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Caring for an older person with dementia in the Emergency Department (ED): An Appreciative Inquiry exploring family member and ED nurse experiences.

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Abstract

Aims and objectives: To generate insights about what matters and is valued by family members of older people with dementia in the Emergency Department. To explore the experiences of emergency nurses looking after older people with dementia in an episode of care.

Background: In the emergency department older people with dementia are at risk of suboptimal care. Little is known of the experiences of family members of being with an older person with dementia in the Emergency Department or the experiences of emergency nurses looking after older people with dementia in this environment.

Design and methods: Phase 1 Data Analysis of the Discovery Phase of an Appreciative Inquiry study. Study participants were family members of older people with dementia and emergency nurses. Data collection methods included interviews with family members of older people with dementia and 30 hours of participant observation working alongside emergency nurses. This study was guided by the Standards for Reporting Qualitative Research (SRQR).

Results: Two themes emerged from the analysis: What matters to family members with four sub-themes and Challenges for family members and nurses in the ED with two sub-themes.

Conclusion: This study demonstrates that some emergency nurses are connecting with family members even in the briefest of clinical encounters. It is feasible for more emergency nurses to do the same more of the time.

Relevance to clinical practice: The older person with dementia must be given a triage category of no less than 3 (to be seen by the doctor within the hour) on arrival in the department. Further education is needed to assist emergency nurses to establish rapport and incorporate family member insights as part of care planning and assessment of the needs of the older person with dementia.

Keywords

Emergency nurses, dementia care, appreciative inquiry, experiences, family members.

What does this paper contribute to the wider global clinical community?

- Generates new insights about family member experiences of being with an older person with dementia in ED. Negative emotions and experiences are reframed as values, provoking thoughts about how emergency nursing practice should be re-shaped in the future.
- Provides rare insight into the experiences of ED nurses looking after older people with dementia in an episode of care. ED nursing practice is sometimes out of kilter with what matters and is valued by family members. There is a need to strike a balance between the relational and technical aspects of care delivery.
- The focus of this study is on finding out what is working well in every day emergency nursing practice. There are instances of excellent care and these are being overshadowed by the emphasis on deficits.

1 Introduction

Approximately 35.6 million people have dementia worldwide. This number is predicted to double by 2030 and triple by 2050 (WHO 2012). The Emergency Department (ED) can be a critical point of access for older people to the acute hospital system (Close et al. 2012). The vulnerability of older people in ED and particularly the vulnerability of older people with dementia is widely recognised (Aminzadeh & Dalziel 2002, Patterson et al. 2011, Schnitker et al. 2011, Skar et al. 2015, Šteinmiller et al. 2015). It is estimated that 21- 40% of acutely unwell older adults who present to ED are cognitively impaired and over half of these will screen positive for dementia (Clevenger et al. 2012). There is growing concern that the culture of hospital care with regard to older people with dementia is undesirable (Schnitker et al. 2011, Coffey et al. 2014, Dewing & Dijk 2016).

2 Background

Emergency departments were conceived in the 1960s to care for patients with acute conditions requiring rapid assessment, stabilisation and transfer to definitive care (Taylor et al. 2015). The ED setting is fast paced. A high value is placed on the acquisition of knowledge and skills to prepare the ED nurse for unpredictable and oftentimes life threatening presentations in patients of all ages

(Parke et al. 2013). The physical aspects of care such as checking vital signs, administering blood or fluid infusions and preparing for emergency interventions take precedence (Mollaoğlu & Çelik 2016). In ED, the less technical elements of caring (pressure area care, providing assistance with personal hygiene) may be subordinated resulting in a failure to meet the needs of older people with dementia (Parke et al. 2015).

Older people with dementia are likely to attend ED more frequently in the last year of life (Sleeman et al. 2018). In addition to cognitive impairment, they may have multiple co-morbidities and will require greater nursing support to cope with an acute illness, an unfamiliar environment and their personal care needs (Dewing & Dijk 2016, Burgstaller et al. 2018). Admission to an ED may expose older people with dementia to complications of care such as malnutrition, dehydration, poor pain management and deterioration in behavioural symptoms (Burgstaller et al. 2018, Digby et al. 2017, Digby et al. 2016). It is evident that older people with dementia require a different type of care that involves more than management of the acute condition they present with (Coffey et al. 2014). How best to enhance their experiences in ED, where rapid assessment and treatment of the acute condition is the cornerstone of care, remains elusive.

Relationship or person centred care is proffered as central to high quality dementia care (Digby et al. 2016, Burgstaller et al. 2018, Pinkert et al. 2018). It calls for a reframing of nursing practice and a movement away from medically dominated interventions. Establishing connections and building relationships is perceived to be fundamental to meeting the needs and expectations of patients and family members (Parke et al. 2013, McConnell et al. 2016). A relationship centred approach offers potential for nurses to shape the care they provide and articulate their skills and contribution (Kitson et al. 2013). With growing numbers of older people with dementia attending ED, relationship centred care may offer ED nurses new ways of thinking and doing to meet the needs of the older person with dementia in this setting.

Linked to such an approach is the need to gather insights of family members when caring for the older person with dementia in ED. These insights are critical to informing the development of strategies for improvement (McConnell et al. 2016, Dewing & Dijk 2016, Parke et al. 2016, Digby et al. 2017). Such contextualised knowledge and understanding is essential to discern how relationship approaches might work or indeed be constrained in such a complex clinical environment. There is however, a paucity of research evidence to support emergency nurses to enhance the quality of care for older people with dementia and their family members. This makes the insights presented in this paper timely and important.

3 Methods

3.1 Study aims

To generate insights about what matters and is valued by family members of older people with dementia in ED and to explore the experiences of ED nurses looking after older people with dementia in an episode of care. An episode of care refers to the period of time that the older person with dementia and their family member are in ED.

3.2 Study design

The study design is Appreciative Inquiry (AI). This is a branch of action research which is grounded in social constructionist theory (Bushe 2012). AI emerged in the late 1980s in America in a business context. AI is purported to have the capacity to produce generative theory, where new ideas and ways of doing increase the potential for transformation in organisational behaviour (Bushe 2012). AI is described as a shadow process that may prompt us to face issues such as-missed nursing care-we would rather avoid (Fitzgerald et al. 2010). AI calls for collective progression through four distinct phases; Discover, Envision, Co-create and Embed (Figure 1). This paper focuses on the Discovery Phase of AI, the purpose of which was to explore personal experiences and what mattered or was valued by the key people involved in episodes of caring.

Watkins et al. (2016) conducted an integrative review of the impact of AI as an intervention to change nursing practice in in-patient settings. This review identified an overall limited number of AI studies but suggested that nurse researchers were beginning to value the potential of AI across a broad range of contexts and settings. AI was perceived as a refreshing contrast to the traditional deficits approach to change management and was determined therefore to be more likely to engender trust and dialogue.

AI was the appropriate methodology in this case, to identify knowledge that could be used to achieve optimal practice and to challenge assumptions about care. The focus was to highlight aspects of care that were valued and worked well and to think about how practice might be developed to ensure these aspects happened more frequently (Dewar & Kennedy 2016). These findings will provide a foundation for the Envision and Co-Create phases of the study (Figure 1) where ED nurses will be invited to further share and explore experiences and discuss implications for their own practice through appreciative dialogue (Sharp et al. 2018). This study is guided by the Standards for Reporting Qualitative Research (See Supplementary File 1).

3.3 Setting

This study took place in an ED in the southwest of Ireland from February 2017 to March 2018. The department sees approximately 65000 patients a year and covers a wide geographical area providing emergency care for diverse patient groups including older people with dementia. The rate of admission to the hospital exceeds bed capacity. It is not unusual to find patients boarding on trolleys in ED for hours or days until in-patient beds become available.

3.4 Participant selection

There were two groups of participants in the study, family members of older people with dementia and ED nurses. Though other groups such as healthcare assistants and doctors are involved in providing care for older people with dementia and their family members in ED, the emphasis here was on nursing actions and interventions. The rationale for this is that nurses are increasingly called upon by policy makers and the general public to articulate their impact, effectiveness and contribution in relation to patient outcomes and quality of care (Scott et al. 2014). Additionally, the contribution of ED nurses is under represented in the literature to date.

3.5 Recruitment

For the family member interviews, purposive sampling (Elo et al. 2014) was used. Family members who accompanied an older person with dementia to ED in the previous 12 months were included. The triage nurse or the named nurse looking after the older person informed the researcher of the patient and family member's attendance. The nurse introduced the researcher to the family member where the family member had given their permission for this to happen. Family members were approached when the older person was being discharged from ED or admitted as an in-patient. Those family members who were distressed or who accompanied an older person who was gravely unwell or in the Resuscitation Room were not approached.

Community nurses caring for older people with dementia were also contacted. Community nurses gave information on the study to family members. If family members were interested in participating they permitted the community nurse to pass on their contact details to the researcher. The researcher then liaised with family members to arrange a convenient time, date and place for interview.

Purposive sampling was also used to invite nurses (n=12) from the team of 80 working in ED. Flyers about the study were pinned up in strategic locations throughout the department. Nurses who were interested in taking part were provided with written and verbal information about the study. The researcher worked as a participant observer, shadowing ED nurses who agreed to participate and were looking after an older person with dementia in an episode of care.

3.6 Study methods

The findings reported here are drawn from the first phase of analysis of 15 family member interviews and 30 hours of observation of nurses looking after older people with dementia in an episode of ED care.

3.7 Data generation

Semi-structured individual Interviews with family members (n=15) were conducted by the researcher. Interviews ranged from 30 to 75 minutes and were audio-taped and transcribed verbatim. Three interviews were conducted over the phone as this was more convenient for family members. Interview questions were open ended (Table 1) to enable family members to freely express their thoughts and feelings and to facilitate generation of in-depth information.

Data collection included 30 hours of participant observation in ED conducted by the researcher working alongside individual ED nurses (n=12) looking after older people with dementia in an episode of care. Within AI, participant observation was important to facilitate non - judgemental inquiry, to observe relational processes and to identify potential strategies for dementia care that might work well in this context (Dewar & Sharp 2013). Periods of observation were typically of three to four hours duration and afforded the researcher the chance to engage with and be genuinely

curious about the ED nurse's thoughts, interpretation and understanding of what was happening in the episode of care.

The 7Cs of Caring Conversations (Dewar & Nolan 2013) guided the observation (Table 3). The researcher was specifically interested in interactions both verbal and non-verbal that seemed to work well. As it was considered important to feedback observations to the ED nurse, the 7Cs framework (Table 3) was used to generate discussions about why these particular interactions worked well and to explore how they may become more prominent in daily practice (Dewar & MacBride 2014). This framework strives for development of relational capacity through conversations about human interactions, experiences and emotions. Where possible, field notes including key phrases or statements made by the ED nurse were noted during the observation. Additional field notes were made as soon as possible after the period of observation was completed. Being reflexive was essential, as the researcher was a clinical facilitator working in the research setting and this might influence the interpretation and explanation of findings.

3.8 Ethical considerations

Approval was obtained from the local hospital Research Ethics Committee (Ref 113/16). Written consent was obtained from family members prior to interview. Three family members were interviewed by telephone and gave verbal consent prior to being interviewed. Written consent was obtained from ED nurses before the period of observation began and was ongoing throughout.

All data were kept strictly confidential and stored in accordance with general data protection regulation (Data Protection Acts 1988 & 2003). As talking about experiences can be an emotive subject, family members were informed that their interview could be stopped at any stage upon request. No family members became distressed during interviews. ED nurses were also informed that the episode of observation could be stopped at any point if they so wished. No ED nurses became distressed during observation or requested the observation be stopped.

3.9 Data analysis

The framework described by Braun and Clarke (2006) was used to guide thematic analysis because it emphasises the importance of reflexivity and the nature of meaning in situation and context (Clarke & Braun 2018). Discussions between co-authors facilitated conversations around the development of themes and how these should be defined and named. The researcher immersed themselves in the data by listening to the audio recordings and by reading and rereading verbatim interview transcripts. Each line of each interview was scanned to identify key statements and words. Key words and statements were then categorised to create codes and themes. The 7C's framework (Table 3) guided analysis of field notes from observation. Also, each line was scanned to get a good sense of the context of care and to establish connections or diversity between data generated from observation and those generated from family member interviews.

During analysis of interviews and field notes from observation, the researcher tracked personal feelings in response to what respondents said. This was a key step in ensuring that analysis remained authentic to the experiences as described by family members and not as the researcher might interpret them. In keeping with AI, data were analysed so that the emphasis was on what family members said mattered and was valued. For example, in the negative statement 'nobody came near me' this indicated that family members valued contact with ED nurses.

4 Findings

Of the 15 family members who were recruited, 14 were female ranging in age from mid - thirties to seventies and the main carer for a parent or spouse with dementia. Data suggested that older family members (60s and 70s) were less likely to question interventions or approaches to care. Family members did not want to leave the older person unattended in ED. Some family members

operated a rota system to ensure that their loved one was accompanied at all times. Those family members who could not operate a rota system remained in the ED for hours or days as required.

Of the twelve nurses who were recruited, five were newly qualified or had two years or less experience in the ED. It was not apparent from observation that level of experience influenced approaches to caring for the older person with dementia and their family member. The busier the department became the more evident it was that senior and junior nurses reverted to a task orientated approach to patient care. From the analysis of the observational and interview data two main themes emerged; *'What matters to family members'* with four subthemes and *'Challenges for family members and nurses in the ED'* which had two sub-themes (Table 2). The letters FMC denotes verbatim data provided by family members. The letter N is used to identify data provided by ED nurses.

4.1 What matters to family members

Family members provided insights about what was valued and mattered to them on arrival and during their stay in ED. Being triaged quickly and having a cubicle for privacy enhanced experiences. Conversations with ED nurses were valued over technical skills.

4.1.1 Being triaged quickly

Family members felt that the older person with dementia was deserving of priority by being triaged quickly. Family members were especially worried about being left in the waiting room for long periods of time before being called by the triage nurse. They remarked that the behaviour of the older person with dementia often drew attention from onlookers, other patients and family members who were also in the waiting room.

'He had come down on the chair very hard. And that startled the people beside us and they were trying to move away from him' (FMC6).

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These situations compounded the apprehension of family members and compromised the dignity of the older person with dementia.

In some cases the older person was given priority by the triage nurse.

'And I found people very understanding. Accommodating. When they hear that somebody has dementia. That was a very important thing the nurse trying to accommodate her as soon as possible' (FMC10).

For others including FMC12 the experience at triage could have been better. As FMC12 saw it, her mother was left waiting at triage. It seemed a long time before anybody came to check on them.

'Well when we arrived it didn't seem to be that busy. Now I explained at the counter that she had Alzheimers. I had to go back up there forty five minutes later to say that we hadn't been seen yet. It looked like people had gotten in ahead of us and I don't really know why. We felt unimportant' (FMC12).

During observation it was noted that the triage nurse was under pressure to assess everybody coming into ED and assign them an appropriate triage category as soon as possible after arrival.

There were five levels of priority (P) in the triage system; P1 patients required resuscitation, P2 were very urgent (15 minutes to see a doctor), P3 were urgent (one hour to see a doctor), P4 were stable patients who could wait two hours to see a doctor and P5 patients could wait four hours or more.

When staff numbers permitted, a second triage nurse was allocated. In informal discussions with triage nurses they indicated that some days they faced the dilemma of trying to decide who they should triage first. Patients who were having heart attacks or strokes had to be prioritised with the result that other patients including older people with dementia were oftentimes left waiting.

The triage nurse had a responsibility to assess people in the waiting room and those patients arriving by ambulance. Frequently there were more than 20 people waiting to be triaged. It was observed that there were times when the waiting room appeared empty but in the ambulance entrance there was five, six or seven ambulance crews queued up and waiting to handover. The ambulance entrance could not be visualised from the main waiting area so it was easy to see how a family member sitting in a relatively empty waiting room might have thought that the department was not busy and that they had been forgotten about.

Family members would like older people with dementia to be prioritised on arrival in ED. This can sometimes be difficult to achieve given the competing demands for nurses in the current triage system.

4.1.2 A cubicle space offers sanctuary

A recurring theme in interviews with family members was a perception of being in the public gaze.

Family members feared that the way an older person with dementia behaved could negatively impact on them and other people around them. One family member (FMC11) described the awkwardness she felt when her mother started pulling her trousers down in front of onlookers before she made it to the toilet.

‘Normally it’s an issue with my mother wanting to go to the toilet, wanting to go to the toilet right now. Pulling down the trousers too soon that kind of thing. Yea you would be nervous about what might happen’.

In these situations family members felt that they were being intensely scrutinised as the mother of a naughty child might be in the middle of a busy supermarket (FMC15). Family members described their powerlessness to control these circumstances which were generally made worse if it was not obvious the person had dementia (FMC6). Family members were keen to stress that they weren’t embarrassed by the older person with dementia but rather the older person with dementia was

likely to become a public spectacle in ED and so needed to be shielded from becoming distressed or causing distress to other people.

Another family member (FMC14) recalled her aunt screaming and shouting as she was been transferred from the ambulance trolley in a very public and crowded area. There were lots of other patients on trolleys and family members standing close by. In this case FMC14 did not get the sense that other people were intensely scrutinising her, on the contrary they seemed to want to console her, to offer her reassurance that they understood the circumstances.

'She was being off loaded in the corridor there and transferred over. And then there were, she was shouting at me and giving out. People in front and behind were trying to reassure me which I thought was lovely of them' (FMC14).

Some family members worried that the person with dementia would say something that was deemed inappropriate or offensive by other people. This was the experience of FMC13 who believed that all the trolleys stuck together in a confined space exacerbated feelings of stress and increased the risk of some people becoming angry or hostile. When her father was in ED she constantly worried about what he might say next.

He could come out with anything especially in front of women. Some people could take offense to it. When you are in a situation like that then everybody is kind of on their guard. If Dad had come out and said that to the wrong person it could have exploded' (FMC13).

From a family member perspective, being in a cubicle offered security and sanctuary from the public gaze but cubicle spaces in ED were at a premium. Family members identified that once they had acquired a space in a cubicle they felt they could not give it up without a fight. The prospect of being

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moved from the cubicle stirred up emotion and sometimes created tensions between family members and nursing staff.

The challenge for ED nurses in allocating cubicle spaces became apparent during observation. It was difficult from a nursing perspective to determine who should get a cubicle, since each case seemed just as deserving as the next. Additionally, there were patients in ED who required isolation for infection control purposes. Once the isolated patient was in the cubicle, this further depleted the number of quieter spaces available for older people with dementia.

Emergency nurses frequently worried about what would become of the older person with dementia if they had to be moved out of a cubicle. There was a concerted effort made by nurses to keep the older person with dementia in the cubicle for as long as possible. The decision by an ED nurse to move the older person with dementia out onto the main floor was not taken lightly (field notes 23/01/2017). There was a fear that moving the older person with dementia out onto the main floor would result in that person *'getting less care because the nurses in the trolleys section are under too much pressure'* (N3).

The fear of being in and needing to escape the public gaze is important to many family members of older people with dementia in ED.

4.1.3 Contact and conversation with ED nurses

Family members acknowledged that ED nurses were working in a challenging and difficult environment. This was seen to impact the ability of ED nurses to engage on a meaningful level, thus the distress of family members could go unnoticed. Almost all family members remarked that ED nurses were *'too busy'* (FMC15) and had *'little time to engage in pleasantries'* (FMC4). As a consequence family members were reluctant to disturb them.

'It seemed to be a bit of the headless chicken sort of. Nobody had an idea. I don't know how many people they did have to look after but there was people running and I wondered how productive to be honest that running really was' (FMC2).

However, contact with ED nurses was perceived by family members to be important. When family members experienced little or no contact with nurses, it made them feel as if nobody cared, as if they were on their own or had been abandoned. *'Nobody was there with us. We were just left there. Nobody was bothering' (FMC1).*

Family member experiences of interactions with ED nurses were varied. Some family members recounted positive conversations that alleviated anxiety and provided them with comfort.

'He had pulled his line out of his arm or something like that. And the young nurse, he said that's alright. Don't worry about it. I will keep an eye on him. And when I heard him being calm I was calm as well you know. It influenced the whole hectic a little bit. It toned it down' (FMC5).

There were more negative interactions too. In the case of FMC7, the intonation in the nurse's voice made her feel like she and her mother were insignificant. She had enquired how much longer it might take for her mother to see a doctor. She was informed by the nurse that there was another *'four pages of patients ahead of them'* to be seen. The term four pages ahead annoyed FMC7. Her mother had already waited a number of hours. She believed that her mother was being made to wait because the nurse had stated that they couldn't find anything wrong with her. This family member (FMC7) wondered if her mother had been forgotten about because she was constantly asked the same questions over and over as if nobody knew who they were.

'Mum was still being asked what was wrong with her, what's your name, what happened to you. Nobody knew what was wrong with her. No one seemed to know what happened or you know' (FMC7).

The researcher had met FMC7 and her mother in the hours after they had been assessed by the ED doctor. During participant observation (when FMC7 was not present), the nurse (N6) spent time ensuring that FMC7's mother took her tablets and was keen to ensure that she was with the doctors when they discussed FMC7's mother in the morning round.

4.1.4 Compassion over technical skills

From observation it was clear that ED nurses were under pressure trying to look after large numbers of acutely unwell patients of different ages with diversity of need. The constant influx of new patients meant that ED nurses were consumed in 'work-ups' where every patient required bloods and an electrocardiograph (ECG) as soon as possible after arrival. In order to complete a single workup it was necessary for the ED nurse to move patients on trolleys in and out of cubicles and juggle any other available space to make way for other patients coming through.

The ED nurse was under pressure to look after new ED patients but also admitted patients who because of a lack of bed capacity were boarding in ED. Many of the nurses were junior and appeared to be struggling to keep on top of everything that needed to be done. Whilst family members valued contact and conversation with ED nurses, it was observed that the busier ED got the more likely it was that the ED nurse would delegate the more personal dimensions of care to healthcare assistants. Thus healthcare assistants were observed to be in close contact with older people with dementia and their family members and in a position to provide emotional support and assistance with personal care needs.

This family member (FMC13) described being at her wits end after spending many hours in ED. She was approached by a healthcare assistant who noticed her distress.

'I was trying to hold it in but I just cracked up. So I had to go to the end of the corridor. And even for him to notice. Yea it was lovely. He saw I was crying. And he said do you need anything? He gave me a tissue and asked me what was wrong. Then I was better. He didn't have to take the time' (FMC13).

Another family member (FMC4) remarked that it was the healthcare assistants and not the nurses who made eye contact with her. She surmised that the nurses were reluctant to make eye contact *'because they were afraid it would mean giving time, time they didn't have it to give'*.

There were instances where ED nurses managed to integrate the routine and relational aspects of care in their approach. This enhanced the experience of the older person with dementia and their family members.

'A big smile on her face and they would be all about him. Talking to him and calling him by his first name and coaxing him around. He was buying into it. After a while he could see that this was, that this wasn't a bad place to be and all the nurses were all about him' (FMC9).

'The nurse came to take her bloods. The nurse made eye contact with her and one to one she assured her. The nurse explained it to her and gave her that precious time. The nurse asked for her permission to take blood. Can I try that? Would you mind if I looked at this arm? So she was in control of the procedure' (FMC14).

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During observation N7 accompanied C to the toilet. The researcher observed that N7 touched C's face as they talked and moved the fringe away from her eyes. The nurse (N7) seemed genuinely pleased that she had this opportunity with C because she liked *'the human stuff and a chat'*. She felt the need to offer human comfort was an innate thing and an important part of emergency nursing (field notes 09/02/2017).

Family members placed value in making connections with ED nurses, seeking out human contact and simple demonstrations of empathy and compassion. Family member experiences were enhanced further when the older person with dementia was prioritised at the point of triage and when there was access to a cubicle space to protect them from being in the public gaze. There were times when ED nurses could provide the type of care that was valued by family members but there were times too when the overcrowding and nursing workload made person centred approaches difficult to achieve.

4.2 Challenges for family members and nurses in the ED

Family members believed that overcrowding and congestion in ED impacted the safety and wellbeing of the older person with dementia. As a consequence, some family members felt they had to remain in ED at all times to protect the older person with dementia from harm. Therefore family members were also vulnerable in this environment.

4.2.1 Vulnerability

All family members were moved by the plight of older people with dementia in ED. However, older people with dementia were perceived by family members to be even more vulnerable. Older people with dementia were mostly nursed in 'Trolleys', that section of ED for patients who were unwell and required admission. Usually there were three nurses allocated to Trolleys with upwards

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of thirty patients in this area most days. There were so few cubicle spaces that many patients allocated to this section were scattered throughout the entire ED and not always visible to the nurses looking after them. The ED was a crowded noisy place. The air was stifling and stagnant. A lack of windows made it difficult to tell what time of day it was.

All family members interviewed were distressed to see older people lined up on trolleys *'packed together as animals in a pen'* (FMC2).

'It was no one's fault in terms of nurses but it was a horrendous place to be and the longer that I was standing there and I was listening to these poor women and they had no voice' (FMC11).

One family member remembered that her mother was squashed in between two men. The man on the right had dementia too and exposed himself whenever he needed to go to the toilet.

'Really and truly it's not the way they were brought up. Not, it's not their way of life. It never was and they don't understand it. Even if their mind was perfect it's not the way to go' (FMC10).

Family members believed that it was inappropriate too for older people with dementia to be put on a trolley next to somebody who was under the influence of drink or drugs.

'And then my mother started saying I like green money, oh we all like a bit of that miss from the two girls on the trolley. Do you have a bit of that miss? Have you got some? And I'm like because my mother will go off on one then. And they're not going to understand what she is saying. And that's going to wind me up then' (FMC15).

It was during the day this guy came in. He was drunk or whatever on drugs. He was really bad now. He had to have two security guards with him, lashing out and swearing (FMC13).

Family members thought that the vulnerability of the older person with dementia was magnified because their diagnosis of dementia was rarely mentioned or explored.

'We weren't asked has my mother got dementia. Everybody was centred on her physical problem but nobody actually said has she got dementia. In fact, the dementia wasn't mentioned at all in the ED' (FMC3).

'Unless something medically bad happens there's no story to tell' (FMC6).

'It was never discussed' (FMC12).

Family members felt that if ED nurses asked them more about the dementia, they would be able to retrieve information that might be useful in the management of agitation and distress.

'Give her a cup of tea with two sugars. She relaxes straight away' (FMC7).

'They didn't know the patient they had. He was wearing nappies and going to the toilet in bed. This was totally unnatural for him and he was not one bit happy' (FMC9).

'I think he relates a cup of tea to home. He would have been happy instead of getting ready to walk out' (FMC13).

Lack of cubicle space meant that older people with dementia were nursed in overcrowded and congested areas of ED. Family members thought this was unsuitable. Also, family members have personal knowledge of the older person with dementia. These insights could assist ED nurses to better alleviate the distress of older people with dementia while they are in the ED.

4.2.3 Keeping vigil

Family members felt ED nurses lacked knowledge about the older person with dementia as an individual. Family members believed that their presence was essential in protecting and maintaining the well-being of the older person with dementia in an unsafe environment. The vulnerabilities of family members and the older person with dementia were interlinked (FMC11). Family members felt they had to keep vigil to ensure care needs were met and they had to have the capacity to act as a strong advocate when the situation demanded it.

'You know I was a voice for Michael. I would be strong enough to say what I wanted. But I can think of may be if you know, there was an older, if it twas a husband and wife, older people and older people come from that era, age, where you kind of don't question anything, that you know, they could be treated very badly, you know' (FMC1).

'You couldn't take off anywhere. It would have been too much pressure for me. I had to be there to make sure. She's not able to answer anything' (FMC2).

Keeping vigil over the older person with dementia while they were in ED took its toll on family members.

'I was trying to lean my head up against her trolley to rest my head but I actually couldn't sleep because I wasn't in the least bit comfortable' (FMC12).

'I was standing there the whole time. There were no seats anywhere so that was five hours. I started to get sick myself. I felt weak and I thought I can't stick it' (FMC14).

For family members a difficult scenario was trying to look after an older person with dementia on the main floor. Family members in this circumstance described being driven to despair and experiencing extremes of emotion and exhaustion.

'He was jumping and trying to get off the end of the bed. In his mind he was back in London. He was looking for the keys to his flat and all sorts of stuff. I was crying at this stage cos I had no sleep and I was wrecked' (FMC1).

'My biggest problem was that I was climbing up onto her trolley every time another trolley passed. I was awake 37 hours'. I was ready to throw myself into the lake at this point' (FMC4).

In ED the vulnerability of the older person with dementia is recognised. However, the vulnerability of family members may go unnoticed.

5 Discussion

This study explored the experiences of family members of being with an older person with dementia in ED and the experiences of ED nurses looking after them in an episode of care. Preserving the dignity of the older person with dementia on arrival and during their stay in ED was a primary concern for family members. Family members had a fear of the older person with dementia being in the public gaze. They described situations where their loved one was in a very public space and other patients and family members as onlookers did not understand the behavioural symptoms associated with dementia. Being triaged quickly and being offered a cubicle space were key factors in preserving the dignity of the older person with dementia in ED. The vulnerability of the family member and the older person with dementia were interlinked. Positive relationships with ED nurses were critical to allaying family member apprehension and anxiety. That family members valued human contact and compassion was unsurprising. The potential for distress in ED is well documented.

EDs have been described as warzones (McConnell et al. 2016). Long waits in this setting potentially exposes the older person with dementia to a host of harms including hunger, dehydration, incontinence and worsening behavioural symptoms (Parke et al. 2013, Dewing & Dijk 2016, Digby et al. 2017, Burgstaller et al. 2018). Emergency nurses acknowledge that the older person with dementia requires greater support but this is hard to achieve in a climate that is conveyor belt and task orientated. In this study, nurses were consumed in 'work ups', taking bloods and recording ECGs on high volumes of patients arriving in ED. As in previous studies, the busier the ED became, the less opportunity there was for nurses to provide individualised care (Boltz et al. 2013, Taylor et al. 2015). In these circumstances family members felt they could not leave the older person with

dementia unattended. After hours or days of maintaining vigil, family members became physically and emotionally exhausted.

The literature to date emphasises negative experiences of dementia care. There is therefore little guidance for ED nurses to provide optimal care for older people with dementia in ED settings. The constant highlighting of negative experiences without offering meaningful strategies to make things better, is counter-productive (Gergen 2015). This is not to say that nurses should relinquish their responsibility for poor care or that negative accounts of experiences should be camouflaged or glossed over. Rather, a focus instead on what family members say matters and works for them might assist ED nurses to reframe their practice in an experience enhancing way.

In this study, family members identified that the triage process needed to be changed when triaging older people with dementia. Triage is the system used by ED nurses to ensure that patients presenting with serious or life threatening complaints are identified and prioritised for medical attention. As it stands, this process is geared towards time critical presentations such as heart attack or stroke. It may be possible with education and increased awareness to ensure that no older person with dementia is given less than a P3 on arrival in ED. Priority 3 is for patients who are urgent but can wait up to one hour to be seen by an ED doctor. Undoubtedly, there are challenges for triage nurses who are under pressure to manage the queue of people arriving in ED in the fastest time possible (Hitchcock et al. 2013). The triage nurse may not have full access to all of the relevant knowledge about the person. In addition, they may be more attuned to the presenting clinical problem and less aware of other key issues such as dementia, experienced by older people attending ED (Boltz et al. 2013, Parke et al. 2013, Taylor et al. 2014).

This study did identify however, that some triage nurses found a way to prioritise the older person with dementia. This positively impacted the experiences of family members and offers a potential approach for integrating relationship centred behaviours in ED. Asking a question as simple as what is worrying you about being in ED today is a small step change that could validate the concerns of family members and perhaps initiate a supportive connection without adversely affecting triage times.

Supportive connections and the relational aspects of care matter to family members of older people with dementia. Small kind gestures and conversations can supersede the technical aspects of care on the scale of importance (Digby et al. 2016, Burgstaller et al. 2018). This study demonstrated that some ED nurses were providing 'sympathetic presence' even in the briefest of clinical encounters (Dewar & Nolan 2013). The basic premise is that if one ED nurse is capable of completing routine tasks whilst connecting with family members, then it is feasible for more ED nurses to do more of the same, more of the time.

Relationship centred care is central to high quality dementia care (Digby et al. 2016, Burgstaller et al. 2018, Pinkert et al. 2018). Yet, relationship centred care can be considered as the antithesis of ED care which values technical expertise and subordinates relational processes (Bridges et al. 2012). While emergency nurses cannot be all things to all people, they can go some way to integrating relational approaches in their daily care. Tasks such as blood taking and recording ECGs could be undertaken by those who are non – nurses. This expands the possibility of freeing ED nurses up to re-establish those connections that matter so much to older people with dementia and their family members.

Knowledge of the person and understanding what matters to those on the receiving end of care is recognised as a core nursing dimension and fundamental to enhancing nursing care of older people (Dewar & Kennedy 2016, Dewing & Dijk 2016). In ED, person knowledge involves recognising the vulnerability of family members and the factors that may conspire to magnify their stress and apprehension. It means asking family members about their situation and seeing the value of their insights in alleviating the distress of the older person with dementia. Person knowledge is knowing when a cup of tea with two sugars calms the person down or when taking blood requires a more tailored approach to lessen the fears of the older person with dementia who does not like blood taking.

A shift in thinking is required so that caring conversations are weaved into routine, everyday encounters (Sharp et al. 2017). The idea is that the technical and relational components of clinical practice intertwine and unearthing person knowledge is seen as a critical part of shaping emergency nursing assessment and care planning.

6 Conclusion

In this study negative findings from the personal stories of family members are reframed as values.

In using an appreciative gaze the experiences of family members of older people with dementia become provocative in the sense that they engender contemplation of how elements of nursing practice might be reshaped in the future. The ED is a complex setting. This study shows that aspects of ED nursing practice and process are sometimes out of kilter with what is valued and matters to family members. However, the study also shows areas of practice that are working well and areas where raising awareness and introducing small changes could make a very real difference to family members. Family members identify that the relational aspects of nursing practice matter in the provision of high quality dementia care. This provides impetus for further thoughts about creating a balance, delivering vital technical skills as nurses and providing the type of nursing practice that is valued and matters to family members who are with an older person with dementia in ED. The fact that some ED nurses are successfully blending the two, shows that this is possible in everyday practice.

7 Relevance to clinical practice

The current ED triage system needs to be adapted to give priority to older people with dementia.

Reception staff should notify the triage nurse as soon as an older person with dementia registers in

ED. Departmental policy should ensure that no older person with dementia is given less than a P3

on arrival in ED. The older person with dementia who is distressed should be given no less than a P2.

In addition, family members value contact and conversation with ED nurses over medical – technical

skills. Additional education is required to raise awareness of the needs of older people with dementia in ED. Whilst tasks such as ECG and blood taking are necessary, ED nurses must be encouraged to establish rapport and incorporate family member insights as part of care planning and assessment of the older person with dementia.

8 Limitations

This is a small, single site study. The researcher originally intended to invite older people with dementia to participate. However, older people with dementia presenting to ED were in an advanced stage of the disease or were too ill to take part. Future stages of this research will consider how the perspectives of the older person with dementia may be included.

Further limitations must be acknowledged. The period of participant observation of 30 hours is relatively small. Participant observation had to be conducted at a time that suited departmental activity and nursing workload. However, this period of observation provides an opportunity to gain contextualised understanding and rare insight into the real life, day to day experiences of emergency nurses. Three interviews with family members were conducted by telephone although the researcher would have welcomed the opportunity for face to face interaction. Telephone interviews resulted in a shorter interview time but facilitated participation by those family members who would otherwise have been too busy to participate. A high proportion of nurses in this study were newly qualified or had less than two years ED experience (41%). Junior nurses may have felt obliged to participate since the researcher was a Clinical Facilitator in ED. The experiences of dementia care reflected in this research could have been negatively impacted by a lack of senior nursing skill. In addition, ED nurse participants may have provided care that differed from their usual approach because they were being observed. Other groups such as doctors and healthcare attendants were not included as the emphasis was on nursing perspectives and interventions. The perspectives of

healthcare attendants who have substantial contact with older people with dementia and their family members may have provided further insights. This needs to be considered in future research.

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Tables

Table 1 Indicative Interview Questions

Tell me a little bit about yourself
Can you tell me what it is like living with somebody with dementia
What happened that you needed to come to the ED
How did this make you feel – your initial thoughts/feelings
What were your initial thoughts on arrival in the ED?
What did you value about your experience?
What could have made your experience better?

Table 2 Overview of themes and subthemes

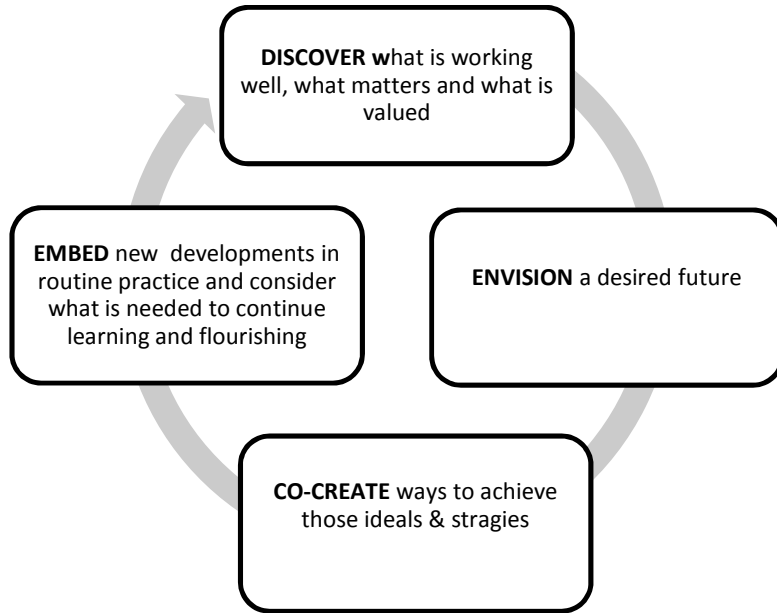
Themes	Subthemes
<i>Theme 1: What matters to family members</i>	Being triaged quickly
	A cubicle space offers sanctuary
	Contact and conversation with ED nurses
	Compassion over technical skills
<i>Theme 2: Challenges for family members and nurses in the ED</i>	Vulnerability
	Keeping vigil

Table 3 7Cs of caring conversations (Dewar & Nolan 2013)

BE COURAGEOUS: What matters? What would happen if we gave this a go? What is the worst that could happen if you did that?
CONNECT EMOTIONALLY: How did this make you feel? You made a difference today because.....
BE CURIOUS: What strikes you about this? Help me to understand what is happening here? What prompted you to act in this way? What helped this to happen? What stopped you acting in the way you would have wanted?
CONSIDER OTHER PERSPECTIVES: Help me to understand where you are coming from? What do others think? What do you expect to happen? What is real and possible?
COLLABORATE: How can we work together to make this happen? What do you need to help you make this happen? How would you like to be involved? How would you like me to be involved? What would the desired goal or success look like for you?
COMPROMISE: What is important to you? What would you like to happen? How can we work together to make this happen? What do you feel you can do to help us to get there?
CELEBRATE: What worked well here? Why did it work well? How can we help this to happen more of the time? If we had everything we needed what would be the ideal way to do this? What are our strengths in being able to achieve this? What is currently happening that we can draw on?
BEING COURTEOUS: Statements such as my name is

Figures

Figure 1 4D Cycle (Sharp et al. 2018)



Supplementary File 1

Title: Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach.	See title page
Abstract: Summary of key elements of the study using the abstract format of the intended publication.	See abstract
Introduction: Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement. Purpose of the study and specific objectives or questions outlined.	Please see Section 1 Introduction/Section 2 Background, p. 1-4.
Methods: Qualitative approach and research paradigm and guiding theory if appropriate; identifying the research paradigm is also recommended; rationale.	Research paradigm identified (Section 3.2, Study Design p. 4).
Researcher characteristics and reflexivity: Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability.	Identified in Section 3.3 (Setting, p. 6) that researcher was a facilitator in the ED and in Limitations (Section 8, p. 38).
Context: Setting/site and salient contextual factors; rationale.	Identified in Setting (3.3, p. 6).
Sampling strategy: How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary; rationale.	Please see Section 3.4 Participant Selection (p. 6).
Ethical issues pertaining to human subjects: Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	Yes. Please see Section 3.7 Ethical Considerations (p. 09).
Data collection methods: Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale.	Described in Section 3.5 Study Methods (p. 8) and Section 3.6 Data Generation (p. 09).
Data collection instruments and technologies: Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study.	Described in Section 3.6 Data Generation (p. 09).
Units of study: Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results).	Please see Section 4 Findings (p. 12).
Data processing: Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation/de-identification of excerpts.	Described in Section 3.7 Ethical Considerations (p. 9).
Data analysis: Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.	Described in Section 3.8 Data Analysis (p. 11).
Techniques to enhance trustworthiness: Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale.	Please see Section 3.8 Data Analysis (p. 11).
Results/findings: Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	Findings in Section 4 (p. 12).
Links to empirical data: Evidence to substantiate analytic findings.	Please see Section 5 Discussion (p. 31)
Discussion: Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	Described in Section 5 Discussion (p. 31), Section 6 Conclusion (p. 36) and Section 7 Relevance to Clinical Practice (p. 37).
Limitations: Trustworthiness and limitations of findings.	Section 8 Limitations (p. 38).
Other: Conflicts of interest declared.	Yes
Funding: Sources of funding and other support; role of funders in data collection, interpretation, and reporting.	Yes