Obtaining information from family caregivers to inform hospital care for people with dementia: A pilot study

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Christine Toye*

School of Nursing, Midwifery and Paramedicine, Curtin University, Australia

Centre for Nursing Research, Sir Charles Gairdner Hospital, Australia

Email: c.toye@curtin.edu.au. Phone: 61-8-9266 1756

Susan Slatyer

School of Nursing, Midwifery and Paramedicine, Curtin University, Australia

Centre for Nursing Research, Sir Charles Gairdner Hospital, Australia

Eleanor Quested

School of Psychology, Curtin University, Australia

Mary Bronson

Medical Division, Sir Charles Gairdner Hospital, Australia

Andrew Hill

Medical Division, Sir Charles Gairdner Hospital, Australia

Jan Fountaine

Medical Division, Sir Charles Gairdner Hospital, Australia

Hannah Velure Uren

School of Psychology, Curtin University, Australia

Lakkhina Troeung

Population and Public Health, The University of Western Australia

Sean Maher

Department of Rehabilitation and Aged Care, Sir Charles Gairdner Hospital, Australia

*Corresponding author

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Contributions to the study

CT, SS, and EQ substantially contributed to study design, acquisition of data, data analysis, and interpretation of data

MB, AH, HU, and JF substantially contributed to the acquisition of data and interpretation of data

LT conducted the quantitative data analyses and substantially contributed to the interpretation of data

SM substantially contributed to the interpretation of data

CT, EQ, and SS drafted the paper

All authors revised the paper critically for important intellectual content, approved the version to be published, and agree to be accountable for all aspects of the work

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Abstract (300/300 words)

Background

Appropriate hospital care for people living with dementia may draw upon: information from the patient and family caregiver about the patient's perspective, preferences, and usual support needs; nursing expertise; and opportunities the nurse has to share information with the care team. Within this context, planned nurse-caregiver communication merits further investigation.

Aim

We aimed to implement a systematic nurse-caregiver conversation, examining fidelity, dose, and reach of implementation; how implementation strategies worked; plus feasibility and mechanisms of change.

Methods

In Phase I, we established the ward staff's knowledge of dementia and Alzheimer's disease, prepared seven nurse change leaders, finalised the planned practice change, and developed implementation plans. In Phase II, we prepared the ward staff during education sessions and leaders supported implementation. In Phase III, evaluations were informed by interviews with change leaders, follow-up measures of staff knowledge, and a nurse focus group. Qualitative data were thematically analysed. Statistical analyses compared nurses' knowledge over time.

Results

Planned practice change included nurses providing information packs to caregivers then engaging in, and documenting, a systematic conversation. From 32 caregivers, 15 received information packs, 5 conversations were initiated, and one was completed. Knowledge of

dementia and Alzheimer's disease improved significantly in change leaders (n=7) and other nurses (n=17). Three change leaders were interviewed, six other nurses contributed focus group data. These leaders reported feeling motivated and suitably prepared. Both nurses and leaders recognised potential benefits from the planned conversation but viewed it as too time consuming to be feasible.

Conclusions

The communication initiative and implementation strategies require further tailoring to the clinical setting. A caregiver communication tool may be a helpful adjunct to the conversation. Implementation may be enhanced by more robust stakeholder engagement, change leader inclusion in the reference group, and an overarching supportive framework within which change leaders can operate more effectively.

SUMMARY STATEMENT OF IMPLICATIONS FOR PRACTICE

What does this research add to existing knowledge in gerontology?

Comprehensive, systematic, and well-documented staff-family caregiver conversations to inform safe person-centred hospital care for people with dementia can be challenged by competing clinical priorities.

Feasible ways to access adequate information from family caregivers of hospital patients living with dementia can help the care team provide safe person-centred care and require urgent implementation.

What are the implications of this new knowledge for nursing care with older people?

Processes for nurses to elicit information from caregivers to inform safe, person-centred hospital care for people with dementia need to be tailored to the clinical context with stakeholder input.

Nurses have a role in ensuring a collaborative, whole of clinical team, commitment to using information provided by family caregivers to inform safe, person-centred hospital care for people with dementia.

How could the findings be used to influence policy or practice or research or education?

Recognition of the challenges faced by change leaders in clinical settings demonstrates a need to value and support them as well as equipping them with skills to drive practice change.

Educational approaches for nurses can help to reinforce their important role in helping to promote the provision of caregiver-informed care for people with dementia that might reduce adverse patient outcomes.

Background

Hospitalisation is common for people living with dementia and may be precipitated by comorbid conditions (Timmons et al., 2016) or related to the deterioration in functional status typical of dementia (Draper, 2013). However, admission to hospital for the person with dementia can be problematic, especially as the condition progresses and symptoms become more complex. When compared with other similar hospital patients, patients with dementia are at increased risk of urinary tract infections, pressure areas, pneumonia, and delirium (Bail et al., 2013); as well as falls and lengthy hospital stays (Australian Institute of Health and Welfare, 2013). Person-centred care for the hospital patient with dementia has the potential to minimise such risks via an in-depth understanding of the usual care and support needs of that person, how additional needs might be communicated, and ways in which meeting these needs might be consistent with personal preferences and perspectives.

Person-centred care for a person with dementia is considered 'best practice' in many care settings (Clissett, Porock, Harwood, & Gladman, 2013). Person-centred care respectfully values the person, recognizes and addresses their perspective, and includes making a connection with the person (Brooker, 2003). Person-centred care also recognises that living with dementia is an individual experience, affected by personality, life experiences, coping ability, and the way psychological and social needs are met (Kitwood, 1997), as well as by the dementia itself and any comorbid health conditions.

Person-centred care is recognised as being particularly problematic to implement in acute hospitals because speedy diagnosis, treatment, and discharge is prioritised (Clissett et al., 2013), meaning that an understanding of, and connection with, the person with dementia needs to develop rapidly. Yet even relatively early symptoms of dementia, such as the word finding difficulties reported by people with Alzheimer's disease (Farrell et al., 2014), can mean

that rushed conversations between the patient and the hospital staff become problematic. Comorbid illness, the unfamiliar environment, and more advanced dementia symptoms are likely to compound this issue.

A Patient and Family Centred Care (PFCC) approach has clear potential to both complement and facilitate person-centred care for hospitalised people with dementia. This PFCC health care approach involves patients and families in care with the intent of enhancing care quality and patient safety (Mackie, Mitchell, & Marshall, 2018). Such an approach would mean that family members who routinely support, or speak on behalf of, the person with dementia (family caregivers, also known as care partners) can support the hospital staff's understanding of the perspective of the person with dementia, when providing this information unassisted becomes too challenging for the patient. In contrast, Burgstaller and colleagues (2017) identify that a negative cycle can be initiated when the family is insufficiently involved in care, care is inadequate as a result, and family needs and expectations related to the hospitalisation are influenced by this outcome.

Our team has drafted a model that focuses on person-centred care for the hospital patient with dementia within the context of such a PFCC approach, the <u>Person</u>-focussed and <u>C</u>aregiver-<u>I</u>nformed <u>N</u>urse-<u>D</u>riven model (Person-CIND) (Figure 1). In this model, appropriate hospital care for people with dementia is presented as care drawing upon:

1.   Communication from the hospital patient living with dementia and their caregiver about the patient's perspective, preferences, and usual support needs.

2.   The clinical expertise of the nurse who has an understanding of dementia, a person-centred approach, presenting medical conditions, and the risks known to occur when a person living with dementia is hospitalised.

3.   The opportunity that nurses, in particular, possess to connect with patients and their families and to become a conduit between the patient-caregiver dyad and the inter-professional care team.

These components, which can drive person-centred care that minimises risk and therefore promote better outcomes for patients, also promote recognition and valuing of the caregiver role. In addition, caregiver distress may be minimised because of better patient outcomes.

The Person-CIND model was drafted based upon reviews of the literature, then reviewed and refined in collaboration with the study reference group to help ensure face validity. This group included consumer, hospital, and academic representation.

In this study, just one element of the model – the process to access family caregiver input – was to be implemented by nurses. Implementation was to be driven by nurse change leaders who were appointed to instigate change, provide guidance and feedback to colleagues, monitor progress, and address challenges (Leeman et al., 2007).

Implementation was guided by the COM-B system, a framework for understanding behaviour that can inform interventions involving behaviour change (Susan Michie, van Stralen, & West, 2011). In that framework, it is considered critical to address Capability (capacity to perform the desired behaviours [e.g., knowledge and skills]), Opportunity (factors external to the person that help facilitate these behaviours), and Motivation (cognitive processes that energise and direct the behaviours) to support change.

For this study, addressing the motivation of the change leaders was also grounded in Self-Determination Theory (SDT), a meta-theory of human motivation that focuses on the factors that can facilitate autonomous motivation. Autonomous motivation is evident when a person carries out relevant activities because he or she recognises and personally values why they are necessary, and is driven to engage in the behaviour for reasons underpinned by personal

values, to experience a sense of personal satisfaction and accomplishment. This means that the person acts with a sense of volition and freedom (i.e., autonomy), has the skills and competencies to be effective in their role (i.e., competence), and is meaningfully connected to and respected by those around them (i.e., relatedness).

Aims

The study aim was to implement a systematic nurse-caregiver conversation, examining fidelity, dose, and reach of implementation; how implementation strategies worked; plus feasibility and mechanisms of change.

Method

Design

This implementation study included a multiple methods evaluation based upon recommendations for the evaluation of complex interventions (Moore et al., 2015). Most elements of the evaluation were exploratory and descriptive although statistical comparisons informed the evaluation of staff knowledge of dementia and Alzheimer's disease across study phases.

The study was approved by the Human Research Ethics Committees (HRECs) of the participating hospital (2014-034) and university (HR128/2014). Written informed consent to study participation was obtained from all participants contributing study data. Non-identifiable audit data related to patients with dementia were collected under a waiver of consent approved by the HRECs in accordance with national guidelines (Australian Government, 2007). The nursing staff members documenting auditable data were made aware of the audit via information sheets and completion of the documentation to be audited signified their consent to the use of those data in the study. There was no requirement for family caregivers to provide written informed consent for inclusion in conversations to inform

care, given that this was already recommended practice and the conversations themselves were not used as data. However, family caregivers were provided with written information explaining the planned conversations and that they might be invited to contribute to them. The three study phases are summarised in Figure 2. The reference group that reviewed the model also reviewed plans for staff education, resources to be used to help implement the practice change, and other processes planned for implementation.

Setting and participants

The study was undertaken in a 32-bed acute medical ward in a tertiary metropolitan hospital in Western Australia (WA). All members of the multi-disciplinary care team were invited to participate: nurses, assistants in nursing (AINs), the allied health staff, and junior doctors.

In this setting, existing (pre-implementation) practice, when patients with dementia were admitted, involved individual practitioners liaising with patients and their caregivers when specific queries needed to be answered. Responses to these questions were documented in various sections of the medical records. A hospital-developed Carer Questionnaire was available for the nursing staff to record brief details of the patient and caregiver to help inform care. This questionnaire was seldom used prior to implementation but was integrated into the intervention (see the checklist in the Appendix).

Measures

Staff knowledge of Alzheimer's disease and dementia was measured by two questionnaires (Table 1). The *Alzheimer's Disease Knowledge Scale (ADKS)* (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). The *Dementia Knowledge Assessment Tool Version 2 (DKAT2)* (Toye et al., 2014). Demographic details collected included the age groups, experience, and work roles of the staff.

Procedures

Phase I: Baseline evaluations, change leader preparation, and planning for implementation

In December 2014 (Time 1 [T1]), all members of the ward's clinical staff were invited to complete baseline knowledge measures. Senior nurses (co-investigators on this study) asked seven ward-based nurses if they would undertake the role of change leaders based upon their evident level of interest in, and commitment to, the care of patients living with dementia, and their known availability during the project. These nurses agreed to undertake the role. Preparation for the change leaders was undertaken over two days and sessions addressed their capability, opportunity and motivation (Table 2). Behaviour change techniques (BCTs) (Susan Michie et al., 2013) were also included in the training to ensure that the change leaders had the capacity to support behaviour change among other nurses. The plan for operationalising the practice change was finalised in collaboration with the change leader group. According to this plan, when caring for a patient with dementia, nurses were to:

1. initiate contact with the caregiver;

2. provide informational resources to that caregiver in the form of a pack that included information sheets relevant to the hospital care of a person with dementia plus a letter explaining the information to be sought from caregivers;

3. engage in a pre-planned conversation with them to elicit information to support person-centred care for the patient that could also reduce risks from hospitalisation; and

4. document this information to inform care delivery by the multidisciplinary team.

The caregiver-nurse conversation checklist (see Appendix) listed topics that drew upon a synthesis of relevant local (evidence-based) nursing practice guidelines and policies already specified to guide practice within the participating hospital. Conversations were intended to inform person-centred care and help alleviate risks of developing respiratory or urinary tract

infections, sustaining injuries from falls and pressure, and developing delirium. The potential for compromised fluid and dietary intake was also considered, as was discharge planning. Nurses undertaking these conversations were asked to indicate on the checklist when these occurred (within the first 24 hours of arriving at the ward, later than that, or not at all), where in the patient records the conversation was documented, and any difficulties encountered or other comments.

Phase II: Staff preparation, implementation, process evaluation

In March and April 2015, the remaining nurses (n = 20), allied health staff (n = 3) and AINs (n=4) attended preparatory education sessions. Doctors were invited but failed to attend. Sessions addressed:

a) knowledge of dementia,

b) risks faced by people living with dementia who are hospitalised,

c) how person-centred care can address these risks, and

d) the four steps of the planned new practice plus how these would be supported by change leaders.

The staff's knowledge of dementia was reassessed at T2, immediately after the education sessions.

From the beginning of May until the end of August 2015, the practice change was implemented on the ward. During this period, the dose and reach of the practice change were established via tallying numbers of patients on the ward with a documented diagnosis of dementia who had a caregiver and comparing this number with numbers of checklists completed, and to what extent, plus the numbers of caregiver packs utilised (Table 3). Change leader meetings, planned to occur monthly, provided an opportunity to establish the fidelity

of implementation; any concerns around dose and reach; and any specific challenges to implementation that could be addressed.

Phase III: End of study evaluation

All baseline questionnaires were re-administered to the staff during Phase III (at T3), occurring from September 2015 until January 2016. The perceived feasibility and mechanisms of the practice change were explored in an audio-recorded focus group with nurses. An additional focus group was arranged but cancelled because the nurses could not attend due to clinical priorities. The nurses were asked about their understanding of the practice change and the model from which it was drawn, their involvement and the nurses' role, the feasibility of the practice change, any impacts observed, and any suggestions for future efforts to improve the accessing of information from caregivers.

 The perspectives of change leaders were captured in individual interviews 18 weeks after the end of the intervention period. All the leaders were invited to attend but only three responded to the invitation. The procedural recommendations of Scanlan and colleagues (Scanlan, Ravizza, & Stein, 1989a, 1989b) were employed for these interviews using a pre-determined guide with follow-up probes. Specific questions addressed these change leaders' reasons for agreeing to take on the role, what the role entailed, their preparation to undertake this role, the extent to which they experienced autonomy in the role and felt that they were motivated and/or had the competence to fulfil the role, and their connectedness with others during the preparation and implementation processes.

Data analysis

Demographic characteristics were summarised using descriptive statistics. Score changes for the subset of participants who completed knowledge measures at all of the time points were calculated to assess change over time using Wilcoxon signed-rank tests for repeated

measures. Focus group data were transcribed and subjected to thematic content analysis (Braun & Clarke, 2006) using QSR International's NVivo 10 Software (2012). Change leader interview data were subjected to theoretical thematic analysis, that is, analysis was theory-driven to identify the degree to which SDT (Ryan & Deci, 2017) could explain the change leaders' experiences of implementing change. This approach was taken because change leaders' training was underpinned by principles of effective motivation for change, drawn from SDT. Qualitative analyses were undertaken independently by an investigator experienced in the relevant approach and by the respective interviewer, who also had relevant experience. When discrepancies in coding between the investigator and the interviewer emerged, the data were re-examined and discussion resulted until consensus was reached.

Results

Results presented firstly relate to the fidelity, dose and reach of implementation (process evaluation). How implementation strategies worked is then considered with particular reference to how successful change leader preparation and support was (from interviews with change leaders) and how successful the educational preparation of the wider body of the staff was (from knowledge surveys). The perceived feasibility and mechanisms of the practice change are addressed in the focus group findings.

Fidelity, dose, and reach of implementation: Results from the process evaluation

During implementation there were 32 patients on the ward with a documented diagnosis of dementia who also had a caregiver. The most consistently implemented intervention component was the distribution of family information packs. When used at all, the first section of the conversation checklist (caregiver recognition) was consistently completed and

the last (discharge planning) was only completed on one occasion, with a declining completion rate as the sections progressed (Table 3).

Change leaders demonstrated their commitment to leading practice enhancement by role modelling and further explaining benefits from caregiver input (supporting motivation in other nurses), prompting nurses to implement the agreed steps of the model (addressing opportunity), and provided further resources and information for the other nurses about dementia and care for people with dementia (addressing capacity). They also extended their role by developing signage to more clearly label patient toilets and drafting a potential pathway for patients with dementia admitted from the Emergency Department (ED).

How change leader implementation strategies worked: Findings from leaders' interviews

Although all seven change leaders were invited to participate in an interview, just three accepted this invitation (designated as CL1, CL2, and CL3). Demographic details are not reported here because these might make individuals identifiable in the local context. Themes emerging from the data described their motivation to become and remain involved, and their perception of the training provided as preparation.

Theme 1: Motivation to become and remain involved in the project

SDT identifies certain motives to engage in behaviour as more 'autonomous' (i.e., self-determined), whereas other behaviours are more 'controlled'. When autonomously motivated, engagement in the change leader role is derived from internal sources, such as the perceived importance of the intervention as well as alignment with one's personal philosophy and value system (Ryan & Deci, 2017). These values could stem from personal experience with a family member with dementia and consequent empathy for caregivers during the care recipient's hospitalisation. As evidence, one change leader explained that she understood the need for high quality care after experiences looking after her own family:

Personally I've been through the system with an elderly relative that's unwell from

a medical point of view, but I've also been through it with an elderly relative that

had Alzheimer's so I actually know how it feels from the other side. (CL2).

While these nurses' decisions to participate as leaders were not entirely self-initiated, having been asked by superiors, there was evidence of autonomous motives to undertake the role. For example, one change leader recalled, *"I was asked, but I probably would have volunteered"* (CL1), while another declared, *"A dementia champion [change leader] is there to help people . . . and that's in line with my values I suppose"* (CL3). Learning was another autonomous motive underpinning the change leaders' desire to fulfil this role, *"I just thought it would be a good area to learn more about . . . I'm interested in that kind of thing. Looking after those patients"* (CL1). Once engaged in the change leader role, this desire to learn then helped to keep the nurses involved. Choosing to attend professional development activities emerged as an important motivating factor, *"We went to education session[s] outside of work as well and that kind of motivates you more to hear other people's experience"* (CL3).

Change leaders also found that the ability to initiate changes on the ward that they believed were needed was motivating. For example, two participants especially valued the opportunity to create a dementia information board and new signage directing patients with dementia to the toilets and bathrooms.

Despite the enthusiasm that served to initiate their engagement in the role, the change leaders encountered barriers in the ward environment that influenced their motivation to persist. These barriers included the time required to converse with caregivers, which conflicted with their value of patient care as the primary nursing goal:

> *[There was] a lot of time spent just filling in the documentation . . . I know it was*
>
> *kind of to benefit the patient . . . but that was time away from the patient, doing*
>
> *that with the carer.* (CL1).

<u>Theme 2. Perceptions of change leader education</u>

According to SDT, promoting the basic psychological needs to feel autonomy, competence and relatedness in connection to the task at hand is fundamental for autonomous motivation to ensue. Findings from these interviews indicated that the application of SDT principles in the change leaders' education sessions was effective in creating a learning environment supportive of these three basic needs. For example, one change leader felt as though their expertise as health professionals was taken seriously::

> *We were able to actually discuss things. It wasn't just 'listen to us', so I thought*
>
> *that was quite important because I think it's important that they get feedback*
>
> *from us because not everybody . . . has a nursing background so they don't*
>
> *necessarily look at things the way that we do . . . letting us have some input, some*
>
> *say, into how we think things might change or what would benefit people that*
>
> *come after us.* (CL2)

How the education strategies worked: Results from knowledge surveys

Education was the primary strategy intended to prepare the other nurses for the practice change, with change leaders providing ongoing support. Consistent with achieving a 'whole of ward' understanding of the change, other clinical staff also attended the nurses' education sessions. We report the extent to which nurses' knowledge of dementia and Alzheimer's disease changed during the study because this related to the nurses' capability to implement the practice change. Table 4 presents participant characteristics. Table 5 displays changes in survey scores over time for nurse respondents who completed measures at all of the time

points, with scores for change leaders presented separately. All nurses, including change leaders, showed significant improvement between T1 and T3.

Feasibility and mechanisms of the practice change: Findings from the nurse focus group

Six female nurses attended the focus group that sought their perspectives on the feasibility and mechanisms of the practice change. Most participants worked full time on the ward, and all had been working on the ward during implementation. None of these participants was a change leader. Age groups ranged from 20 to 30 years to over 50 years. Four nurses had been in their current position for less than 6 months, two had been nursing for more than 5 years, and four had received some kind of dementia specific education. Themes that emerged addressing feasibility and practice change mechanisms were *Elements of the change* and *Leading change.* Additional related themes were *Barriers,* and *Suggested refinements*.

Elements of the change

Nurses all indicated an awareness of the caregiver information pack, although not all of them had used it. One nurse recalled a caregiver's response to receiving a pack:

> *It was the daughter, and she was like 'Oh thank you so much' . . . she kind of appreciated the fact someone recognised her as her carer. Recognised that . . . she needed some support … it [was] hard for her to see her mum like that.*

However, when participants considered the conversation with caregivers that was prompted by the checklist, concerns were expressed regarding the feasibility of meeting with the caregiver. The option of making contact by telephone was considered, but face-to-face contact was preferred and some nurses felt that the staff-caregiver communication aligned more naturally with social worker role. Nevertheless, participants recognised that this discussion could (or did) provide information that would help the patient, the caregiver, and the staff providing care, such as, *"They have aids [but]… we won't know how they are at home,*

so once the carer or the families say 'he was being like this' then we can get more information". In turn, this communication was considered by the participants as, *"Helpful. According to that we can manage our plan and that will help calm them [the patient] down".* Participants also saw the opportunity for the caregiver-nurse conversation, guided by the checklist, to become part of routine practice, referring to how model implementation could be led by Link (resource) Nurses, who were already used to drive other components of nursing practice such as falls prevention:

> *That's what your Link Nurses would do . . . they'd go to an education session….*
> *And then they come back and regurgitate that information and just do regular*
> *education sessions . . . and then do audits on it.*

Another potential benefit of model implementation was that the information from caregivers might support care via engagement with the other staff (e.g., the doctors) when implementing the model. However, it was noted that the medical staff changed frequently, diminishing their ability to engage with the practice change.

Leading change

There were two elements of leadership raised by nurses. First, in regard to change leaders prompting ward nurses to engage with the change, one participant recalled, *"[Name] chased me up to remind me to give the pack to a family . . . it is good because they know what I should expect and what … to talk to the family about".*

Second, there were thoughts expressed that the nurse leadership role, as shown in the model, should not necessarily be taken by nurses:

> *I think it [the role of linking with caregivers to obtain information that is then*
> *shared with the team] should be combined . . . I think we are all on the same page*

> *.... I reckon OT [an Occupational Therapist] would be good . . . OT, us, and Social*
>
> *Work . . . . Speech [a Speech Therapist] would be a good one.*

Barriers

Lack of time for nurses and caregivers to meet was seen as the primary barrier to the systematic conversation with the caregiver because it was seen as *"lengthy and also you have so many patients"*, and difficult to schedule because *"if they [family members] come [unclear] will the nurse be free? . . . the problem in this issue will be time"*.

Caregiver stress was also considered an issue, as this nurse explained: *"They [caregivers] are quite happy to help but it depends on how stressed out they are. So if they are really stressed they will just be like 'do your job'"*.

There were also concerns that the same questions being asked of the caregivers by nurses might already have been addressed in, for example, conversations occurring in the ED. However, the nurses explained that finding documentation relating to previous conversations was time consuming and seldom feasible.

Suggested refinements

The nurses discussed how speaking with families and documenting relevant information in an accessible way might be managed by using the checklist from the point of entry to the hospital:

> *While the carer is there, ED [staff members] are already asking them all these*
>
> *questions anyway . . . [so] maybe doing a tick box there and then so 'this is ED's*
>
> *bit' . . . 'this is the ward transfer bit'.*

However, it was anticipated that there would be resistance from the ED staff to this additional form being introduced in that setting. When asked if it would be helpful for the caregiver to

bring from home the kind of information that was being requested, there was a positive response. As one nurse explained:

> *That would be a lot of help . . . that's a very good idea . . . You would know their baseline then anyway 'this is what they're normally like. Yes, they've changed it at the moment but this is their baseline', so that would be brilliant . . . like what they eat without having to do the ring around . . . those sort of little things can also help to keep agitation down.*

Discussion

This study aimed to pilot a process to access family caregiver input to inform hospital care for people with dementia as a preliminary step towards testing the Person-CIND model. The proposed practice change was primarily the inclusion of a structured and documented conversation initiated by the nurse with the family caregiver. This process was consistent with existing practice recommendations within the hospital but was more proactive, systematic, and comprehensive than current practice. Eventual model implementation will have a goal of risk reduction for people with dementia admitted to hospital.

The nexus between person-centred care and a patient and family-centred care approach

The planned conversation with caregivers had a strong focus on the kind of information that would inform care to minimise risk, alongside information to help ensure some understanding of the background, preferences, and perspective of the person with dementia. To this extent, the conversation can be criticised as having limited value in terms of being 'person-centred'. However, the conversation is clearly consistent with the PFCC approach as described by Mackie and colleagues (2018). In effect, this initiative sets person-centred care within the context of the PFCC approach, which can thus facilitate safer care for the hospitalised person with dementia who is experiencing communication limitations at that time. Moreover family

caregivers who observe care delivery that is enhanced by their input may have their anxieties about the hospitalisation alleviated, with positive outcomes for their own health (Burgstaller et al., 2017) and, consequently, their capacity to continue in the caregiving role.

Other studies testing the PFCC approach

Mackie and colleagues' (2018) review identifies research into the PFCC approach for adults in acute care as a newly developing area. When critiquing five studies that aimed to enhance information sharing between the patient, their family, and the clinical team, they note that just one, conducted by Berube and colleagues in 2014, included family in the design of the practice change, although engagement of all stakeholders is viewed as the 'gold standard'. Our study was guided by a stakeholder reference group that included family caregivers but, in consideration of their caregiving responsibilities, accessed input via email rather than during meetings. This form of input may limit robust discussion and merits review in further work. Moreover, the change leaders were not engaged as stakeholders in the reference group. According to Reed, Howe, Doyle, and Bell (2018), a strategic principle when engaging in healthcare improvement via evidence translation is to engage with and empower all stakeholders. In future work, including change leaders in the study reference group would help to ensure both their commitment to driving change and the feasibility of that change. Consideration also needs to be given to ensuring that the consumer representatives recruited to the reference group (people living with dementia and their caregivers) are those trained, supported, and remunerated for this role so that they can participate more fully.

Problems related to the planned conversation with caregivers

The number of change leaders and other nurses contributing qualitative data was limited in this study. However, these participants consistently indicated that length of the proposed conversation with caregivers was impracticable. Reasons provided for this concern included

that nurses' clinical commitments, particularly the reactive nature of clinical responsibilities, made it difficult to plan time away from the bedside, factors that also contributed to the low interview and focus group participation rates. It was also noted that some family caregivers might have limited capacity to engage with the staff at a time of great stress. How best to access information from families to enhance hospital care for people with dementia, given these constraints, has been recognised by others, and alternatives have been proposed. For example, the TOP 5 program is initiated by the hospital staff to obtain information from caregivers to agree upon up to five strategies intended to enhance communication and personalised care for the person with cognitive impairment (Luxford et al., 2015). There is also a questionnaire, 'This is Me' (Alzheimer's Society & Royal College of Nursing, 2017a), available to help obtain information from caregivers to accompany the person living with dementia into hospital to inform person-centred care. However, neither tool is designed specifically to address risks from hospitalisation for this patient group.

As one response to ensure that the planned Person-CIND conversation between the nurse and caregiver is feasible, our team has developed a new tool (reference withheld for blinding purposes) that specifically addresses these risks. The form was designed with the hospital staff and family caregivers to translate as easily as possible into care planning and was refined after its completion was trialled with caregivers. This tool can now be used to help ensure the feasibility of model implementation.

Concerns related to implementation strategies

In this study, implementation strategies to support practice change were critical and a review of these can now inform future practice change initiatives. The most obvious concern in this study was that the primary responsibility for motivating the other nurses and supporting their opportunities for engagement rested solely with the change leaders, which was a heavy

responsibility in addition to their usual clinical role. Education for the remaining nurses, addressing their capacity to implement the change, was provided by others, but on one occasion only. Although knowledge of dementia and Alzheimer's disease improved, this single session may have been insufficient to ensure the nurses' understanding of, and engagement with, the practice change and failed to address the issue of staff members returning from extended leave or moving from another area. Unsurprisingly, considering the emphasis on promoting autonomy in change leaders, the change leaders channelled their commitment into enacting other initiatives to improve the care of people with dementia that were more feasible to achieve than the agreed change.

A more supportive overarching framework for change leaders, demonstrating that the planned practice change and their role is valued, might help change leaders to problem solve rather than disengage with existing plans for change. Early collaborative dialogue with other members of the clinical team, with regard to the importance of accessing information from families to enhance care, might help to provide the foundation for such a framework.

Conclusions and recommendations

This study was conducted on one hospital ward and does not provide generalizable findings. Moreover, fewer than half of the change leaders agreed to participate in study interviews and a single focus group provided data from just six nurses, all of whom were female. Data saturation was not reached and member checks were not achieved. However, these data inform a critique of the reasons for the somewhat negative findings that can inform further work intended to enhance practice in this setting and others that are similar.

In summary, the study attempted to implement a practice change that proved not to be feasible. In response, a more feasible process will be introduced in a follow-up study. When this occurs, more robust input into implementation plans will be facilitated from all

stakeholders, including change leaders, and the need for a supportive overarching framework

to provide the context for change implementation will also be addressed.

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Table 1. Tools used to measure changes in staff members' knowledge of dementia

Tool	Items	Item format	Response options	Scoring	Psychometric properties
Alzheimer's Disease Knowledge Scale (AKDS) (Carpenter et al., 2009).	30	Factual statements; respondents indicate whether correct.	True, False.	Correct items totalled to indicate overall knowledge. Maximum score 30.	Adequate content, predictive, concurrent, and convergent validity. Adequate test-retest reliability correlation co-efficient (0.81, p<0.001). Satisfactory internal consistency reliability (0.71). (Carpenter et al., 2009).
Dementia Knowledge Assessment Tool, Version 2 (DKAT2) (Toye et al., 2014).	21	Factual statements, respondents indicate level of agreement.	Yes (agree), No (disagree), Don't know (coded as incorrect).	Correct items totalled to indicate overall knowledge, Maximum score 21.	Satisfactory internal consistency reliability (0.79). Established content validity (Toye et al., 2014).

Table 2. Change Leader (CL) COM-B implementation strategies and outcomes (Susan Michie et al., 2011)

Framework component	Strategy	Outcomes
Capability: capacity to perform the desired behaviours	Phase I: Education on hospital care for people with dementia, from Alzheimer's Australia WA (AAWA).	Agreement with CLs on their role and the steps to be implemented.
	Phase I: Program to enhance skills in care of people with dementia and their families in hospitals (Elvish et al., 2014) (Clinical Nurse Consultant, aged care).	
	Phase I: Presentation about person-centred care for people with dementia delivered by the hospital's Clinical Nurse Consultant (general medicine), a dementia champion prepared by AAWA.	
Opportunity: factors external to the person that help facilitate or prompt these behaviours	Phase I: Family caregiver presentation explaining the caregiver perspective of hospitalisation and subsequent discussion related to the usefulness of the nurse-caregiver conversation.	Agreement on value of nurse-caregiver engagement.
	Phase II: Identifying and addressing challenges to implementation during CL meetings.	Fewer meetings than planned limited input.
Motivation: addressing individual CL motives to enact the new behaviour	Phase I: Education based on SDT. Included activities to foster feelings of autonomy, competence and relatedness, to develop more self-determined and sustainable motivation. Included goal setting tasks, strategies to maintain own and others' motivation; confidence-building; future planning for overcoming challenges.	CLs described self-determined motives to fulfil the role, training as supportive, and CL meetings as opportunities for input that also strengthened motivation

Table 3. Implementation evaluation and outcomes

Implementation	How addressed	How evaluated	Outcome (caregiver n=32)
Fidelity	Nurse-caregiver conversations enacted and documented on checklists after provision of information packs.	CL meeting field notes and interview data. Nurse focus group data. Audited use of packs and checklists.	Implementation as planned with just one caregiver (3%).
Dose	Extent to which nurse-caregiver conversations implemented in full.	Audited completion of sections of checklist.	Completion: Full, 1 (3%) Partial, 4 (12.5%) Zero, 27 (84%)
Reach	Family information packs provided to all eligible caregivers.	Number of packs used compared with number of eligible caregivers	Provided: 15 (47%)
	Documented conversation held with all eligible caregivers.	Numbers of checklists used compared with number of caregivers.	Usage: 5 (16%)

Table 4. Staff characteristics

Characteristic	All respondents (n = 59)	Completed all time-points (n = 26)
Age		
20-30 years	25 (42.4%)	13 (50.0%)
31-40 years	13 (22.0%)	4 (15.4%)
41 years or older	21 (35.6%)	9 (34.6%)
Designation		
Nurse or AIN	53 (89.8%)	26 (100%)
Doctor or Allied Health	6 (10.2%)	-
Time in current position		
Less than 12 months	15 (25.4%)	6 (23.1%)
More than 12 months	44 (74.6%)	20 (76.9%)
Years in profession		
0-5 years	28 (47.5%)	15 (57.7%)
6-12 years	19 (32.2%)	4 (15.4%)
13 years or more	12 (20.3%)	7 (26.9%)

Table 5. Changes in the staff's knowledge from baseline (number correct)

Outcome	Time	Change leaders (n = 7) Median (range)	P	Other Nurses (n = 17) Median (range)	p
Knowledge of Alzheimer's disease	1	22 (18-27)	-	24 (17–27)	-
Maximum possible score=30	2	27 (19–29)	**0.02***	24 (16–27)	0.32
	3	27 (19–29)	**0.02***	25 (19-29)	**0.003***
Knowledge of dementia	1	17 (14–19)	-	18 (11–20)	-
Maximum possible score=21	2	20 (18–21)	**0.04***	19 (16–21)	**0.005***
	3	19 (16–21)	**0.04***	19 (17–21)	**0.001***

*Statistically significant change from T1 (p < 0.05)
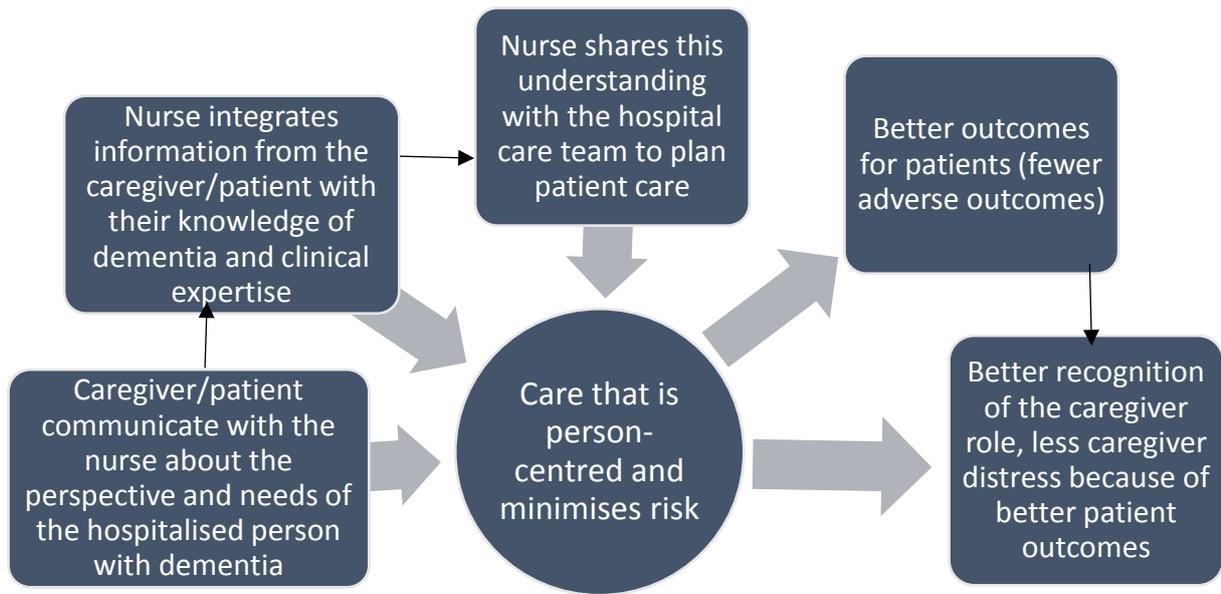
Figure 1. The Person-Focussed and Caregiver-Informed Nurse-Driven model (Person-CIND)

Phase I

Knowledge of dementia and Alzheimer's disease assessed in clinical staff.

Nurse change leaders selected and prepared.

Plan developed for how ward nurses would access and document family caregiver input.

Resources prepared (pack for caregivers, checklist to prompt nurse-caregiver conversations).

Phase II

Education for clinical staff (dementia, risks for people with dementia in hospital, person-centred care, the practice change).

Reassessment of staff knowledge of dementia and Alzheimer's disease

Practice change implementation plus dose and reach evaluation.

Change leader meetings addressing challenges to implementation and helping establish fidelity

Phase III

Reassessment of staff knowledge of dementia and Alzheimer's disease

Nurse focus groups considering feasibility and practice change mechanisms

Change leader interviews considering the role, capacity/competence to fulfil the role, motivation/autonomy, connectedness with the team, any barriers or opportunities that were relevant

Figure 2. Summary of the three study phases

Appendix. Nurse-caregiver conversation checklist

This conversation checklist supports the recognition of family caregivers of patients with dementia plus relevant planned and documented communica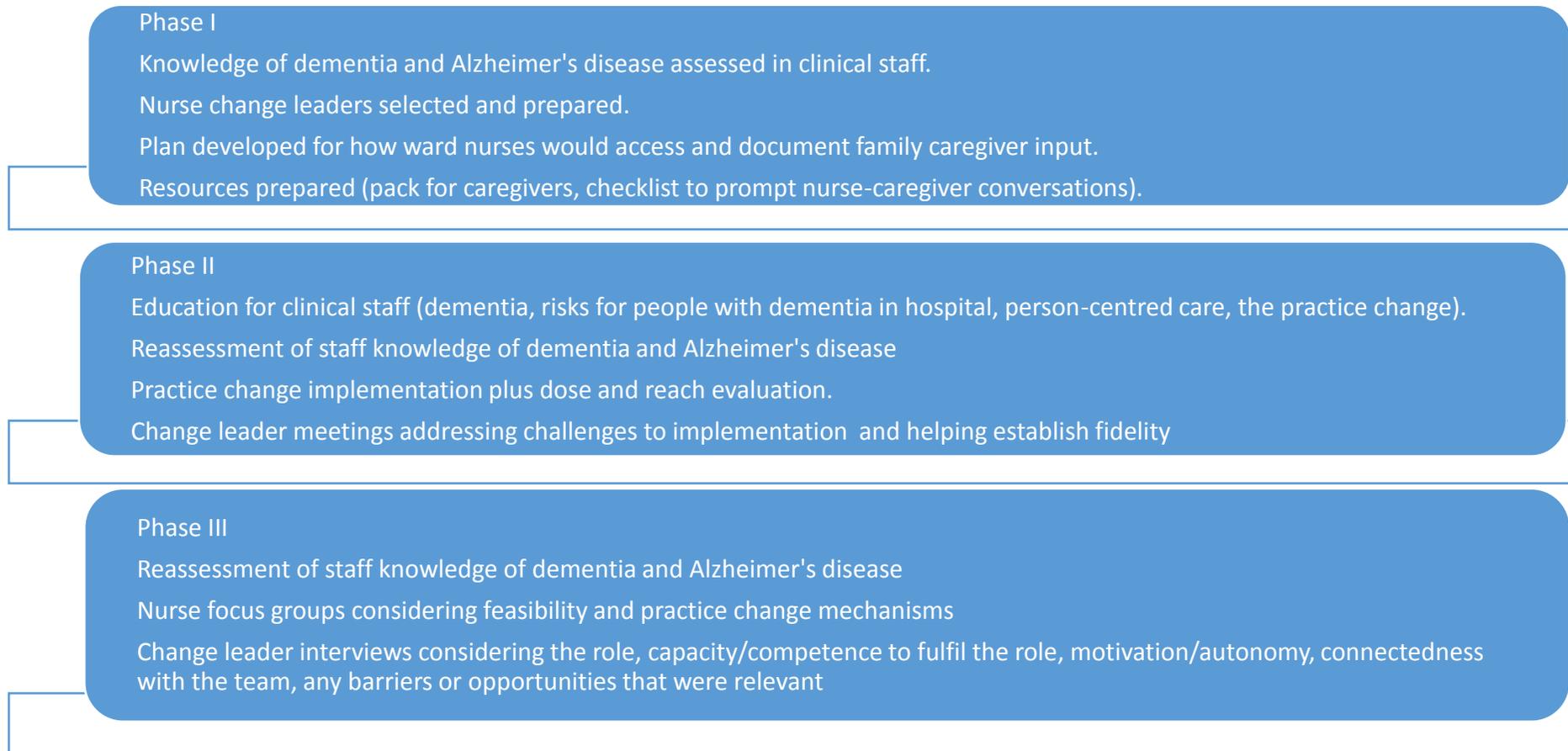tion, ideally undertaken within 24 hours of arrival on the ward. **Please tick the appropriate column and list any difficulties with tool completion/reasons for non-completion in comment boxes.**

CAREGIVER RECOGNITION	<24h	>24h	NA	Where documented
1. Nurse has identified primary caregiver *(if none, form cannot be used)*				
2. Nurse has contacted caregiver (in person or by phone) to initiate communication				
3. Caregiver provided with Family Information Pack *See purple envelopes at nurses' station - inclusions listed at end of this tool*				
4. Pack explained to caregiver with reference to particular needs of the patient				
5. Caregiver invited (in person/ by phone) to complete Carer Questionnaire in pack				
6. Carer Questionnaire information integrated into care plan (patient's care needs, routines, preferences, caregiver desired involvement).				
7. Carer Questionnaire retained in patient record				
8. Unmet needs for caregiver support (from Carer Questionnaire) actioned.				

Comments (please include list of any inter-professional liaison):

Difficulties with completion or reasons for non-completion:

AVOIDING RESPIRATORY AND URINARY TRACT INFECTIONS PLUS ENSURING ADEQUATE NUTRITION AND HYDRATION	<24h	>24h	NA	Where documented
9. Caregiver has provided details about patient's:				
a. Known swallowing difficulties				
b. Safe swallowing strategies employed				
c. Needs for assistance with eating and drinking				
d. Dietary and fluid preferences/needs (eg, for soft diet)				
10. Plan to maintain nutrition/hydration discussed with caregiver				
11. Plan documented				

Comments (please include list of any inter-professional liaison):

Difficulties with completion or reasons for non-completion:

AVOIDING INJURIES FROM FALLS	<24h	>24h	NA	Where documented
12. Caregiver has provided details of patient's previous falls				
13. Nurse completed Falls Risk Assessment with caregiver including identifying:				
a. aids used to assist mobility/transfers/vision/ hearing				
b. mobility limitations (refer also Carer Questionnaire)				
c. bathing routines, preferences, aids				
d. environmental adaptation needed – signage/wayfinding/reducing clutter				
e. sleep patterns				
f. type of footwear required				
g. toileting routines/requirements (refer also Carer Questionnaire)				
14. Falls risk management plan discussed with caregivers				
15. Falls risk management plan documented				
16. Mobility plan discussed with caregivers				
17. Mobility plan documented				

Comments (please list any inter-professional liaison):

Difficulties with completion or reasons for non-completion

AVOIDING PRESSURE INJURIES	<24h	>24h	N A	Where documented
18. Caregiver provided details of previous/existing pressure areas				
19. Caregiver identified strategies used to relieve pressure/manage incontinence				
20. Pressure area risk management plan discussed with caregiver				
21. Plan documented				

Comments (please list any inter-professional liaison):

Difficulties with completion or reasons for non-completion:

AVOIDING/RECOGNISING/ADDRESSING DELIRIUM	<24h	>24h	N A	Where documented
22. Orientation has occurred to ward layout and routine				
Patient				
Caregiver				
23. Caregiver has provided details about patient's:				
a. Other routines or rituals/previous occupation (refer also Carer Questionnaire)				
b. Familiar objects/comfort aids that can be brought in				
c. Religious and spiritual beliefs/observances				
d. Known triggers of distress/behavioural responses/coping strategies				
e. Communication aids (refer also Carer Questionnaire)				
f. Vision/hearing limitations (see also 13a)				
24. Cognitive test baseline discussed with caregiver				
25. Plan to minimise risk of - or management of - delirium discussed with caregiver				
26. Plan documented				

Comments (please list any inter-professional liaison):

Difficulties with completion or reasons for non-completion:

PLANNING FOR DISCHARGE FROM ADMISSION	<24h	>24h	N A	Where documented
27. Discussed arrangements for post-discharge with caregiver:				
a. Follow-up appointments				
b. Community services (see Carer Questionnaire for pre-admission status)				
c. Equipment (see question 13a)				
28. Any other caregiver identified issues discussed (refer Carer Questionnaire)				
29. Discharge plan documented				
30. Patient provided with copy of discharge letter and caregiver aware	**Date:**			
31. Medications explained to caregiver (eg, by doctor or pharmacist)	**Date:**			

Comments (please list any inter-professional liaison):

Difficulties with completion or reasons for non-completion:

This information is to inform person-centred caregiving.
STEPS:
1 CONTACTING CAREGIVER, PROVIDING INFORMATION PACK.
2 HAVING CONVERSATION.
3 RECORDING THIS HAS OCCURRED (THIS FORM).
4. DOCUMENTING CONVERSATION/OUTCOMES (USUAL PATIENT RECORDS).
4. RECORDING ON THIS FORM WHERE IN THE RECORDS THE DOCUMENTATION CAN BE FOUND.