

Grey area nursing: high-dependency nurses' experiences of caring for patients approaching the transition from curative to palliative care

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Abstract

Background: Nurses in high-dependency units frequently facilitate the withdrawal of life-sustaining treatments and provide end-of-life care. Providing this care has been shown to cause distress, burnout and cumulative grief. There remains a lack of understanding of high dependency nurses' experiences of caring for patients approaching withdrawal of life-sustaining treatments. Aim: To explore experiences of high dependency nurses caring for patients approaching withdrawal of life-sustaining treatment and highlight any support or needs they may have. Methods: Interviews were conducted and analysed using qualitative thematic analysis. Findings: Nurses experienced conflict in decision making, which was reported to prolong patient distress and cause nurses moral anguish. Nurses need time to talk and further education to support them to provide withdrawal of life-sustaining treatment. Conclusion: High-dependency nurses need time to talk following caring for this patient group and more extensive education to support them to provide quality end-of-life care.

Key words

Nursing, critical care, palliative care, palliative nursing, qualitative research.

Key points

- Critical care nurses report negative experiences when caring for patients approaching the transition from curative treatment to supportive care.
- Critical care nurses report needing time to talk, or a debriefing service, to support them to process their experiences.
- There is a need for education focused on how to wean and withdraw life sustaining treatment, and focused on end-of-life care specific to a critical care setting.

CPD reflective questions

- How can end-of-life care for deteriorating patients and their family/friends in a critical care setting be improved?
- What do you think would be the challenges and benefits of developing an High Dependency Unit focused end-of-life care education programme?
- Does your workplace offer any support for nursing staff to process difficult experiences, reflect on how this has/could help you or your colleagues?

Main copy

Despite advances in healthcare, 20% of patients admitted to a critical care unit (CCU) in the UK will not survive (Intensive Care National Audit and Research Centre (ICNARC), 2017). This figure remained static over the past 5 years, with the Society of Critical Care Medicine (2020) reporting a 10–29% mortality rate for intensive care units (ICU) internationally. This highlights the need for critical care nurses to be skilled in caring for dying patients (Coombs et al, 2012; ICNARC, 2017). Due to the curative focus of critical care, deaths generally follow difficult decisions to withdraw life-sustaining treatment (Coombs et al, 2012). This requires specialist skills from nurses to co-ordinate withdrawal of treatments, while providing emotional and holistic support for patients and families (Long-Sutethall et al, 2011). Critical care provides intensive medical and nursing care for patients (Marshall et al, 2017). Within a critical setting, there are two levels of care according to the amount of nursing support needed by the patient (Table 1).

Table 1 here

Similar challenges have been reported in studies investigating withdrawal of dialysis for people with end-stage renal failure (Song et al, 2015; Lazenby et al, 2016), as well as within the heart failure arena (Whitlock et al, 2011).

A literature review regarding tools to support nurses when weaning patients off life-sustaining treatments reported challenges related to decision making (Crowe, 2017).

Disagreement between members of the medical team were reported, with nurses focusing on quality-of-life and reducing distress, and medical staff focusing on extending life. This difference in focus caused nurses moral and professional distress, being required to continue treatments they believed were not in the patient's best interest. This echoes Gawande's (2014) argument that modern medicine promotes extending life, regardless of the quality-of-life. Cumulatively, these studies suggest there has been little recent progress in mediating between the two perspectives.

Psychological distress

As noted above, staff who are working in the CCU regularly face complex situations. This combination of uncertainty in care planning and caring for patients throughout the process of decision making, treatment withdrawal of care of the dying person, is reported to cause nurses psychological distress (Vanderspank-Wright et al, 2011; Bloomer et al, 2016; Kisorio and Langley, 2016).

Providing end-of-life care and facilitating the withdrawal of treatment exposes nurses to patients' distress, causing emotional anguish for the nurses and moral dilemmas, which can make them feel as if they are not providing the best care for their patients, which can lead to burnout (Stayt, 2009; Long-Sutehall et al, 2011; Kisorio and Langley, 2016). Nurses often felt they were unable to facilitate a dignified death due to treatments being continued too long (Vanderspank-Wright et al, 2011).

The aim of this study was to explore experiences of High Dependency Unit (HDU) nurses caring for patients approaching withdrawal of life-sustaining treatment and highlight any support or needs they may have. It is important to note the focus of this study is on situations in which decisions were being made to withdraw life-sustaining treatments which had already commenced, rather than those situations where a decision is made not to add interventions.

Methods

Design and setting

A qualitative descriptive methodology using semi-structured interviews was conducted. The setting was one HDU in a National Health Service hospital in the North-West of England. This unit consists of 14 beds, with nine nurses per shift. A purposive sampling approach was employed (Green and Thorogood, 2009; Polit and Beck, 2020), with specific inclusion criteria of nurses on the professional nursing register with a minimum of 12 months working within an HDU in a UK hospital. The study was advertised in the communal areas of the unit and highlighted in daily staff meetings. Participant information sheets were provided to those who expressed an interest. Written consent was obtained prior to commencement. Interviews were planned at a time convenient for participants and facilitated in the hospital setting.

Participants

A total of 15 nurses were self-selected as participants from a potential 75. All participants were female with varying experience of up to 20 years in the field. To ensure anonymity, participants were allocated a unique identifying number, followed by an indicator of band e.g Participant 1, who was a band 5 nurse became P1/B5 (see table 2).

Table 2 here

Data collection and analysis

Audio recorded interviews were conducted by one researcher in summer 2018. They lasted between 20–45 minutes. Recruitment was discontinued when both participant's target of 15 and data saturation were achieved. Data saturation was determined when no new information or themes were identified (Guest et al, 2006) (Figure 2).

Figure 2 here

All interviews were transcribed. Analysis was guided by the Attride-Sterling's (2001) framework, which provided sequential steps to organise, reduce, refine and analyse data. Each transcript was read in its entirety by one researcher, and sample checked by the second researcher to ensure the accuracy of the transcription and context. These measures enabled consensus to be reached on the final coding frame, which was then applied across all transcripts to support initial conclusions from the data. Finally, themes were organised into a visual 'web-like thematic diagram (Figure 1).

Figure 1 here

Note to ed: Figures 1 and 2 need to be swapped, as 2 is mentioned in-text before 1.

Ethics

Ethical approval was obtained from a University Faculty Research Ethics Committee and NHS Research and Development team at the NHS organisation where the research took place. All data were stored in accordance with NHS and university data management and storage policies. The information sheet outlined the study, risks and benefits of joining and reiterated that participation was voluntary, they had the right to withdraw at any time and that personal information was kept confidential. Signposting to staff support in house services was included due to the sensitive nature of the study.

Findings

One theme and five sub-themes emerged from the data:

Major theme:

Supporting HDU nurses to provide and survive withdrawal of life-sustaining treatment

Sub theme 1: Conflict in decision making

Participants reported difficulty with the uncertainty caused by conflict in clinical decision making, stating this affected their ability to provide what they perceive as good care. Furthermore, they described feeling that they were caught in the middle of indecision, as the nurses knew what needed to be done, but were unable to action due to conflict or delay in decision making. This was reported to cause confusion, stress and frustration. Participants discussed the challenges when families did not agree with medical plans to stop life-sustaining treatments, which resulted in unease about continuing treatments when they did not think it was in the patient's best interest:

'I always find it tough, especially when the families are upset and "combative"...they don't...they're not on board with what is happening.' (P14/B6)

Participants described situations where they wanted to make the patient comfortable and remove distressing treatments but were unable to, which left them feeling frustrated and upset:

'One lady who was in her 90s...she was clearly dying, she died in the CPAP (continuous positive airway pressure) hood. The family wasn't accepting the fact that she was in her last

moments really and it wasn't a nice way to die to be honest...it was upsetting for everyone.'
(P06/B5)

Conflict in decision making between different medical staff and the effect this had on providing the best care for patients was also reported. This included differences in opinions internally—between HDU doctors, and HDU doctors and different medical treating teams.

'I'm trying to think if there's anything else we could do better and it's more leading up to withdrawing treatment when there are discrepancies between parenting teams and intensivists. I think something there needs to change where we're...nobody's making the decision.' (P13/B6)

Subtheme 2: Prolonging distress

There was a consensus from participants that they experienced issues with continuing life-sustaining treatments for patients who were not expected to survive, one nurse simply put it:

'...sometimes I feel like we leave it too long.' (P10/B5)

The issue was multi-faceted: feeling that the nurses were prolonging death rather than life and no longer in the patient's best interests:

'I remember [the patient] saying to me you wouldn't treat a dog like this!' (P15/B8)

This led to nurses, regardless of longevity of experience, questioning the ethics of continuing care in these situations:

'I find this situation quite difficult because you know that this treatment is not going to help the patient and it's a bit frustrating because you think, "why are we doing this to somebody, this just isn't right. Why are we putting the patient through this in their last hours of life?'"
(P13/B6)

One participant talked of maintaining some hope that the patient might survive and the respect they had for medical decisions due to the knowledge the medical team hold. She reflected on times where she felt the patient could not survive an illness, but they did:

'The reward is much more if they get better. Because...I didn't think it will happen and then it happens! Sometimes, even the families will say it's a miracle and we've seen miracles here!'
(P10/B5).

Subtheme 3: Moral distress

The issues of conflict in decision making, unclear care planning and the feeling that some patients were experiencing prolonged deaths, led to participants experiencing moral

distress. This was evident when participants voiced concerns that the patient was dying but the medical decision was to continue treatment. This participant, who wanted to facilitate some quality time for the patient and their family, explains:

'I feel like we let families down, we let the patient down because they're not spending that time [together], and as soon as the non-invasive ventilation came off, it was her niece with her and she told her she loved her and she died.' (P09/B5)

When nurses did not agree with the treatment plan, they did not feel morally settled continuing some treatments:

'Sometimes you see that the patient's deteriorating really bad[ly]...and it's like...you don't know why we keep trying. Because there are some cases where you think this is clear. This is going to happen. I don't know what we are waiting for...and you feel like you might be pushing something that we shouldn't be pushing that much.' (P10/B5)

Several participants used language surrounding loss of control, feeling unheard and unable to advocate for their patients, in conjunction with how this affected them emotionally and morally:

'You don't feel like you're doing something wrong because you're still giving them full treatment, even though it doesn't feel 100% right that you're prolonging the inevitable.' (P07/B5)

Subtheme 4: The need to talk

Most participants discussed the benefit of talking through situations they found difficult, either as formal de-briefing or access to talking therapy services. This was the primary suggestion for service improvement. Senior staff not only discussed a desire for an opportunity to talk, they also described ways in which they introduce informal debriefing when they are managing the unit:

'When I co-ordinate and I'm the nurse in charge and I can see somebody's had a challenging day, I'll always go and see that person before they go home and say..."are you ok? How do you feel? Do you think we could have done anything better?" I try and talk to them, but it's not official. It's really informal.' (P13/B6)

All participants could remember caring for a patient approaching treatment withdrawal, recalling patient's names and details of experiences, indicating how challenging and indelible these times were. Participants reiterated that talking about these experiences is important in order to move on. However, sometimes nurses found themselves finishing a shift and never revisiting these experiences, contributing to lasting negative memories. In these cases, they wished for a dedicated time to undertake these discussions:

'I think sometimes you don't get to debrief informally every time something happens. So, I wasn't on shift when he did die, but I looked after him on the days leading up when he was still receiving treatment and then I had a few days off and I found out that he had died. Then there's not really the opportunity to debrief, because the staff that was there that did deal with him when he died, they probably did have their own debrief, but you're not involved so it's just sort of like a little 2 minute conversation like, "Oh, when did he pass? How was it?" and that's about it.' (P03/B5)

Subtheme 5: The need for further education

The final theme outlines the lack of preparation for caring for patients who are approaching withdrawal of life-sustaining treatment. Nurses referred to the long period of time, 6 to 8 weeks, when they were working alongside an experienced nurse as part of their induction when starting on HDU. This induction included education sessions focusing on life saving care and treatments, but lacked sessions regarding withdrawal of life-sustaining treatment, communication or end-of-life care.

Once the decision to withdraw life-sustaining treatment has been made, medical staff will have a discussion with families and prescribe any appropriate comfort medications as needed. However, despite this lack of education or preparation, the physical removal of treatment is a nurse-led process:

'I think when we decide to palliate someone it's just sort of left to us, and this is the decision that the doctors have made, get on with it and just help the patient to be palliated' (P03/B5)

Discussion

These findings corroborated previous research where nurses reported the difficulties encountered when there is indecision between different medical teams, consultants within the critical care team and between families and the medical staff (Alaskson et al, 2012; Coombs et al, 2012; Efstathiou and Walker, 2014).

Conflict in decision making results in continuation of life-sustaining care for patients for whom the nurses felt a supportive and dignified death would be in their best interest. These conflicts caused frustration leading to nurses feeling like 'we carry on too long' and prolong death, rather than support a quality-of-life (Long-Sutehall et al, 2011). This substantiates previous findings which report the most challenging time being the transition from curative treatment to end-of-life care, with the most distressing aspect of the trajectory being a delay in decision making leading to carrying on treatments 'too long' (Coombs et al, 2012). There was an underlying narrative of participants experiencing moral distress, evidenced by long lasting memories described by participants. Overwhelmingly participants in this study reported the negative psychological impact of caring for this group of patients feeling their professional morality was challenged and they were 'not doing the right thing'.

One interesting aspect raised by participants in this study and the wider literature, was the distinction between withdrawal of life-sustaining treatment as the medicalisation of death, versus simply being part of end-of-life care in an HDU setting, a concept which remains unclear (Coombs et al, 2012; Gawande, 2014). The move away from experiencing death and dying at home has resulted in the normalisation of death being in a medical setting (Illich, 1975). However, more recently there is a move to open the conversation about death and dying and question the prolonging of life with technical and medicinal intervention,

suggesting the desire for a return to a more 'natural' death experience (Illich, 1975; Gawande, 2014; Mannix, 2017).

Need for further training

There was a consensus from participants that there is a need for further education. Junior nurses reported a lack of training regarding end-of-life care in this setting. The National Council for Palliative Care report 'Staff prepared to care?' (2016) outlined the importance of high quality, effective end-of-life care across all settings stating this can only be provided by staff who have adequate education. The National Institute for Health and Care Excellence (NICE) (2017) quality standard for end-of-life care in adults clearly states that nurses should have adequate knowledge, skills and ability to provide good quality support for those approaching the end of their life. This finding, and recent policy drivers, suggest that by improving education about end-of-life care during the initial training period for HDU, nurses could be better prepared. This could avoid future distress and is supported in the wider literature (Vanderspank et al, 2011; Alaskson et al, 2012).

Methodological considerations

To our knowledge, this study is the first to focus on HDU nurses' experiences of caring for patients who are approaching a decision regarding withdrawal of life-sustaining treatment. There are limitations to the design including it was a single centre study, with a female sample, however, the results resonate with previous literature suggesting that our findings could be comparable. The data were collected by a researcher who was a nurse with extensive experience in the HDU. This added value to the study in the ability to probe for responses, thus enabling a richer set of data.

This study was undertaken prior to the COVID-19 pandemic. Two further areas of research emerged as important:

A multidisciplinary study, using focus groups in which each profession is heard by the other, would allow an integrated approach for studying this phenomenon

A study which compared family and nursing staff experiences would allow for a holistic perspective.

Conclusion

HDU nurses reported experiences of caring for patients approaching withdrawal of life-sustaining treatment and how this affected them emotionally, often creating lasting negative memories. Participants described ethical dilemmas when they were required to provide uncomfortable treatments for patients who were dying. Situations were often described in which they felt life-sustaining treatments were continued past the point of being in the patients' best interest, and the negative impact this had. The key finding from this study was that HDU nurses reported negative experiences regarding management of withdrawal of life-sustaining treatment. Primarily identified was a desire for a formal talking service to allow nurses to process their grief and distress. Additionally, there is a need for more extensive education to support nurses when caring for these patients. Providing support for nurses is vital to avoid cumulative grief and burnout. This could contribute towards maintaining good mental health and developing a more effective workforce who are able to provide optimal care for patients and families.

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Tables and figures

Table 1 Levels of critical care in the United Kingdom
Level 0 Patients whose needs can be met through routine/basic care
Level 1 Patients requiring higher levels of care or are at risk of their condition deteriorating, whose needs can be met with advice and support from the critical care team.
Level 2 Patients requiring higher levels of care and more detailed observation/intervention. They may have a single failing organ system or require post-operative care.
Level 3 Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes complex patients requiring support for multi-organ failure

(From Comprehensive Critical care. Department of Health, 2000)

Participant	Age group	Band	Years qualified	Years/Months in critical care	Nationality
01/B5	20-30	5	1 .5	13m	British
02/B5	20-30	5	3	2y	British
03/B5	20-30	5	4	1y 6m	British
04/B5	20-30	5	4	2y 6m	British
05/B5	31-40	5	5	5y	British
06/B5	31-40	5	6	4y	Portuguese
07/B5	31-40	5	7	7y 6m	British
08/B5	20-30	5	8	7y	British
09/B5	41-50	5	10	18m	British
10/B5	31-40	5	11	2y 6m	Spanish
11/B6	31-40	6	8	8y	British
12/B6	31-40	6	10	8y	British
13/B6	31-40	6	14	13y	British
14/B6	41-50	6	22	17y	British
15/B8	41-50	8	25	20y	British

Table 2. Participant information

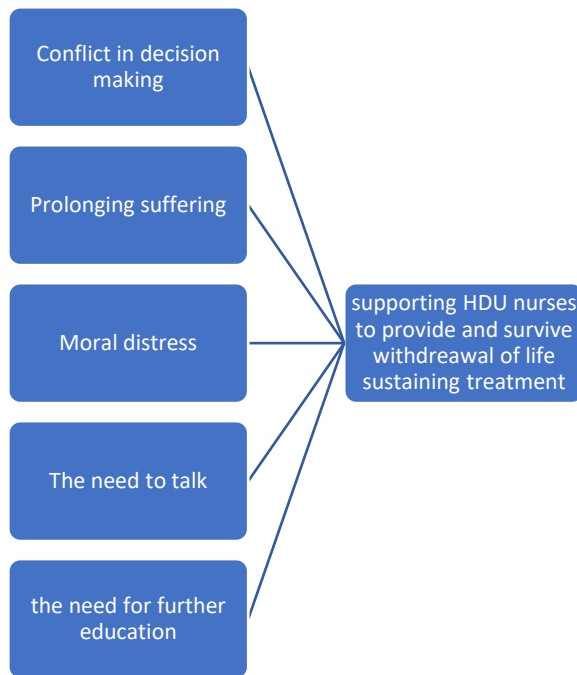


Figure 1. Thematic network

Figure 2. Interview guide