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Navigating communication with families during withdrawal of life-sustaining treatment in intensive care: a qualitative descriptive study in Australia and New Zealand

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Abstract

Aim

The aim of this study was to explore how nurses navigate communication with families during withdrawal of life-sustaining treatment in Intensive Care.

Background

Death in the intensive care unit is seldom unexpected and often happens following the withdrawal of life-sustaining treatment. A family-centred approach to care relies on the development of a therapeutic relationship and understanding of what is happening to the patient. Whilst previous research has focused on the transition from cure to palliation and the nurse's role in supporting families, less is known about how nurses navigate communication with families during treatment withdrawal.

Design

A qualitative descriptive approach was used. Semi-structured focus groups were conducted with adult critical care nurses from four Intensive Care Units, two in Australia and two in New Zealand.

Results

Twenty-one nurses participated in the study. Inductive content analysis revealed five key themes relating to how nurses navigate family communication: (1) establishing the WHO; (2) working out HOW; (3) judging WHEN; (4) assessing the WHAT; and (5) WHERE these skills were learnt.

Conclusion

Navigating an approach to family communication during treatment withdrawal is a complex and multi-faceted nursing activity that is known to contribute to family satisfaction with care. There is need for support and ongoing education opportunities that develop the art of communication in this frequently encountered aspect of end-of-life care.

Relevance to Clinical Practice

How nurses navigate communication with families during treatment withdrawal is just as important as what is communicated. Nurses need access to supports and education opportunities in order to be able to perform this vital role.

Keywords

Communication; Death and Dying; End of Life Care; Family; Intensive Care; Life Support Care; Nursing Care; Withdrawal of Treatment;

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

- This study provides insight into the ways nurses assess how to navigate communication with families during treatment withdrawal
- Understanding HOW to navigate communication with families is just as important as WHAT is communicated

Introduction

Despite the primary goal of intensive care being to assist patients to survive critical illness (Truog et al., 2008), death is inevitable for many intensive care unit (ICU) patients, and seldom unexpected (Bloomer, Tiruvoipati, Tsiripillis, & Botha, 2010). Rather, patient death is often the result of a planned and deliberate withdrawal of life-sustaining treatment (Psirides & Sturland, 2009, Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011), often referred to as 'treatment withdrawal'.

With the acceptance of family-centred care as a core feature of many ICUs (Mitchell & Chaboyer, 2010), how decisions and processes associated with treatment withdrawal and end-of-life care are communicated with families is of utmost importance (Scheunemann, McDevitt, Carson, & Hanson, 2011, Truog et al., 2008) as poor communication with families is known to contribute to family anxiety and depression after the patient's death (Scheunemann et al., 2011). Often multiple family conferences are necessary to help families comprehend what treatment withdrawal means (Efstathiou & Walker, 2014) and that death of their family member is likely (Bloomer et al., 2010). Despite the availability of clear guidelines recommending family involvement in end-of-life care decision-making in the intensive care setting (Truog et al., 2008), there is continued evidence of families still not fully comprehending what is being communicated to them (Endacott & Boyer, 2013).

Caring for and supporting families around death in the ICU has been extensively described in the research literature. Caring has been described as facilitating the family's experience (Ranse, Yates, & Coyer, 2012), offering reassurance, providing information and listening (Wilkin & Slevin, 2004), demonstrating interpersonal sensitivity and intimate relationships (Efstathiou & Walker, 2014) and communicating information to families (Coombs, Tang, & Long-Sutehall, 2016). What is common to all these descriptions is the importance of communication. High quality communication is the backbone of the art and science of nursing (Akroute & Bondas, 2015) and an essential component of

family-centred care (Mitchell & Chaboyer, 2010). Communication is reliant on the development of a therapeutic relationship and mutual understanding (O'Toole, 2012). The concept of mutual understanding means that those involved in the communication share a common meaning and comprehend both verbal and non-verbal signals used during the interaction, rather than just understanding the spoken word (O'Toole, 2012). Hence there is a need to understand how nurses navigate communication with families through reading and interpreting verbal and non-verbal cues provided by the family during treatment withdrawal.

Aim

The aim of this study was to explore how nurses navigate communication with families during treatment withdrawal processes.

Methods

A qualitative descriptive approach, based on naturalistic inquiry (Lambert & Lambert, 2012) was used. Semi-structured focus groups were utilised to gather data on how critical care nurses navigate communication with families during treatment withdrawal processes.

Participants and settings

This study was conducted in four adult intensive care units, two in Australia and two in New Zealand. The ICUs used in this study were specifically selected according to their characteristics and staffing profile. All four units were large Level 3 tertiary referral ICUs, capable of providing complex multisystem life support for an indefinite period (College of Intensive Care Medicine of Australia and New Zealand, 2011). The ICUs were separated geographically by some distance and were from unrelated larger health care organisations.

Information about the study was initially circulated to nursing staff via the Nurse Unit Managers in each unit. Potential participants were asked to self-select according to the following inclusion criteria:-

- (i) employed as a registered nurse
- (ii) working in an adult Intensive Care Unit
- (iii) experience in providing end-of-life care.

Data Collection

Four focus groups were conducted, one in each ICU, in July 2015. Focus groups were conducted in quiet spaces, such as an empty office or meeting room located nearby the ICU to facilitate participant attendance. The purpose of the focus group was explained and any questions answered before signed consent was obtained. An interview guide, developed using results from a previous integrative review (Coombs, Parker, Ranse, Endacott, & Bloomer, in press) was used as an 'aide memoire' for the researcher who utilised a conversational approach to encourage interaction between focus group participants and to keep the conversation flowing (Liamputtong, 2009). Focus groups were facilitated by two members of the research team (MB and MC) and a research assistant (RP). All focus groups were digitally recorded and professionally transcribed for analysis purposes.

Data Analysis

Prior to analysis, interview transcripts were checked against the original recording to ensure accuracy in the transcripts. The lead researcher (MB) read and re-read the transcripts to get a sense of the whole prior to analysis. Inductive content analysis, in which coding categories are derived directly and inductively from the data (Moretti et al., 2011), was then used to analyse the data. The advantage of this method of analysis is that it attempts to limit the researchers' subjective interpretations or preconceived outcomes (Moretti et al., 2011). A second researcher (MC) also read and re-read the transcripts to get a sense of the whole. Subsequent to this, the second researcher read and negotiated the themes derived by the lead researcher (MB) until both researchers settled on the themes. Findings were shared amongst remaining members of the research team for open discussion and as part of a quality check, until the final themes were determined.

Whilst it was important to consider group dynamics and the risk of data becoming the result of 'group think' (Schneider, Whitehead, LoBiondo-Wood, & Haber, 2014) rather than the comments of individuals with similar experiences, the researchers who conducted the focus groups (MB, MC and RP) monitored for cues or body language of participants to indicate lack of agreement or discomfort in participants; none was noted.

Ethical considerations

This study received 'low risk' ethical approval from the Australian (CF15/2267 – 2015000914) and New Zealand University Human Research Ethics Committee (ID 0000021642). Subsequent research governance approval was also obtained at all four participating health service sites.

Results

Twenty-one critical care nurses participated in the study. Two focus groups had seven participants, another had five participants and given the acuity in the ICU at the time, the final interview had only two participants. Hence there were a total of twelve participants from New Zealand and 7 from Australia. The focus groups lasted between 39 and 58 minutes. Participants had a mean of 13 years experience in critical care (range 1 to 30 years) and all had recent clinical experience of treatment withdrawal and providing end-of-life care. Where relevant, participant voices are presented in conversation form as it occurred between focus group participants, acknowledging the importance of the context and group dynamics (Barbour & Kitzinger, 1999). For the purposes of representing participant voices, quotes have been labelled according to the chronological focus group number and focus group participant number.

Inductive content analysis revealed five themes related to how nurses navigate communication with families; (1) establishing the WHO; (2) working out HOW; (3) judging WHEN; (4) assessing the WHAT; and (5) WHERE these skills were learnt.

Establishing the WHO

In this theme, participants acknowledged that “...not treating the family as a monolithic whole...” (3/2) was an important perspective to maintain. This theme is represented by two sub-themes; ‘Reading the Room’ and ‘Building Connections’.

Reading the Room

The initial approach to communication with families began with the nurse looking for verbal and non-verbal cues in family members in order to inform who the initial contact was to be made with. This important activity was described as a “reading of the room” (1/3). The following conversation between participants details that this involved looking for cues such as noticing family members who were particularly attentive to care as an invitation to initiate contact:

Participant 5: *“Sometimes they can just look really interested in a particular point that someone else has made or you know sometimes they look at you, you know like they kind of really look like they’re watching very, very closely to what you’re doing and kind of look like they want to ask something but haven’t.”*

Participant 6: *It’s interesting sometimes as well when some families when you, the decisions are made they want to be able to be instant or made the decision and because you don't know how long the process is, it’s like well they want to go back to the bed space and they want to extubate, they want to just get on with it and getting it over and done with because it’s so painful.....*

Participant 3: *... Yes that’s right. They sometimes struggle with that a lot when you can’t give them an answer about how long this is going to be that’s quite difficult.*

(Focus Group 1)

“people look like they are wanting to talk to you but just not say anything unless you can kind of see those cues.” (1/5)

Another participant added however that family can also give cues to indicate when communication is not working such as *“when their eyes glaze over”* **(1/3)**.

The importance of noticing these subtle signs was also acknowledged in other focus groups with participants reflecting: *“It’s that non-verbal radar”* **(2/1)**, *“you also observe...they can’t deal with it...so you’ve got to use your observational skills”* **(4/1)**.

Building Connections

After reading the room, participants described how the next important step was to build connections with family members who were willing to engage in communication. Nurses described how in reality, nurses could be introduced to, and work with, family members at any stage from admission of the patient to the ICU through to the treatment withdrawal process itself. This required rapport to be developed rapidly with family members at potentially intense and stressful times.

Participants in focus group four described the challenges in connecting with families: *“Coming in cold makes it really challenging”* **(4/2)**.... *“I think you hope you’ve got an established rapport”* **(4/1)**. But when there is no established rapport, one participant described how being transparent about care helped build trust and rapport with family: *“I try and be approachable so I open up that relationship for them to trust me, and that I’m not going to hide anything from them, and just reassuring them.”* **(4/1)**

This was also reflected in the following conversation:

Participant 3:The hardest one is when you come on at handover, and it will usually have been a bit chaotic, and the nurses handing the patient over may not have got to the meeting [with the family]. So then you're suddenly meeting a family and you don't know quite what's been said, and you're not quite sure who's who and what the dynamics are. So you try and work that out before you - depending on how fast things are happening....

Participant 4: ..I think you can usually get a lot of cues from their language, like whether they're talking about that person hopefully or fatalistically. I think that's probably something I would be picking up on - just the language that the family's using when they're talking about their loved one, and that might help ascertain where you're at.....

Participant 2:And you can often tell when somebody wants to ask a question.....

(Focus Group 3)

Similarly, the idea of the care provided acting in a way to establish rapport and a connection with families was also identified in another focus group: *“the care that you give the patient and family is a great way of developing a rapport with the family.” (2/2)*. In affirmation of this, others commented:

*“I just used to ask the family you know what kind of person was **** or whatever and that would be just a great way of opening... it was just nice to get that level of...talking.” (2/3)*, describing how affirming the patient’s status and importance as a member of the family further assisted rapport building and opened communication channels.

“When you’re trying to build rapport quickly, showing that you’re compassionate, things like the tea trolley.... like you said ‘You know, what are your needs? What do you need right now? What can I do for you? Parking? Accommodation?’ ” (2/4)

Others suggested that acknowledging family’s situation and being compassionate assisted with rapport building and through this, using family members to identify the information required:

“A lot of acknowledging that it’s really crap, and you can’t do anything to make it less awful. I would always say to somebody, ‘This is really awful, and all we can do is make it less terrible than it might be, because we can’t make it all right’. I’ll say to them, ‘I need you to guide me in how we do that today’. ” (3/3)

Participants reported that when the family designated a spokesperson, this assisted in directing initial communication: *“There’s usually a spokesperson that has been identified so you can talk to the spokesperson within the family” (2/4)*. Even when a spokesperson had not been formally designated, it was recognised that one family member may step forward, or that families organised themselves to manage the communication and information flow:

“Sometimes...somebody within the family will step forward and say “Keep such and such information to yourself they don't want to know this. Come to me if you've got details you want give”, often somebody will take that role on ...to relieve the burden on the rest of the family.” (1/3)

However, in identifying that it was important for each family member to have their individual communication met, even when a spokesperson was present, participants reported that being able to connect with family members individually, rather than collectively was also important.

Participants reported the subtle approaches they used to invite all family members to engage with them. For some, these were specific: *“you'll also use swapping over [when family members enter and leave the patient area] and grabbing people as they come in and out, saying, ‘Just checking in - do you want to talk?’ ” (3/3)*

Working out HOW

Working out how to frame communication with family was considered by participants to be just as important as what might be communicated. Each family was reported as unique in terms of their readiness for information, what their understanding was, and how much detail they needed or wanted. Noting the language used by families was seen as an important in assessing this and in therefore knowing how to frame the communication:

“I think you can usually get a lot of cues from their language, like whether they're talking about that person hopefully or fatalistically. I think that's probably something I would be picking up on - just the language that the family's using when they're talking about their loved one” (3/4)

“Sometimes that can be met with people saying well they'd not dead yet so can we stop talking about it please” (1/3)

Another consideration was that that families may struggle to cope with information about treatment withdrawal, the impending death and a possible request for organ donation. From this, participants were aware that information needed to be delivered in an incremental way, and in stages:

“...they’ve just had really bad news, so there’s got to be a bit of decoupling [emotional processing] with what they do, and I try and give it to them in small amounts so they don’t get a big waft of information all at once” (4/2)

Cues read by nurses from family members during and after communication were used to inform decisions about whether the communication, or perhaps more specifically, the language or content of communication was working for families.

“You gauge whether they’ve been receptive to what you’re saying, whether they respond in the eye contact, they smile, like and I think that’s sort of how often you would initially start. ...how the family responds to you coming into the bed space... the way they talk to you...they can be quite withdrawn” (2/5)

Judging WHEN

Being able to judge when to communicate was highlighted in focus group four as equally important to aid family understanding and coping. *“The timing is really important” (4/2)*. *“having a good handover...I’ll expect a handover to say ‘This is the stage we’re at, this is what we’re doing, this is how the family are’” (4/1)*.

Participants in other focus groups also explained how they strategically used time away from the bedside to engage family members in further communication:

“That meeting [family meeting] I use as an opportunity once the doctor has left I invite the family just to stay in the meeting room for a few minutes and stop and say look let’s talk about some of the nursing stuff, “Have you ever seen someone die before? ... What questions do you have about what’s going to happen?” because... so often they’re more

relaxed talking about that way from the patient. So I often use that as an opportunity to assess their needs.” (1/1)

The importance of attending to non-verbal behaviours e.g. body posture and avoidance actions as indicators of whether family members wished to talk at that particular time was discussed by nurses:

“...you know there’s always the crossed arms and there’s the not wanting to see the patient and not wanting to be in the room or avoidance of the situation or driving off to go somewhere else and not being able to be rung” (1/1)

This was often complex, requiring assessments to be undertaken across multiple family members to understand an individual’s need (or not) to talk:

“You can often tell when somebody wants to ask a question, and it’s actually interesting, because often in one family there will be a range of people, of needs... And you can pick that up, because the person who wants the information, you can see they’re almost straining... to ask more things, but they’re aware that the person over there actually doesn’t want to hear about all this sort of stuff. So it’s actually picking up on as well - there’s the verbal cues and asking those questions. Actually, there’s a lot of non-verbal cues in conversation that we will actually recognise as where somebody wants to talk, or when somebody’s not.” (3/2)

Assessing the WHAT

It was clear that unit-based guidelines were used by participants to guide and inform areas spoken about with families regarding treatment withdrawal and end of life care:

“We have, like, a protocol for the end of life and we follow that. That’s very helpful... it’s a great checklist for the nurse in the bed space particularly just to remind her or him about chaplaincy or social worker or you know conversations regarding tissue donation, that’s there.” (2/2)

However, this was not followed as a routine script but rather tailored to individual family need. Participants gave illustration as to how open questions were used for example *“Is there anything you want clarified? Do you understand what’s going to happen?” and take it from there.”* (4/2) with families to guide the level and content of communication and information giving:

“You can ask them you know how explicit do you want me to be. Some people don't want the nitty gritty details and some want to know every little detail. And sometimes you need to separate those sorts of people because hearing all the nitty gritty details is not going to be beneficial or kind to mum who doesn't actually want to hear that. All she wants to hear is that her son/daughter is not going to suffer, doesn't want to hear those other things.”

(1/7)

As indicated in the quote above, this also required an understanding of the multiple and potentially contrasting needs of individual family members. Participants in Focs Group One described attempting to anticipate these:

Participant 3: *...you try and cover things that might, that they might be thinking about if it's going to be extended and long and encourage them to get a support in, to have regular rest and that they're not going to be on their own if they step out for a break, that yeah....*

Participant 7: *I mean that's the big thing isn't it, I mean the families always want to know if they're not there, then you will be because they don't want the person to be on their own when it happens. I think that's a big key thing.....*

Participant 3: *Yes you're not going to suddenly take the tube out when they're not there or do things when they're not there. A lot of families that didn't want to be there as well. Yep....*

(Focus Group 1)

WHERE these skills were learnt

When discussion focussed on how skills were developed with regards to assessing and managing communication with families, participants described how communication skills, in particular those

needed in highly emotive situations such as treatment withdrawal, were not formally taught.

Participants in focus group three discussed it this way:

“It’s not something that we’re ever formally taught. There’s no - not even the principles, not - it’s not spoken about at all and - in our preparation for nursing; either at the undergraduate or the postgraduate level. What that means is that we all learn, to a greater or lesser extent, by trial and error. There are patients of mine, and those families that I know I didn’t do as good a job as could have been done.” (3/2)

This participant went on to detail that whilst the technical and procedural critical care activities including the process of treatment withdrawal were taught, how to communicate with family members during this process was not part of any recognised curriculum:

“You learn about the processes [of treatment withdrawal]... so, ‘Extubate like you normally do and don’t be afraid to give as much morphine as you need to make them feel comfortable,’ and, ‘You don’t have to leave them on her [monitoring equipment].’ Those were practical things, but they didn’t ... get to the deeper needs of the family and the deeper needs of what I do.” (3/2)

In response, another offered:

“But weren’t there always nurses that you watched and you thought, ‘God, how did they do that?’ because there would be something that was so awful, and they’d go in, and it would just turn to be not [no longer so awful]. They’re the ones I used to go, ‘I’ll work next door to them and I’ll try this,’ and, ‘What was the turn of phrase that they used, or how did they...?’ Especially when it was a really difficult family, because there are people who just - they just - they get it from this to this, and then it works.” (3/1) suggesting that opportunities to witness how other nurses communicate with families about treatment withdrawal was beneficial and appreciated.

In recognition of the absence of formal communication training, a reliance on other ways of learning how to navigate communication in the lead up and during treatment withdrawal in the ICU was described:

“I think that’s a key point in how... we learn about that process because the first few times you do it yourself you’re not going to be confident that this is normal or that there’s something you can or can’t do about it. I think you know it can be read in your eyes that you’re worried as well and so gaining that confidence and that assuredness about your own practice I think is quite difficult.” (1/1)

Acknowledging that each nurse might develop a different approach or style when communicating with families during treatment withdrawal, it was suggested that it was difficult to share communication expertise with inexperienced nurses in the workplace:

“A lot of this [communication] does happen in a side room away from other nurses, that those little conversations which are meant to be quite personal, they’re not situations where you’d have you know a couple of medical students and a couple of nursing students you know listening and all nodding along with you, they’re meant to be sort of personal situations and if you’ve got your junior nurse on the opposite side of the unit they’re not going to be able to listen in and hear that magic way that you made it sound okay. And so unless you’re particularly gifted with communication right off which I don’t think any of us are, you’d have to have a bit of luck you have to be around on that slow day when you’re in the next bed chasing and you just happen to hear it happening.” (1/1)

Given the rare opportunities such as this for on-the-job learning, one participant suggested *“It should be part of our program and I can’t remember from [undergraduate] nursing. It was so long ago, what we did as undergraduates” (4/2)* suggesting that perhaps these skills should be taught to those working in ICU, closer to when they may be required.

Discussion

Effective communication between nurse and family leading to the development of a positive therapeutic relationship is core to the provision of family-centred care. This study has demonstrated that there is considerable challenge in determining how to navigate communication with families during treatment withdrawal. The nurse needs to be skilled in identifying and reading verbal and non-verbal cues from individuals, and also assessing who to speak with as a way of assessing how to establish rapport (Coombs & Meyer, 2016). The nurse must also understand the information to be shared with grieving families at this time and tailor communication with the family accordingly during the treatment withdrawal process.

Despite the need to demonstrate highly effective communication skills (Vanderspank-Wright et al., 2011), which includes active listening (Coombs et al., 2016) and offering timely reassurance (Efsthathiou & Walker, 2014), this study has shown that there are other perhaps less tangible skills, that also impact on communication with family. Being able to determine who to communicate with, how and when to communicate with family in terms of their readiness for information and the speed at which information should be communicated was also important. To inform such assessments nurses made use of the subtle non-verbal signs. These were used to give context to the verbal communication and to read any concealed agendas. Nurses used non-verbal behaviours such as body posture, head movements, and eye contact to indicate interest, readiness for information and positional power in the communication process. Whilst the use of these to determine quality of, and satisfaction with communication from the perspective of patients (Griffith, Wilson, Langer, & Haist, 2003), this area has not been explored to date for families in this specific context and setting. This study also raises an important issue about how ICU nurses develop and acquire these less tangible skills in managing communication with families during treatment withdrawal. Participants expressed concern that there was little opportunity to formally learn these skills as part of formal education or continuing professional development opportunities in the workplace. Whilst communication

training programmes do exist, their focus is often on the dramatic, high-stakes conversations such as discussing do-not-resuscitate orders (Coombs & Meyer, 2016) and is out of step with the need identified in this study. Rather, participants described how they relied on experiential opportunities in the ICU, where they could observe and model their practice on that of others, who demonstrated skills in how to navigate communication, such as the who, how, when and what of communication.

The need for ICU nurses to have access to educational and/or experiential opportunities to develop their skills in the provision of end-of-life care has been identified previously in the research literature (Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2013, Ranse, Yates, & Coyer, 2016). As Coombs and Meyer (2016) point out, there are scripts, toolkits and mnemonics available to assist communication, but it is the development of the more subtle skills in navigating communication, as identified in this study, that is lacking. Our findings indicate that any education or training provided to ICU nurses should also include opportunities for nurses to develop and practice skills in the art of communication such as described herein.

Conclusion

The findings of this study overtly acknowledge that the nurse's role in providing family-centred care is about more than just providing information for families. This study has contributed new understanding about how ICU nurses determine how to navigate communication with families during treatment withdrawal. Communication skills, both verbal and non-verbal are as important and fundamental to family-centred care and effective communication as what is communicated. Whilst this study was conducted in Australia and New Zealand, further work is required to determine transferability to other countries or settings.

Relevance to clinical practice

There is a need to support nurses who communicate and support families during treatment withdrawal. Educational opportunities that focus on the development of communication skills,

including ways to assess how to navigate communication would be beneficial. These skills could be applied across all communications with families in the ICU, not just during treatment withdrawal. Further research could be conducted to evaluate the effectiveness of nurse communication on family satisfaction with nurse-family interactions.

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