A qualitative study exploring challenges and solutions to negotiating goals of care at the end of life in hospital settings

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Abstract

Background: Negotiating goals of care (GoC) with patients is an essential skill for all health-care professionals (HCPs) in hospitals. End-of-Life Essentials (EOLE) is a Commonwealth-funded project that delivers free, peer-reviewed, evidence-based, online education and practice change resources. To date, around 26 000 doctors, nurses and allied health professionals have registered to access the education. ‘Planning End-of-Life Care—Goals of Care’ features in the suite of EOLE modules and includes education around negotiating GoC with patients and families.

Objective: The aim of the study was to explore the views of module learners (HCPs) on challenges they have faced when negotiating GoC at the EOL with patients and families.

Methods: Participants were learners (HCPs) who registered to the EOLE website and engaged with the GoC module. Learners’ responses to the question posed at the end of the module ‘What are the hardest or most challenging things about negotiating GoC with patients and families?’ were extracted for a 12-month period. Qualitative data were analysed thematically in NVivo V.12, guided by the theoretical framework of pragmatism. An open, inductive approach was used to code the data, with axial coding used to refine and organize themes and subthemes.

Results: A total of 451 learner statements were analysed. Five themes emerged from the data: (i) differing views and opinions; (ii) challenges to understanding; (iii) managing emotions; (iv) initiating the EOL conversation and (v) lack of professional knowledge or capacity. Five subthemes were also organized under the theme ‘differing views and opinions’.

Conclusion: Planning EOL care demands high-level, compassionately skilful and sensitive care and services, which are in line with the patient’s and family’s wishes. In practice, however, there are many challenges to this, such as ensuring that patients, families, and HCPs are aware of different expectations regarding future health-care possibilities, and that HCPs are prepared for negotiating GoC to achieve quality and safe EOL care in hospitals.

Key words: end-of-life care, goals of care, hospital care, patient-centred care, negotiation, shared decision-making, online learning

Introduction

The leading causes of death in Australia are coronary heart disease, dementia and Alzheimer’s disease, cerebrovascular disease, lung cancer and chronic obstructive pulmonary disease [1]. All these conditions are generally characterized as being slow and complex in their trajectory, with the patients’ conditions fluctuating and deteriorating over time. Over 50% of deaths in Australia occur in hospitals (similar figures to many Western countries) with the diagnoses well represented in recorded deaths [2]. Australian health-care systems have been described as a ‘freeway’ to intensive care units [3] and to unnecessary treatment for patients at the end of life (EOL), due to the default ‘fix it’ mode [4]. With so many deaths in hospitals and a ‘treat and cure’ mindset, providing good quality EOL care in hospitals is imperative. EOL care, however, requires a different route of action, one that is responsive and aligns with goals of care (GoC), sensitive to a patient’s wishes while providing supportive care in line with their stage of illness [5].

Negotiating GoC with patients who have advanced serious illnesses is an essential skill for all health-care professionals (HCPs) in hospitals. Most Australians want the opportunity to discuss and plan for their EOL, which is not happening enough [6]. GoC incorporate what matters to the patient and will change over time, particularly as the patient enters the terminal phase [7]. Identifying and negotiating GoC are highlighted as an essential component of care and part of the shared decision-making process for patients at the EOL [7].

In 2015, the Australian Government Department of Health funded the EOLE project, which provides free, evidence-based, online education and implementation toolkits for doctors, nurses and allied health professionals who work in hospitals [8]. EOLE is based on the Australian Commission on Safety and Quality in Health Care National Consensus...
Statement: essential elements for safe and high-quality EOL care [7], with the aim of improving knowledge and driving practice change. The project translates the five processes of care elements from the statement: patient-centred care; teamwork; GoC; using triggers and responding to concerns [7], directly into a suite of education modules each developed following consultation with industry and clinical partners [2]. ‘Planning End-of-Life Care—Goals of Care’ (hereafter referred to as the GoC module) features in the suite of EOLE modules and includes education around identifying and negotiating GoC with patients and families.

The aim of the study was to explore the views of module learners (HCPs) on challenges they have faced when negotiating GoC at the EOL with patients and families.

Methods
The EOLE modules
Each EOLE education module was designed to focus on a specific element or process of clinical care. Modules consist of learning content in the form of written information, infographics, videos demonstrating practical care scenarios and a downloadable implementation toolkit to use in practice. The EOLE modules are offered as continual professional development, with certificates provided to learners on module completion. To date, more than 26 000 learners have registered to access the education, with each learner able to selectively engage with any or all modules at their own pace.

The GoC module explores the process of negotiating GoC, taking 35–60 min to complete.

Ethical considerations
Ethics approval was obtained from the Flinders University Human Research Ethics Committee (Project 7012). Participation in all module evaluation questions is voluntary (opt-in). Learners could engage with the GoC module without answering the evaluation questions. All responses are anonymous as responses were not identifiable or linked to participant details. Participants are informed that all de-identified responses to the evaluation questions will be used for reporting and possibly publication.

Data collection and analysis
Participants in this study were self-selected learners (HCPs) who had registered to the EOLE website and engaged with the GoC module. Qualitative data in the form of learner statements responding to the open-ended, free-text question posed at the end of the module: ‘What are the hardest or most challenging things about negotiating GoC with patients and families?’ were extracted from the EOLE learning platform. Data were extracted for a 12-month period, 1 October 2020–1 October 2021. Data were cleaned, de-identified and imported into NVivo V.12 software package. There was a wide variation in the nature of participant responses to the question; therefore, a time period of 12 months was deemed necessary in order to include the sufficient amount of data needed to reach saturation.

Data were thematically analysed in NVivo V.12 by author M.W. using an open, inductive approach to privilege learner voices [9]. Pragmatism, which focusses on gaining a practical understanding of real-world issues, was used as an overarching theoretical framework to guide the analysis [10]. Learner statements were coded line-by-line using open coding, with similar words and sections of text grouped into existing codes, and new codes added as concepts emerged [9, 11]. Axial coding was used to refine and organize the codes into themes and subthemes [11]. To enhance the rigour and reliability of the results, all authors reviewed and discussed the data analysis process in detail, with minor modifications made to the themes and subthemes. In addressing reflexivity, the authors were conscious of the need for the learner’s own statements and words (via exemplar quotes) to drive the analysis, rather than their own prior experiences and preconceptions [12].

Results
In total, n = 941 learners completed the GoC module between 1 October 2020 and 1 October 2021, among which 62.4% (n = 587) of learners were nurses, 24.0% (n = 226) were doctors and 13.6% (n = 128) were allied health professionals. 61.4% (n = 578) of learners were from hospitals, and 38.6% (n = 363) were from other settings. From those who completed the module during the 12-month period, 451 learners responded to the free-text question, a response rate of 47.9%. The 451 learner statements (one statement per learner) were thematically analysed.

Qualitative analysis of the data resulted in five themes around negotiating GoC with patients and families. The most prominent theme was (i) differing views and opinions, between members of the family, the patient and HCPs, including navigating conflict and finding a middle ground. Other themes included (ii) challenges to understanding, e.g. patients’ and families’ understanding of the patients’ condition, GoC that were ‘unachievable’ or ‘unrealistic’, and the family or patient being in ‘denial’ that the patient was dying, (iii) managing emotions (their own or those expressed by the patient or family), (iv) initiating the EOL conversation, e.g. bringing up the ‘uncomfortable’ topic of dying, and (v) lack of professional knowledge or capacity, e.g. feeling unprepared or ill-equipped to communicate with patients and families and negotiate GoC, and organizational restraints which hindered their capacity to do so. Theme and subtheme descriptions, quantitative counts of codes (number and percentage of learner statements which related to each theme and subtheme) and exemplar learner quotes are presented in Table 1.

Discussion
Statement of principal findings
In this evaluation of an online education module ‘Goals of Care at the end of life’, we found challenges to patients and HCPs reaching mutual understanding and expectations. We recognized the importance of GoC conversations within organizations is needed, and that HCPs require education in negotiating GoC with patients who have advanced serious illness.

Interpretation within the context of the wider literature
Differing views and opinions
GoC incorporate what matters to the patient, considering their underlying values and priorities [14]. A patient’s goals can change over time as they enter different stages of their
### Table 1 Descriptions of themes and subthemes

| Theme/Subtheme | Description | No. (%) of learners | Example quotes |
|----------------|-------------|---------------------|----------------|
| 1. Differing views and opinions | Almost half of all learners discussed the challenges differences in individual views, opinions, ideas, goals, and plans posed when negotiating GoC. | 203 (45.0%) | *'often families and the patient can have different opinions or decisions about their end of life care, some patients have accepted and planned their end of life, where as some have not, some families accept and support their loved ones decisions where as some families do not accept or want to support their loved ones decisions'.*
| 1.1. Between patient and family | Learners wrote about differences of opinion occurring between the patient and their family members. Learners voiced concern that such differences, disagreements, or 'disconnects' were often tricky to navigate, but that it was important to keep the patients' wishes front of mind when doing so. | 124 (27.5%) | *'having the patient's wishes be heard if they are able to communicate. Too often family members all think they know what's best for patient (or really most convenient for themselves) and a conversation with patient and family be facilitated'.* |
| 1.2. Between patient or family and health professionals | Learners wrote about differences of opinion occurring between the patient or family, and HCPs. Learners either spoke of their own disagreement with the patient/family, or differing views and goals between the patient/family and members of the health-care team in general. | 23 (5.1%) | *'you can come across a GP that do not really understand the situation or does not know what the patient wants or wishes and they over-ride the whole scenario. Another is when you have staff that are fearful and they either want to step away from the whole issue or they just simply make all the decisions for the patient so they can get on with their life and ignore what the patient really wants. What Matters most!'* |
| 1.3. Between members of the health-care team | Learners wrote about differences of opinion occurring between members of the health-care team, regarding patient care. | 10 (2.2%) | *'not having all medical staff striving for the same goals'.* |
| 1.4. Conflict | Learners were challenged by the conflict arising due to differences of opinion. Learners expressed that having to mediate and manage such conflict was sometimes difficult. | 34 (7.5%) | *'Conflict between physicians, patients and family members'.* |

(continued)
| Theme/Subtheme                                      | Description                                                                                                                                                                                                 |
|----------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1.5. Coming to an agreement/finding a middle ground | Learners wrote about the challenge of navigating the differing views and opinions to come to an agreement or resolution on a plan which the patient, family, and health-care team are all able to agree upon. |
|                                                    | Example quotes: 'For me as a worker is getting family all together at once and getting them all on the same page when it comes to next steps and goals for their loved one'. |
|                                                    | 'I would say the hardest thing is coming to a shared consensus or compromise with between what the patient wants, what the family wants, and what the health-care team recommends'. |
|                                                    | 'When the family or patient is in denial about death or their stage of disease'. |
|                                                    | 'I think there is often a disconnect between the expectations/hopes of the patient’s family for the patient’s recovery, and the objective reality/gravity/outlook of a patient’s poor/worsening condition that is known by medical professionals'. |
|                                                    | 'It can be tricky when they are not aware of how advanced their disease is – especially if they only have weeks to months left and they are wanting full resus, active treatment and to live for a few more years. I have found that it depends on how well they have been managed by the medical profession and whether or not these conversations have been discussed before, the patients understanding of where they are on their trajectory'. |
| 2. Challenges to understanding                     | Learners discussed challenges related to patient and family understanding, either of the patient’s condition/prognosis, or of the purpose/achievability of GoC. Learners discussed the challenge of managing expectations of patients and/or their families and negotiating ‘realistic’ GoC. Learners also wrote about patient and/or family not accepting or ‘denying’ that the patient was nearing the end of their life, and that further life-prolonging treatment may not be beneficial. |
|                                                    | Example quotes: 'unrealistic expectations by both family and patient e.g. I want to die at home while maintaining my independence and not being a burden to my family isn’t often possible'. |
|                                                    | 'When the family or patient is in denial about death or their stage of disease'. |
|                                                    | 'I think there is often a disconnect between the expectations/hopes of the patient’s family for the patient’s recovery, and the objective reality/gravity/outlook of a patient’s poor/worsening condition that is known by medical professionals'. |
|                                                    | 'It can be tricky when they are not aware of how advanced their disease is – especially if they only have weeks to months left and they are wanting full resus, active treatment and to live for a few more years. I have found that it depends on how well they have been managed by the medical profession and whether or not these conversations have been discussed before, the patients understanding of where they are on their trajectory'. |
| 3. Managing emotions                               | Learners wrote about the challenges surrounding dealing with and managing emotions. Some learners found it difficult to navigate the distress and heightened emotions of the patient and family, and some mentioned challenges regarding their own emotions in these situations. |
|                                                    | Example quotes: 'Every decision that they make is going to change their lives forever. That is something that is hard to handle and navigate through. Emotions are high and it is difficult to bring logic into the picture'. |
|                                                    | 'I find it difficult when the conversation becomes emotional, and I wonder if I’ve said or done the right thing. I often find it hard to stop thinking about the conversation at the end of the day'. |
|                                                    | 'Opening up conversations brings on intense emotion—for all involved, including yourself and the other medical staff'. |
|                                                    | 'being comfortable with the conversation to bring up the issue of dying' 'confronting the truth that the patient doesn’t have much time left' 'It’s a difficult conversation for patients and families to have, and can be difficult for health care team too'. |
| 4. Initiating the end-of-life conversation          | Learners expressed that the biggest challenge was bringing up the topic of dying, and initiating discussions about EOL care at the ‘right time’. Learners wrote that patients and families generally seek to avoid the ‘uncomfortable’ conversation. |
|                                                    | Example quotes: 'When working on a busy ward and stressed you have to always be careful to not rush these conversations and say the right thing and with the right tone. Giving them time to respond with periods of silence'. |
|                                                    | 'Fear of conversation not going smoothly'. |
|                                                    | 'Having to work with the patient to reach their goals when healthcare resources needed to reach these goals may be limited'. |
|                                                    | 'The constraints of care that can be given by hospitals. Not being able to send everyone home immediately with the care they need and deserve'. |
| 5. Lack of professional knowledge or capacity      | Learners discussed challenges related to a lack of professional skills or capacity to effectively facilitate GoC discussions. Learners wrote about the challenges of communicating honestly and effectively with patients and families, along with challenges of organizational restraints such as time, busy ward environment, or limited health-care resources. Learners expressed feeling unprepared in negotiating GoC due to lack of professional knowledge/guidelines, lack of confidence, or lack of experience in doing so. |
|                                                    | Example quotes: 'When working on a busy ward and stressed you have to always be careful to not rush these conversations and say the right thing and with the right tone. Giving them time to respond with periods of silence'. |
|                                                    | 'Fear of conversation not going smoothly'. |
|                                                    | 'Having to work with the patient to reach their goals when healthcare resources needed to reach these goals may be limited'. |
|                                                    | 'The constraints of care that can be given by hospitals. Not being able to send everyone home immediately with the care they need and deserve'. |
illness and may be medical, such as specifying use of medical interventions, or nonmedical, such as attending a family event [7]. Differing views among HCPs, patients, and families arise when it comes to negotiating GoC. HCPs should expect this and be skilled in navigating this complex process, as discussions about GoC do not always go smoothly, and there is the potential for conflict. How HCPs respond to conflict is important, and the best way to manage this is to be prepared with strategies and tools [15]. Tips for managing conflict include finding a non-judgemental starting point, giving full attention to other people, identifying where the conflict lies and articulating it as a shared interest and brainstorming options that recognize everyone’s interests [16]. There are advantages of routine family meetings around illness progression, prognosis and care options, which provide a way for families and patients to keep up with ongoing changes in health, have questions answered and facilitate ongoing dialogue about possible changes to patients’ wishes and values [4].

Challenges to understanding

A challenge faced by some HCPs was that they themselves wanted to discuss GoC with the patient and/or family, but this was not reciprocated. When considering the concept of ‘denial’, 13 learners in the current study used this word specifically, for example: ‘Getting the conversation started if the patient is in denial’, ‘Realistic expectations and being in denial about the trajectory’ and ‘when families are in denial that the patient is dying’. At first glance, it may seem like the HCPs in the current study are saying that the patient’s or family’s denial is the cause of any difficulty around having GoC discussions. It is worth noting that the concept of denial is used only once in the GoC module, referring not to patient denial, but rather to that of HCPs denying death and dying [8]. This is in line with the purpose of EOLE education, to assist HCPs to become confident and skilled in EOL discussions. The comments by learners reflect what is in the palliative care literature; denial is often equated with the patient’s failure to realistically accept a life-limiting illness, and any long-term patient display of denial (i.e. not wishing to discuss poor prognosis, dying or the possibility of death, or negative impact of progressive illness) is viewed as ‘pathological’ [17]. Denial has been viewed as an obstacle to the delivery of palliative care, hindering EOL conversations, advance care planning, and the stopping of ‘futile’ treatments [18]. Another way to articulate the concept of denial is to see it as a way for patients and families to normalize and cope with the dying experience. Patients may maintain their identity through the process of psychological ‘bracketing’ of the impact of the illness [17]. Patients may also display ‘engaged avoidance’, actively avoiding discussing EOL issues or refusing to engage in decision-making, to maintain their sense of control and autonomy [19]. It appears that for older people in particular, ‘denial’ may be an important coping strategy [17]. In a study on older people’s views of what constitutes a ‘good death’, many participants did not want to discuss and dwell upon the imminence of their death, as they felt that doing so would remove hope and the foundation for enjoyment in everyday life [17]. It is possible that patient denial makes GoC discussion by HCPs more nuanced, as HCPs should be aware of patient bracketing and engaged avoidance and have appropriate skills in how to navigate this in a respectful and compassionate way.

Family members offer crucial support to the dying person, and this comes with an enormous emotional burden. Family members do not always understand hospital care or clinical cues/illness trajectories leading up to death [20]. Such confusion or unawareness of the seriousness of illness, coupled with the possibility of a range of emotions, requires HCPs to assess families for their readiness of conversations about GoC [4]. Understanding the nuance of each family may include the willingness or not to engage with conversations about EOL, or the timing and carefully tuned communication that includes non-verbal signals. Quality and safe communication includes the documentation of important details of family meeting and other details that allow for compassionate EOL care [4]. For example, documentation of whether a family member wishes to be called by the hospital during the night should a death occur, allows the whole team to know the family’s wishes. Bereavement outcomes for families and friends are linked to shared decision-making, communication, and support from health-care teams [21]. The patient’s family should be included in GoC discussions, invited to contribute to the decision-making process, and provided with education and support as per their unique needs [21].

Table 2 provides a summary of the study findings and overall recommendations for practice when negotiating GoC.

Managing emotions

 Learners expressed difficulty in navigating the distress and heightened emotions of the patient and family, and some mentioned challenges regarding their own emotions. This challenge has been exacerbated in recent times due to the COVID-19 pandemic, with HCPs in hospitals noting an increase in the intensity of emotion among family members and staff due to fear and uncertainty [22]. The theme of emotional awareness and the importance of HCPs being able examine and manage their own emotional triggers when delivering EOL care, have been identified in previous studies by the authors [23]. Self-awareness and proactive self-care are key to managing emotions, building resilience, and preventing HCP burnout when working in the challenging space of EOL care. Debriefing with colleagues and formal workplace support systems are also important [2].

Initiating the EOL conversation

Most HCPs are not well educated in when to initiate EOL conversations with patients, who may be assuming that such conversation will occur if appropriate [2]. One study with a cohort of 130 emergency medicine doctors, found that 66% of respondents expressed difficulty in initiating GoC discussions [13]. The main barriers to doing so were time, lack of relationship with the patient, patient expectations (e.g. the perception of bad outcomes when GoC discussions are undertaken) and that the busy emergency department environment was not conducive to these discussions [13]. Another study involving patients who died of blood cancers found that most initial GoC discussions occurred close to the patient’s death, however when GoC discussions occurred more than one month before death, patients were less likely to experience intensive medical care (such as ICU admission) close to death and more likely to enrol in hospice more than three days before death [24].

Lack of professional knowledge or capacity

An educated and skilled workforce is required to increase confidence and overcome hesitancy to raise EOL conversations and GoC planning with patients and families [4]. A previous
study by the authors found that a lack of skills in EOL communication can be improved with additional training such as the EOLE education modules [25]. Using a framework like Reframe, Expect emotion, Map out patient goals, Align with goals, and Propose a plan or the mnemonic (REMAP) can also be helpful in thinking about and discussing GoC with patients [26]. Currently, there is little consistent evidence to support one particular approach to GoC planning, and there are calls for further research to develop standardized initiatives and documentation [27].

The capacity of HCPs to effectively engage in GoC discussions is also impacted by issues surrounding professional hierarchies and roles, i.e. whose role is it to initiate these discussions with patients and families? One study sought to critically examine nurse and physicians’ perceptions of the nurse’s role in communication with seriously ill patients and their families, finding different approaches to engaging in these conversations by nurses (more spontaneous) and doctors (more formal), albeit with the latter including nurses in the communication, recognizing the strengths of what they contribute [28]. However these authors also noted that practice boundaries contributed to some hesitancy from nurses, and emphasized the need to legitimize the nursing role in this space as they can play a key role [28].

**Strengths and limitations**

The strengths of this study lie in the fact that module learners (HCPs) considered their clinical practice around negotiating GoC and reported challenges faced. This can be used to improve the quality and effectiveness of care for patients at the EOL.

While 941 learners completed the module during the study period, this included data from only those learners \( (n = 451) \) who responded to the free-text module question. This difference in module completion and response rates is due to the voluntary nature of the evaluation. Learners were self-selected in engaging with the GoC module, with responses self-reported and by nature subjective, and likely to differ from those of HCPs who choose not to do this, with a tendency towards acquiescence [29]. The study focused on the views and experiences of individual HCPs and did not explore organizational/structural challenges around negotiating GoC. Demographic data beyond learner profession and type of setting (e.g. role, length of service) were not captured, which limits more in-depth analysis of characteristics of learners. Learner responses to the open-ended question varied in length, and learners were not probed to elaborate further, potentially reducing the richness of the data.

**Implications for policy, practice, and research**

From an HCP’s perspective, the themes are factors that need to be considered when negotiating GoC in the EOL care space. Learners have told us what they find challenging and have given examples of barriers they face to negotiating GoC, although should they instead be viewed as opportunities for professional growth and skill development? Negotiating GoC is an evolving process rather than a single point in time [13], a process requiring many skills.

Illness that naturally leads to a patients’ death, after years of oscillation in effective or supportive treatments, requires ongoing discussions between patients, families, and HCPs. Safe and quality EOL care is dependent on shared decisions over time, implemented via GoC. What matters to a patient, coupled with what is medically possible, may not always meld neatly or be easily delineated, requiring clarification of different expectations regarding future health-care possibilities. Moving away from the ‘fix it’ mode of hospitals requires attention at all layers of the health-care system, to identify the challenges and create solutions to negotiate GoC.

**Conclusions**

Most Australians would like to plan for the end of their lives, and this planning, in line with the patient’s and family’s wishes, is essential for quality and safe care. There are many challenges to this in practice, however, including differing...
views and opinions between the various stakeholders and challenges to patients and HCPs reaching a place of mutual understanding and expectation. What is also apparent is the recognition of the importance of GoC conversations within organizations, and that HCPs need to be educated in negotiating GoC with patients who have advanced serious illness. Evidence-based training and education resources such as the EOLE module ‘Planning End-of-Life Care—Goals of Care’ can help HCPs improve their skills and confidence in this area, to ensure ongoing GoC conversations occur for all patients in hospitals who are approaching the EOL.

**Data availability statement**

The data underlying this article will be shared on reasonable request to the corresponding author.

**Contributorship**

K.D. is principal investigator for the EOLE project and led the writing of the manuscript. D.R. is co-principal investigator for the EOLE project and contributed to the drafting of this manuscript. M.W. is research assistant for the EOLE project, contributed to the drafting of this manuscript and managed the qualitative analysis. All authors have read and approved the final manuscript. All authors have read and agreed to the published version of the manuscript.

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