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# Challenges for nurses when communicating with people who have life-limiting illness and their families: A focus group study — Source link

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### A focus group study

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### TITLE

Challenges for nurses when communicating with people who have life-limiting illness and their families: a focus group study.

### **RUNNING TITLE**

Challenging conversations by nurses

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### **CONFLICT OF INTEREST STATEMENT**

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### TITLE, ABSTRACT AND KEY WORDS

### **TITLE**

Challenges for nurses when communicating with people who have life-limiting illness and their families: a focus group study.

### ABSTRACT

Aims and objectives: The proposed study aimed to answer the following question: What communication issues do nurses find challenging when caring for people with life-limiting illness?

Background: Evidence suggests that attitudes, skills and knowledge about how nurses communicate effectively with patients and their families could be improved. However, the literature predominantly focuses on nurses working in oncology and the medical profession. Design: A qualitative descriptive design was used.

Methods: Focus groups were conducted with 39 nurses from three wards within a regional healthcare organisation in Victoria, Australia. Data were analysed using thematic content analysis. The COREQ checklist was used to document reporting of the study.

Results: In their view, nurses have the potential to develop a strong bond with patients and their families. Three key themes were identified: 1) Feeling unskilled to have difficult conversations with patients who have life limiting illness; 2) Interacting with family members adds complexity to care of patients who have life-limiting illness; 3) Organisational factors impede nurses' capacity to have meaningful conversations with patients and their families. Conclusions: Caring for individuals with life limiting illness is-complex, and often occurs in an emotionally charged environment. However, nurses report being hampered by time restraints and lack of information about the patient's condition and goals of care. Limitations in conversation structure and a comprehensive range of core communication skills affects their ability to confidently engage in conversations, particularly when they are responding to prognostic questions.

Relevance to clinical practice: Whilst nurses are responsible for performing technical skills, they can maximise care by developing a trusting relationship with patients and their relatives. Increased acuity limits the time nurses have to talk with patients. In addition, they lack

confidence to deal with difficult questions. Specific training may increase nurses' confidence and efficiency when communicating with patients and their families.

### **KEY WORDS:**

Clinical Care, Communication, Family, Life-Limiting Illness, Nurses, Patients



### **MAIN TEXT**

### Introduction

Nurses spend considerable time with patients while they provide clinical care; thus have many opportunities to engage in meaningful conversations with patients and their relatives. One of the prerequisites for developing the nurse—patient relationship is competence to connect with people. Halldorsdottir (2008) used the metaphor of a bridge to "symbolize the openness in communication and the connectedness experienced by the patient in an encounter" they perceive as caring (p. 646). In contrast, she used the metaphor of a wall to symbolise uncaring nurse-patient encounters that have negative or limited communication, detachment and a poor caring connection.

Unfortunately, research shows that ineffective communication by nurses occurs in various settings, including in-hospital (Feder, Britton, and Chaudhry, 2018, Kastanias et al., 2009); primary care (Ellington, Reblin, Clayton, Berry, and Mooney, 2012) and outpatient departments (Golsäter, Enskär, and Knutsson, 2019). Regarding patients with a life limiting illness (LLI), Chamberlin et al., (2019) found that when clinicians are engaging in futile care or probable inappropriate care for dying patients, they avoid both the patient and the family. They propose that strategies to improve communication between the health care team, the patient and the family may reduce futile care, which will consequently minimize these avoidant behaviours.

### Background

The Australian Commission on Safety and Quality in Healthcare (ACSQH) recently released the second edition of the National Safety and Quality Health Service Standards (ACSQH, 2017). It is proposed that these Standards should be used to implement safety and quality systems. Of significance to the current research, Standard 6, 'Communicating for Safety', was predicated on the understanding that effective communication is inherently linked to safety and quality.

In the United Kingdom (UK), the 'End of Life Care Strategy for England' (National Health Service, 2008) (NHS) highlighted that effective communication between patients and healthcare professionals (HCPs) is integral to facilitating patient involvement in advance care planning. They also proposed that all HCPs require the necessary knowledge, skills and attitudes to communicate and manage patients at the end of their life, and their families. The NHS suggested that such conversations should be honest and open, including clarifying

what the person understands, how much they want to know, and preference for having family members in the discussion. The report suggested that communication in the care of patients with non-cancer life-limiting conditions, such as chronic obstructive pulmonary disease (COPD) and heart failure, is likely to be inadequate and HCPs require communication support and training. Likewise, Synnot et al. (2018) explored research priorities for consumers and other stakeholders in health communication. Key recommendations included prioritising research that addresses structural barriers to health communication and building health professionals' communications skills and practices.

Patient-centred communication focussing on shared decision making has been linked to improved outcomes for patients with LLI (Land, Parry, and Seymour, 2017). LLI is a concept adopted by palliative and community care, defining a population of patients at high risk of dying in the subsequent 12 months (Orford et al., 2016). A LLI might be expected to shorten an individual's life, and can include diagnoses such as cancer, ischaemic heart disease, COPD, dementia, frailty, heart failure, neurodegenerative disease, chronic liver disease and renal disease (Palliative Care Australia, 2005). In a prospective before-and-after cohort study, Orford et al. (2019) demonstrated that communication skills training (CST) decreased 90-day mortality and readmission rates for critically ill patients with an LLI.

Nurses play a vital role in the management and care of patients with an LLI, and they are often required to advocate on the patient's behalf to uphold their rights and maintain their wellbeing. As they are likely to spend considerable time with patients and their families across a shift, they are in a strong position to develop strong rapport, an essential ingredient for effective communication (Head et al., 2018). Therefore, understanding the challenges that nurses' experience when communicating with patients who have an LLI is imperative in the development of practice improvements. The aim of this study was to identify challenges for nurses when they communicate with people who have LLI, and their families.

### Methods

### Design

This paper reports on a qualitative descriptive study that consisted of a series of focus groups. The EQUATOR's COREQ checklist (Tong, Sainsbury & Craig, 2007) for qualitative research was followed (Supplement 1). The study was undertaken at one healthcare organisation, and nurses were recruited from two acute wards (one medical and one surgical), and one palliative care ward. Two separate focus groups were conducted in each ward to maximise opportunity for nurses to participate and enable a wide range of opinions to be heard. A total of six separate focus groups were conducted.

Focus groups are an effective method of collecting data from a number of participants at the same time and enables researchers to construct shared meaning about the topic under study (Jayasekara, 2012). A key feature of focus groups is that they enable

active interaction among participants to explore views and opinions about the topic under discussion.

### **Ethics approval**

Ethics approval was obtained from the institutional ethics committee, meeting the principles of the National Statement on Ethical Conduct in Human Research (2018). Investigators did not hold a clinical or supervisory role in the wards where the study was conducted, which reduced the possibility of coercion. Participants were reimbursed for their time with a monetary voucher, equivalent to approximately 45 minutes of their wage. Written consent was obtained. The study was supported by an institutional internal grant.

### Sample

Purposive sampling was used, and included employment in one of the three wards, nurses (registered or enrolled), and aged at least 18 years of age. We aimed to recruit approximately ten nurses from each ward. According to Jayasekara (2012), the most appropriate number of focus groups to achieve adequate data is four to six. The total number of focus groups in this proposed study was guided by data saturation. This means that as we became aware that no new themes were emerging, we concluded recruitment.

### **Recruitment Process**

An email was sent by ward managers to invite eligible nurses to participate in the study, and it included information about the study in the form of a 'Participant Information and Consent Form'. Nurses who wished to participate advised the ward manager, who then advised the research team about focus group numbers. Each focus group began with introductions, an explanation of the study and confidentiality and informed consent procedures.

### Data collection

Prior to the group interview, data regarding demographic (age, gender, employment category) and previous CST was collected using an anonymous self-report questionnaire. Focus groups were audio recorded using a digital recorder. Each digital recording was transferred to an electronic password protected file. All files were sent to a professional transcription service, and transcriptions were returned as individual Microsoft word files. Any identifiers were removed on return of the transcriptions, prior to distribution to the researchers.

Focus groups were conducted in a staff meeting room located in each ward. At least two investigators attended each focus group. One experienced researcher (\_\_), with qualitative and quantitative research experience and expertise in CST, facilitated each session. One other investigator (\_\_), a doctoral candidate and experienced CST facilitator, took notes and provided a verbal summary of the key findings to participants at the end of each focus group. The researchers also used the summaries to determine when data

saturation occurred. A research assistant attended each focus group session to maintain the audio recordings and manage any situation in which a participant became upset.

Data were collected using two techniques: 1) a Nominal Group Technique (NGT) and 2) an Interview Schedule (Figure 1). NGT is a process that can be used to encourage all participants to contribute to a group conversation, such as a focus group. McMillan, King and Tully (2016) propose that the technique involves four key stages: 1) silent generation; 2) round robin; 3) clarification; and 4) voting (ranking). In the current study only the first two steps were utilised because of the limited time (less than 60 minutes per session) available to undertake the focus groups. We were particularly interested in identifying participants' views in response to our guided questions. After providing a description and rationale of the study, participants were asked to silently write comments to the two NGT questions. First, participants were asked to think back to when they had a difficult conversation with a patient who had a LLI, or their relatives. Then they were encouraged to write down in a few sentences what made the conversation difficult, including the patient's condition and what they found challenging. The two specific questions were: "What factors made the conversation difficult?" and "What was challenging about the conversation?" (What did you find hard?). The purpose of this exercise was to foster involvement from all focus group members. Participants were asked to verbally share their written responses during the focus group. With their permission, we also collected their written responses for analysis purposes.

Second, using the Interview Schedule, the facilitator posed open-ended questions that focused on eliciting participants' opinions regarding their experiences when communicating with patients who have LLI, and needs for CST. The facilitator used probes and clarifying questions when necessary to continue or build discussion of a specific question or to keep the focus on LLI. Focus groups ranged from 40 to 80 minutes in duration and were scheduled during double-staffing times to maximise participation.

Communication skills for the proposed study were defined as 'the direct or indirect transmission of information between two or more people that is achieved through verbal and non-verbal methods, including speech units, eye contact, body language, gestures and facial expressions, as well as listening methods." (Ditton-Phare, Loughland, Duvuvier, and Kelly, 2017) (p. 675).

### Analysis

Thematic content analysis was used to summarise data retrieved from focus group interviews. Analysis followed the process as first described by Smith and Osborn (2008). Data was analysed in two stages: Transcript analysis and NGT analysis.

The focus groups transcripts were combined in one document. First, the whole transcript was read and re-read several times to gain a general sense of the overall accounts. Second, transcripts were examined using line-by-line analysis. Notes indicating

striking issues were made in a separate column as a form of coding, with the development of themes to reflect the researcher's interpretation of the data. Third, themes were clustered and re-developed as main themes and sub-themes.

Written responses to the NGT question were collected and inserted in an electronic file. Like the transcript analysis, data was analysed by thematic analysis. Finally, after careful scrutiny of the grouped interview transcripts and NGT responses for clarity and order, themes and subthemes were tabulated in a summary table.

The analysis process for transcripts and NGT responses were followed by a second researcher who independently identified themes and sub-themes. A consensus meeting was held to compare interpretation of the data. A joint thematic framework regarding the themes was established by the conclusion of the consensus meeting. All investigators read the transcripts, NGT responses and field notes; and confirmed interpretation of the data

The themes are explained and explored using quotations arising from the transcripts and NGT written responses. Quotes that represent the theme or sub-theme were labelled according to the focus group they attended. For example, the first focus group is labelled FG1, the second focus group FG2.

### Results

Thirty-nine nurses participated in the focus groups. There was an even distribution of participants from each ward (medical ward: n=13, surgical ward: n=15, palliative care ward: n=11), shown in Table 1. Approximately half (43.6%) of the participants were aged 26 to 35 years. The majority were female (92.3%) and most were registered nurses (89.7%). The gender and age ratio is representative of the nursing demographics for the healthcare organisation. Less than half (38.5%) of the participants had received some form of CST after completing their undergraduate degree.

Three main themes emerged from the data as shown in Table 2: 1) Feeling unskilled to have difficult conversations with patients who have LLI; 2) Interacting with family members adds complexity to care of patients who have LLI; 3) Organisational factors impede nurses' capacity to have meaningful conversations with patients and their families.

Theme: Feeling unskilled to have difficult conversations with patients who have life limiting illness

This theme describes participant's experiences of their preparedness for engaging with patients who have an LLI. Nurses expressed the view that there are times when they are involved in difficult conversations, often emotionally charged, but they report feeling unskilled for the more challenging discussions. A few participants had received some form of professional development for communication skills, but there was little recall of

undergraduate training in this field. Three related sub-themes emerged from the data: 1) Absence of a communication toolkit and framework inhibits capacity to respond to difficult questions and gather information; 2) Dealing with heightened emotions; 3) Interactions are difficult when there is denial.

<u>Sub-theme</u>: Absence of a communication toolkit and framework inhibits capacity to respond to difficult questions and gather information

Participants discussed that, in general, nurses should be capable of having challenging conversations with patients. In their view, nurses spend most of the time with patients, and they are in a position to develop strong bonds which should make it easier to have difficult conversations.

'It's hard ... I think our nurses especially are very capable of having those conversations and we can read the patients well enough that we know who to talk to and when the time is good enough.' (FG2)

There was overall acknowledgement that basic communication skills, such as listening, empathy and developing rapport, are utilised regularly and are important. However, several participants discussed the challenge associated with initiating the conversation and gathering information from patients.

'Sometimes it's hard to start that conversation. You don't always know how much information the patient already knows. What are they aware of with their illness? Are they aware it's life limiting, or are they aware they've got so many months to live? ... Are they in denial, or are they pretty au fait with it?' (FG4)

When describing the most challenging conversation they had experienced, some nurses explicitly raised concerns that they do not have a communication toolkit to rely on when conversations get hard, and occasionally just improvise. They discussed that provision and understanding of a structure might have improved past interactions.

'I have no confidence whatsoever ... I self-doubt myself all the time ... A real fear for me is communicating with patients at times that you're not sure about ... Sometimes it's ... bravado. You've just got ... [to] put on that face so you can communicate because if you show that you're not able to communicate then you lose that rapport. You lose that trust of the patient. So a huge fear of mine is communication.' (FG2)

Participants from each focus group recalled the challenges they experienced when responding to questions about patients' prognosis. These questions are received from patients and family alike, and are usually emotionally laden. The most frequent questions

discussed by participants included 'When am I going to die?', 'When is he/she going to die?', 'Will I be going home?'

'I guess when patient's relatives ask how long their loved one ... has got left. That's always hard ... to answer. Being blunt - letting them know. It might not be very long and sometimes they don't realise it.' (FG2)

Nurses also talked about the challenges associated with gathering information about the patient's understanding of their illness and/or prognosis. There was explicit discussion about lack of awareness of a formal structure to enhance and expedite the interaction.

'Sometimes it's hard to start that conversation. But you don't always know how much information the patient already knows. What are they aware of with their illness? Are they aware it's life limiting, or are they aware they've got so many months to live? ... Are they in denial?' (FG4)

Participants discussed that, in their view, communication is a skill that improves with practice and with experiential training. However, few recalled receiving explicit CST during their undergraduate course, and fewer than 40% had undergone post graduate training. Some participants employed in the palliative care ward reported on their experience of CST as part of a Master of Palliative Care course, which incorporated online theory, face-to-face workshops and role plays. Others discussed participation in the organisation's training program, iValidate, which is usually delivered as a two-day face to face workshop and includes theory and experiential learning and role play (Simpson et al., 2019). iValidate is a clinical communication training program, designed specifically for communicating with patients with LLI, which is founded on identifying values, listening, and advising.

'I recently did a postgrad[uate] course, and ... we'd act out scenarios with trained actors. It was incredible learning it that way. Little things like looking at your watch, how off-putting that is.' (FG1)

'I ... wish we had [iValidate] at the start of the [graduate] year because we covered so much about communication ... like how to get the answers that we need from patients and trying to navigate the conversation. It was really good.' (FG2)

The practicality of observing experienced nursing colleagues when they communicate with patients was proposed as a potential strategy to learn how to more effectively communicate with patients. However, the presence of a third person during an indepth conversation between a nurse and the patient was considered less than ideal.

'That's the problem. Being obtrusive ... Because you don't want it to be like a speech, where you've got observers watching ... It really needs to be ... private ... an intimate

conversation ... You can be hands on and touch them if you need to and you don't want people there watching. It is hard.' (FG4)

Hence, it was evident that there are limited opportunities to learn about, and practice, communication skills.

### Sub-theme: Dealing with heightened emotions

Nurses in this study described the challenges they experience when communicating with patients when the conversation is emotionally charged. They also discussed the difficulties associated with feeling emotionally upset or identifying with the patient and/or family.

Most prominent was the reluctance for nurses to disappoint patients by knowingly giving them 'bad' or disappointing news about their diagnosis and/or prognosis. This is particularly challenging when there may be a poor prognosis or limited treatment options. Several participants discussed how difficult they found it to not be able to offer patients hope for their future well-being.

'I think we have a fear of disappointing people ... Some relatives might ... say, "Dad was going to church every Sunday before he came here ... We want him to get back to going to church". Sometimes it's difficult to word or to convey the message that [it's not] going to happen'. (FG6)

One participant in particular recalled a situation where she deliberately encouraged the patient to think positively, dismissing his comments which eluded to his impending death. She stated that she most likely ignored important cues. He died within two days of that conversation, and the participant regretted not acting on those cues and acknowledging his feelings in that previous conversation.

'He mentioned small things like "I might not even make it home" or "I can't bounce back from this" ... and even in that situation, you sort of need to keep your patient positive ... I came back from having one day off and he'd ... passed away...To me, that was pretty awful because he said things like that and I [said], "No, no, try and be positive." ... That's the hardest part ... [you] can't tell them that they're going to be fine when you don't know.' (FG3)

Participants also identified the challenges associated with conversing with patients and their families when they demonstrate anger and frustration. Several participants

described situations in which family members were upset, and often this arose from their lack of understanding about the patient's plan of care or an unexpected patient demise.

'They weren't expecting mum or dad to deteriorate so quickly so they're all quite anxious ... concerned ... scared ... [and] angry.' (FG6)

They also reported that, at times, patients can be upset about the proposed plan of care. Frustration can be expressed when they disagree with the plan, or are not involved or informed about the decisions regarding their health. One example, provided in written form, described a situation in which a patient demonstrated abusive behaviour, and it was difficult "to calm him down to have a rational conversation". (FG6) In that situation, the patient expressed frustration that he was not given a choice about when he started rehabilitation. Other situations that are difficult include patient requests to go home prematurely or to go outside for a cigarette against medical advice. This also speaks to lack of shared decision making and ineffective provision of information.

Nurses in our study discussed their heightened emotional response when they identify with the situation. Most evident was that nurses discussed their emotions when patients or family members are of the same age. This affects their confidence when conversing because they can see themselves in the same situation.

'If you ... come across this parallel to your life, sometimes that can be difficult ... I'm not saying that I wouldn't nurse them but ... that sort of [exhausts me] ... of my emotions because you know that you've got to ... give them the empathy and ... compassion. It's not that you don't want to give them any of that but ... you've got in the back of your mind that [you relate to the] patient.' (FG2) 'It brings back flashes of situations where I think there but for the grace of God this

### Sub-theme: Interactions are difficult when there is denial

could be my child or my husband. It's really hard.' (FG2)

Challenges were also reported in situations whereby, in the nurses' view, the patient and/or their family is in denial about their prognosis. For example, despite initiation of palliative care, some patients continue to discuss their intention to go home, when nurses are confident that this is highly unlikely as their care needs are too high.

'I think it's hard too when people don't want to know. Like they ask the question but they don't want to hear the answer ... Someone might say "How long have I got?" ... In their eyes ... they're thinking two weeks, where we might say three days.' (FG2)

Nurses also discussed the challenges associated with conversing with family members who, in their view, are in denial about the prognosis. When asked how they managed this type of resistance, participants did not disclose knowledge of a structured approach which might assist the management of this dilemma.

'I think it's difficult to remain focused on ... why you're having this conversation and to reach the goal of the conversation at the end. Because you could be talking to somebody about their father and how unwell he is and next thing you know, this person's saying, "I had a car accident last year and I had a fractured pelvis" ... [They are] diverting away from the actual subject and it's hard to pull them back ... They may be doing that because ... they don't want to be having that conversation.' (FG2)

# Theme: Interacting with family members adds complexity to care of patients who have life limiting illness

The second theme that emerged from the data related to the complexities that interacting with family members adds to care of patients with LLI. Two related sub-themes emerged from the data: 1) Unrealistic and mismatched expectations; and 2) Balancing relational dynamics with patient values and needs.

### Sub-theme: Unrealistic and mismatched expectations

Participants reported the challenges associated with dealing with families who have unrealistic and/or mismatched expectations compared with the patient, their relative. A common experience recalled by participants is when the patient has decided to not receive further treatment, and is comfortable with the possibility of death, but the family want treatment to continue. Often, the family members were demonstrating unrealistic expectations of treatment, and mismatched expectations with their relative. In these situations, family members often become upset. Nurses discussed their efforts to primarily uphold the patient's decision, but also to support family members during this difficult time.

'I find it difficult sometimes when you've got a patient that wants [to die], whereas the family doesn't want to acknowledge that they're going and they want to try and keep saving this person ... [The patient] says "Just leave me alone, I want to die." ... You almost feel responsible to be able to support both of them ... I ... find ... it difficult to try and ... keep both parties happy, which you can't.' (FG3)

Mismatched expectations about goals of care between different family members creates confusion for the healthcare team and the patient. As mentioned, there can also be mismatched expectations between the patient and family members.

'I think sometimes our patients [are] ready for their death well before they [are given their prognosis]. They know their bodies have limited time, [but] the families just aren't ready to let go.' (FG1)

In addition, they discussed the unpredictable nature of LLI, as well as acute deterioration. Nurses discussed the pressure associated with responding to family member's questions in response to predicting the time of the patient's death.

'Death's a tough one. It's like "How long is a piece of string?" We think we might know that someone doesn't have so long and then they go on another week or another [day] or another hour, so it's hard to make that call.' (FG5)

### Subtheme: Balancing relational dynamics with patient values and needs.

Nurses reported they feel compromised when they are required to balance family dynamics and requests, with patient values and care needs. Of particular concern is when family members become upset about particular components of palliative care. For example, the administration of opioids to keep the patient comfortable can be perceived by family members as nurses deliberating advancing the patient's demise. Arising from these types of misunderstandings, and compounded by low death literacy, families do not always understand or cope with the patient's transition to death, and this can be expressed as anger when communicating with nurses.

'You still will get some patients' families [who] ... think that they're loved one's not dying. So that's a whole different conversation again. And they're not wanting the medications ... even though we can see that they need something for pain or agitation. It's like "No, no. That'll make them go to sleep."' (FG2) 'The word morphine, as soon as that [is said], they're like "No, they can't have that because that's going to kill them." ... But they are not educated enough to understand.' (FG2)

A common occurrence is family members requesting that information about the patient's diagnosis and/or condition not be disclosed to the patient. An ethical dilemma for nurses occurs because they believe that patients are entitled to know, demonstrating their role in advocating for the patient.

'They often document if the ... family don't want the patient to know anything. ... I've seen that documented at times, and it's very hard when you see that.' (FG6) 'There's also instances where you have family who don't want the patient to know of their diagnosis. That sometimes becomes ... a situation where you're ... treading carefully, making sure that none of the staff actually slip and tell them.' (FG6)

Regarding the challenges associated with family involvement, nurses are occasionally involved in family dynamics, including requested restriction of some visitors. Family structures are increasingly complex. Certain requests can be difficult, because in their view, patients should be entitled to visitation from whoever they choose, not who the family chooses to visit.

'Sometimes here we can get family conflicts that happen - like there's a stepmother and the children or the stepfather ... and they don't want to visit when each other's here ... That can be hard because as a nurse we don't get into all that.' (FG2)

# Theme: Organisational factors impede nurses' capacity to have meaningful conversations with patients and their families

The third and final theme that emerged from the data suggested that organisational factors impede nurses' capacity to have meaningful conversations with patients and their families. Two sub-themes were prominent: 1) Inadequate degree of information; and 2) Lack of time.

## Sub-theme: Inadequate degree of information

Participants expressed the view that nurses play a strong role in advocating for their patients, however, they sometimes feel that they don't have an adequate amount of important information about the patient's condition and/or prognosis to deal with difficult conversations. There was strong agreement that being informed by the treating team is important. Nurses expressed feeling excluded from treatment discussions and decisions by the rest of the team. They indicated they feel that they are not being "informed", but also that they are not being included. Many participants indicated that they were not always verbally updated about the patient's condition during a shift, but rather, they found information whilst reading the medical notes. This also limits their ability to advocate for their patients.

'A lot of it is actually about balancing who knows what and who should know what and who does know what, or doesn't know. ... It's very, very hard if you don't know that real vital information. You might not need all of it ... but actually there are some things that are really important. If you don't have that, it set[s] you up to [have] ... a much more difficult ... conversation.' (FG1)

'I just find it hard sometimes because ... there is ... lack of communication between nursing and medical staff so we don't know exactly where the doctors have led that patient to.' (FG2)

They also reported that it is not always clear to them whether nurses can disclose diagnostic and/or prognostic information. There is a lack of clarity about who can disclose information,

and when that disclosure can occur. Indeed, they reported there were times they were informed explicitly not to divulge certain information to patients. This tension may impair their ability to respond to patient's concerns, arising from fear they might act outside their scope.

'Not knowing how much the patient already knows, not knowing how far to clarify misunderstanding. Not wanting to over-step scope.' (FG5)

'If we have information, we want to ... tell them what we know but ... we're not allowed to. We feel that they should know but it's not our role to do it so we've got to stop ourselves and halt back and wait.' (FG6)

### Sub-theme: Lack of time

In addition to a perceived lack of information about the patient's condition, and concerns about practising outside their professional scope of practice, nurses in our study discussed the lack of time they have to engage with patients and their families. The burden of completing more technical tasks, coupled with frequent interruptions, limits their capacity to have meaningful conversations.

'Family ... want that conversation right now and ... I can't walk away from that. ... I'm here to ... talk to people, to be able to help them with their problems and it is very conflicting.' (FG2)

'It's challenging finding time to have ... deep conversations with patients and relatives. Nightshift is a good time for that. You're not task-orientated every night ... You're not driven by washes and all that kind of stuff'. (FG2)

Participants discussed the complexity of dealing with multiple family members, which leads them to repeat information regarding the patient's care. This also adds to the demands of caring for a patient with an LLI, and adversely affects time management.

### Discussion

This study contributes to the literature in that it explored nurses' communication challenges beyond just cancer life-limiting conditions. Nurses were recruited from an acute medical, an acute surgical ward, and a sub-acute care ward. In this study, we identified that nurses do not feel confident when having difficult conversations with patients who have LLI. Various factors affect the way in which they communicate with patients and their families. There was acknowledgement that communication is a skill that can improve with practice and specific education.

First, our study shows that nurses appear to be familiar with the use of listening, rapport and empathy as effective communication skills. This is encouraging; however, perception of skills and their deployment may not align (Davis et al., 2006). Also, there was

less awareness of the structure and full range of core communication skills that could be used in healthcare, such as identifying and exploring cues, responding to emotions, asking open questions, using pauses and silence, screening and clarifying. They specifically discussed the challenges with certain conversations, and there was strong emphasis on the difficulties associated with responding to prognostic questions and time management. According to Silverman, Kurtz and Draper (2013), there are 73 core communication process skills that guide medical consultations. Many of these skills were included in a European consensus document, the Health Professions Core Communication Curriculum (HPCCC) (Bachmann et al., 2013). The findings of our study suggest that nurses are unfamiliar with many core communication skills, which may reflect a lack of focus on communication skills in nursing curricula.

Whilst some nurses in our study expressed confidence in engaging in conversations with patients who have LLI, evidence suggests that giving 'bad news' such as a cancer diagnosis can be challenging for nurses. (Warnock et al., 2017). Others have also identified that nurses are challenged when negotiating patients' end of life care (Adams et al., 2017, Anderson et al., 2016; Aslakson et al., 2012 and Holms, Milligan and Kydd, 2014).

Another strong theme in our study was nurses' lack of confidence when gathering information about patients' understandings about their prognosis. It is feasible, and was proposed by some participants, that lack of familiarity of a prescribed structure to guide nursing conversations may contribute to the challenges they experience when gathering information from patients. As part of the Calgary-Cambridge Guide (Kurtz and Silverman, 1996), a framework is provided for organising the skills of a medical consultation. This framework is used in postgraduate CST programs for healthcare professionals (Simpson, 2019), including nurses, and in undergraduate medical training (Taylor et al., 2018). However, to the authors' knowledge, no such framework is utilised in undergraduate nursing programs in Australia, and it is not recommended in nursing-specific communication textbooks (Sully & Dallas, 2010; McCabe & Timmins, 2013). The HPCCC was developed in lieu of concerns about a universal teaching curriculum for undergraduate education in health care (Bachman et al., 2013). Those authors proposed that the instrument be used as a guide for teaching communication in undergraduate education in health care, including nursing.

Of note, no participant in the current study recalled receiving education about communication skills in their undergraduate program, and few had received specific post-graduate training. This is in stark contrast to international programs, such as in Southern Denmark, where all employees of Lilliebaelt Hospital are expected to undergo mandatory CST during their employment (Ammentorp et al., 2018). It is worth noting that the organisation in which this study was conducted has invested significant effort into implementation of the iValidate program (Simpson, 2019), including recruitment of nurses.

Enrolment in this program is not compulsory, but is gaining popularity as more participants complete the course. To date, 152 nurses (RN and EN combined) employed within the organisation this study was conducted have completed the course (approximately 4.7% of nurses employed in the organisation) (Informal communication, Milnes, 2019). It is possible that nurses employed at other healthcare organisations are likely to have received less training in the area of communication skills, compared with the organisation in which this study performed. This is an area for further research. Participants in our study proposed that observing experienced colleagues is a useful way to learn about how to communicate more effectively with patients. However, this will only be successful if nurses have a shared language and framework, such as the Calgary Cambridge Guide (Silverman et al., 2013) and HPCCC, to reflect and deconstruct what they observe.

Nurses appreciate that communicating with patients and their families is an important component of their role, however the literature suggests they need professional development which focuses on communication efficacy (Adams, Mannix, and Harrington, 2017; Furman, Kelly, Knapp, Mowery, and Miles, 2006). To address these concerns, the American Society of Clinical Oncology and American Academy of Hospice and Palliative Medicine published guidelines that identified the need for CST for clinicians in palliative care (Bickel et al., 2016). The findings of our study support the development of specific training resources for nurses to enhance their ability to communicate efficiently and effectively with patients who have a LLI. There are resources, primarily developed for the medical consultation, which could be used. For example, the Calgary-Cambridge Guides (Silverman, Kurtz and Draper, 2013) highlight the core communication skills and different conversation stages (e.g., initiating the session, gathering information, providing structure to the consultation, building relationship, explanation and planning, and closing the session). This framework has been used successfully in organisation-wide training programs, as described in the previously mentioned study (Ammentorp et al., 2018), that included a significant number of nurses. Awareness of the structured guide and the full repertoire of core communication skills is likely to strengthen nurses' ability to communicate with patients and their families. Interestingly, our systematic review (Manuscript submitted for publication) identified that whilst CST enhances nurses' ability to communicate with patients, most studies have been performed in the oncology setting. Hence, there will need to be greater emphasis on a broader scope of LLI such as functional decline (e.g., frailty and co-corbidity) and organ failure (e.g., congestive cardiac failure, renal failure and COPD).

Whilst nurses in our study acknowledged the important role that nurses can play in contribution to significant conversations, their capacity is limited by perceived lack of important information. Without adequate information, they are concerned about their ability to effectively and accurately discuss goals of care and discharge planning with patient and

their families. This appears to be a new finding, and highlights difficulties with intraprofessional communication and a systems issue.

Interestingly, whilst nurses in this study expressed confidence in dealing with some challenging conversations, such as breaking bad news, concern exists regarding what falls within their scope of practice. We know they have an important role in supporting the patient and responding to questions the patient may have after receiving 'bad news'. Role confusion has been identified as a particularly significant barrier to the inter-professional collaboration and expansion of nurse consultant roles, such as nurse practitioners in Australia (Gardner, Chang and Duffield, 2007) and internationally (Brault et al., 2014). Poorly defined roles can become a source of conflict in clinical teams and reduce the effectiveness of care and services delivered to the population. As an organisational process, clarification is required about nurses' scope of practice before this type of conversation can be incorporated in CST programs. Nurses often feel obliged to with-hold information from patients and their families. This can result in uneasiness and may contribute to delays in provision of test results and diagnosis for patients. Whether or not nurses should be expanding their repertoire of responsibility in this regard is worthy of further research.

Nurses in this study feel generally time poor. In their view, this lack of time affects their ability to talk with patients and their families, which weakens rapport building. Several researchers identified that nurses can be more concerned about physical tasks rather than engaging in conversations with patients, families and caregivers (Ellington, Clayton, Reblin, Donaldson, and Latimer, 2018; McCabe, 2004; Tay, Hegney, and DNurs, 2010). However, what they may be unaware of is that learning how to communicate effectively can actually save time (Rosenbaum and Axelson, 2013).

As others have found (Adams et al., 2017; Furman et al., 2006), nurses in this current study consider that communicating with patients and their families is an important component of their role. They did raise concern, however, about the impact of family member involvement in patient care, resulting in repetitive questioning, mismatched and unrealistic expectations, and emotional responses. Zaider et al. (2016) undertook a study including acute care nurses working in oncology in the United States, and found discrepant goals of care were one of the leading challenges for nurses when communicating with family. Likewise, our study showed that dealing with family issues, such as relational difficulties within the family itself and mismatched expectations, is time consuming for nurses. Training is likely to strengthen nurses' capacity to communicate effectively and efficiently with family members, whilst maintaining their patient advocacy role which is of the upmost importance to nurses.

Part of the strength of this study were the procedures used to uphold trustworthiness: credibility, transferability and dependability. Credibility was achieved using three techniques.

First, an established research methodology (qualitative descriptive) and method (focus groups) were used. Second, data from the focus groups was obtained from two separate sources – the NGT and interview questions. Field notes were used to document main observations and end points of discussion, which were compared with the identified key themes. The use of multiple data sources (transcripts, NGT responses and field notes) was used as a form of triangulation, often used in qualitative research to develop a comprehensive understanding of phenomena (Carter, Bryant-Lukosius, DiCenso, Blythe, and Neville, 2014). Third, interview questions were designed after review of the literature, structured to collect descriptive data that reflected real experiences and perspectives of participants. The Interview Schedule was piloted with three registered nurses before use in the focus groups, and revised based on their feedback. Transferability was addressed by providing a detailed description of the setting (three separate wards in one regional healthcare service) and context (the aim of this study was to inform the development of a CST intervention for nurses) in which this study took place. The dependability of this study was upheld by maintaining an audit trail to demonstrate systematic documentation, data collection and analysis. Member checking was undertaken with four participants who reviewed key themes identified in the analysis process. This process validated the results of our study. Finally, to reduce bias, preliminary analysis was performed independently by two researchers who separately generates codes and developed themes.

The limitations of the study include that this is a single-centre study which might affect generalisability. However, we have provided details of the setting and context. It is likely that the themes identified in this study are not unique to our organisation. Details regarding the setting and context should provide readers with adequate information to enable application in their centres. The study did not include nurses employed in critical care or primary care settings. Nurses employed in these areas might experience different types of challenges when communicating with patients who have LLI.

### Conclusion

In summary, this qualitative study provided unique nurses' perspectives on challenging conversations for patients with a LLI. Nurses are often in a position which requires them to engage in difficult conversations. Whilst they are confident with some core communication skills (listening, rapport building, empathy), they are less familiar with the full repertoire of core communication skills and conversation structure, as provided by the Calgary Cambridge Guide. This focus group study has also identified that nurses perceive they are restricted in their capacity to communicate effectively by time restraints and limited information about the patient's diagnosis and goals of care. It is also unclear to them to what depth they are responsible for conversing with patients, arising from fear of practising outside their scope of practice.

### Relevance to clinical practice

These findings provide insight that will support the further development of training interventions aiming to improve communication skills for nurses. Strategies need to be developed to increase exposure of communication skills training, including conversation structure, in undergraduate and post-graduate nursing education programs. This may improve confidence by which nurses communicate with patients who have life limiting illness. Further research might explore the nurses' role in contributing to difficult conversations, including breaking bad news and dealing with prognostic questions.

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### **IMPACT STATEMENT**

- What does this paper contribute to the wider global clinical community?
  - Nurses have the potential to develop a strong bond with patients and their families through empathic and engaging conversation.

- Perceived lack of time, unclear scope of practice and inadequate information about the patient's diagnosis and prognosis pose significant barriers to effective nursepatient and nurse-relative communication.
- Prognostic questions pose the greatest challenge for nurses, and lack of confidence and knowledge of conversation structure and effective core communication skills impedes the way they interact with individuals who have life limiting illness, and their family members.

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Author

**Table 1: Participant Characteristics** 

Variable			
Ward (N, %)	A <sup>†</sup>	15	38.5%
	B <sup>‡</sup>	13	33.3%
+	C§	11	28.2%
Age group (years) (N, %)	≤ 25	7	2.6%
	26 to 35	17	43.6%
	36 to 50	5	12.8%
	>50	10	25.6%
Gender (N, %)	Female	37	94.7%
	Male	2	5.1%
Years of Practice (years) (M, SD)		13.2	10.8
Nursing classification (N, %)	Registered nurse	36	92.3%
	Enrolled nurse	3	7.7%
Communication Skills Training	Yes	15	38.5%
Type of Communication Skills Training	iValidate	8	20.5%
	Post-Graduate Course	5	12.8%
	Diploma Course	1	2.6%

†: A: Orthopaedic Surgical Ward; ‡: B: Medical Ward; §: C: Palliative Sub-acute Care Ward

Author Man

Table 2: Themes constructed from focus groups

Feeling unskilled to have difficult	Absence of a communication toolkit and framework
conversations with patients who have	inhibits capacity to respond to difficult questions and
ш	gather information
	Dealing with heightened emotions
	Interactions are difficult when there is denial
Interacting with family members adds	Unrealistic and mismatched expectations
complexity to care of patients who	Balancing relational dynamics with patient values and
have life limiting illness	needs
Organisational factors impede nurses'	Inadequate degree of information
capacity to have meaningful	Lack of time
conversations with patients and their	
families	

What conversations do you find efficult in your rote as a nurse in this world?

Think back to when you have tead difficult conversations with a patient or their relatives.

Write down in a few sentences what made the conversation difficult including the satient's condition and what they found challenging What factor's made the est-resistion difficult?

Jone skip of copery. What was challenging about the conversation? Jone skip of paper) (what city you find hard?)

Currently, which herethours professional takes responsibility for discussing patient values and professional regarding their treatment and care on your unit? For example, transfer to soute if they deteriorate, resuse totan, distribution, intusation.

What die do nuses have in communicating with people who takes with friend of east.

[curing first states for?]

Imagine you were cannoting a postern with a life limiting ithree and you national that the goals of care form was not correlated. How competable would you feel in faling a conversation with them about their values and preferences?

If you want to reflect back to a conveniention you had that didn't go well, what factors contributed to that?

What strategies were you taught in your course, on job trening or post graduate study about communicating with patients?

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