Influencing factors for Mental health nurses caring for people

with Delirium Superimposed on dementia

Delirium superimposed on dementia has facets of physical, mental, and cognitive

health. Mental health nurses' experiences of caring for this complex condition are

overshadowed by a focus on general or adult nursing experiences. This paper reports

a first exploration of the mental health nurse experience.

Aims:

To explore UK mental health nurses' experiences of providing care for people with

delirium superimposed on dementia, and to describe what factors may affect this

within the care setting.

Design: Exploratory sequential mixed methods.

Methods: Semi structured 1:1 interviews were conducted with a sample of UK mental

health nurses from one NHS Trust. Data were analysed using framework analysis.

Findings: Mental health nurses have specific skills to "know" the people they care

from as individuals with positive support from the wider team. However, this "knowing"

is not readily assimilated into binary tools or scores, and an integrated approach is

required to support the person with delirium superimposed on dementia.

Background

Delirium manifests as a rapid onset of global cognitive dysfunction which fluctuates

(McCrow 2020, Wilson, Mart et al. 2020), and in some cases can be prevented, and

treated (National Institute for Health and Care Excellence 2023). As such, it may be

seen as a mental health condition, and this is demonstrated by its inclusion in the

Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM V) criteria

(American Psychiatric Association 2013), and situated under mental, behavioural and

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neurodevelopment disorders within the International Classification for Diseases (World Health Organization 2022). In conjunction with the recognition of a decline in mental wellbeing, there needs to be a focus on the clinical diagnosis, treatment and management of the causative underlying medical condition or withdrawal from intoxicating substances (Echeverria, et al. 2023). This refined focus on the general medical condition inextricably links the psychological manifestation of delirium to the physiological process occurring (Pryor and Clarke 2017).

Delirium superimposed on dementia (DSD) arises when a person with dementia has delirium at the same time (Morandi and Bellelli 2020). It can be missed or misidentified as part of the dementia process (Boettger et al. 2011, Morandi and Bellelli 2020). It is well recognised that delirium straddles the traditional siloed practices of mental health and physical health, but they are connected, and need seeing as a continuum (Pryor and Clarke 2017). Whilst this holistic premise of delirium, and DSD may seem common sense, current nurse registration, discreet care environments and the general medical dominance in guidelines, present challenges for mental health nurses.

In the UK, people whose primary morbidity is dementia, and have care needs that cannot be safely met in general community settings such as home care or general care homes, may be cared for in NHS mental health units and care homes with specialist mental health provision. With in these specialist services, nursing staff will predominantly be Nursing and Midwifery Council (NMC) registered mental health nurses.

The nature of separating healthcare services and registrants into acute (physical) orientated care, and mental health, places the care of someone with DSD at odds with its multifaceted etiology and presentation, which encompasses the physical, mental,

and cognitive wellbeing of the individual. There is growing recognition that acute general medical or nursing staff (i.e. adult field registered nurses, or doctors not specialising in mental health) struggle to manage patients with delirium, and may request support from mental health peers, or request patients are moved into specific mental healthcare settings. Whilst transfers of care into mental health settings or with oversight of mental health clinicians may better support some the cognitive and psychological factors of the DSD presentation, these settings may struggle to meet physical healthcare needs (Pryor 2021). Importantly, the majority of literature pertaining to delirium and dementia stems from countries who do not have single field registration of nurses (e.g. America, Europe and Canada), or is written from a general medical stance (Pryor 2021).

There have been recent inroads into recognising the connection between delirium and dementia, and DSD within guidance (National Institute for Health and Care Excellence 2018, National Institute for Health and Care Excellence 2023) however there remains a lack of UK based or mental health literature and understanding (Pryor 2021)

Aim:

To explore UK mental health nurses' experiences of providing care for people with delirium superimposed on dementia, and to describe what factors may affect this within the care setting.

Methods:

Design: The full study was undertaken using a mixed methods, exploratory sequential design. This paper reports phase 1: A qualitative exploration of the mental health nursing experience of DSD.

The full study is reported elsewhere (Pryor 2021). As secondary quantitative phase was undertaken to provide breadth of experience to the qualitative depth of experience, leading to integration and analysis of both data sets (Figure 1)

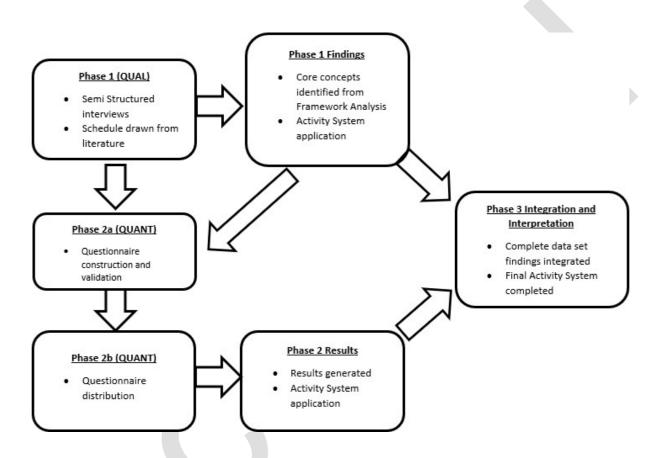


Figure 1 Overall Study Design (Pryor 2021)

Concerned with what influences the nurses' experiences, it was important to explore their experiences to show any tensions, influences or supportive elements. To help this, Activity Theory (second generation) was used (Engeström 2001) as a sensitising lens. This offered a visual model for investigation of their interactions within their work systems (Engeström et al. 1999). Key to activity theory is the understanding that all experiences are influenced and mediated by factors within the community (Bedny and Karwowski 2007). These influencing factors may be "tools" or things that are used in

practice, the objects (or intended activity such as providing care), divisions of labour, the community (in which the nurses work), rules (such as nursing or local policy), and the subject of the activity (being the nurses) (Engeström 2001).

An initial scoping literature review was undertaken to build a conceptual framework and to inform an interview schedule. Search terms included *delirium superimposed on dementia: Nurs*, Care, acute confusion.* Literature found was screened via abstract review, and process of terms checking was undertaken to clarify instances where differing terms describing cognitive issues or loss were in relation to dementia. 53 articles were selected for review. Developing themes within the literature included the use of tools to detect delirium and requests for additional support, failure to assess, levels of organisational support, patient and carer experiences, expectations placed on mental health care settings, and recognition of delirium subtypes. These themes were used to build an interview topic guide.

Data collection and analysis

Initial data collection was undertaken via individual semi structured interview.

Interviews were audio recorded and transcribed into the NVivo™ data management platform.

Framework analysis supported the generation of key themes, due to its flexibility, and ability to demonstrate an audit trail of analysis (Gale et al. 2013, Spencer et al. 2014). Initial familiarisation with the data was undertaken by transcript review, and re-listening to the initial interviews. Patterns, phrases and topics were noted and created a matrix into which data from all other interviews could be considered and appraised (Ritchie and Spencer 2002, Spencer et al. 2014) (figure 2). Indexing and sorting further data

into cohesive themes was completed before a final data summarisation and interpretation of the interview data (figure 3). All analysis was undertaken by the author, and secondary checking and agreement was completed by two supervising senior researchers.

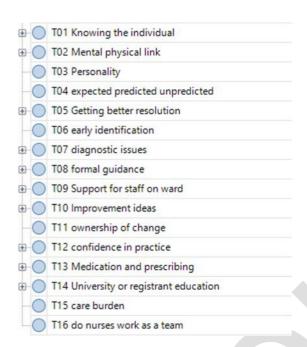


Figure 2 The evolving thematic framework

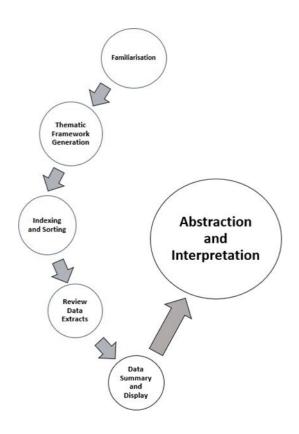


Figure 3 Framework Analysis

Sample

The phase 1 study location was a NHS mental health foundation trust in the North of England. Purposive sampling of mental health nurses working in inpatient dementia care services was undertaken (N=52). Invitation emails and full study details were sent to all eligible nurses. Seven individuals agreed to participate (n=7), including five staff nurses (NHS employment band 5) and one junior manager (NHS employment band 6).

Ethical approval was granted by the Faculty of Health and Life Sciences, Northumbria University and the Trust Research and Development Department. All participants gave written, informed consent and were able to contact the research team throughout. In keeping with sequential studies, the initial interviews reported here were undertaken from December 2016 to February 2017. Participants were assigned a unique identifier

to maintain confidentiality. Subsequent phase 2 and 3 data collection and analysis was undertaken throughout 2019, with final integration and data analysis concluding the full study in 2021.

Findings

Six themes encompassed the participants' experiences of providing DSD care. These are presented in accordance activity theory system positions in Figure 4.

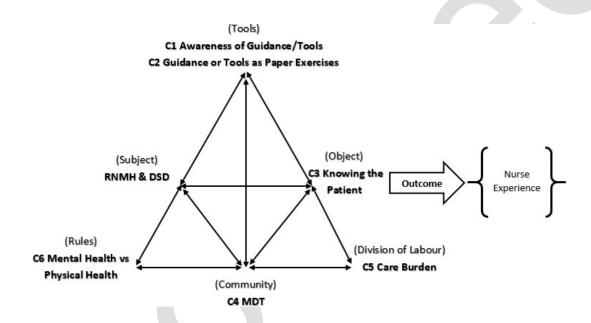


Figure 4 Participants' themes of experience (Pryor 2021)

Tools: Awareness

There was variation between participants in relation to the use of and knowledge of tools to identify DSD. Some participants said they did not use any formal resources, others reported that they had used tools in the past, but no longer did. They indicated a shift in focus away from delirium assessment.

"...there used to be a delirium assessment tool what we kind of trialled here for a while, but

we have kind of stopped that now and I don't really know...'

Participant B

Some participants did discuss using tools to support assessment, but others appeared

to be using tools for dementia or cognitive impairment assessment rather than specific

delirium assessment. These included the Mini-Mental State Examination (MMSE)

(Folstein, Folstein et al. 1975), and the Addenbrooke's Cognitive Examination 3 (ACE

3) for cognitive impairment, Alzheimer's disease, and fronto-temporal dementia

assessments (Bruno and Schurmann Vignaga 2019).

'...so we have got MMSE which, ACE-3...'

Participant C

Tools as "paper exercises"

Some participants did use tools to support their assessment, however this seemed to

be part of a standardised monitoring processes, not as a response to individual patient

needs or presentation. This highlighted a separation from how the tools had been

designed to be used, and their actual use.

"...I would say, I would just class it as part of the monthly tool you know..."

Participant C

It seemed that the interviewees did not think the number based scoring tools were

useful for their practice decisions. Whilst this was evident, it did not indicate that the

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right care was absent, more so that the tools were not seen as something that supported their care decisions. This was echoed in other participants discussion, and a concern was raised about the possibility of reducing a person to a numerical score, 'giving them' a diagnosis of delirium, even if this is not warranted.

... [tools] are valid, the questions are, but it's your knowledge, you need to expand your knowledge... I think it's become too standard...., ticky box', [...] but prior to that [using the DRS] ... a lot of people went undiagnosed...'

Participant E

Participant E proposes that having underpinning knowledge of delirium, and knowing the person as an individual are more effective and accurate ways of supporting care than using tools which become 'tick box' exercises. Participant E suggests that tools do 'serve a purpose', as a means of increasing diagnosis, however this is potentially to the point of over-diagnosis. Participant E proposes that while this is not ideal, at least it reduces the risk of missing cases.

Object: Knowing the patient

Participants felt strongly that their knowledge of the person receiving care was paramount. This demonstrated the specific onus that mental health nurses place on individualised, caring relationships, and the concept of aesthetic ways of knowing people. This is reported in Pryor 2023. The person centred process appeared more influential in their assessments than outcomes or numbers generated by clinical scoring tools.

Community: The Multidisciplinary Team

Within the community in which the nurses practiced, their colleagues and supporting MDT was significant to their care experiences. The MDT was perceived as supportive, and participants appreciated the range of medical, nursing, and allied professionals that could guide their care.

"...there is always a doctor on or a nurse, * Nurse practitioners named*, there is always someone to talk about or bounce ideas off, [...] I would like to think that if anybody had got delirium it would not go unnoticed..."

Participant B

The accounts highlighted the range of support available, and the participants willingness to work within a team. However there was an uncertainty about whether DSD would be identified without the MDT input; the MDT was a mechanism for "catching" delirium presentations, and their experience is influenced by other professions.

Division of labour:

The participants demonstrated confusion and concern that people with DSD were being brought to their specialist areas of dementia care for reasons not attributed to dementia, and (in their opinion) might be better cared for elsewhere. This resulted in distress for the patients involved, and an empathetic emotional burden for the nurses.

'...inappropriate admissions ... when they get here we identify delirium, and once the delirium has gone that person is absolutely fine...'

Participant F

'...had their infection been recognised and treated whilst they were in the community, they

might not have needed to come into hospital...'

Participant A

Here, the burden of care was both emotional, understanding the distress of patients and

families moving between care settings, but also a burden of providing care for people which

(in the participants opinion) should have been provided pre-admission. There is a recognition

that where care is situated, and when it is undertaken directly influences the patients journey

and overall outcomes. Here the nurses felt a burden of doing work that would have been

completed prior to admission, and potentially have prevented an admission.

Rules: Siloed Mental and Physical Health

The participants' discussions resonated with current literature; they consider that care

should be driven by the individual's needs, and mental health nurses' knowledge of

that person, but organisational constraints, and professional registrations separated

care into that of mental or physical health. Three key tensions were seen across the

accounts: the siloes of mental and physical healthcare provision, complexity of DSD,

and the infrastructure of care provision.

Separation of mental and physical health

The participants clearly understood the complexity at play with a DSD presentation.

"... Because we are working with the elderly, and we are working with people who have a

cognitive problem and it's not always mental health problems it's normally their physical health

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problems...'

Participant D

Here the three core facets of DSD are identified (mental, physical, and cognitive) and the intertwining of these. Other participants demonstrated a separation in relation to mental and physical, but that an awareness of both was important in delirium care.

"... when I was at university, I was with nurses from...they had no idea about dementia, and I think it is the reverse of the coin in here ..."

Participant C

The complex condition of delirium

While the participants were aware of delirium, they struggled to articulate what it was. Instead they recounted common physical causative agents, predominantly infection.

"...so that's what it keeps coming back to, not knowing exactly, knowing about delirium ..."

Participant G

'...I was never quite sure, I know people get chest infections and urine infections that's like a delirium...'

Participant B

The accounts highlight that when the participants were faced with a potential DSD, they considered isolated, individual potential physical causes (e.g. Infection/pain/constipation), *hoping* that the delirium would subside if these causes were addressed. At no point did participants discuss patients' mental health care

needs arising from DSD, or the supportive engagement, orientation or therapeutic activity that may form part of DSD care.

<u>Infrastructure of care provision</u>

The RNMHs clearly expressed the tensions that the traditional separation of physical and mental health services had upon their care provision and the patient.

"...the line between mental health and physical health. People get admitted to physical wards with delirium and there's batting from side to side,..."

Participant E

The nurses felt that patient care was shunted between speciality services. They displayed frustration clinically, but also for the patient being treated. They suggested that while RNMHs strive to provide holistic care, their mental health training, care environments and professional role boundaries create divides, which the nurses find challenging to work within, and detrimental to the person with DSD.

Discussion

This study is the first to the authors' knowledge to focus specifically on mental health nurses' experiences of caring for people with DSD.

DSD is clinically complicated. Nurses caring for people with DSD must navigate clinical scores, observational and behavioural information, and marry this with an understanding of the individual. This study highlights that whilst mental health nurses strive to provide person-centred care, organisational, educational, and diagnostic silos act as barriers to cohesive care provision. A significant concept within contemporary healthcare has been *parity of esteem*. This seeks to support a person's mental

wellbeing equally with their physical wellbeing (or health) (Mental Health Foundation 2020). Whilst the notion of parity has become common place in nurse education, governance, and policy this study demonstrated that there remain challenging organisational and practice divisions between mental and physical healthcare provision. Recently the Kings Fund (2016) have stipulated that education for healthcare professionals must provide adequate preparation across both mental and physical health; supporting all nurses, no matter what field registration is held, to care for people as individuals and be able to support their needs. This is echoed by the NMC, detailing that all nurses must be able to care for people with cognitive, mental, behavioural and physical care needs, and have provided a core set of proficiencies that all nurses, irrespective of field registration must poses (Nursing and Midwifery Council 2018). This move towards seemingly more generic nursing skills has raised concern however around an erosion of the unique skills that mental health nurses hold (Haslam 2023) and is in contrast to Health Education England (2022) who highlight the importance of mental health nurses' skills in communication, relationship centred care, and therapeutic relationships.

Despite the complexity surrounding professional nurse registration, there is movement towards integrated services that have a focus on physical and mental health care, spanning primary and secondary care; and health and social care. (NHS England 2014). However integration of services does not necessarily mean a move towards a generalised workforce, more so appropriate integration of professions to support all facets of a person's care. The support for mental health nurses by their peers and MDT is central to their experiences in this study. This echoes Teodorczuk et al. (2015) who found that care for the confused person was felt to be improved through learning about the patient as an individual, and by an inclusive team based dissemination of

knowledge. The development of a supportive, integrated MDT may strengthen and celebrate the unique position that mental health nurses hold in DSD care, whilst allowing different professionals to contribute to the overall care of a person with DSD, attending to their mental, physical, and cognitive needs.

Adding to the complexity demonstrated in the nurses' experience of providing DSD care, is a lack of consensus between delirium experts in regards to use of specific tools/scales to assess for DSD, and a lack of specific diagnostic criteria for DSD (Richardson et al. 2016). This lack of a standard approach, or use of several tools is echoed in this study. This study did find however a consistency in that personal knowledge of the individual, and awareness of a change in their presentation was central to their experience and felt that was sufficient for them to suspect DSD. It is evident that for the nurses in this study, "knowing" the person, whether individually, or through a formulation process forms the basis of their clinical assessments and care provision, rather than the outcome of a numerical score or tool.

Whilst readily accessible, multi professional tools to assess for delirium are available such as the 4AT (MacLullich et al. 2011-2014) they remain focussed on a quantification of a person's presentation, and may not be readily used by mental health nurses if there is a reluctance to distil a person's presentation to a number or score. In contrast the Single Question in Delirium (SQiD) (Sands et al. 2010) highlights the change in a person's manner or "self" as its only element, highlighting this observational value and may act as a prompt to assess or address factors in delirium further. This may feel more natural, and appropriate to mental health nurses who's work is based upon forming human connections, and understanding a person's world, their values and perceptions of that world (Haslam 2023)

Strengths

This paper reports the first phase of a wider study which is to the authors knowledge the first to specifically focus on registered nurses from the mental health field, and how they experience providing DSD care. This supports professional recognition of the unique skills of mental health nurses, and how these directly influence and support patient care. From this first qualitative exploration, key themes can be further explored and addressed to support advances in patient care, understanding of professional roles, and contextual influences within mental health settings.

Limitations

This paper reports the first phase of an larger study. The sample, and findings reported in this paper are drawn from a sample of mental health nurses from one NHS Trust. This could be seen to limit the transferability to other settings, however this paper offers the first exploration of mental health nurses experience, and could lead the way for further, larger scale research.

Conclusion

The study presented here, is the first to consider DSD care provision through the lens of UK mental health nurses. It demonstrates that the nursing experience is guided by a fundamental drive to understand people receiving care as individuals. Whilst there has been advances in DSD care, there remains complexity and challenges in providing care that spans mental, cognitive, and physical health requirements within the UK healthcare service. And whilst parity of esteem and integrated care agendas have supported the recognition of all facets of care for DSD, it has generated debate and discourse regarding professional erosion of roles and specialist skills.

Implications for practice

There is a clear need to further understand DSD from a mental health perspective and contextualise this across both health and social care settings. Findings from the full study strive to do this (Pryor 2021). Six key implications for practice from this study are presented below.

- Those working with people with or at risk of DSD must understand their own professional roles, and also have an understanding of the role and responsibilities of their colleagues. There needs to be a cohesion within teams to support DSD care provision.
- Nurses must be education to ensure parity of esteem whilst maintaining their distinct field of registration and professional focus within a wider healthcare context.
- Integrated and supportive MDTs should be fostered to allow for a collective approach to DSD care.
- Silo working should be addressed to foster a cautious, but collective approach
 to any transitions of care. Allowing people to access care provision in the most
 appropriate setting for their needs, but without avoidable moves based upon
 lack of understanding or support needs.
- The professional way in which mental health nurses "know" and construct care
 for their patients should be recognised and celebrated for its unique
 contribution to the healthcare system.
- A streamlined approach to using the most appropriate assessment strategy should be embedded. Taking into account different professional backgrounds, and how a supported amalgamation of information gleaned can enhance care.

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Comment	Change
Refer to NOP article rather than section on "knowing"	Brief overview offered and signposted to NOP. Ref inserted
Name Ethics committee	University named.
	Author initials given to identify who undertook analysis
Consent information needed	Informed consent and contact detail for PI added
Add strengths	Strength of study added
Implications for practice	MDT and Parity of esteem+ education added as bullet points
Similarity raised with thesis	Revised and appraised against similarity