by informed consent on admission to the ward. Where the patient lacked the mental capacity to consent the carer or next of kin provided informed proxy consent. Where consent was not obtained the patient was not included in the mapping exercise. The observations made during the period of Covid-19 pandemic were registered as an additional clinical audit and subject to appropriate risk assessment. Approval for secondary data analysis was obtained through the Healthcare and Medical Sciences Academic Ethics Committee at Bangor University.

Methodology

Dementia Care Mapping

DCM is an observational tool, deeply rooted in Kitwood and Bredin's (1992) theoretical concept of personhood, which they described as a status or standing conferred by others based on their understanding of social projections relating to other people. Kitwood (1997) called DCM a skilful and empathic process, which seeks to seriously understand the lived experience of people living with dementia. The tool is predominantly used to inform practice development that supports the delivery of person centred approaches in dementia care, although the efficiency of DCM for this purpose continues to be debated.

The DCM process involves the observation of a person or persons over the whole or part of a day. Observations are recorded in five minute time frames, with a supporting narrative informing the allocation of a behaviour category code (describing the person's dominant

behaviour during the time frame) and a mood/engagement score (a six point numerical scale, indicating the person's emotional state or their persistence or enjoyment regarding their observed actions). An analysis of the raw data provided during this preliminary stage produces a well/ill being score, which illustrates the overall experience of an individual, or group, during the mapping period.

Dementia Care Mapping – Theoretical Base

Theoretically the well-being indicators are a reflection of the premise that human wellness is influenced by the extent to which a social or physical environment can support or thwart the individual's need for autonomy (Ryan and Deci, 2017). The presence of cognitive impairment does not alter this although it is recognised that in meeting basic psychological needs the person with dementia becomes increasingly reliant upon others (Baldwin and Capstick, 2007). Where those needs are met well-being occurs, where they are frustrated ill-being occurs. DCM therefore observes for a prescribed range of actions and interventions by others, which have the effect of upholding or threatening the personhood of the individual.

Kitwood (1997) described actions, which promoted individual personhood as moments of positive person work, when psychosocial support is effectively provided by care givers. In DCM these actions are reframed as personal enhancers, as they enhance the well-being of the individual. The opposite of these actions was described as incidents of malignant social psychology (Kitwood, 1997). The theoretical construct of a malignant social psychology as set out principally by Kitwood (1997) is observed when a care giver, typically without ill intent, interacts with a person living with dementia in a psychosocially unsupportive manner. In DCM these actions are referred to as personal detractors, as they decrease the well-being experienced by the individual.

The underpinning theory for the observation of these actions is Kitwood's (1997) psychological model of needs, which identifies six interlocking themes that represent the non-physical needs of all human beings but with a focus on the person living with dementia. Whilst the central theme of *Love*, encompasses an unconditional acceptance of the individual, integral to all quality dementia care, the remaining five themes (*Comfort, Attachment, Identity, Occupation and Inclusion*) are more individually diverse as each person's respective needs under each theme may differ depending on their own personhood. The identification of enhancing or detracting behaviours by care staff does not presume the precise content of the individual's needs but rather illustrates behaviours, which uphold or withhold the individual's personhood within the theoretical model.

Kitwood (1997) described the provision of *Comfort* as a holding together of the person through tenderness, closeness, warmth and strength. *Attachment* finds its origins in the theoretical work of Bowlby (1969), acknowledging the human need to be close to others, particularly during periods of anxiety or crisis. *Identity* encapsulates the uniqueness of the person, underlining the universality of the theme but a requirement to consider individual idiosyncrasies to uphold personhood. *Occupation* describes the need for ongoing purpose or meaningful activity, to counter states of boredom or feelings of worthlessness. Isolation represents the opposite of *Inclusion*, with Kitwood (1997) describing the human requirement to be part of a group as essential to survival.

DCM and well-being in a transient patient population

In a previous paper (XXX) we argued that the data regarding the overall well-being of participants within mapping could not be directly compared between care locations or periods of time. A focus on the personhood of the individual, renders a comparison of data between different people, counter intuitive to the person centred ethos of DCM. Equally, comparing data about the same person on different mapping days, reduces the person to a group of statistics and does not consider the holistic experience of the individual. Therefore, higher well-being scores in one care setting does not necessarily indicate a greater provision of person centred care but rather, a more obvious finding, that different people are being observed in different settings.

In the aforementioned paper, we argued that the incidence of personal enhancers and detractors was a valid mechanism to compare the provision of person centred approaches between care settings or at different periods of time. The delivery of person centred care is not dependent on an individual's emotional state but should be the basis of all care giving actions with a person living with dementia. We established that the frequency of personal enhancers and detractors could be recorded as: $x \div y = p$ where x indicating the number of time frames and y, the total number of observed personal enhancers or personal detractors. The final score denotes the enhancer or detractor score observed during the mapping period. The frequency calculator may be applied to mapping data of any time period to produce scores to indicate how often personal enhancers and detractors occur between time frames. For personal enhancers, a lower score is preferable (e.g. a score of 1, indicates a personal enhancer has occurred every time frame), although a score of 0 would indicate an absence of personal enhancers during a mapping period. A 0 score is the most desirable score for personal detractors for the same reason but otherwise a higher score is preferable, to indicate these actions occur infrequently.

Infection Prevention Measures

The Covid-19 period mapping exercises followed the strict infection prevention measures in place at that time. Surgical face masks and scrubs were worn by mappers and paradoxically this helped them to blend into the background and unobtrusively observe. Patient selection was slightly impacted as patients that were shielding or in isolation areas of the wards could not be included. There was some limitation on movement around the wards by mappers that were not involved in clinical care and as such were required to maintain social distancing.

Data Collection

Demographic, cognitive and non-cognitive data was captured so as to set in mapping exercises in a broader context and to outline the characteristics of the patient cohorts involved in the audit. Cognitive status indicating the severity of dementia was captured using the Clinical Dementia Rating Scale (Morris, 1997) and presented as the sum of the boxes (CDR/SB). Non-cognitive symptoms were captured through the twelve item Neuropsychiatric Inventory (Cummings et al, 1994). Final allocation of CDR/SB measurements and NPI outcomes for each patient were based on consensus between the ward manager, the patient's consultant psychiatrist and one of the authors (XX).

The DCM data was captured by two qualified DCM practitioners utilising DCM 8 User Manual (University of Bradford, 2005). In total there were 576 time frames which represented 48 observed patient hours however, for 76 time frames the patient was not present or asleep and as such the analysis was based on 500 time frames representing 41.6 observed patient hours.

The Clinical Environment

DCM was undertaken in two mental health wards acting as acute admission areas for people affected by dementia. Both wards had been involved in regular DCM since 2013 and both wards had experienced high levels of Covid-19 infection and, a number of associated deaths. Following National Guidelines for Wales there were infection prevention and control restrictions in place for both wards on the day of mapping. These included, no visiting by family members other than for strictly controlled compassionate visiting for patients at the end of life; no unnecessary visiting by health and social care professionals; social distancing of two metres; rigorous hand washing and sanitizing and, the wearing of appropriate personal protective equipment by clinical staff (and mappers) including a surgical face mask at all times.

The Patient Cohort

In total sixteen patients were mapped, ten on ward A and six on ward B. There were some differences between the two cohorts Ward A had a larger female patient group at 80% (compared to 30% for Ward B) and a higher mean age of 83.1 years (compared to 75.8 years) than Ward B. Both wards were comparable in terms of dementia severity with average scores on the Clinical Dementia Rating Scale (Morris, 1997) of 2.47 and 2.64 respectively indicating a cohort of people at the higher end of moderate to severe impairment. In respect of distress response and behaviour change average scores on the Neuropsychiatric Inventory (Cummings et al. 1994) were, 34.0 for Ward A and 32.2 for Ward B. Both cohorts achieved high scores for psychotic symptoms and agitated behaviours. The patient characteristics of the cohort involved in the Covid-19 mapping exercise were essentially the same as for pre-Covid-19 mapping exercises on both wards. This perhaps reflects the level of mental health need compounded by severe cognitive impairment which leads to admission to a mental health ward.

The mapping exercises were undertaken at a point in time when none of the patients had experienced face to face contact with family members or carer for at least thirteen weeks.

Results

Well or Ill-Being (WIB) Scores

An analysis of the raw data collected during a map produces a final 'well/ill-being' score (WIB). This WIB is recorded on a six point scale (-5, -3, -1, +1, +3, +5) with a score of 5 indicating that the person is experiencing either a substantially high positive mood or is greatly engaged with an activity or behaviour. A score of -5 indicates a person is experiencing high levels of distress or disengagement. A person observed to be experiencing a neutral emotional state or neutral engagement would be scored +1. The group WIB scores for both wards were 2.52 and 2.56 respectively. When compared to the historical record for each ward these were the highest scores recorded since the mapping commenced on these wards in 2013.

Mood and Engagement

The WIB profile for the patient cohorts on each ward were compared to the outcomes from the five most recent previous mapping exercises which accommodated all mapping carried out in 2019 and one pre Covid-19 restriction mapping exercise in 2020 (Figures 1 and 2). For both wards the pre-Covid-19 ME scores clustered around a neutral score of +1 which is

consistent with findings from the analysis of around 43,000 observation time frames reported by Sloane et al (2007). However, for both wards during the Covid-19 period, observations were seen to shift towards a higher ME value and cluster at the score of +3.

Figures 1 and 2 about here

Enhancing and Detracting Actions

As noted above we have previously reported on how enhancing and detracting actions can be used to mediate for a non-static patient cohort and, provide a reliable measure to compare the culture of care at different points in time (XXX). These actions are patently either positive, and consequently rooted in positive person work or, negative, and rooted in the concept of malignant social psychology. To support a scoring framework we coined the terms 'D' score to refer to the presence of detracting actions and, "E' score to refer to actions that are enhancing of well-being (XXX).

For both wards there was a reduction in detracting actions seen at the mapping exercises during Covid-19 restrictions in comparison to the mean value for the five most recent pre Covid-19 restrictions mapping exercises. For Ward A the reduction was from an average of 1.4 actions to 1.0 and, for Ward B the reduction was greater from an average of 2.6 actions to 1.0.

Both wards achieved high scores for the number of staff actions which promote patient well-being. In comparison to the mean score obtained pre Covid-19 restrictions both wards show an improved E score; Ward A from an average of 11.4 to 8.1 and, Ward B from 11.78 to 8.5. This has potential therapeutic impact on well-being as patient cohorts in the period marked by Covid-19 restrictions were, on average, experiencing enhancing actions from staff more frequently than previously.

We focussed upon the nature of the enhancing actions in the context of the psychological needs of the patient cohorts. Five of the six universal human needs (comfort, identity, occupation, inclusion and attachment) are intimately included in a DCM exercise and codings apply to each enhancing or detracting action that is observed. There were too few detracting actions to support a robust analysis so attention is placed on the enhancing actions that were observed and recorded (Figures 3 and 4).

Figures 3 and 4 about here

Discussion

The intuitive feel

The patient group in this study represent the cohort of people with moderate to severe dementia whose needs are so great and whose severity of mental illness so acute that their care cannot be provided anywhere else other than in an NHS Mental Health Unit. They are the cohort whose ability to comprehend and comply with infection prevention measures is seriously compromised by the severity of their dementia. Instinctively one feels that they are the cohort most in need of the freedom to move, of nursing care that is not delivered from behind masks and gowns and, perhaps most importantly for the sustained presence of those to whom they are attached to for unconditional love and acceptance.

It is often claimed in media reports that the restrictions placed on social contact and in particular on hospital or care home visiting can increase distress and worsen the symptoms of dementia and, intuitively one feels that each person's well-being must be negatively impacted upon although, as Verbeek et al, (2020) have acknowledged there is no primary evidence of this. What we report is a positive shift in the ME score clustering during the pandemic restrictions that move both wards away from their previous neutral position into a higher level of mood and engagement indicating that a greater proportion of patient time was spent in a state of well-being. This is in contrast to the historical trend for both of these wards and suggests that something other than 'care as usual' is involved.

More than 'care as usual'?

We suggest that these outcomes did not occur by chance but were directly attributable to sensitive and adaptable mental health nursing care with practitioners deliberately shifting their focus, to aspects of care they believed would provide the greatest patient benefit. As such we observed that the needs based focus of nursing care changed in different ways for both wards during the pandemic period and, we posit that this reflects the tension that pandemic restrictions bring to practitioners striving for balance between placing the emphasis on the physical, including barriers, to achieve higher levels of safety or, to focus on the psycho-social aspects of care.

Prioritising comfort - Observations on Ward A suggested staff had a greater propensity to deliver enhancing behaviours aligned to the thematic need of *Comfort*. The wearing of personal protection equipment could be positioned as a potential barrier for delivering quality care, as the essential coverings may frighten people living with dementia (Velayudhan, Aarsland and Ballard, 2020). Staff were observed adjusting their communication style, amplifying their non-verbal communication to reduce the

barriers imposed on verbal exchanges due to face coverings. Whilst, the non-verbal communication used by people with moderate to severe dementia is often poorly understood by care staff (Cameron, Fetherstonaugh, Bauer and Tarzia, 2020) the results of this study actually suggest that staff became more sensitive to this form of communication, due to the restrictions placed upon them by the pandemic. Non-verbal communication was delivered with greater volume, similarly, to how a stage actor may augment their movements to allow an audience to know their intentions during a performance. This communication was reciprocated by both parties, allowing the provision of warmth, an enhancing action integral to *Comfort*, to be upheld despite the limitations placed on the staff's more traditional communication style.

Prioritising attachment - The provision of enhancing actions aligned to the *Attachment* need were more commonly observed on ward B. This need is directly threatened by the lockdown restrictions, as those people with the most familiar attachments (e.g. family members, caregivers) were prevented from visiting due to the restrictions. This need was upheld by actions, which acknowledged the absence of close personal attachments with staff validating the emotions of the people on the ward, rather than allowing the task related activities of care to dominate their interactions. The increased occurrences of enhancing actions based on this need, was instrumental in maintaining the standard of well-being observed during the mapping period. Whilst family members and caregivers may be concerned that the need of *Attachment* can only be met through their presence, the staff on ward B were able to provide a degree of Attachment, which possibly countered their absence.

Overall we suggest that although each ward adopted a different focus for care the levels of well-being were equally high. As such in a short term period of restrictions mitigation is possible however, we are conscious that not all needs were being met equally. It is therefore unclear if subsequent waves of Covid-19 will see further changes in practitioner's behaviour and if a balance can be achieved. The bio-medical model has long been a seductive force around dementia care and nothing reflects this approach more than a germ theory focus on infection and infection prevention. It may be that dementia care services are at risk of stalling the progress made regarding person centred approaches as the physical barriers, potentially symbolised by PPE, may result in care givers feeling less able to provide psychosocially supportive care and, may lead to a focus on the physical tasks of meeting the need for comfort at the loss of the psychological comfort. This could occur alongside a dialling down of other needs such as identity, as the ongoing pandemic will position people with moderate to severe dementia only as frail, vulnerable and highly at risk, or occupation as fear of infection enhances the desire for social distancing or activity resources are seen as vectors for transmission..

Implications for mental health nursing

Dementia care is not easy and perhaps nor should it be, the anxieties, uncertainties and restrictions brought by the Covid-19 pandemic make it no easier. Despite that the key finding from this study is that adequately trained, supported and regulated mental health nurses can still provide care considered enhancing of wellbeing within the context of the Covid-19 pandemic. This is an important finding to remind mental health nurses as they continue to experience the effects of the pandemic on services. The interplay between physical and mental health factors is important and one would expect an increased focus on physical health care within the context of the pandemic, and whilst mental health nurses should play their part in providing this holistic care they should be mindful as to how this plays out over time and cautious as to when the focus shifts too far towards the physical at the expense of the psychological.

Our findings show that in the short term nurses were able to focus on wellbeing factors within the context of the pandemic. We have therefore reported that practitioners exhibited an ability to adapt to restrictions, allowing a greater use of non-verbal communication to meet the *Comfort* needs of people living with dementia. The provision of positive *Attachment* was also upheld by staff who acknowledged and validated the emotions of the people living with dementia, despite the absence of their more familiar attachments. It is reasonable to assume that similar actions by mental health nurses in other facilities caring for people living with dementia could also result in these needs being upheld during periods of restriction.

Overall, mental health nurses have a professional responsibility to ensure mental health wards are therapeutic environments to provide holistic care, this small study has demonstrated mental health nurses can do this within a Covid-19 pandemic and using DCM may provide mental health nurses with a framework to understand and improve how they interact with people with moderate to severe dementia.

Conclusions

This paper opens up a discussion about achieving patient well-being at a time when care environments are subject to restrictions which threatened individual autonomy. Findings are derived from a small case study with limited time series data on repeated DCM on two OPMH wards delivering care to people with moderate to severe dementia carried out during the Covid-19 pandemic of 2020. Results indicate a positive attainment of well-being in the mapped population. Implications for mental health nursing are the importance of therapeutic optimism

within the context of the Covid-19 pandemic, having sensitivity and empathy to refocus on universal needs that may not be met by others closer to the patient and ultimately to uphold high standards of compassionate care for perhaps the most vulnerable group in society.

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