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## **An Evaluation of the Newcastle Model in Supporting Stress and Distress in People with Dementia in Acute General Hospital Settings.**

### **Abstract:**

This service project evaluated the clinical utility of the Newcastle Model in supporting 'stress and distress' in people with dementia in acute general hospital settings. Significant reductions were observed in both the perceived severity of stress and distress experiences, and the perceived difficulty for hospital staff in supporting stress and distress experiences. There is a promising role for Newcastle model-led interventions in supporting stress and distress experiences for people with dementia in acute general hospital settings. However, further practice-based evidence is required to demonstrate its full utility within this setting.

**Key words: stress, distress, dementia, behaviours, challenge.**

## **Introduction:**

In the United-Kingdom, there are estimated to be around 900,000 people with dementia (Alzheimer's Society, 2021), and this is expected to rise significantly to over one million by 2025, and over two million by 2051 (Prince et al., 2016). With the rising ageing population and prevalence of dementia, it is now believed that, at any one time, 25% of acute hospital beds are occupied by people with dementia (Royal College of Psychiatrists, 2019). The unfamiliar surroundings, frequency of staff changes and disruption to usual routines following admission can be overwhelming and distressing (Gwernan-Jones et al., 2020). Resultantly, people with dementia often experience increased distress, longer stays, and poorer health outcomes on discharge (NICE, 2018).

For many people with dementia, changes in cognition and verbal communication will result in a great deal of confusion, worry, frustration, sadness (Patterson et al., 2018). Distress behaviours may manifest, often observed by care staff as 'verbal' or 'physical aggression', 'agitation', or 'repetitive movements' (Campbell et al., 2020). However, these may be the person's only way of communicating their experience of stress and distress, or an unmet need (Cohen-Mansfield et al, 2015). Care staff often feel unconfident and deskilled in understanding and responding to this distress (Doherty & Collier, 2009; Tadd et al., 2012), and may even misinterpret the person as being 'challenging' or 'resistant to care' (Featherstone et al, 2019).

Such expressions of distress have historically been viewed as 'problematic' or 'challenging behaviour' (Algase et al., 1996), and this view creates widely systemic problems. Such labelling invokes a sense of the person and their behaviour as being 'socially unacceptable', is stigmatising, and may 'block' carers from treating people with dementia with dignity and respect (Cahill, 2018). These labels may also imply the behaviour originates 'within the individual', reinforcing an entrenched pathologising view of the person being 'the problem' (Jorgensen et al., 2023), and necessitating needless pharmacological intervention (Medea et al., 2020). Important social and environmental contexts and physical health needs driving the distress may also become ignored (James & Jackman, 2017).

The need for a paradigm shift in research and practice has been acknowledged in recent years to tackle these systemic issues. This has largely been driven through reorientating dementia care towards a person-centred and values-based approach; emphasising a psychosocial understanding of a person and their distress, considering distress behaviours as a means of communicating an unmet need (Cohen-Mansfield et al., 2015), and ultimately, seeing 'the person' behind the behaviour (James & Gibbons, 2019). The current paper refers to 'stress and distress' when referring to the distress experiences of people with dementia.

Clinical guidelines maintain that psychosocial and environmental interventions should be the first line approach to supporting stress and distress in people with dementia; unless immediate risks present (Brechin et al., 2013; NICE, 2018). However, specific guidance relating to psychosocial interventions for stress and distress in people with dementia remains unclear (Aerts et al., 2019), and arguably, may have inadvertently led to the use of pharmacological intervention as a first line response (Medea et al., 2020). Formulation-led interventions are recommended as an important non-pharmacological approach in understanding and intervening with stress and distress for people with dementia (Brechin et al., 2013; Moniz-Cook & James, 2018); however, further research is needed (Holle et al., 2017). This is particularly evident in acute general hospital settings, where there is a paucity of research evaluating the use of formulation-led approaches to stress and distress for people with dementia (White et al., 2017).

Arguably, the most empirically supported formulation-led approach in dementia care is the Newcastle Model (James et al., 2006). The approach posits that stress and distress are expressions of unmet needs, occurring as the result of a complex interplay between an individual's life story, personality, cognitive abilities, current or past mental and physical health difficulties, medication and challenges within the social environment and context (James & Jackman, 2017). The Newcastle Model is a structured, 12-14 week, idiosyncratic formulation-led approach, and initially involves an intensive assessment phase of the stress and distress. This involves the use of observation, structured assessment tools, and collateral information-gathering from the service user, family and carers (Jackman, 2020). A person-centred, biopsychosocial formulation is consequently developed in collaboration with involved carers and clinicians, and a

care-plan with formulation-specific interventions are produced and delivered by care home staff, with the support of the involved clinician (James & Jackman, 2017).

Support has been shown for the Newcastle Model in reducing the frequency and severity of stress and distress, as well as caregiver distress, in residential care settings (James & Jackman, 2017; Rickardsson & Crooks, 2021; Wood-Mitchell et al., 2006). Yet, limited research has been conducted in acute general hospital settings. Brechin et al. (2013) acknowledge this may partly be due to the complex nature of the model, and thus, the requirement for assistance from specialist teams to carry out the intervention. De Pfeiffer (2016) also argues that the resource-intensive nature of the approach may limit its application within acute hospital settings. However, James & Jackman (2017) maintain that 30-35% of service users do not require the full 12-14 week intervention programme, and trained clinicians can flexibly utilise elements of the approach in everyday practice, rather than the full approach (Jackman & Beatty, 2015).

### **Rationale for the Project:**

The quality of care offered to vulnerable older people admitted to acute general hospital settings in England and Wales has been a prominent issue of concern for several decades (Francis, 2013). Policy-makers have begun to acknowledge the detrimental impacts that a general hospital admission can have for a person with dementia, and national strategies have been implemented to improve their hospital care, such as the Welsh Government Dementia Action Plan for Wales 2018–2022 strategy and the Dementia Friendly Hospitals Charter for England (2014) and Wales (2022).

The current project relates to a Psychology Service operating within acute general hospital settings in a Health Board in West Wales. It was formed to help improve psychosocial care for people with dementia, through increasing access to formulation-led interventions for stress and distress and to optimise wellbeing in dementia in general hospital settings. The Service adopts the Newcastle Model principles and strategies, and works collaboratively with service users, families/carers and hospital staff to:

- Identify and address underlying needs that could drive stress and distress and:
- Increase knowledge and confidence of hospital staff in engaging with non-pharmacological approaches to supporting people with dementia.

The current study thus sought to establish whether involvement from the current Service, in providing collaborative Newcastle Model-informed interventions, would lead to a reduction in stress and distress for people with dementia within acute general hospital settings. Furthermore, whether hospital staff could be supported to feel more knowledgeable and confident in working with the “person behind the distress”, with the benefit of a person-centred formulation. In light of the evidence-base position, and concerns for quality of care for people with dementia in general hospitals, it felt pertinent that the current study was commissioned to evaluate the clinical utility of formulation-led approaches in acute general hospital settings.

## **Method:**

### **Outline of Service Model and Intervention:**

The service model adopts the Newcastle Model (James & Jackman, 2017), offering a formulation-led intervention approach to supporting stress and distress in people with dementia in hospital. The standard protocol outlined by James & Jackman (2017) is difficult to implement as circumscribed in hospitals; due to discharges and largely due to systemic factors, such as pressures on hospital staff, availability and opportunities for liaison, and frequent staff turnaround impeding consistent dissemination of formulations and care plans. Thus, there is a requirement to offer components of the approach more flexibly. Notwithstanding, the service model mirrors the general protocol well, offering: an intensive assessment phase; collaborative formulation with staff and carers; and, the designing, dissemination and implementation of Newcastle Model-informed interventions, and modelling these with staff.

Referrals are made to the psychology service by hospital ward staff who are caring for a person living with dementia who is experiencing stress and distress, whom they feel would benefit from formulation-led input. The formulation is developed collaboratively by a Clinical Psychologist and Trainee Clinical Psychologist or Assistant Psychologist, alongside the hospital staff who are

directly involved in supporting the person with dementia, and family and carers. A collaborative care plan is subsequently developed, with interventions targeted at meeting hypothesised unmet needs, identified within the individuals' psychological formulation. Tailored interventions identified in the care plan are modelled by the psychology service and carried out day to day by hospital ward staff and the person with dementia's family or carers.

**Table 1: Example formulation-led care plan for a service user.**

<b>Unmet Need:</b>	<b>Observed stress and distress</b>	<b>Psychosocial Intervention:</b>	<b>Rationale:</b>
<b>Attachment</b>	Very upset, tearful, missing family and wanting to go home.	Reminiscence techniques: conversations about loved ones, life with family, looking at photo albums.  Facilitating regular visits and phone calls with family.	Engagement of affiliative / soothing system through feeling a sense of love, belonging and connection.
<b>Safety/ Security</b>	Distress from disorientation to the hospital environment (particularly at night).  Frustration at staff who service user felt were keeping him there against his will and did not like him.	Consistent reality orientation.  Communication training with staff (non-challenging, empathic and validating)  Building relationships (regular introductions, spending time getting to know service user, familiarising staff with his formulation document and life story).	Helping him feel safer and more secure within the ward through his relationships with staff, and through feeling orientated to time and place. A felt sense of staff really wanting to look after and care for him.
<b>Comfort</b>	Clutching stomach, in great deal of pain and frustration, but unable to express this.	Resolving pain.  Ensuring underlying delirium and physical health needs are resolved.	Ensuring staff were meeting his pain management needs.
<b>Occupation</b>	Tearful and low in mood, expressing a sense of boredom and being stuck in hospital against his will.	Accessing interests (film and music)  Promoting independence (getting walks around the hospital site and green areas)	Make time in hospital as meaningful as possible. Improve mood.

Unmet needs which often arose related to core psychological needs, such as 'identity', 'occupation', 'safety and security', 'comfort', and 'attachment' (Kitwood, 1997). For additional clarity, Table 1 above provides an example of a formulation-led intervention for a service user, based on evidence-based psychosocial interventions in supporting people living with dementia (James & Jackman, 2017).

### **Design:**

A retrospective study design was employed, evaluating routinely captured clinical outcome data. The data analysed was collected from service inception in September 2019 to the analysis-point in June 2022 to address the above research questions. Staff in the current service routinely record clinical outcomes in a registered database in accordance with regulations from the Health Board's Research and Development (R&D) team. Data from service inception to present was extracted by a member of the team with routine access to the data in their role.

### **Procedure:**

Ethical approval to access the data and conduct the study was obtained from the Local Health Board Research & Development team. NHS ethical approval was not required as data were routinely collected for service evaluation and development purposes. Data analysis commenced following approval from the R&D department. Data was compiled and anonymised prior to being received by researchers.

### **Participants:**

Data was included from participants who: a) were admitted to an acute general hospital within the Health Board; b) had a confirmed or working (hospital-acquired) diagnosis of dementia; c) had been deemed not to be experiencing delirium d) received involvement from the service, and; e) had completed baseline and post-intervention outcome measures. Informed consent was gained via routine clinical activity process for the service where there must be informed consent for service involvement and pre/post data collection/evaluation gained from clients where



possible and/or carers where necessary and in keeping with capacity and best interests. The sample consisted of 82 females (55.8%) and 65 males (44.2%), with a mean age of 83.3 years (SD = 7.57; range 56-98 years). The vast majority of the sample was over the age of 75 (89.1%), with 9.5% of participants being between 65-74 years and 1.4% below 65 years.

## **Materials and Measures:**

### ***Neuropsychiatric Inventory–Questionnaire (NPI-Q):***

The Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer et al., 2000), adapted from the standard Neuropsychiatric Inventory (Cummings et al., 1994), is a validated informant-based questionnaire, which provides a brief assessment of “neuropsychiatric symptomatology” in routine clinical practice settings (Kaufer et al., 2000). The NPI-Q is routinely captured during service involvement at baseline and post-intervention, completed by a member of the ward team, usually a nurse or health care support worker. The NPI-Q has been shown to have adequate test-retest and inter-rater reliability, as well as good concurrent validity (Kaufer et al., 2000). The NPI-Q assesses 12 domains of stress and distress symptomology, present within the previous month, including: “delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, night-time behaviours, and problems with appetite or eating”.

The hospital staff member is asked to indicate whether there is presence of a symptom, using ‘yes’ or ‘no’. If answered ‘yes’, they are subsequently asked to rate the ‘severity’ of that symptom for the service user, using a 3-point Likert scale: mild (1), moderate (2) or severe (3). The staff member then rates the ‘difficulty’ staff experience associated with supporting the stress and distress, using a 5-point Likert scale: not difficult at all (0), minimal (1), mild (2), moderate (3), severe (4), extreme or very severe (5).

The NPI-Q provides ‘Severity’ and ‘Difficulty’ ratings for each symptom reported. A total ‘Severity’ and total ‘Difficulty’ score is consequently calculated, reflecting the sum of severity and difficulty ratings across all reported symptoms.

**Staff Feedback Form:**

The Staff Feedback Form is a 7-item questionnaire, designed within the service and adapted with permission from the Newcastle team (James & Jackman, 2017). It is routinely captured at post-intervention during service involvement and completed by hospital ward staff. Staff are asked, following service involvement, “did it help to optimise the person’s wellbeing?”, “how knowledgeable do you feel in working with the person?”, “how confident do you feel in working with the person?”, “did understanding who the person is help?”, “did understanding potential needs help to optimise the person’s wellbeing?”, “did the optimising wellbeing formulation document help?” and “did a consistent person-centred approach help?” Hospital staff rate their endorsement using a 4-point Likert scale: not at all (0), a little (1), a fair amount (2), or a great deal (3). Each item on the questionnaire is coded during analysis as such.

**Analysis Plan:**

Descriptive analyses, namely frequency and percentage for categorical data, and mean and standard deviation for continuous data, were generated using IBM SPSS statistics software version 27.0 to help describe cases with completed baseline and post-intervention measures. Descriptive data for the NPI-Q domains at both baseline and post-intervention were analysed for normality, using the Shapiro-Wilk test. Reviewing the data, assumptions for normality were violated. Thus, Wilcoxon signed rank test was employed, using SPSS to test for within-group differences between baseline and post-intervention NPI-Q ‘severity’ and ‘difficulty’ domain scores.

**Results:**

Table 2 provides a summary of the baseline and post-intervention median scores and Wilcoxon signed rank z-scores for NPI-Q ‘severity’ and ‘difficulty’ domains. Of the 147 participants, when considering NPI-Q ‘Severity’ scores, 117 participants saw a reduction in scores at post-intervention, compared with pre-intervention, whilst 11 participants saw no change, and 19 participants saw an increase in severity scores. With respect to NPI-Q ‘Difficulty’

scores, for 115 of the participants, staff reported a decrease in ‘difficulty’ scores between baseline and post-intervention, whilst for 13 participants there was no change, and for 19 participants, there was an increase in staff reported ‘difficulty’ scores.

**Table 2: Pre and Post Median scores for NPI-Q ‘Severity’ and ‘Difficulty’ domains, pre-post difference frequencies, and Wilcoxon signed rank z scores.**

<b>NPI-Q Domains:</b>	<b>Pre-Intervention: Mdn (T1)</b>	<b>Post-intervention: Mdn (T2)</b>	<b>Pre-Post Difference: N (%)</b>	<b>Pre-Post Difference: Mdn</b>	<b>Pre-Post z score:</b>
<b>Severity</b>	12.00	6.00	<b>Decreased:</b> 117 (79.6%) <b>Increased:</b> 19 (12.9%) <b>No Change:</b> 11 (7.5%)	-4.00	-8.17***
<b>Difficulty</b>	14.00	6.00	<b>Decreased:</b> 115 (78.2%) <b>Increased:</b> 19 (12.9%) <b>No Change:</b> 13 (8.8%)	-6.00	-8.15***

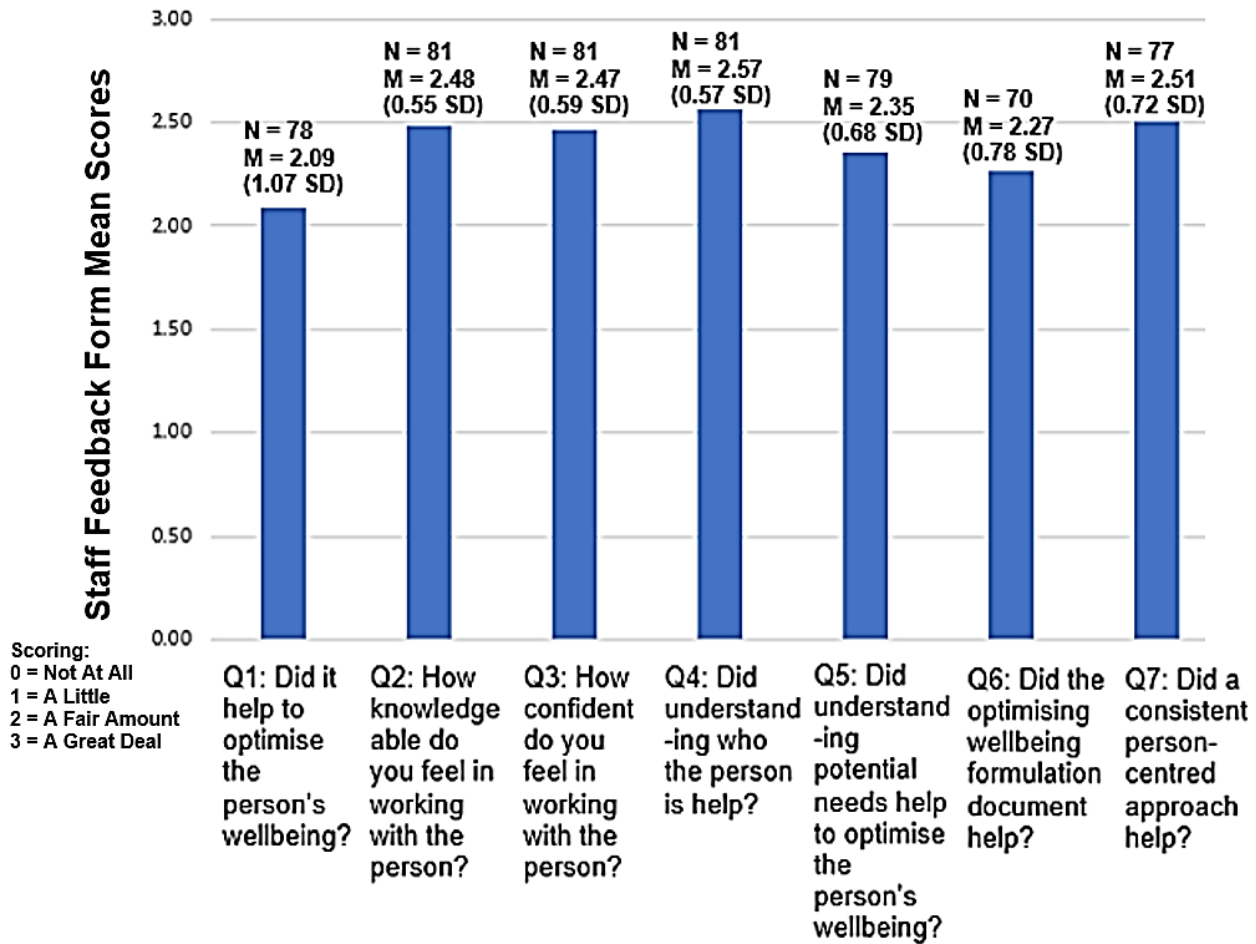
**Note.** NPI-Q = Neuropsychiatric Inventory-Questionnaire; Mdn = Median.  
\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

A Wilcoxon signed-rank test determined that there was a statistically significant decrease in NPI-Q ‘severity’ scores (Mdn = -4.00) at post-intervention (Mdn = 6.00) compared with pre-intervention (Mdn = 12.00),  $z = -8.17$ ,  $p < .001$ . Similarly, there was a statistically significant decrease in NPI-Q ‘difficulty’ scores (Mdn = -6.00) at post-intervention (Mdn = 6.00) compared with pre-intervention (Mdn = 14.00),  $z = -8.15$ ,  $p < .001$ . In terms of the effect sizes for within group baseline to post-intervention comparisons (Rosenthal, 1994), there was a medium effect size with regards to both reductions in severity ( $r = .48$ ) and difficulty ( $r = .48$ ) scores.

Figure 1 below provides a summary of the mean scores from Staff Feedback Form questionnaire items. All items were endorsed by hospital staff, on average, above ‘a fair amount’, with the greatest item endorsement being for “did understanding who the person is help?” ( $M =$

2.57, SD = 0.57), with the least being for “did it help to optimise the person’s wellbeing?” (M = 2.09, SD = 1.07).

**Figure 1: Staff Feedback Form (Staff mean scores per all questions).**



**Note.** N = Frequency; M = Mean ; SD = Standard Deviation.

In summary, findings indicate that staff perceived there was a significant reduction in stress and distress for people with dementia, in conjunction with a significant reduction in the perceived difficulty associated with supporting the stress and distress, following service involvement from the psychology service. Further, hospital staff feedback highlighted that, on average, service involvement helped optimise the person’s wellbeing at least ‘a fair amount’. Similarly, understanding who the person was, having a consistent person-centred approach and understanding potential needs helped at least ‘a fair amount’ with supporting service users.

Lastly, it was identified that, through the process of service involvement, staff felt 'a fair amount' more knowledgeable and confident in supporting stress and distress in people with dementia.

### **Discussion:**

The study sought to evaluate whether involvement from the current service, offering collaborative Newcastle Model-informed interventions, would: lead to a reduction in stress and distress in people with dementia; help hospital staff feel more knowledgeable and confident in working with the person behind the distress; and, whether there was benefit in having person-centred formulations, focused on identifying and addressing underlying needs. Analyses conducted in the current study have arguably been able to partially address these aims.

Wilcoxon signed-rank test showed that, following intervention, the vast majority of cases identified a significant reduction in perceived severity of stress and distress and perceived difficulty for staff in supporting with the stress and distress. This finding is consistent with other studies in the literature (Rickardsson & Crooks, 2021; Wood-Mitchell et al., 2006). However, it is important to note that these studies were conducted within residential care settings, and at present, there is no identified research where the Newcastle Model has been implemented within acute general hospital settings.

The study also determined that, on average, hospital staff perceived that the service involvement helped optimise the wellbeing of the people with dementia at least 'a fair amount'. This is arguably consistent with findings from the NPI-Q scores. Similarly, "understanding who the person was", "having a consistent person-centred approach" and "understanding potential needs" were advocated by hospital staff as helpful processes, and on average, staff rated feeling 'a fair amount' more knowledgeable and confident in supporting stress and distress as a result. These findings are also supported in the literature (Bryony, 2009, as cited in James & Jackman, 2017; James et al., 2020). However, arguably, the current study would merit from gaining more qualitative feedback, exploring specific processes linked with how staff came to feel more knowledgeable and confident, and to explore any process difficulties when the contrary arises.

These findings have important implications for the current service and for hospital ward teams in supporting stress and distress in people with dementia. The findings are promising in advocating for the ongoing role of formulation-led interventions, such as the Newcastle Model, within general hospital contexts; particularly when considering the challenges identified in the literature and policy guidelines around inconsistent care for this group in hospitals. Furthermore, despite concerns raised around the translatability of the Newcastle Model in acute general hospital settings (de Pfeiffer, 2016), the study findings were observed within the context of a flexible working approach to the model, adapted to the individual needs of the hospital settings. However, further evaluation and wider replication is warranted to bolster the evidence base for the model in this setting.

The current study offers important insights, however, there are several noteworthy limitations to address. The use of pharmacological interventions in people with dementia presenting with stress and distress is a widespread issue (Jokanovic et al., 2015), particularly in acute hospital settings (Featherstone et al., 2019). Controlling for the use of pharmacological interventions was not factored into the current analysis, making it difficult to explicitly define the impacts of the current service provision on reducing stress and distress. Similarly, pain, infection and delirium are other possible underlying factors associated with stress and distress in people with dementia; which once resolved, can reduce stress and distress. While the current study tried to control for factors including delirium and pain, by participants having been screened as part of the service's routine clinical activity and these factors addressed before the service involvement, ongoing measures of these factors were not routinely continued. Thus, it is pertinent going forward that future research and evaluation considers more robust means of controlling for the effects of pharmacological intervention and resolving physical health needs. Furthermore, the NPI-Q stress and distress outcomes were completed by hospital staff; arguably introducing some bias without service users' perspective on their stress and distress experiences. Future research may therefore wish to consider incorporating service user involved outcomes or qualitative feedback when evaluating the approach.

**Conclusion:**

There is a promising role for the Newcastle Model in supporting stress and distress in people with dementia in acute general hospital settings. Ongoing research will be helpful to begin grounding an evidence-base within this setting. However, future research within such settings would benefit from examining the role of other contributing variables, such as the use of pharmacological intervention and resolving physical health needs. Further, whilst service involvement helped hospital staff feel more knowledgeable and confident in supporting stress and distress in people with dementia, it may be beneficial to gain more qualitative insight into the specific mechanisms of service involvement that supported this. Lastly, service user involvement was limited within the current analysis. Identifying meaningful ways of incorporating service users' perspectives will likely benefit the intervention offered and the evaluation process.

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