

A Survey of Clinicians Regarding Goals of Care for Patients with Severe Comorbid Illnesses Hospitalized for an Acute Deterioration

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ABSTRACT

Background: Patients with terminal illnesses hospitalized with acute deteriorations often suffer from unnecessary/inappropriate therapies at the end of their lives. Appropriate advance care planning (ACP) practices aligned to patients' goals of care may mitigate this.

Materials and methods: To explore the rationale for clinical decision-making in hospitalized patients with terminal illnesses and formulate a practice pathway to streamline care. Between May and December 2018, a questionnaire survey with three case vignettes derived from intensive care unit (ICU) patients was emailed to ICU, respiratory and renal doctors, and nurses in two Sydney hospitals. Respondents chose various management options ranging from all active therapies to palliation. The primary outcome was the proportion of responses for each management option. With these and a thematic analysis of responses to identify barriers to ACP practice, a practice pathway was formulated.

Results: Of the 310 invited clinicians, 178 responded (57.4%). About 89.2% of respondents reported caring for dying patients frequently. Sixty percent saw patients suffering from prolonged therapies. Most respondents deemed patients in the case vignettes to be terminally ill, warranting ACP discussions. However, many still wanted to treat the acute deterioration with active ICU-level interventions. Most respondents reported being comfortable in having ACP discussions.

Conclusion: The survey showed discordance between the stated opinions and the choice of management options for terminally ill patients with acute deteriorations; possibly due to the lack of a considered approach in choosing management options that align with medical consensus and the patient's/family's wishes, a practice pathway is suggested to improve management.

Keywords: ACP, Advance care planning, ICU, Perceptions, Supportive and palliative care indicators tool (SPICT).

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INTRODUCTION

There is an increasing proportion of patients admitted to Australian intensive care units (ICU) with severe preexisting illnesses that are severe enough to be life-limiting, with a point prevalence study showing that such patients comprised ~26% of the ICU admissions.¹ In such patients, the provision of therapies that may be nonbeneficial may cause unnecessary distress to patients, families, and staff,^{2,3} as well as costing the Australian healthcare system 153 million AUD each year.⁴ Hence, advance care planning (ACP) has been recognized as an important process of clinical care.⁴ ACP is defined as the process of having formal discussions with patients or their surrogate regarding their disease prognosis to formulate appropriate goals of care (GoC) in line with their aspirations.⁴ The prevalence of ACP is very low both in general practices (i.e., community patients) and in hospitalized inpatients.^{5,6}

Very few studies have explored the management approach of doctors and nurses when dealing with patients with severe comorbidities and/or terminal illnesses.^{7,8} We conducted this survey of clinicians to help understand the barriers and challenges around their clinical decision-making in hospitalized patients with terminal illnesses and help formulate a practice pathway to streamline the management approach of such patients.

MATERIALS AND METHODS

This was a questionnaire survey of doctors and nurses working in two hospitals in Western Sydney, Australia.

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Design and Development of the Survey Questionnaire (Table 1)

The broad research topic (opinions on end of life, ACP, and GoC for patients with severe/terminal comorbid illnesses hospitalized for an acute deterioration) and specific domains were decided following a discussion between the corresponding author (AR) with doctors and nurses from intensive care medicine, pulmonology, nephrology, cardiology, and palliative care medicine. The following domains

Table 1: Case vignettes' descriptions

Description	Geriatric age-group		Poor/deteriorating chronic functional status		Lack of improvement with acute supportive therapies		Family requesting advanced supportive therapies		Clinical course and medical decision made during ICU admission by consensus between intensivist, primary physician, and patient/family	
	Yes	No	Yes	No	Yes	No	Yes	No		
<p>1. A 76-year-old woman presents with worsening lower limb edema. She is morbidly obese and a smoker with a 50-pack-year history and has severe COPD, CCF, OSA (on nocturnal CPAP), severe cor pulmonale, severe pulmonary hypertension, and acute-on-chronic renal failure. She is on 24-hour home O₂ and is limited to an exercise tolerance of 10 meters due to exertional dyspnea. Although she still lives at home, she has become increasingly dependent on her 2 daughters for all activities. Also, she has been having 1–2 unplanned hospital admissions every month in the past year. Her most recent discharge was ~1 week ago. She had a deterioration in the ward with acute hypoxemic and hypercarbic respiratory failure requiring ICU admission and continuous (24 hours) BiPAP for the past 5 days, complicated by pressure ulcerations from the BiPAP mask. Her family "wants everything done"</p>	Yes	No	Yes	No	Yes	No	Yes	No	<ul style="list-style-type: none"> • Poor prognosis flagged by ICU nurse to medical team, followed by acknowledgement of likely long-term poor functional status by treating physicians (renal, respiratory, and ICU) • Formal ACP/GoC discussions between multidisciplinary physicians, patients, and families, who understood the limitations and harms associated with supportive therapies • Treatment capped at ward-level measures. Patient discharged home with community palliative care services. 	
<p>2. An 86-year-old man who was previously high-functioning with a very good effort tolerance has had pneumonia requiring ventilation. He has developed severe anuric renal failure. After 2 weeks of ventilation and dialysis in the ICU, he has lost 20 kg and has become weak and deconditioned. He remains anuric, needing thrice-weekly hemodialysis. He and his family have left it to the doctors to determine the appropriate next step</p>	Yes	No	Yes	No	Yes	No	Yes	No	<ul style="list-style-type: none"> • Severe multi-organ dysfunction and supports with significant deconditioning in an elderly man • No discussions by treating team (both primary physician and intensivists) • Family initiated ACP/GoC discussions via the ICU social worker resulted in an acknowledgment by primary physician and intensivist regarding likely long-term poor functional status • Consensus to withdraw active treatments and initiate comfort care measures. 	
<p>3. A 46-year-old man with stage 4 non-small cell lung cancer presents with bilateral pneumonia. Despite broad-spectrum antibiotics and intravenous fluids, he develops hypoxia, hypotension, and oliguric renal failure in the ward, for which he is admitted to the ICU in the middle of the night. Since the on-call oncologist is unaware of prior ACP/GoC discussions, the recommendation is to offer all measures till the primary oncologist is contacted in the morning.</p>	No	No	Yes	No	Yes	No	Unknown	Unknown	<ul style="list-style-type: none"> • No prior ACP/GoC discussions despite the diagnosis of terminal cancer • Acknowledgment by primary physician and intensivist regarding likely long-term poor prognosis • Medical consensus to withdraw supportive therapies and initiate comfort measures 	

ICU, intensive care unit; ACP/GoC, advance care planning/goals of care



were chosen for the survey: (i) background and prior experience of the survey respondent regarding hospitalized patients with severe comorbid/terminal illnesses; (ii) recognition of the terminal nature of severe comorbid illness(es); (iii) potential for reversibility of acute deterioration; (iv) proactive initiation of ACP/GoC by the treating doctor in the setting of acute deterioration, including eliciting the opinion of the patient and/or surrogate; (v) documenting appropriate levels of medical therapies to be offered in the case of acute deterioration, such as a resuscitation plan, ranging from palliation to offering advanced invasive organ supportive measures, such as mechanical ventilation, renal replacement therapy, etc.; and (vi) decision-making in the event of discordance between the medical and family opinion.

To design and validate the survey, we followed a standard process recommended by statistical experts.^{9–12} To maintain real-world relevance, the domains were explored using clinical case vignettes that were created from real ICU patients (Table 1). Using the validated supportive and palliative care indicators tool (SPICT),¹³ the electronic medical records at Nepean ICU were screened between January and April 2018 to identify patients with a high risk of dying/deteriorating within 12 months, historical exposure to multiple healthcare professionals in the previous 6–12 months, and potential “gray-zones” with a range of possible medical management options for the acute deterioration. Fifty-two patients were identified with these criteria; of whom twelve patients fit the criteria for having a terminal illness, namely end-stage disease that cannot be cured or adequately treated which would reasonably be expected to result in the death of the patient within 1 year.¹⁴

Following consultation with other clinicians, three patients were chosen for the clinical case vignettes. A draft electronic survey tool with these vignettes and other details was designed in the form of a Google Forms™ questionnaire and administered to five clinicians (two intensivists, one palliative care physician, and two nurses) to improve clarity and minimize ambiguity. Based on their feedback, the questionnaire was redrafted and administered to a different cohort of five clinicians (two nurses and one specialist each from renal, cardiology, and respiratory medicine) for validation and reliability. The final questionnaire comprised predominantly of structured drop-down menu options. In addition, an open-ended response field was provided for the respondent to comment. After approval by the Human Research Ethics Committee, Nepean Blue Mountains Local Health District Human Research Ethics Committee, (NBMLHD HREC) [approval number: 17—34(A)], the survey was emailed to doctors and nurses working in the ICU, respiratory, and renal wards in Nepean and Fairfield Hospitals between May and December 2018. Participation was voluntary and consent was implied. No incentives were offered. Two reminders were sent 4 weeks apart.

RESULTS

The survey was emailed to 310 doctors and nurses working in the ICU, respiratory, and renal wards in Nepean and Fairfield Hospitals. One hundred seventy-eight responses were obtained (57.4% response rate) from 73 (41%) senior doctors and intensivists, 6 ICU trainees (6%), 6 ICU advanced trainees (6%), 48 non-ICU trainees/junior medical officers (JMOs) (27%), 5 (3%) non-ICU nurse unit managers, and 30 (17%) ICU nurses (Fig. 1).

One hundred fifty-nine respondents (89.2%) reported caring for dying patients at least 1–2 times a month; of whom 72 (40.4%) reported caring for such patients at least 1–2 times per week. One hundred six respondents (60%) reported frequently encountering

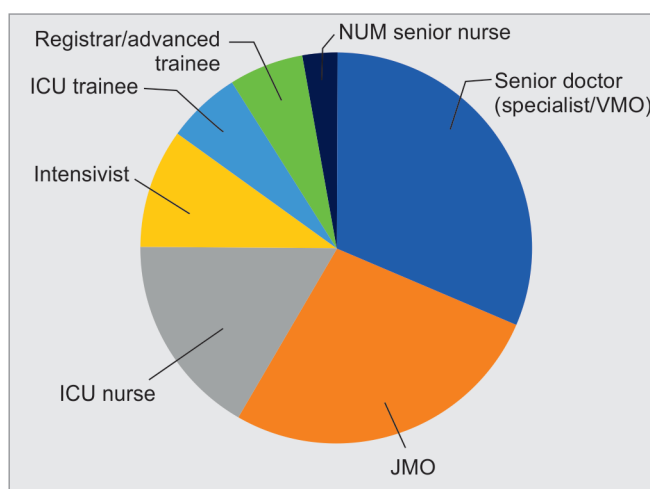


Fig. 1: Demographics

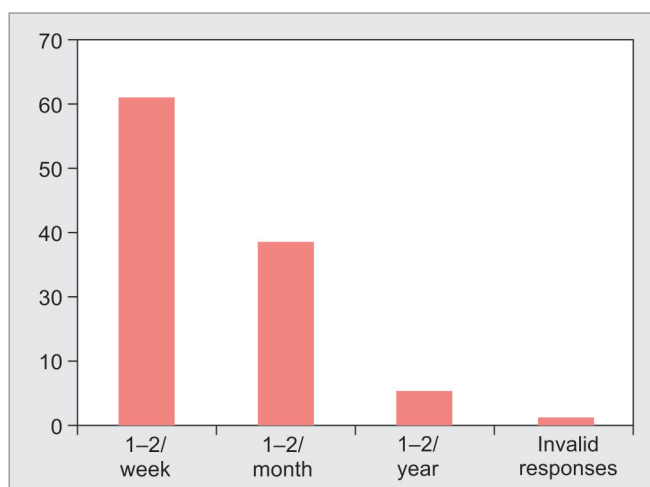


Fig. 2: Frequency of perception of prolonged therapies at end of life

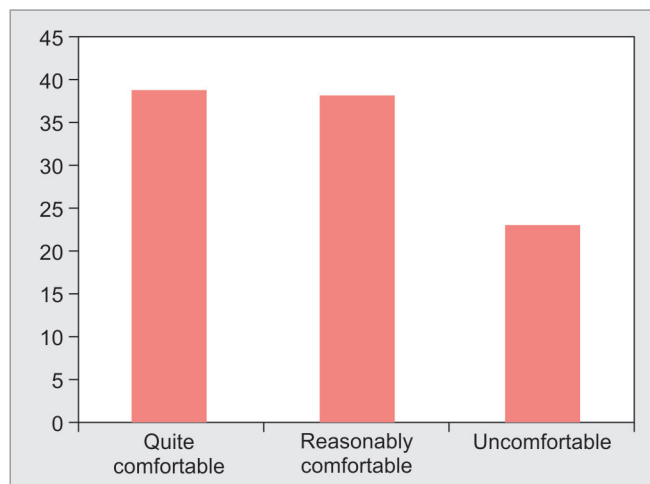


Fig. 3: Participant comfort in end-of-life discussion

such patients suffering from prolonged therapies (Fig. 2). One hundred thirty-seven (77%) reported being comfortable in talking to terminally ill patients about their poor prognosis (Fig. 3). One hundred fifty-four respondents (86.5%) stated that they would

consider using validated prognostic tools such as SPICT, the “surprise question,” or a frailty index to help guide the direction of management of such patients. If patients were deemed to have a high risk of dying or deteriorating from their underlying comorbid illness(es), 163 respondents (91.6%) stated that patients’ treating doctors must establish consensus medical plans on ACP/GoC, considering the potential for the reversibility of the acute condition, assessing the benefits and harms of therapies required to reverse the acute deterioration and patients’ wishes. All respondents stated that it is a duty of care to discuss goals of therapy (including limitations) when the prognosis was poor, with only five respondents (2.8%) stating that it was wrong to tell a dying patient of his/her prognosis. Only 11 respondents (6.2%) stated that during the discussion on a patient’s poor prognosis, the preferred approach was for the treating doctor to leave it to the patient/family to decide. The other 167 respondents (93.8%) stated that the doctor must have a factual discussion on the patient’s prognosis and the harm vs benefit of various options and give a medical recommendation to the patient/family. One hundred sixteen respondents (65.2%) stated that when there was a family disagreement with the consensus medical opinions on therapeutic options, doctors were not obliged to go against their own consensus opinions to provide all possible therapies to the patient (Fig. 4). One hundred twenty-two respondents (68.5%) stated that ACP/GoC discussions should not be delegated to a junior medical staff and needed more senior input. As soon as GoC changed to comfort measures, 144 respondents (81%) supported a referral to palliative care.

The case vignettes yielded interesting themes (Table 2). Case vignette 1 explored an elderly woman with a chronic progressively worsening functional status with an acute deterioration. Most respondents (n = 160, 89.8%) stated that the patient’s comorbid illnesses made her terminally ill with a life expectancy <12 months. Despite this, 114 respondents (64%) wanted to treat the acute deterioration with active ICU-level interventions, not with just

ward-level management. However, all 35 nurses and most doctors (n = 137, 95.8%) recommended a ceiling of treatment and withholding of advanced interventions like intubation and dialysis. Only one respondent (0.6%) recommended changing the treatment goals to comfort measures. However, most participants (n = 170, 95.5%) stated that the treating doctor must immediately have ACP/GoC discussions with the patient/family.

Case vignette 2 explored an elderly man with a good premorbid functional status with an acute infective deterioration from pneumonia but requiring a long stay in ICU with ongoing multi-organ ICU support. Most (n = 151, 84.8%) participants stated that it would not be a surprise if he died in the next 12 months and that he had a poor outcome due to his acute deconditioning. Most (n = 106, 60%) also believed that his current state was not acutely reversible. Despite

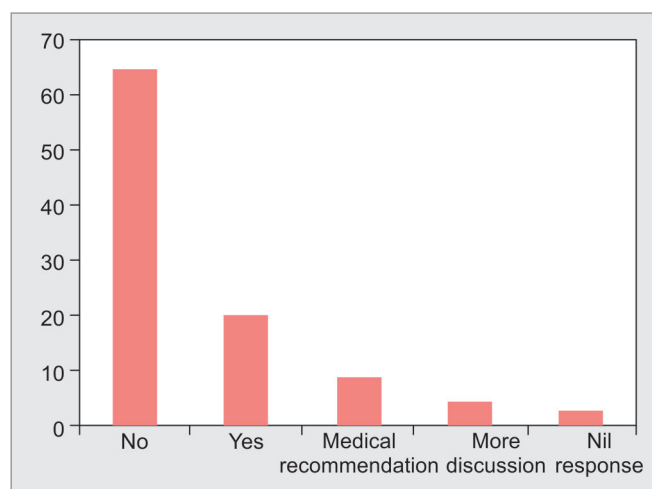


Fig. 4: Doctors’ obligation to go against medical recommendation if family members want all possible therapies

Table 2: Responses across three case vignettes

		ICU trainee	NUM/senior nurse	Registrar/advanced trainee	Junior doctor (JMO)	Intensivist	ICU nurse	Senior doctor (specialist/VMO)
Case 1	Terminal illness diagnosis (%)	5.6	2.5	5.6	25.6	10.6	18.8	31.3
	ACP recommendation (%)	5.9	2.9	5.3	26.5	8.8	17.7	32.9
	Reversibility (%)	6.7	0.0	5.6	43.3	6.7	5.6	32.2
	Ward-based management only (%)	6.3	7.8	9.4	9.4	12.5	15.6	39.1
Case 2	Terminal illness diagnosis (%)	16.9	6.2	9.5	26.9	2.8	6.1	31.5
	ACP recommendation (%)	16.2	6.2	9.6	27.1	2.8	6.2	31.1
	Reversibility (%)	17	6.2	9.7	27.3	2.8	6.3	30.7
	Ward-based management only (%)	16.9	6.2	9.6	26.9	2.8	6.2	31.5
Case 3	Terminal illness diagnosis (%)	12.5	7.4	9.6	30.9	1.5	5.9	32.4
	ACP recommendation (%)	23.2	8.1	7.1	23.2	2	8.1	28.3
	Reversibility (%)	9.2	6.3	10.6	29.6	2.1	7	35.2
	Ward-based management only (%)	29.4	11.8	14.7	20.6	2.9	8.8	11.8

ICU, intensive care unit; NUM, nurse unit manager; ACP, advance care planning

this, 162 respondents (92%) wanted to continue providing active organ supports, including efforts to liberate mechanical ventilation ($n = 74, 42\%$), increasing supportive therapies in the event of another major deterioration ($n = 72, 40.9\%$), tracheostomy ($n = 94, 53.4\%$), and chronic dialysis ($n = 94, 53.4\%$). Interestingly, 168 respondents (94.4%) did not choose the option of discussing ACP/GoC with the patient/family, but 94 respondents (52.8%) stated that patients needed palliation.

Case vignette 3 explored a young man dying from terminal cancer. One hundred thirty-six respondents (76.4%) reported that the patient was terminally ill with a life expectancy <12 months. One hundred forty-two respondents (79.8%) wanted to limit his treatment to ward-based therapies and withhold ICU-level therapies. At the same time, many respondents ($n = 117, 65.7\%$) were willing to offer a short trial of noninvasive ventilation (NIV) for hypoxia and a short trial of inotropes for hypotension ($n = 107, 60.1\%$). Many respondents were not in favor of a short trial of intubation ($n = 98, 55\%$) or dialysis ($n = 117, 65.7\%$). Interestingly, although 136 (76.4%) respondents stated that this man's comorbid illnesses were terminal, only 14 (8.9%) chose the option of discussing ACP/GoC with the patient/family. Only one respondent suggested changing the focus of therapy to active palliation (0.6%).

DISCUSSION

Statement of Principal Findings

This study explored the opinions of clinicians on the management options for patients with severe comorbid illnesses who are hospitalized for an acute deterioration, with a particular focus on ACP and GoC. There were five principal findings from our study. First, most clinicians reported encountering terminally ill/dying patients quite frequently, including patients suffering from prolonged therapeutic interventions. Second, from the vignettes provided, most respondents were able to identify terminally ill patients. Third, it was common for clinicians to consider the acute deterioration as potentially reversible. As a result, from the management options provided, most respondents chose to either initiate or prolong invasive ICU therapies. Fourth, many respondents opined that the treating specialist doctor must provide medical recommendations on ACP/GoC to the patient/family. They also reported being comfortable discussing ACP/GoC with such patients and/or families. Finally, although for case vignette 3, almost 80% of respondents opined that patients must only receive ward-based management, they were still inclined to offer ICU-level therapies, such as inotropes and NIV. Given that these two are inherently contradictory management strategies, it likely reflects the lack of clarity by the clinician on the management options. It is not unreasonable to surmise that such contradictory recommendations may accentuate the lack of clarity for patients and families.

In our survey, the three case vignettes were based on real patients with severe comorbid illnesses who had received prolonged life-sustaining therapies without prior ACP/GoC discussions despite several clinicians being involved in their care. This highlights the common worldwide problem of suboptimal ACP practice in such patients.^{15,16} Previous studies have identified knowledge deficit and inexperience as common barriers to good ACP/GoC practice in the acute setting.¹⁷⁻¹⁹ However, since most respondents in our survey were able to identify terminally ill patients with poor life expectancy, it may be argued that knowledge deficit was not a barrier against ACP/GoC. Similarly, skills deficit

may also not be a problem since most respondents reported being comfortable with conducting ACP/GoC discussions. Therefore, as reported previously,¹⁷ we believe that the primary barrier against good ACP/GoC practice in our study was "provider attitude," i.e., clinicians failing to apply their knowledge and skills to discuss ACP/GoC with terminally ill patients and/or their families. One possible reason for this may have been that the respondents considered the acute deterioration to be potentially reversible, thereby warranting acute medical therapies. While this is justifiable, it does not preclude an early discussion to determine the GoC in line with patients' wishes and clinicians' expectations.²⁰

An interesting finding in our survey was the preference of most respondents ($n = 122, 68.5\%$) that ACP/GoC discussions should not be delegated to a JMO. It is possible that this attitude coupled with the limited time available to specialist doctors may be a contributory factor for suboptimal ACP/GoC practices. Given that a recent study demonstrated a significant improvement in ACP practice by appropriate training of JMOs, clinicians need to be educated on the benefits of such educational initiatives.⁶

Strengths and Weaknesses of the Study

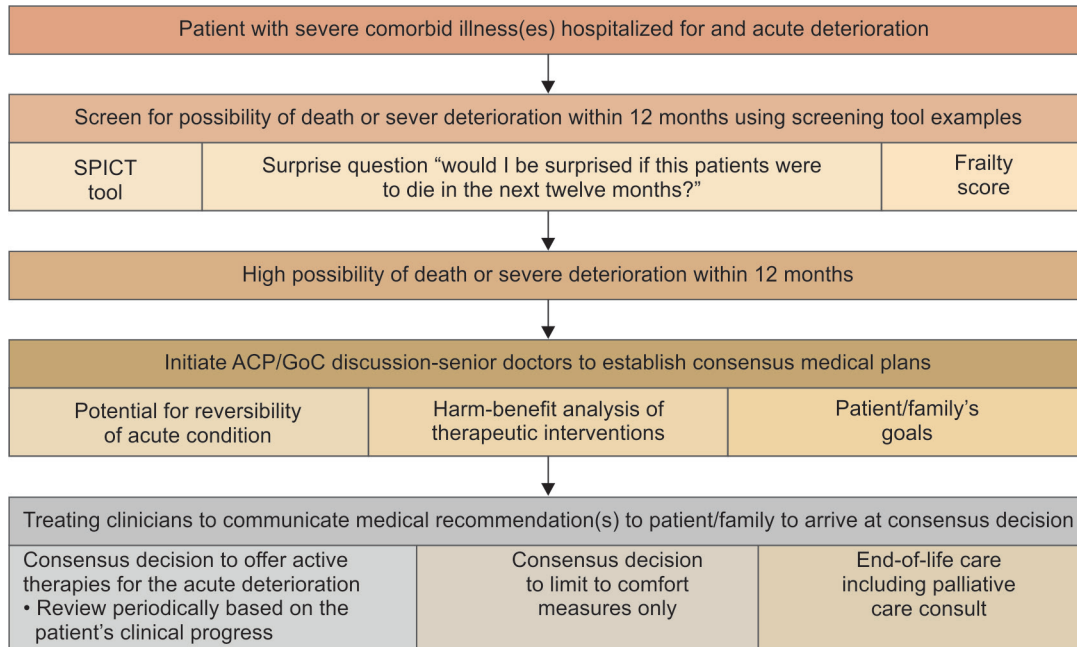
This study has several strengths. To the best of our knowledge, this is the first such study from Australia. A rigorous methodology was employed in planning/conceiving the domains of the study and designing and validating the survey questionnaire. The case vignettes were based on de-identified real-life patients commonly encountered by clinicians to help overcome some limitations associated with questionnaire surveys, such as response bias, acquiescence bias, and conformity bias. The questionnaire was also designed with multiple checkbox options to minimize straight-lining and near straight-lining phenomena.^{21,22} A range of nurses and doctors were surveyed ranging from senior to junior staff in the ICU as well as from the wards.

There are several weaknesses. First, inherent to any survey design, the participants' responses were self-declared statements, lacking independent corroboration of their actual clinical practice. For instance, since most respondents identified that the patients in the clinical vignettes had terminal illnesses warranting ACP/GoC discussions, we have concluded that there is no cognitive deficit to explain the discordance from the actual management of these patients. However, since answering a survey does not evoke the emotional barriers to ACP/GoC that clinicians encounter when managing real patients, our conclusion may be erroneous.²³ Second, it is also possible that some of the respondents may have had a recall bias by recognizing the patients in the case vignettes, although we took care to de-identify them and modify some details. Third, the relatively low response rate of only 57.4% may have contributed to the nonresponder bias. Finally, given that only two hospitals were involved, the external validity/generalizability across other Australian hospitals is debatable.

Implications of the Study and Future Directions

This study demonstrates a discordance between clinicians' knowledge and their actual practice of ACP/GoC for patients with severe comorbid illnesses who are hospitalized for an acute deterioration. As a solution, we suggest a practice pathway based on previous studies²⁴⁻²⁶ that clinicians may follow to improve ACP/GoC in patients with severe comorbid illnesses who are hospitalized for an acute deterioration (*Flowchart 1*). Benefits of this practice pathway need to be evaluated in prospective studies.

Flowchart 1: Practice pathway



CONCLUSION

This survey of clinicians' opinions on the management options for patients with severe comorbid illnesses who are hospitalized for an acute deterioration demonstrated a discord between their stated opinions and the actual management followed for these patients. It shows that the primary barrier against good ACP/GoC practice may not be a deficit of knowledge or skills but rather the lack of a considered approach to choose the management option(s) that align with the medical consensus and the patient/family's wishes. We suggest a practice pathway to improve the management of such patients. Future research should include prospective studies on the impact of such an approach.

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