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# Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

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**Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study**

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ABSTRACT

**Objectives**

We aimed to identify factors influencing communication and decision-making and to learn how physicians and nurses view their roles in deciding about the use of life-sustaining technology for seriously ill hospitalized patients and their families.

**Design**

The qualitative study used Flanagan's critical incident technique to guide interpretive description of open-ended in-depth individual interviews.

**Setting**

Participants were recruited from the medical wards at three Canadian hospitals.

**Participants**

Interviews were completed with 30 healthcare professionals (9 staff physicians, 9 residents, and 12 nurses; age 25- 63 years; 73% female) involved in decisions about the care of seriously ill hospitalized patients and their families.

**Measures**

Participants described encounters with patients and families in which communication and decision-making about life-sustaining technology went particularly well and unwell (i.e., critical incidents). We further explored their roles, context and challenges. Analysis proceeded using constant comparative methods to form themes independently and with the interprofessional research team.

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## Results

Several factors interacted to make communication and decision-making about life-sustaining technology challenging or easier for physicians and nurses: A) conceptualizations of medical practice as '*saving lives and warding off death*', B) work towards '*making sense of the situation*', C) '*(in)effective family engagement*' highlighting the inherent and systemic tensions in achieving consensus about the goal of care, and D) a '*team-based approach*' contrasted with the '*solitary nature*' of professional work. Participants described incidents in which these factors interacted in dynamic and unpredictable ways to influence decision-making for any particular patient and family.

## Conclusions

A focus on more meaningful and productive dialogue with patients and families by (and between) each member of the healthcare team may improve decisions about life-sustaining technology. Work is needed to acknowledge and support the non-curative role of healthcare and build capacity for the interprofessional team to engage in effective decision-making discussions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The qualitative component of the mixed method DECIDE study adds depth to the understanding of contextual elements that influenced the engagement of healthcare professionals, patients, and families in communication and decision-making about life-sustaining technology

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- Flanagan's critical incident technique was an effective mechanism to elicit the broadest range of experiences experienced by participants; however further research is needed to establish the frequency of experiences in the range.

- We interviewed participants in their native language (English or French) and integrated interviews for analysis in the language provided. Translation of French language quotes was only done if they were included in research reports.

- Participants included healthcare professionals most likely to be involved in communication and decision-making about life-sustaining technology, however understanding could be strengthened by including perspectives of social workers, clinical ethicists, and others who work with patients and families in the hospital in future research.

COMPETING INTERESTS STATEMENT

The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript. No financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Seriously ill hospitalized patients and their families should be engaged in decisions about their healthcare in order to ensure that their care meets their needs and preferences. Further, the engagement optimizes patient health. For example, patients who were engaged in decisions experienced less anxiety and depression, less fatigue, and had higher overall quality of life, physical and social functioning, and have better control of diabetes and hypertension[1,2]. As the end of life approaches, decisions about the use of life sustaining technologies (such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission) are implemented for seriously ill patients. However, communication about these treatment options is often poor, and many patients receive care that is inconsistent with their values and preferences[3]. Many authors have described interventions aimed at improving patient/family engagement and improving the match between patient preferences and care delivered[4-14], but these have often been ineffective or poorly adopted outside of the studies where they are tested. The mismatch between patient preferences and the care provided at the end-of-life (a "preference misdiagnosis") occurs when healthcare professionals make a decision about treatment without integrating the informed preferences and priorities of their patients[15-17]. A preference misdiagnosis has important implications for a patient's quality of life and end-of-life care.

In the context of a broader research program to improve end-of-life care for seriously ill patients, we conducted a mixed-methods study called DECIsion-making about goals of care for hospitalized meDical patiEnts (DECIDE). The study involved a cross-sectional survey of physicians and nurses from 13 hospitals in five Canadian provinces, as well as open-ended qualitative interviews with physicians and nurses from three of these hospitals[18]. The mixed methods design sought to understand factors which affect communication and decision-making about life-sustaining technology from the perspectives of healthcare providers and offer

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suggestions about potential solutions, through the collection of complementary quantitative and qualitative data.

The quantitative component of DECIDE found that that a range of professionals (i.e. nurses, social workers) supported key decision-making activities, such as initiating discussions and decision coaching. Participating healthcare providers felt it was most acceptable for staff physicians to make the final determination about the use or non-use of life-sustaining technology with patients and their families. Physician and nurse participants related that family- and patient-related factors were the most important barriers, whereas barriers related to their skills and system factors were relatively less important[18].

In this qualitative component, we sought to provide richer, more nuanced data than what we obtained in the survey methods. Specifically, we aimed to explore physicians' and nurses' experiences, with a view to identifying their roles and factors influencing communication and decision-making with seriously ill hospitalized patients and their families.

**METHODS**

**Study Design**

The qualitative study used Flanagan's critical incident technique (CIT) and interpretive description of open-ended interviews[19,20]. Interviews were conducted between 2012 and 2013 with staff physicians, residents, and nurses (n=30) at the in-patient medical teaching units of three large Canadian hospitals. The goal of CIT is to explore specific incidents with those who have lived them and to uncover assumptions, values, or impacts that participants may not themselves appreciate. Strengths of the CIT are that it commonly elicits very effective or very

ineffective practices and aims to provide findings that are highly focused on solutions to practical

problems[21].

**Sample**

Eligible professionals for inclusion were staff physicians, residents, and nurses who cared

for seriously ill patients and their families in the inpatient medical ward setting. Professionals

received an email about the study and indicated their willingness to participate in a subsequent

individual interview in the quantitative DECIDE survey. We used a purposive sampling strategy

to ensure balanced representation amongst the three hospital centers, between nurses and

physicians, men and women, and amongst clinicians with diverse levels of experience. We

obtained research ethics board approval at each participating site; all participants gave informed

consent before taking part.

**Data Collection**

Individual interviews at all sites were conducted by the same experienced qualitative

interviewer in a location of the participant's choice (a private room located close to the hospital

ward or in their home). Each participant provided one audio recorded interview lasting between

27-91 minutes (mean 47 minutes) in their native language (English or French). The interviewer

used a standard introduction and set of questions, and the research team added additional

prompts as the interviews progressed (Figure 1). During the in-depth interviews, participants

were invited to describe specific encounters with patients and families in which discussions

about the use or non-use of life-sustaining technology went particularly well and unwell (i.e.

critical incidents). We further explored participants' perceptions of professional roles and the

context and challenges encountered by healthcare professionals, patients, and their families. The

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interviewer wrote detailed field notes, to record what stood out for her, immediately after each

interview. We transcribed audio recorded interviews verbatim and audited transcripts for

accuracy. Both transcripts and field notes were organized in NVIVO 10 to facilitate data

management.

**Qualitative Analysis**

The team developed a codebook by reviewing critical incidents to code them inductively

into themes. We coded the data, and met frequently to discuss, challenge and make decisions

about codes and to interpret emerging findings. We further refined interview questions and

prompts for subsequent interviews using synchronous distance technology (Skype) after each set

of two or three interviews. We integrated all passages into the coding framework in their native

language. In particular, two bilingual investigators analyzed French interviews. Translation of

specific representative quotes into English, preserving the participants meaning, was done by the

researchers only to communicate results in written English communication/publications. We

worked together in an analytic process that involved synchronous and asynchronous meetings to

reflect on the evolving conceptual framework in light of new interview data and increased

immersion in the data.

Saturation in CIT is achieved when adding 100 critical incidents to the sample

contributes only 2 or 3 more themes to the analysis[19]. In our study, a total of 30 interviews

conveyed data about 120 critical incidents (mean 4, range 2 – 9 critical incidents).  We

considered the data categories had reached saturation since the first 4 interviews provided 18

critical incidents and all but two themes to the description of factors influencing communication

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and decision-making process; the remaining 26 participants described a further 102 critical

incidents. We did not add new themes to the analysis in the last 20 interviews.

In summary, we used constant comparative methods combining independent and then

group analysis. Auditing by a team member external to original analysis ensured themes fit with

data. We continued until analysis indicated we had reached saturation.

**RESULTS**

A total of 30 individuals participated, 10 from each of three in-patient medical teaching

units (Quebec, Ontario, Alberta): 9 staff physicians, 9 residents, and 12 nurses (Table 1).

Participants were 25 to 63 years (mean 39 years), and mainly female (73%) - a distribution

skewed by the high representation of female nurses (11 out of 12 in the study).

We found that several factors interacted to make discussions and decision-making about life-

sustaining technology challenging or easier for physicians and nurses: A) Conceptualizations of

medical practice as '*saving lives and warding off death'*, B) Work towards '*making sense of the*

*situation'*, C) *'(In)effective family engagement'* highlighting the inherent and systemic tensions

in achieving consensus about the goal of care, and D) *'Team-based approach'* contrasted with

the *'solitary nature'* of professional work (Table 2). These contextual elements influenced the

engagement of healthcare professionals, patients, and families and had significant implications

for the quality of communication and decision-making about the use of life-sustaining

technology. Participants described incidents in which these factors interacted in dynamic and

unpredictable ways to influence decision-making for any particular patient and family.

**A.  Conceptualizations of medical practice as '*saving lives and warding off death.'***

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Death and dying were spoken of as largely a culturally taboo topic in hospitals. Participants' attitudes towards end-of-life communication and decision-making reflected a dominant cultural, economic construction of hospitals, doctors, medicine as primarily about saving lives: warding off death, _not_ overseeing the dying (Table 2). Participants' descriptions reflected a general assumption on their part and the part of patients and families that patients were admitted for hospital care to regain health, not to die. Care continued under this assumption until death was imminent. Importantly, participants described a norm where that discussions were avoided until doctors (and sometimes nurses) recognized that life-saving interventions were increasingly futile and that death could not be postponed. Physicians and nurses characterized communications with patients or more often families as difficult and stressful when they felt the urgency to communicate with families primarily to prevent delivery of futile care. Discussions about life-sustaining technology at such late points in the patient's life (or illness) focused on to *"getting the DNR [do not resuscitate]" (Resident Physician)*, and writing it in the chart.

Throughout the interviews, many participant accounts conveyed existential issues with regards to witnessing suffering and managing the dying patient, and the perceived failure of medical expertise. Mainly, since such discussions were equated with death and dying, healthcare professionals often waited to have these decision-making conversations until there was, in their words, '*nothing to be done'* for the patient. When this happened, the timing of communication resulted in disclosure that the patient was almost certainly dying.

**B. Work towards '*making sense of the situation*.'**

We found that *'making sense of the situation'* was work and a process that was essential to advancing decision-making (Table 3). Participants described progress in decision-making as

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contingent on having been able to make sense of a patient's situation. Work towards *'making sense of the situation'* involved a process of establishing a relationship, knowing them over time, and integrating information about the patient's health and treatment options with (ideally the patients') illness beliefs and (ideally the patients') goals of care. In cases that went well, dialogue with patients and/or families created opportunities to construct a shared understanding of the patient's situation and the use of life-sustaining technology. A perceived failure to be emotionally ready for discussions or to make sense of the situation, caused patients, families and/or healthcare professionals to '*get stuck'* and be unable to progress towards a decision. This contributed to delays in even initiating decision-making, and was perceived by nurses as a missed opportunity to ease patient and family suffering.

In their examples of discussions that went well, both physicians and nurses saw it as their role to facilitate this process. They described work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. When physicians struggled to make sense of the situation, often due to uncertainty about prognosis or the reversibility of the patient's condition, they delayed initiating the decision-making process. Both physicians and nurses reported experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering.

**C.** ***'(In)effective family engagement'* highlighting the inherent and systemic tensions in achieving consensus about the goal of care.**

An important contextual factor was that, in the face of patient suffering and imminent death, participants perceived that patients and families were emotional, even irrational at times. Patients and families were defined as 'difficult' based on what physicians and nurses saw as their

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inability to understand or accept the situation. Further, being difficult was linked to a failure to come quickly on board with the plan the physician saw as ethically and clinically appropriate. Engaging such patients and families in the decision-making process could be particularly challenging. Nurses who were left behind with patients and families in the wake of heated discussions between physicians and patients wanted more strategies for managing their stress and for speaking to stressed families.

In addition to the stress and challenges that are inherent to achieving consensus among patient, family and their healthcare team about the use of life-sustaining technology (Table 4), our data points to systemic limitations to consensus building and shared decision-making with patients and families. Achieving consensus is intricately interwoven with works accomplished together towards '*making sense of the situation'* (described above). Making sense of a situation requires some reflection and processing of information. The invitation to patients and families to make sense of dying is routinely occurring when active care has already been determined by healthcare team members to be futile; this can be very late. As noted above (A), situations described as challenging revealed that healthcare professionals tended to flag patients as urgently requiring goals of care discussions when patients were beyond rescue and often facing imminent death.

In cases where a team-based approach was preferred or possible, participants emphasized the importance of finding agreement within the team, before helping patients and families towards *"getting on the same page"*.  Team discussion prior to engaging patients and families is logical towards ensuring all relevant information is gathered before a discussion with family, and was emphasized as important to avoid patients and families being exposed to conflicting messages. The problem is that where goals of care communication and decision-making is occurring within

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such a compressed time frame, as seems to be the norm at study sites, patients and families may

have even less time than healthcare team members to make sense of circumstances and thus

meaningfully engage in decision-making. Such conditions could render patients and families

emotional, irrational, or 'difficult'. Moreover, one can presume it would be more difficult for

healthcare team members to defuse stressful communications when they are themselves feeling

pressure to adjust the patient's care plan before the patient dies and/or is exposed to futile

measures.

What seems to be key here, is that when communications with families did not go well,

most nurses and physicians did not have the experience and skill set to unblock tense

disagreements, nor did they have much time to do so. Not surprisingly, participants defined as

easy those decisions where both healthcare professionals and the patient and their family had

constructed the same meaning about the situation before a patient arrived in hospital or before a

discussion: *"It's easy when everyone is thinking the same thing"* (Staff Physician).

**D) *'Team-based approach'* contrasted with the *'solitary nature'* of professional work.**

The institutional/practical construction of communication and decision-making about

life-sustaining technology was solitary and physician-centered (Table 5). A majority of

participants perceived communications as the physicians' responsibility, as opposed to a team

responsibility. Participants described physicians who largely worked alone and asynchronously

from other team members to prepare, inform, and guide patients and families through decision-

making. Leading emotional end-of-life discussions alone placed a great deal of pressure on

physicians, especially residents.

Descriptions of nursing work were largely absent in physicians' narratives, even when invited to reflect on nurses and other health professionals' roles. For most participants, work done by nurses was not recognized as contributing to communication and decision-making about life-sustaining technology (even for nurses themselves). Nurse participants described their work as happening asynchronously around physicians' encounters. They described preparing the groundwork for physicians' discussions about life-sustaining technology, as well as "*picking up the pieces*" after physicians delivered unexpected prognostic news and decisions.

Most participants highlighted their recognition of the value of team-based approaches to goals of care communication and decision-making. Nurses and residents continue to feel isolated in the work they did connected to goals of care discussions. Where residents acknowledged the importance of more training, a number of nurses felt it would be beneficial to patients for nurses to be more fully informed and even included in physician-led goals of care discussions with patients and family. Mentorship, modeling, and support to develop the necessary skills to engage patients and families in productive discussions were frequently raised by participants. Most physicians are well prepared for 'breaking bad news', but less so for 'breaking bad news' to patients and families who were too distressed to listen to a 15-minute presentation and recommendation of care. More experienced physicians shared strategies to help patients and families be ready for these discussions. For example, two physicians in different cities advocated for a "step-wise" approach. They gently planted the seeds that a decision would soon need to be taken by commenting on the patient's declining health. They emphasized to their residents that patients and families needed time to adjust to a prognosis. Another physician stressed the importance of being present for these conversations: turning the phone off, putting time aside for this serious conversation, and listening to what the patient or family had to say. Many senior

physicians explicitly included junior residents in discussions about the use or non-use of life-sustaining technology. They knew that residents experienced more stress in these conversations and required particular abilities to listen to, and respond to, families.

**DISCUSSION**

The evolution of decision-making about life-sustaining technology for any particular patient were influenced by social constructions of medical practice as life saving, the need for dialogue to 'make sense of the situation' together, inherent and systemic tensions in achieving consensus, and the solitary nature of professional practice in the medical teaching unit. Indeed, it seemed that three conditions were present for a decision that "went well": 1) the patient needed to be beyond rescue, 2) the "correct" option needed to be clear to healthcare professionals, patients and families, who also needed 3) to agree about goals of care and the interventions that should be used to achieve those goals. Unfortunately, these three conditions are rarely present in the medical ward setting. Prognosis is hard to establish for seriously ill patients[22], and physician perceptions of prognostic certainty affect the timing of decision making [23].

The social construction of medical practice as *'saving lives and warding off death'* reported by participants in this study, has significant implications for the quality of communication about life-sustaining technology. First, the presumption within such a construction of medical practice is that a life-saving focus is logical and by default in the patient's best interest.  This is contrary to evidence that shows that at the end-of-life, palliative care approaches result in the same or better quality of care and better health outcomes than high intensity and costly life-sustaining technology care[24]. Essentially, what is important to note is that with an equation of medical care as life-saving care, warding off death dominates decision-

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making in the hospital ward. Only when death cannot be warded off is communication needed with patients, and this is communication aimed primarily at preventing life-sustaining care which at that point has become futile. Preventing delivery of futile care is a provider centered problem, and is intensified for healthcare professionals for whom death becomes personal and uncomfortable.

Our findings echo other studies that have found that while patients and families desire involvement in decision-making[25,26], they are seldom presented with alternatives to life-sustaining technology[27]. Framing alternatives as '*there was nothing to be done*' corresponds to the social construction of medical practice as '*saving lives and warding off death'*. Such wording perpetuates the assumption that non-lifesaving care is equivalent to failure or abandonment[28]. We caution that language such as '*nothing to be done'* is unhelpful in that it frames non-aggressive healthcare, including nursing care, pain management, and palliative care, as nothing. This leaves little room for strategizing, valuing, and improving the work that is involved in comfort care. Reframing this message to what *we can provide* is critical to conveying to patients and families that we will not abandon them.

While clinicians felt it was crucial for them to know the code status to prevent futile care, this may be a low priority for patients/families. A focus on more meaningful and productive dialogue with patients and families is needed. We found that work towards "*making sense of the situation*" was central to the decision-making process and was most effective (i.e. incidents that went well) when dialogue occurred with others. Establishing relationships with patients and families is a key element of the process, and occurred alongside the process of meaning making. Participants' narratives described the search for meaning in the situation by healthcare professionals, patients and families. Individual understandings of circumstances and

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opportunities for health were developed in dialogue with patients and families and their

healthcare professionals (or between healthcare professionals). We suggest that work '*getting*

*everyone on the same page*' should fully involve patients and their families. The quantitative

survey results of the larger DECIDE mixed method study[18], which highly ranked patient/family-

related barriers as impeding communication and decision-making, are reflected in the stories of

patients and families who struggled to make sense of the decision and context they were facing.

And, since it is likely that patients and families will experience grief and loss with changing

health status[29], we should expect that for patients and families, making sense of illness will

require time and support from their healthcare team. In contrast, we found that the heavy result-

oriented agenda inherent in "*getting the DNR*" seemed to abbreviate communication and

minimize the engagement of patients and families. This important dialogue should not be rushed

or hurried to 'get a code status', especially when the box checked on the order sheet has such

enormous implications for the patient's future well-being. We suggest that an organized

approach to supporting early dialogue between healthcare professionals, patients, and their

family members is needed; shared decision making facilitate the integration of information about

options with the patient's values and preferences [30,31]. We know that such dialogue occurs in

complex environments, where listening to the patient and their family is essential to providing

care that fits best for each person at the end-of-life [13,32-38].

Overall, there was an impoverished understanding of the potential for interprofessional

practice. While our earlier survey findings described the perception that everyone *could* get

involved[18], qualitative findings suggest that this is not yet happening. Participants described

usual conditions in which they tended to work in isolation from other professionals and were

unclear about each others' roles. While other professionals roles were invisible to most

participating physicians, nurses could articulate related nursing work. Overwhelmed physicians believed that they worked alone with patients and families throughout the decision-making process, which is consistent with other research in the medical teaching unit setting[39]. However, interprofessional collaboration can decrease professionals' distress[40], and therefore it is possible that team-based approaches to decision-making could maximize the opportunity to share the emotional burden of providing care, and to receive support from colleagues. Identifying optimal team roles may be an important first step in developing an intervention tailored to the clinical setting that would support patients, families and health providers in navigating this necessary, yet emotionally challenging territory.

Participants shared strategies that effectively engaged patients and families - for example, making time, sharing support roles, explicitly helping families make meaning and progress in decision-making. In their stories of what went well, participants engaged with and managed conflict within interprofessional teams and during challenging family situations. In such situations, the team proactively supported patients and their families to make sense of the situation, to understand recommendations, and supported them to make decisions. Such support requires excellent communication skills, therefore like others[41-43], we advocate for improved communication training for healthcare professionals. We also recognize that the clinical teaching unit needs an organizational culture that supports decision-making processes that will work under the conditions of usual practice.

Several factors may limit the transferability of this research. First, not all perspectives of healthcare professionals in the medical ward setting are represented by this work. Further research should include the views of social workers, clinical ethicists, and others who work with patients and families in the hospital. Second, our results may not be transferable to other

healthcare settings or other countries. We provide quotes to help readers decide whether our experience resonates with their settings.

## CONCLUSIONS AND RELEVANCE

An integrative approach to decision-making about the use of life-sustaining technology, that acknowledges and supports the non-curative role of healthcare and hospitals, is needed. We must strengthen the interprofessional team's capacity to cope with and communicate about uncertainty and related existential issues, and support patients and families who are suffering as they make decisions about care in advanced serious illness. The qualitative component of the mixed method DECIDE study adds depth to the understanding of contextual elements that influenced the engagement of healthcare professionals, patients, and families. This understanding about context is key to developing improvement strategies that harness the potential and actual roles of healthcare professionals. Policy makers should consider the impact of policy on creating healthcare environments where improvement is possible, and where patients and their families can be optimally engaged by a cohesive healthcare team.

### Authorship Statement

JK and PHS designed the qualitative study, analyzed and interpreted data, drafted and revised the manuscript and approved the final version for publication. EN conducted interviews and analyzed and interpreted the data, revised the manuscript and approved the final version for publication. JJY contributed to the design of the study, obtained funding, and both JJY and JD audited the analysis and interpreted the data, revised the manuscript and approved the final version for publication. JK, PS, and EN had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors agree

to be accountable for all aspects of the work in ensuring that questions related to the accuracy or

integrity of any part of the work are appropriately investigated and resolved.

**Data Sharing Statement**

Data in the form of unattributed quotes may be available for research purposes upon

request to the corresponding author. Full transcripts are not available in order to protect

participant confidentiality.

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**FIGURES**

**Figure 1. Interview guide with prompts**

Interview introduction: *"Communication and decision-making about goals of care includes decisions about the use of life sustaining technologies at the end of life, such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission.*

*Can you tell me of an experience you have had with a patient or their family in which communication and decision-making about goals of care and the use of life-sustaining technologies went particularly well?*

*Can you tell me of an experience you have had where communication and decision-making about goals of care and the use of life-sustaining technologies did not go well?"*

**Examples of prompts**

1. About critical incident: What in particular defines this experience for you as a good/bad one? What made it easy/difficult? Where was this happening? What happened in this case? What was the outcome?

2. About participant role: What was your role in any meetings with the patient or their family? Is it normal for you to play this role? Did you do anything to get yourself, other members of the medical team, the family or the patient ready for discussing or deciding on goals of care? Is this normal?

3. About others' roles: What other members of the medical team were involved in the discussion(s) of goals of care and the use of life-sustaining technologies in this case? What were their roles? How did they become involved? What role does the nurse or do the nurses play, in your experience? Are nurse usually informed of upcoming family meetings?

4. About factors influencing decision –making: Are there certain circumstances that make discussions about goals of care of life-sustaining technologies particularly difficult, either for you or for the patient or their family? What makes it easier for families or patients to be actively involved in communication and decision-making about goals of care and life-sustaining technologies?

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**TABLES**

**Table 1**. Participant demographics

| Characteristics | Staff physicians (n=9) | Residents (n=9) | Nurses (n=12) | TOTAL (n=30) |
|---|---|---|---|---|
| Female | 6 (67%) | 5 (55%) | 11 (92%) | 22 (73%) |
| Experience | | | | |
| <5 yrs | 2 (22%) | 9 (100%) | 4 (33%) | 15 (50%) |
| 5-10 yrs | 0 (0%) | 0 (0%) | 3 (25%) | 3 (10%) |
| 10+ yrs | 7 (78%) | 0 (0%) | 5 (42%) | 12 (40%) |
| Hospital | | | | |
| Ontario | 3 (33%) | 3 (33%) | 4 (44%) | 10 (33%) |
| Alberta | 3 (33%) | 4 (44%) | 3 (25%) | 10 (33%) |
| Quebec | 3 (33%) | 2 (22%) | 5 (42%) | 10 (33%) |

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**Table 2**. Conceptualizations of medical practice as '*saving lives and warding off death*'

| Description | Examples |
|---|---|
| Dominant cultural, economic construction of hospitals, doctors, medicine as being officially about saving lives: warding off death, not overseeing the dying. | "I think one of the things that's important is we go into this profession and, you know, doctors it's all about we need to fix things, and we need to, you know, cure things. That's kind of the mindset we have. And we sometimes lose sight of the fact that we can't actually fix everything." (Staff Physician)<br><br>"It's as though for the physicians it's always life at any cost. Always. They are always focused on saving lives. Death is like a failure. It's not something we talk about." (Nurse)<br><br>"One of the daughters was angry. She was saying we were abandoning her mother. That we weren't allowed to do that. That we had to keep it up until the end." (Nurse) |
| Discussions avoided until life-saving was not possible, or death occurred | "It's usually a pretty clear next step. Like the person is probably hours from dying and they change them to comfort [care]. Often it's that close." (Nurse)<br><br>"A lot of times when the physician is having that conversation on a medical unit, it's when things have gone badly, when things have changed, when the patient is doing poorly so the family is really distressed about how their family member is doing." (Nurse) |
| Discussions focused on 'getting the DNR' | "I think we get task oriented. We want to get to a goal of care because we think it's appropriate, and we just want enough from the patient to justify in our own minds that they're in agreement with that. And I'm not sure, in an informed consent way, that that's enough." (Staff Physician) |
| Professionals' identity wrapped up in ideas of saving lives | "The residents say 'She's really sick, and she's not doing well.' 'Yeah, but we're doing everything. We are doing everything, and the rest is because the person is failing. It's not because we're failing.' So changing that mindset from we should be able to cure everybody all the time, and nobody should ever die which is crazy, right? Doesn't make sense." (Staff Physician) |

**Table 3**. Work towards '*making sense of the situation*'

| Description | Examples |
|---|---|
| Focus on getting to know the patient and their personal life story | "We know everything medically about them, but we don't know their story and we don't know what informs the decisions they've made to this point and sometimes it can be as simple a thing as they had a really bad illness when they were young, and they got better, therefore they're going to get better this time." (Resident Physician) |
| Recognizing that the patient has a unique interpretation of what is happening, and what a 'correct' course of action might be is individual | "We're not the patient and although we have our own opinion about what is the best thing to do but regardless that's... you know, the goal should be to try to make the patient make the decision with our help in terms of trying to choose the best thing" (Resident physician). |
| Work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. | "They've just been told something potentially devastating. So you've got to ask how much they actually retained. So that's usually the best place. So gleaning a bit of an insight into what they understand, what they retain, what this means to them, or what they're understanding it means, is probably the biggest step for the nurse to take after they've had that change. (Nurse) |
| Experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering | "I went in, and I saw the patient and I literally had tears in my eyes. It's like oh my gosh, I cannot believe that this body still has a soul living in it because it was terrible. And yet I wanted to be very respectful of the decision maker who I thought had a very valid perspective. So there's that conflict sometimes of perspective. I think I realize people just need time to absorb things." (Staff Physician) |
| To make a recommendation for care, healthcare professionals also needed to establish meaning. | "Sometimes it's denial; sometimes it's that we don't have time, or sometimes it's about us, we're not comfortable making that decision either. If we aren't… if I am not sure of the prognosis, if I think they might get better through some intervention, but at the same time there's other factors, like the intervention is pretty invasive, then in those cases [we delay the decision]." (Resident Physician) |

**Table 4.** *'(In)effective family engagement'* highlighting the inherent and systemic tensions in achieving consensus about the goal of care

| Description | Examples |
|---|---|
| Easy decisions were preceded/accompanied by work 'making meaning' together | "It's easy when everyone is thinking the same thing" (Staff Physician) |
| Perceived failure to progress towards meaning making or be emotionally ready for discussions led to delays in (initiating) potentially supportive discussions and decision-making. | "I had numerous conversations with the family, the husband particularly; it was his wife that was sick and very ill. He made a lot of comments that this person was his life and he couldn't live without her and all these things and so I started to wonder if we were more treating him instead of her for her symptoms. Anyway there was never any discussion over the next few weeks of goals of care, and they kept treating her and treating her and treating her. And I understand then, maybe two or three weeks after, then she coded, and she died later that day. I had had some struggles talking to the doctors that I worried if we hadn't broached the subject ahead of time then we weren't really helping to treat or ease this man's grief or the patient's suffering." (Nurse) |
| Holding strong opinions contributed to less discussion and dialogue, ultimately making it harder to reach agreement | "It becomes more problematic when people are demented, and you've got, I think it's less common now, but I ran into a public guardian once who would not change the level of care in those days and I resigned from the case, told them to get another doctor because I thought it was inhuman keeping an absolute vegetable alive, you know." (Staff Physician) |
| Working at cross purposes with patient's priorities and goals | "There was one time when neither the family nor the patient wanted any aggressive care. She was really not doing well. She had spoken clearly, as had her family. I had to call the physicians back in because we had been told to kick off a battery of antibiotics, take blood, get tests, this, that, and the family was not happy. And the physicians told them that it was pneumonia, that it was reversible which is why they were proceeding the way they were. But the family and the patient didn't want that." (Nurse) |

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**Table 5**. *'Team-based approach'* contrasted with the *'solitary nature'* of professional work.

| Description | Examples |
|---|---|
| Working alone to prepare and inform and guide patients. | "Everybody [patient and family] went with me to the quiet room… And I just spoke to all of them, like giving a speech." (Resident physician)<br><br>"… I was sort of leading the meeting and the neurologist was just somewhat of a Silent Sam, just allowing me to lead the discussion and not offering a whole lot in the way of support or guidance, which was frustrating because patients who have this condition, this is how the condition goes. By and large this is how their life ends."<br><br>(Staff physician) |
| Reacting to (non) decision-making discussions, rather than working together to support and create conditions for dialogue. | "Often we are picking up the collateral damage of non-decision-making, of non-discussions. Now things are really not going well. A decision needs to be taken right now. So we are more often in that mindframe. It's rare that we are ahead of the ball."<br><br>(Nurse) |
| Feeling unprepared for challenging discussions about existential issues and end-of-life. | "And I can say this with certainty, that there are people, and I've seen it with colleagues as well as students, who are afraid of this: who are afraid of talking about anything related to end of life with people."<br><br>(Staff physician) |
| Nurses remain in the background, behind the scenes. | "I will usually stand behind the curtain and not go on the other side of the curtain and be present with the conversation that's happening. I'll just listen. I won't be a contributor in that conversation. I don't know why I do that. (Nurse)<br><br>"It's usually always been the physician that has that conversation and then we just, reinforce the conversation afterwards." (Nurse)<br><br>"It's out of my hands whether or not it's taken into consideration or not. You can tell residents all they want but if they have something set in their mind that this is going to happen then that's going to happen. Most of the times we can't change their minds. But you never know." (Nurse) |

Appendix 1. Consolidated criteria for reporting qualitative research (COREQ)

Submission to BMJ Open

Title: Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

Authors: J Kryworuchko, PH Strachan, E Nouvet, J Downar, JJ You

| Item | Criteria | Location in manuscript | Response |
|---|---|---|---|
| 1. Interviewer/ facilitator | Which author/s conducted the interview or focus group? | | Kryworuchko and Strachan led the study, Nouvet completed interviews. Downar, You audited analysis. All contributed to final analysis. |
| 2. Credentials | What were the researcher's credentials? *E.g. PhD, MD* | | Kryworuchko and Strachan: PhD Nursing. Nouvet: PhD, Anthropology. Downar: Master's degree in Bioethics, physician. You: Master's degree in Science, physician. |
| 3. Occupation | What was their occupation at the time of the study? | | Kryworuchko, Strachan, Downar, You: Research faculty at Canadian universities. Nouvet: Research Coordinator |
| 4. Gender | Was the researcher male or female? | | 3 female, 2 male |
| 5. Experience and training | What experience or training did the researcher have? | | Kryworuchko and Strachan are registered nurses with extensive experience in the medical ward and critical care settings. Nouvet had no previous experience in the clinical setting. All had qualitative research training and experience, and have published qualitative research. Downar is a researcher and physician with expertise in Internal Medicine, Critical Care Medicine, and Palliative Care Medicine. You is a hospital-based general internist and researcher. |
| 6. Relationship with participants | Was a relationship established prior to study commencement? | | No |
| 7. Participant knowledge of interviewer | What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research* | | Informed of general research goal: to identify barriers and potential solutions to improve communication and decision- |

| Item | Criteria | Location in manuscript | Response |
|---|---|---|---|
| | | | making about goals of care, focusing upon the perspectives of hospital-based physicians and nurses.. |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic* | | Participants knew Nouvet was a research coordinator, and that she was not a clinician. |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* | p. 7 | Interpretive thematic analysis, Critical Incident Technique |
| 10. Sampling | How were participants selected? *e.g. purposive, convenience, consecutive, snowball* | p. 7 | Purposive sampling to ensure balanced representation amongst the three hospital centers, between nurses and physicians, men and women, and amongst clinicians with diverse levels of experience |
| 11. Method of approach | How were participants approached? e.*g. face-to-face, telephone, mail, email* | p. 7 | Email, prior involvement responding to quantitative survey |
| 12. Sample size | How many participants were in the study? | p. 7 | n=30 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | | More people agreed to interviews that the number selected. All people approached agreed to participate in the study. |
| 14. Setting of data collection | Where was the data collected? e.*g. home, clinic, workplace* | p. 8 | In a location of the participant's choice (a private room located close to the hospital ward or in their home) |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | | Participants were interviewed individually |
| 16. Description of sample | What are the important characteristics of the sample? *e.g. demographic data, date* | p. 9, 24 | Professional role and years of experience, site, gender, age, |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | p. 8, 23 | Standard interview guide was developed, piloted and evolved as interviews progressed |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | p. 8 | No |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | p. 8 | Audio recorded |
| 20. Field notes | Were field notes made | p. 8 | Nouvet wrote detailed field |

| Item | Criteria | Location in manuscript | Response |
|------|----------|------------------------|----------|
| | during and/or after the interview or focus group? | | notes directly after each interview. |
| 21. Duration | What was the duration of the interviews or focus group? | p. 8 | 27-91 minutes (mean 47 minutes) |
| 22. Data saturation | Was data saturation discussed? | p. 7 | Yes – data collection ended when saturation was achieved |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | p. 8 | No. Transcripts were reviewed by researchers who listened to the audio recordings to verify their accuracy. |
| 24. Number of data coders | How many data coders coded the data? | p. 9 | 2 analysts coded each transcript independently (Kryworuchko, Strachan, Nouvet) |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | p. 9 | Not explicitly, major themes presented. |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | p. 9 | Derived from the data |
| 27. Software | What software, if applicable, was used to manage the data? | p. 8 | QSR NVivo version 10 |
| 28. Participant checking | Did participants provide feedback on the findings? | p. 8 | No. Auditing of analysis provided by two team members external to the initial analysis (Downar, You) |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number* | p. 9, 25-28 | Quotes presented throughout results and in Tables 2-5. Participants identified by professional role. |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | p. 9 | Yes |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | p. 9 | Yes |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | p. 9 | Yes – word count restrictions did not permit more extensive theme discussion. |

# BMJ Open

## Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

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Manuscripts

Factors Influencing Communication

1

**Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study**

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ABSTRACT

**Objectives**

We aimed to identify factors influencing communication and decision-making and to learn how physicians and nurses view their roles in deciding about the use of life-sustaining technology for seriously ill hospitalized patients and their families.

**Design**

The qualitative study used Flanagan's critical incident technique to guide interpretive description of open-ended in-depth individual interviews.

**Setting**

Participants were recruited from the acute medical inpatient wards at three Canadian hospitals.

**Participants**

We interviewed 30 healthcare professionals (9 staff physicians, 9 residents, and 12 nurses; age 25- 63 years; 73% female) involved in decisions about the care of seriously ill hospitalized patients and their families.

**Measures**

Participants described encounters with patients and families in which communication and decision-making about life-sustaining technology went particularly well and unwell (i.e., critical incidents). We further explored their roles, context and challenges. Analysis proceeded using

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constant comparative methods to form themes independently and with the interprofessional

research team.

**Results**

        We identified several key factors that influenced communication and decision-making

about life-sustaining technology. The overarching factor was how those involved (healthcare

providers, patients, families) conceptualized the goals of medical practice. Additional key factors

related to how preferences and decision-making were shaped through relationships, particularly

how people worked towards 'making sense of the situation', how physicians and nurses

approached the inherent and systemic tensions in achieving consensus with families, and how

physicians and nurses conducted professional work within teams. These key factors interacted in

dynamic and unpredictable ways to influence decision-making for any particular patient and

family.

**Conclusions**

        A focus on more meaningful and productive dialogue with patients and families by (and

between) each member of the healthcare team may improve decisions about life-sustaining

technology. Work is needed to acknowledge and support the non-curative role of healthcare and

build capacity for the interprofessional team to engage in effective decision-making discussions.


STRENGTHS AND LIMITATIONS OF THIS STUDY

- The qualitative component of the mixed method DECIsion-making about goals of care for

    hospitalized meDical patiEnts (DECIDE) study adds depth to the understanding of contextual

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elements that influenced the engagement of healthcare professionals, patients, and families in communication and decision-making about life-sustaining technology

- Flanagan's critical incident technique was an effective mechanism to elicit the broadest range of experiences experienced by participants; however further research is needed to establish the frequency of experiences in the range.

- We interviewed participants in their native language (English or French) and integrated interviews for analysis in the language provided. Translation of French language quotes was only done if they were included in research reports.

- Participants included healthcare professionals most likely to be involved in communication and decision-making about life-sustaining technology, however understanding could be strengthened by including perspectives of social workers, clinical ethicists, and others who work with patients and families in the hospital in future research.

Factors Influencing Communication                                                                                    5

## INTRODUCTION

Seriously ill hospitalized patients and their families should be engaged in decisions about their healthcare in order to ensure that their care meets their needs and preferences. Further, such engagement optimizes patient health. For example, patients who were engaged in decisions experienced less anxiety and depression, less fatigue, and had higher overall quality of life, physical and social functioning, and have better control of diabetes and hypertension[1,2]. As the end of life approaches, decisions about the use of life sustaining technologies (such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission) are implemented for seriously ill patients. However, communication about these treatment options is often poor, and many patients receive care that is inconsistent with their values and preferences[3]. Many authors have described interventions aimed at improving patient/family engagement and improving the match between patient preferences and care delivered[4-14], but these have often been ineffective or poorly adopted outside of the studies where they are tested. The mismatch between patient preferences and the care provided at the end-of-life (a "preference misdiagnosis") occurs when healthcare professionals make a decision about treatment without integrating the informed preferences and priorities of their patients[15-17]. A preference misdiagnosis has important implications for a patient's quality of life and end-of-life care.

In the context of a broader research program to improve end-of-life care for seriously ill patients, we conducted a mixed-methods study called DECIsion-making about goals of care for hospitalized meDical patiEnts (DECIDE). The study involved a cross-sectional survey of physicians and nurses from 13 hospitals in five Canadian provinces, as well as open-ended qualitative interviews with physicians and nurses from three of these hospitals[18]. The mixed methods design sought to understand factors which affect communication and decision-making

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about life-sustaining technology from the perspectives of healthcare providers and offer

suggestions for potential solutions, through the collection of complementary quantitative and

qualitative data.

The quantitative component of DECIDE found that that a range of professionals (i.e.

nurses, social workers) supported key decision-making activities, such as initiating discussions

and decision coaching. Participating healthcare providers felt it was most acceptable for staff

physicians to make the final determination about the use or non-use of life-sustaining technology

with patients and their families. Physician and nurse participants related that family- and patient-

related factors were the most important barriers, whereas barriers related to their skills and

system factors were relatively less important[18].

In this qualitative component, we sought to provide richer, more nuanced data than what

could be obtained through the survey methods. Specifically, we aimed to explore physicians' and

nurses' experiences, with a view to identifying rich description of their roles and factors

influencing communication and decision-making with seriously ill hospitalized patients and their

families.

**METHODS**

**Study Design**

The qualitative study used Flanagan's critical incident technique (CIT) and interpretive

description of open-ended interviews[19,20]. Interviews were conducted between 2012 and 2013

with staff physicians, residents, and nurses (n=30) who provide care to patients admitted to the

acute medical inpatient ward at one of three large Canadian hospitals. The goal of CIT is to

explore specific incidents with those who have lived them and to uncover assumptions, values, or

impacts that participants may not themselves appreciate. Strengths of the CIT are that it commonly elicits very effective or very ineffective practices and aims to provide findings that are highly focused on solutions to practical problems[21].

**Setting and Participants**

Qualitative study participants were purposively recruited at hospitals from three Canadian provinces (Ontario, Quebec, Alberta) and included English- and French-speaking facilities for a more nationally representative sample. Eligible professionals for inclusion were staff physicians, residents, and nurses who cared for seriously ill patients and their families in the acute medical inpatient ward setting, which are patient care units where patients with non-surgical serious illness are admitted when they cannot be managed in the outpatient setting. Participant recruitment took place in parallel with and aided by the DECIDE quantitative (questionnaire-based) study. Professionals received an email about the study and indicated their willingness to participate in a subsequent individual interview in the quantitative DECIDE survey. We selected participants to ensure balanced representation amongst the three hospital centers, between nurses and physicians, men and women, and amongst clinicians with diverse levels of experience. We obtained research ethics board approval at each participating site; all participants gave informed consent before taking part.

**Data Collection**

Individual interviews at all sites were conducted by the same experienced qualitative interviewer in a location of the participant's choice (a private room located close to the hospital ward or in their home). Each participant provided one audio recorded interview lasting between 27-91 minutes (mean 47 minutes). The interviewer used a standard introduction and set of

questions, and the research team added additional prompts as the interviews progressed (Figure

1). During the in-depth interviews, participants were invited to describe specific encounters with

patients and families in the acute medical inpatient ward setting in which discussions about the

use or non-use of life-sustaining technology went particularly well and unwell (i.e. critical

incidents). We further explored participants' perceptions of professional roles and the context

and challenges encountered by healthcare professionals, patients, and their families. The

interviewer wrote detailed field notes, to record what stood out for her, immediately after each

interview. We transcribed audio recorded interviews verbatim and audited transcripts for

accuracy. Both transcripts and field notes were organized in NVIVO 10 to facilitate data

management.

**Analysis**

The team developed a codebook by reviewing critical incidents to code them inductively

into themes. We coded the data, and met frequently to discuss, challenge and make decisions

about codes and to interpret emerging findings. We further refined interview questions and

prompts for subsequent interviews using synchronous distance technology (Skype) after each set

of two or three interviews. We integrated all passages into the coding framework in their native

language. In particular, two bilingual investigators analyzed French interviews. Translation of

specific representative quotes into English, preserving the participants meaning, was done by the

researchers only to communicate results in written English communication/publications. We

worked together in an analytic process that involved synchronous and asynchronous meetings to

reflect on the evolving conceptual framework in light of new interview data and increased

immersion in the data. The draft code book evolved throughout the study and included key

themes, sub-themes, and their definitions. The names and descriptions of key themes changed,

collapsed and expanded based on new data, and considering the context of previous data. The

four factors presented here represent key themes in the interview data, sub- themes are described

as they relate to each of the key themes.

Saturation in is achieved when adding 100 critical incidents to the sample contributes

only 2 or 3 more themes to the analysis[19]. In our study, a total of 30 interviews conveyed data

about 120 critical incidents (mean 4, range 2 – 9 critical incidents). We considered the data

categories had reached saturation since the first 4 interviews provided 18 critical incidents and all

but two themes to the description of factors influencing communication and decision-making

process; the remaining 26 participants described a further 102 critical incidents. We did not add

new themes to the analysis in the last 20 interviews.

In summary, we used constant comparative methods combining independent and then

group analysis. Auditing by a team member external to original analysis ensured themes fit with

data. We continued until analysis indicated we had reached saturation.

**RESULTS**

A total of 30 individuals participated, 10 from each of three in-patient medical teaching

units (Quebec, Ontario, Alberta): 9 staff physicians, 9 residents, and 12 nurses (Table 1).

Participants were 25 to 63 years (mean 39 years), and mainly female (73%) - a distribution

skewed by the high representation of female nurses (11 out of 12 in the study). We found that

while participants' accounts reflected their different perspectives based on their different levels

of experience and professional identities, certain key themes were prominent across participant

categories (12 nurses, 9 residents and 9 staff physicians).

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We found several key factors influenced communication and decision-making about life-sustaining technology. The overarching factor was how people conceptualized the goals of medical practice. Other factors related to how a patient or family's choice was shaped by their relationships, particularly how people worked towards 'making sense of the situation', how physicians and nurses approached the inherent and systemic tensions in achieving consensus with families, and how professional work regarding end-of-life issues was conducted within acute medical unit teams (Table 2). These contextual elements influenced the engagement of healthcare professionals, patients, and families and had significant implications for the quality of communication and decision-making about the use of life-sustaining technology. Participants described incidents in which these factors interacted in dynamic and unpredictable ways to influence decision-making for any particular patient and family.

**Factor 1: Conceptualizations of medical practice as '*saving lives and warding off death*'**

Death and dying were spoken of as largely a culturally taboo topic in hospitals. Participants' attitudes towards end-of-life communication and decision-making reflected a dominant cultural, economic construction of hospitals, doctors, medicine as primarily about saving lives: warding off death, <u>*not*</u> overseeing the dying (Table 2). Participants' descriptions reflected a general assumption on their part and the part of patients and families that patients were admitted for hospital care to regain health, not to die. Care continued under this assumption until death was imminent. Importantly, participants described a norm of discussions being avoided until doctors (and sometimes nurses) recognized that life-saving interventions were increasingly futile and that death could not be postponed. Physicians and nurses characterized communications with patients or more often families as difficult and stressful when they felt the urgency to communicate with families primarily to prevent delivery of futile care. Discussions

about life-sustaining technology at such late points in the patient's life (or illness) focused on

*"getting the DNR [do not resuscitate]" (Resident Physician)*, and writing it in the chart.

Throughout the interviews, many participant accounts conveyed existential issues with

regards to witnessing suffering and managing the dying patient, and the perceived failure of

medical expertise. Mainly, since such discussions were equated with death and dying, healthcare

professionals often waited to have these decision-making conversations until there was, in their

words, '*nothing to be done'* for the patient. When this happened, the timing of communication

resulted in disclosure that the patient was almost certainly dying.

**Factor 2: Work towards '*making sense of the situation*'**

We found that *'making sense of the situation'* was work and a process that was essential

to advancing decision-making (Table 3). Participants described progress in decision-making as

contingent on having been able to make sense of a patient's situation. Work towards *'making*

*sense of the situation'* involved a process of establishing a relationship, knowing them over time,

and integrating information about the patient's health and treatment options with (ideally the

patients') illness beliefs and (ideally the patients') goals of care. In cases that went well, dialogue

with patients and/or families created opportunities to construct a shared understanding of the

patient's situation and the use of life-sustaining technology. A perceived failure to be

emotionally ready for discussions or to make sense of the situation caused patients, families

and/or healthcare professionals to '*get stuck'* and be unable to progress towards a decision. This

contributed to delays in even initiating decision-making, and was perceived by nurses as a

missed opportunity to ease patient and family suffering.

In their examples of discussions that went well, both physicians and nurses saw it as their

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role to facilitate this process. They described work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. When physicians struggled to make sense of the situation, often due to uncertainty about prognosis or the reversibility of the patient's condition, they delayed initiating the decision-making process. Both physicians and nurses reported experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering.

**Factor 3: Inherent and systemic tensions in achieving consensus about the goal of care**

An important contextual factor was that, in the face of patient suffering and imminent death, participants perceived that patients and families were emotional, even irrational at times. Patients and families were defined as 'difficult' based on what physicians and nurses saw as their inability to understand or accept the situation. Further, being difficult was linked to a failure to come quickly on board with the plan the physician saw as ethically and clinically appropriate. Engaging such patients and families in the decision-making process could be particularly challenging. Nurses who were left behind with patients and families in the wake of heated discussions between physicians and patients wanted more strategies for managing their stress and for speaking to stressed families.

In addition to the stress and challenges that are inherent to achieving consensus among patient, family and their healthcare team about the use of life-sustaining technology (Table 4), our data points to systemic limitations to consensus building and shared decision-making with patients and families. Achieving consensus is intricately interwoven with '*making sense of the situation*' (described above). Making sense of a situation requires some reflection and processing of information. The invitation to patients and families to make sense of dying is routinely

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occurring when active care has already been determined by healthcare team members to be futile; this can be very late. As noted above (Factor 1), situations described as challenging revealed that healthcare professionals tended to flag patients as urgently requiring goals of care discussions when patients were beyond rescue and often facing imminent death.

In cases where participants described a team-based approach to communication and decision-making, participants prioritized *"getting on the same page"* to establish agreement within the team, before engaging patients and families. Team discussion focused on ensuring all relevant information was gathered before a discussion with family, and was emphasized as important to avoid patients and families being exposed to conflicting messages. The problem is that where goals of care communication and decision-making is occurring within such a compressed time frame, as seems to be the norm at study sites, patients and families may have even less time than healthcare team members to make sense of circumstances and thus meaningfully engage in decision-making. Such conditions could render patients and families emotional, irrational, or 'difficult'. Moreover, one can presume it would be more difficult for healthcare team members to defuse stressful communications when they are themselves feeling pressure to adjust the patient's care plan before the patient dies and/or is exposed to futile measures.

What seems to be key here, is that when communications with families did not go well, most nurses and physicians did not have the experience and skill set to unblock tense disagreements, nor did they have much time to do so. Not surprisingly, participants defined as easy those decisions where both healthcare professionals and the patient and their family had constructed the same meaning about the situation before a patient arrived in hospital or before a discussion: *"It's easy when everyone is thinking the same thing"* (Staff Physician).

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Factor 4: **Approaches to professional work within teams**

In their examples of critical incidents, participants contrasted a '*team-based approach*' with the '*solitary nature'* of professional work. The Overall, the institutional/practical construction of communication and decision-making about life-sustaining technology was solitary and physician-centered (Table 5). While some participants described instances of a team-based approach for a specific individual patient, a majority of participants perceived communications as the physicians' responsibility as opposed to a team responsibility. Participants described physicians who largely worked alone and asynchronously from other team members to prepare, inform, and guide patients and families through decision-making. Leading emotional end-of-life discussions alone placed a great deal of pressure on physicians, especially residents.

Descriptions of nursing work were largely absent in physicians' narratives, even when invited to reflect on nurses and other health professionals' roles. For most participants, work done by nurses was not recognized as contributing to communication and decision-making about life-sustaining technology (even for nurses themselves). Nurse participants described their work as happening asynchronously around physicians' encounters. They described preparing the groundwork for physicians' discussions about life-sustaining technology, as well as "*picking up the pieces*" after physicians delivered unexpected prognostic news and decisions.

Most participants highlighted their recognition of the value of team-based approaches to goals of care communication and decision-making. Nurses and residents continue to feel isolated in the work they did connected to goals of care discussions. Where residents acknowledged the importance of more training, a number of nurses felt it would be beneficial to patients for nurses

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to be more fully informed and even included in physician-led goals of care discussions with

patients and family.  Mentorship, modeling, and support to develop the necessary skills to

engage patients and families in productive discussions were frequently raised by participants.

Most physicians are well prepared for 'breaking bad news', but less so for 'breaking bad news'

to patients and families who were too distressed to listen to a 15-minute presentation and

recommendation of care. More experienced physicians shared strategies to help patients and

families be ready for these discussions. For example, two physicians in different cities advocated

for a "step-wise" approach. They gently planted the seeds that a decision would soon need to be

taken by commenting on the patient's declining health. They emphasized to their residents that

patients and families needed time to adjust to a prognosis. Another physician stressed the

importance of being present for these conversations: turning the phone off, putting time aside for

this serious conversation, and listening to what the patient or family had to say. Many senior

physicians explicitly included junior residents in discussions about the use or non-use of life-

sustaining technology. They knew that residents experienced more stress in these conversations

and required particular abilities to listen to, and respond to, families.

**DISCUSSION**

        The evolution of decision-making about life-sustaining technology for any particular

patient were influenced by social constructions of medical practice as life saving, an existential

and practical need to 'make sense of the situation' together, inherent and systemic tensions in

achieving consensus, and the solitary nature of professional practice in the medical teaching unit.

Indeed, it seemed that three conditions were present for a decision that "went well": 1) the

patient needed to be beyond rescue, 2) the "correct" option needed to be clear to healthcare

professionals, patients and families, who also needed 3) to agree about goals of care and the

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interventions that should be used to achieve those goals. Unfortunately, these three conditions

are rarely present in the medical ward setting. Prognosis is hard to establish for seriously ill

patients[22], and physician perceptions of prognostic certainty affect the timing of decision making

[23].

The social construction of medical practice as *'saving lives and warding off death'*

reported by participants in this study, has significant implications for the quality of

communication about life-sustaining technology. First, the presumption within such a

construction of medical practice is that a life-saving focus is logical and by default in the

patient's best interest.   This is contrary to evidence that shows that at the end-of-life, palliative

care approaches result in the same or better quality of care and better health outcomes than high

intensity and costly life-sustaining technology care[24]. Essentially, what is important to note is

that with an equation of medical care as life-saving care, warding off death dominates decision-

making in the hospital ward. Only when death cannot be warded off, is communication with

patients and families about goals and end-of-life care needed, and this is communication aimed

primarily at preventing life-sustaining care, which at that point is considered futile[25]. Preventing

delivery of futile care is a provider centered problem, and is intensified for healthcare

professionals for whom death becomes personal and uncomfortable.

Our findings echo other studies that have found that while patients and families desire

involvement in decision-making[26,27], they are seldom presented with alternatives to life-

sustaining technology[28]. Framing alternatives as '*there was nothing to be done'* corresponds to

the social construction of medical practice as '*saving lives and warding off death'*. Such wording

perpetuates the assumption that non-lifesaving care is equivalent to failure or abandonment[29].

We caution that language such as '*nothing to be done'* is unhelpful in that it frames non-

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aggressive healthcare, including nursing care, pain management, and palliative care, as nothing.

This leaves little room for strategizing, valuing, and improving the work that is involved in

comfort care. Reframing this message to what *we can provide* is critical to conveying to patients

and families that we will not abandon them.

While clinicians felt it was crucial to know a patient's code status to prevent futile care,

this may be a low priority for patients/families. A focus on more meaningful and productive

dialogue with patients and families is needed. We found that work towards "*making sense of the*

*situation*" was central to the decision-making process and was most effective (i.e. incidents that

went well) when dialogue occurred with others. Establishing relationships with patients and

families is a key element of the process, and occurred alongside the process of meaning making.

Participants' narratives described the search for meaning in the situation by healthcare

professionals, patients and families. Individual understandings of circumstances and

opportunities for health were developed in dialogue with patients and families and their

healthcare professionals (or between healthcare professionals). We suggest that work '*getting*

*everyone on the same page*' should fully involve patients and their families. The quantitative

survey results of the larger DECIDE mixed method study[18], which highly ranked patient/family-

related barriers as impeding communication and decision-making, are reflected in the stories of

patients and families who struggled to make sense of the decision and context they were facing.

And, since it is likely that patients and families will experience grief and loss with changing

health status[30], we should expect that for patients and families, making sense of illness will

require time and support from their healthcare team. In contrast, we found that the heavy result-

oriented agenda inherent in "*getting the DNR*" seemed to abbreviate communication and

minimize the engagement of patients and families. This important dialogue should not be rushed

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or hurried to 'get a code status', especially when the box checked on the order sheet has such

enormous implications for the patient's future well-being. We suggest that an organized

approach to supporting early dialogue between healthcare professionals, patients, and their

family members is needed; shared decision making facilitate the integration of information about

options with the patient's values and preferences [31,32]. We know that such dialogue occurs in

complex environments, where listening to the patient and their family is essential to providing

care that fits best for each person at the end-of-life [13,33-39]. While some of the findings are known

from research in critical care settings (eg. the importance of supporting team-based approaches

or structured family involvement)[40-45], the acute medical ward setting is very different (eg.

higher nurse patient ratios, more daily admissions and discharges). Additionally, patients are

more likely to be able to participate in decision-making than patients in critical care settings.

Taken together, features of the acute medical ward setting may necessitate different strategies to

optimize patient and family engagement.

Overall, there was an impoverished understanding of the potential for interprofessional

practice. While our earlier survey findings described the perception that everyone *could* get

involved[18], qualitative findings suggest that this is not yet happening. Participants described

usual conditions in which they tended to work in isolation from other professionals and were

unclear about each others' roles. While other professionals roles were invisible to most

participating physicians, nurses could articulate related nursing work. Overwhelmed physicians

believed that they worked alone with patients and families throughout the decision-making

process, which is consistent with other research in the medical teaching unit setting[46]. However,

interprofessional collaboration can decrease professionals' distress[47], and therefore it is possible

that interprofessional collaboration in decision-making could maximize the opportunity to share

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the emotional burden of providing care, and to receive support from colleagues. Identifying optimal team roles may be an important first step in developing an intervention tailored to the clinical setting that would support patients, families and health providers in navigating this necessary, yet emotionally challenging territory.

A number of key factors speak to the importance of better supporting resident physicians in the acute medical ward setting. We know that as these Canadian residents advance throughout their training, they become more autonomous to make important decisions without reviewing them first with the staff physician (they would review in retrospect). In theory, attending physicians should not allow a junior learner to be unsupervised when engaging in activities for which they have not demonstrated some baseline level of competency. However, in practice there are varying levels of supervision for a whole range of clinical activities (not just for DNR orders) from one staff physician or one institution to the next depending on personal / local practice patterns. As well, we could not identify "gold standard" criteria for declaring a junior resident as being "competent" to lead decision-making about the use of life sustaining technologies. Such competence would likely be assessed on a continuum, which would further complicate any declaration of competence, as well as further contribute to inconsistent supervision patterns. In Canada, the orders that are written based on these discussions are binding (unless the issue gets raised again by someone else). A combination of these and other factors may lead to situations where relatively inexperienced physicians are having end-of-life discussions on their own. Strategies that better support resident physicians (and others) in the acute medical ward setting were welcomed and suggested by participants in our study.

Participants shared some strategies that worked more effectively to engage patients and families - for example, making time, sharing support roles, explicitly helping families make

meaning and progress in decision-making. In their stories of what went well, participants

engaged with and managed conflict within interprofessional teams and during challenging family

situations. In such situations, the team proactively supported patients and their families to make

sense of the situation, to understand recommendations, and supported them to make decisions.

Such support requires excellent communication skills, therefore like others[44,45,48], we advocate

for improved communication training for healthcare professionals. We also recognize that the

clinical teaching unit needs an organizational culture that supports decision-making processes

that will work under the conditions of usual practice. Institutional guidelines or standard

operating procedures with linked quality indicators might be helpful to promote an effective

team-based approach to communication and decision-making for the acute medical ward setting.

Several factors may limit the transferability of this research. First, not all perspectives of

healthcare professionals in the medical ward setting are represented by this work. Further

research should include the views of social workers, clinical ethicists, and others who work with

patients and families in the hospital. Second, our results may not be transferable to other

healthcare settings or other countries. We provide quotes to help readers decide whether our

experience resonates with their settings.

**CONCLUSIONS AND RELEVANCE**

An integrative approach to decision-making about the use of life-sustaining technology,

that acknowledges and supports the non-curative role of healthcare and hospitals, is needed. We

must strengthen the interprofessional team's capacity to cope with and communicate about

uncertainty to patients and families, discuss related existential issues, and support patients and

families who are suffering as they make decisions about care in advanced serious illness. The

qualitative component of the mixed method DECIDE study adds depth to the understanding of

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contextual elements that influenced the engagement of healthcare professionals, patients, and

families. This understanding about context is key to developing improvement strategies that

harness the potential and actual roles of healthcare professionals.

**Authorship Statement**

JK and PHS designed the qualitative study, analyzed and interpreted data, drafted and

revised the manuscript and approved the final version for publication. EN conducted interviews

and analyzed and interpreted the data, revised the manuscript and approved the final version for

publication. JJY contributed to the design of the study, obtained funding, and both JJY and JD

audited the analysis and interpreted the data, revised the manuscript and approved the final

version for publication. JK, PS, and EN had full access to all of the data in the study and take

responsibility for the integrity of the data and the accuracy of the data analysis. All authors agree

to be accountable for all aspects of the work in ensuring that questions related to the accuracy or

integrity of any part of the work are appropriately investigated and resolved.

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work in the previous three years; no other relationships or activities that could appear to have

influenced the submitted work.

**Data Sharing Statement**

No additional data available.

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**TABLES**

**Table 1**. Participant demographics

| Characteristics | Staff physicians (n=9) | Residents (n=9) | Nurses (n=12) | TOTAL (n=30) |
|---|---|---|---|---|
| Female | 6 (67%) | 5 (55%) | 11 (92%) | 22 (73%) |
| Experience | | | | |
| <5 yrs | 2 (22%) | 9 (100%) | 4 (33%) | 15 (50%) |
| 5-10 yrs | 0 (0%) | 0 (0%) | 3 (25%) | 3 (10%) |
| 10+ yrs | 7 (78%) | 0 (0%) | 5 (42%) | 12 (40%) |
| Hospital | | | | |
| Ontario | 3 (33%) | 3 (33%) | 4 (44%) | 10 (33%) |
| Alberta | 3 (33%) | 4 (44%) | 3 (25%) | 10 (33%) |
| Quebec | 3 (33%) | 2 (22%) | 5 (42%) | 10 (33%) |

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**Table 2**. Conceptualizations of medical practice as '*saving lives and warding off death*'

| Description | Examples |
|---|---|
| Dominant cultural, economic construction of hospitals, doctors, medicine as being officially about saving lives: warding off death, not overseeing the dying. | "I think one of the things that's important is we go into this profession and, you know, doctors it's all about we need to fix things, and we need to, you know, cure things. That's kind of the mindset we have. And we sometimes lose sight of the fact that we can't actually fix everything." (Staff Physician)<br><br>"It's as though for the physicians it's always life at any cost. Always. They are always focused on saving lives. Death is like a failure. It's not something we talk about." (Nurse)<br><br>"One of the daughters was angry. She was saying we were abandoning her mother. That we weren't allowed to do that. That we had to keep it up until the end." (Nurse) |
| Discussions avoided until life-saving was not possible, or death occurred | "It's usually a pretty clear next step. Like the person is probably hours from dying and they change them to comfort [care]. Often it's that close." (Nurse)<br><br>"A lot of times when the physician is having that conversation on a medical unit, it's when things have gone badly, when things have changed, when the patient is doing poorly so the family is really distressed about how their family member is doing." (Nurse) |
| Discussions focused on 'getting the DNR' | "I think we get task oriented. We want to get to a goal of care because we think it's appropriate, and we just want enough from the patient to justify in our own minds that they're in agreement with that. And I'm not sure, in an informed consent way, that that's enough." (Staff Physician) |
| Professionals' identity wrapped up in ideas of saving lives | "The residents say 'She's really sick, and she's not doing well.' 'Yeah, but we're doing everything. We are doing everything, and the rest is because the person is failing. It's not because we're failing.' So changing that mindset from we should be able to cure everybody all the time, and nobody should ever die which is crazy, right? Doesn't make sense." (Staff Physician) |

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**Table 3**. Work towards '*making sense of the situation*'

| Description | Examples |
|---|---|
| Focus on getting to know the patient and their personal life story | "We know everything medically about them, but we don't know their story and we don't know what informs the decisions they've made to this point and sometimes it can be as simple a thing as they had a really bad illness when they were young, and they got better, therefore they're going to get better this time." (Resident Physician) |
| Recognizing that the patient has a unique interpretation of what is happening, and what a 'correct' course of action might be is individual | "We're not the patient and although we have our own opinion about what is the best thing to do but regardless that's... you know, the goal should be to try to make the patient make the decision with our help in terms of trying to choose the best thing" (Resident physician). |
| Work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. | "They've just been told something potentially devastating. So you've got to ask how much they actually retained. So that's usually the best place. So gleaning a bit of an insight into what they understand, what they retain, what this means to them, or what they're understanding it means, is probably the biggest step for the nurse to take after they've had that change. (Nurse) |
| Experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering | "I went in, and I saw the patient and I literally had tears in my eyes. It's like oh my gosh, I cannot believe that this body still has a soul living in it because it was terrible. And yet I wanted to be very respectful of the decision maker who I thought had a very valid perspective. So there's that conflict sometimes of perspective. I think I realize people just need time to absorb things." (Staff Physician) |
| To make a recommendation for care, healthcare professionals also needed to establish meaning. | "Sometimes it's denial; sometimes it's that we don't have time, or sometimes it's about us, we're not comfortable making that decision either. If we aren't... if I am not sure of the prognosis, if I think they might get better through some intervention, but at the same time there's other factors, like the intervention is pretty invasive, then in those cases [we delay the decision]." (Resident Physician) |

**Table 4.** Inherent and systemic tensions in achieving consensus

| Description | Examples |
|---|---|
| Easy decisions were preceded/accompanied by work 'making meaning' together | "It's easy when everyone is thinking the same thing" (Staff Physician) |
| Perceived failure to progress towards meaning making or be emotionally ready for discussions led to delays in (initiating) potentially supportive discussions and decision-making. | "I had numerous conversations with the family, the husband particularly; it was his wife that was sick and very ill. He made a lot of comments that this person was his life and he couldn't live without her and all these things and so I started to wonder if we were more treating him instead of her for her symptoms. Anyway there was never any discussion over the next few weeks of goals of care, and they kept treating her and treating her and treating her. And I understand then, maybe two or three weeks after, then she coded, and she died later that day. I had had some struggles talking to the doctors that I worried if we hadn't broached the subject ahead of time then we weren't really helping to treat or ease this man's grief or the patient's suffering." (Nurse) |
| Holding strong opinions contributed to less discussion and dialogue, ultimately making it harder to reach agreement | "It becomes more problematic when people are demented, and you've got, I think it's less common now, but I ran into a public guardian once who would not change the level of care in those days and I resigned from the case, told them to get another doctor because I thought it was inhuman keeping an absolute vegetable alive, you know." (Staff Physician) |
| Working at cross purposes with patient's priorities and goals | "There was one time when neither the family nor the patient wanted any aggressive care. She was really not doing well. She had spoken clearly, as had her family. I had to call the physicians back in because we had been told to kick off a battery of antibiotics, take blood, get tests, this, that, and the family was not happy. And the physicians told them that it was pneumonia, that it was reversible which is why they were proceeding the way they were. But the family and the patient didn't want that." (Nurse) |

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**Table 5**. Approaches to professional work within teams

| Description | Examples |
|---|---|
| Working alone to prepare and inform and guide patients. | "Everybody [patient and family] went with me to the quiet room… And I just spoke to all of them, like giving a speech." (Resident physician)<br><br>"… I was sort of leading the meeting and the neurologist was just somewhat of a Silent Sam, just allowing me to lead the discussion and not offering a whole lot in the way of support or guidance, which was frustrating because patients who have this condition, this is how the condition goes. By and large this is how their life ends."<br><br>(Staff physician) |
| Reacting to (non)decision-making discussions, rather than working together to support and create conditions for dialogue. | "Often we are picking up the collateral damage of non-decision-making, of non-discussions. Now things are really not going well. A decision needs to be taken right now. So we are more often in that mind frame. It's rare that we are ahead of the ball."<br><br>(Nurse) |
| Feeling unprepared for challenging discussions about existential issues and end-of-life. | "And I can say this with certainty, that there are people, and I've seen it with colleagues as well as students, who are afraid of this: who are afraid of talking about anything related to end of life with people."<br><br>(Staff physician) |
| Nurses remain in the background, behind the scenes. | "I will usually stand behind the curtain and not go on the other side of the curtain and be present with the conversation that's happening. I'll just listen. I won't be a contributor in that conversation. I don't know why I do that. (Nurse)<br><br>"It's usually always been the physician that has that conversation and then we just, reinforce the conversation afterwards." (Nurse)<br><br>"It's out of my hands whether or not it's taken into consideration or not. You can tell residents all they want but if they have something set in their mind that this is going to happen then that's going to happen. Most of the times we can't change their minds. But you never know." (Nurse) |

**Figure 1. Interview guide with prompts**

Interview introduction: *"Communication and decision-making about goals of care includes decisions about the use of life sustaining technologies at the end of life, such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission.*

*Can you tell me of an experience you have had with a patient or their family in which communication and decision-making about goals of care and the use of life-sustaining technologies went particularly well?*

*Can you tell me of an experience you have had where communication and decision-making about goals of care and the use of life-sustaining technologies did not go well?"*

**Examples of prompts**

1. About critical incident: What in particular defines this experience for you as a good/bad one? What made it easy/difficult? Where was this happening? What happened in this case? What was the outcome?
2. About participant role: What was your role in any meetings with the patient or their family? Is it normal for you to play this role? Did you do anything to get yourself, other members of the medical team, the family or the patient ready for discussing or deciding on goals of care? Is this normal?
3. About others' roles: What other members of the medical team were involved in the discussion(s) of goals of care and the use of life-sustaining technologies in this case? What were their roles? How did they become involved? What role does the nurse or do the nurses play, in your experience? Are nurse usually informed of upcoming family meetings?
4. About factors influencing decision –making: Are there certain circumstances that make discussions about goals of care of life-sustaining technologies particularly difficult, either for you or for the patient or their family? What makes it easier for families or patients to be actively involved in communication and decision-making about goals of care and life-sustaining technologies?

Figure 1. Interview guide with prompts
179x186mm (300 x 300 DPI)

Appendix 1. Consolidated criteria for reporting qualitative research (COREQ)

Submission to BMJ Open

Title: Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

Authors: J Kryworuchko, PH Strachan, E Nouvet, J Downar, JJ You

| Item | Criteria | Location in manuscript | Response |
|---|---|---|---|
| 1. Interviewer/ facilitator | Which author/s conducted the interview or focus group? | | Kryworuchko and Strachan led the study, Nouvet completed interviews. Downar, You audited analysis. All contributed to final analysis. |
| 2. Credentials | What were the researcher's credentials? *E.g. PhD, MD* | | Kryworuchko and Strachan: PhD Nursing. Nouvet: PhD, Anthropology. Downar: Master's degree in Bioethics, physician. You: Master's degree in Science, physician. |
| 3. Occupation | What was their occupation at the time of the study? | | Kryworuchko, Strachan, Downar, You: Research faculty at Canadian universities. Nouvet: Research Coordinator |
| 4. Gender | Was the researcher male or female? | | 3 female, 2 male |
| 5. Experience and training | What experience or training did the researcher have? | | Kryworuchko and Strachan are registered nurses with extensive experience in the medical ward and critical care settings. Nouvet had no previous experience in the clinical setting. All had qualitative research training and experience, and have published qualitative research. Downar is a researcher and physician with expertise in Internal Medicine, Critical Care Medicine, and Palliative Care Medicine. You is a hospital-based general internist and researcher. |
| 6. Relationship with participants | Was a relationship established prior to study commencement? | | No |
| 7. Participant knowledge of interviewer | What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research* | | Informed of general research goal: to identify barriers and potential solutions to improve communication and decision- |

| Item | Criteria | Location in manuscript | Response |
|------|----------|------------------------|----------|
| | | | making about goals of care, focusing upon the perspectives of hospital-based physicians and nurses.. |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic* | | Participants knew Nouvet was a research coordinator, and that she was not a clinician. |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* | p. 7 | Interpretive thematic analysis, Critical Incident Technique |
| 10. Sampling | How were participants selected? *e.g. purposive, convenience, consecutive, snowball* | p. 7 | Purposive sampling to ensure balanced representation amongst the three hospital centers, between nurses and physicians, men and women, and amongst clinicians with diverse levels of experience |
| 11. Method of approach | How were participants approached? e.*g. face-to-face, telephone, mail, email* | p. 7 | Email, prior involvement responding to quantitative survey |
| 12. Sample size | How many participants were in the study? | p. 7 | n=30 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | | More people agreed to interviews that the number selected. All people approached agreed to participate in the study. |
| 14. Setting of data collection | Where was the data collected? e.g. *home, clinic, workplace* | p. 8 | In a location of the participant's choice (a private room located close to the hospital ward or in their home) |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | | Participants were interviewed individually |
| 16. Description of sample | What are the important characteristics of the sample? *e.g. demographic data, date* | p. 9, 24 | Professional role and years of experience, site, gender, age, |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | p. 8, 23 | Standard interview guide was developed, piloted and evolved as interviews progressed |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | p. 8 | No |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | p. 8 | Audio recorded |
| 20. Field notes | Were field notes made | p. 8 | Nouvet wrote detailed field |

| Item | Criteria | Location in manuscript | Response |
|---|---|---|---|
| | during and/or after the interview or focus group? | | notes directly after each interview. |
| 21. Duration | What was the duration of the interviews or focus group? | p. 8 | 27-91 minutes (mean 47 minutes) |
| 22. Data saturation | Was data saturation discussed? | p. 7 | Yes – data collection ended when saturation was achieved |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | p. 8 | No. Transcripts were reviewed by researchers who listened to the audio recordings to verify their accuracy. |
| 24. Number of data coders | How many data coders coded the data? | p. 9 | 2 analysts coded each transcript independently (Kryworuchko, Strachan, Nouvet) |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | p. 9 | Not explicitly, major themes presented. |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | p. 9 | Derived from the data |
| 27. Software | What software, if applicable, was used to manage the data? | p. 8 | QSR NVivo version 10 |
| 28. Participant checking | Did participants provide feedback on the findings? | p. 8 | No. Auditing of analysis provided by two team members external to the initial analysis (Downar, You) |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number* | p. 9, 25-28 | Quotes presented throughout results and in Tables 2-5. Participants identified by professional role. |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | p. 9 | Yes |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | p. 9 | Yes |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | p. 9 | Yes – word count restrictions did not permit more extensive theme discussion. |

## Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

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Factors Influencing Communication

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**Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study**

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Factors Influencing Communication                                                                                    2

ABSTRACT

**Objectives**

We aimed to identify factors influencing communication and decision-making and to learn how physicians and nurses view their roles in deciding about the use of life-sustaining technology for seriously ill hospitalized patients and their families.

**Design**

The qualitative study used Flanagan's critical incident technique to guide interpretive description of open-ended in-depth individual interviews.

**Setting**

Participants were recruited from the medical wards at three Canadian hospitals.

**Participants**

Interviews were completed with 30 healthcare professionals (9 staff physicians, 9 residents, and 12 nurses; age 25- 63 years; 73% female) involved in decisions about the care of seriously ill hospitalized patients and their families.

**Measures**

Participants described encounters with patients and families in which communication and decision-making about life-sustaining technology went particularly well and unwell (i.e., critical incidents). We further explored their roles, context and challenges. Analysis proceeded using constant comparative methods to form themes independently and with the interprofessional research team.

## Results

We identified several key factors influenced communication and decision-making about life-sustaining technology. The overarching factor was how those involved in such communication and decision-making (healthcare providers, patients, families) conceptualized the goals of medical practice. Additional key factors related to how preferences and decision-making were shaped through relationships, particularly how people worked towards 'making sense of the situation', how physicians and nurses approached the inherent and systemic tensions in achieving consensus with families, and how physicians and nurses conducted professional work within teams. Participants described incidents in which these key factors interacted in dynamic and unpredictable ways to influence decision-making for any particular patient and family.

## Conclusions

A focus on more meaningful and productive dialogue with patients and families by (and between) each member of the healthcare team may improve decisions about life-sustaining technology. Work is needed to acknowledge and support the non-curative role of healthcare and build capacity for the interprofessional team to engage in effective decision-making discussions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The qualitative component of the mixed method DECIsion-making about goals of care for hospitalized meDical patiEnts (DECIDE) study adds depth to the understanding of contextual elements that influenced the engagement of healthcare professionals, patients, and families in communication and decision-making about life-sustaining technology

Factors Influencing Communication                                                         4

- Flanagan's critical incident technique was an effective mechanism to elicit the broadest range of experiences experienced by participants; however further research is needed to establish the frequency of experiences in the range.

- We interviewed participants in their native language (English or French) and integrated interviews for analysis in the language provided. Translation of French language quotes was only done if they were included in research reports.

- Participants included healthcare professionals most likely to be involved in communication and decision-making about life-sustaining technology, however understanding could be strengthened by including perspectives of social workers, clinical ethicists, and others who work with patients and families in the hospital in future research.

Factors Influencing Communication                                                                                                      5

## INTRODUCTION

Seriously ill hospitalized patients and their families should be engaged in decisions about their healthcare in order to ensure that their care meets their needs and preferences. Further, such engagement optimizes patient health. For example, patients who were engaged in decisions experienced less anxiety and depression, less fatigue, and had higher overall quality of life, physical and social functioning, and have better control of diabetes and hypertension[1,2]. As the end of life approaches, decisions about the use of life sustaining technologies (such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission) are implemented for seriously ill patients. However, communication about these treatment options is often poor, and many patients receive care that is inconsistent with their values and preferences[3]. Many authors have described interventions aimed at improving patient/family engagement and improving the match between patient preferences and care delivered[4-14], but these have often been ineffective or poorly adopted outside of the studies where they are tested. The mismatch between patient preferences and the care provided at the end-of-life (a "preference misdiagnosis") occurs when healthcare professionals make a decision about treatment without integrating the informed preferences and priorities of their patients[15-17]. A preference misdiagnosis has important implications for a patient's quality of life and end-of-life care.

In the context of a broader research program to improve end-of-life care for seriously ill patients, we conducted a mixed-methods study called DECIsion-making about goals of care for hospitalized meDical patiEnts (DECIDE). The study involved a cross-sectional survey of physicians and nurses from the acute medical inpatient ward setting 13 hospitals in five Canadian provinces, as well as open-ended qualitative interviews with physicians and nurses from three of these hospitals[18]. The mixed methods design sought to understand factors which affect

communication and decision-making about life-sustaining technology from the perspectives of healthcare providers and offer suggestions for potential solutions, through the collection of complementary quantitative and qualitative data.

The quantitative component of DECIDE found that that a range of professionals (i.e. nurses, social workers) supported key decision-making activities, such as initiating discussions and decision coaching. Participating healthcare providers felt it was most acceptable for staff physicians to make the final determination about the use or non-use of life-sustaining technology with patients and their families. Physician and nurse participants related that family- and patient-related factors were the most important barriers, whereas barriers related to their skills and system factors were relatively less important[18].

In this qualitative component, we sought to provide richer, more nuanced data than what could be obtained through the survey methods. Specifically, we aimed to explore physicians' and nurses' experiences, with a view to identifying rich description of their roles and factors influencing communication and decision-making with seriously ill hospitalized patients and their families.

**METHODS**

**Study Design**

The qualitative study used Flanagan's critical incident technique (CIT) and interpretive description of open-ended interviews[19,20]. Interviews were conducted between 2012 and 2013 with staff physicians, residents, and nurses (n=30) who provide care to patients admitted to the acute medical inpatient ward at one of three large Canadian hospitals. The goal of CIT is to explore specific incidents with those who have lived them and to uncover assumptions, values, or

impacts that participants may not themselves appreciate. Strengths of the CIT are that it commonly elicits very effective or very ineffective practices and aims to provide findings that are highly focused on solutions to practical problems[21].

**Setting and Participants**

Qualitative study participants were purposively recruited at hospitals from three Canadian provinces (Ontario, Quebec, Alberta) and included English- and French-speaking facilities for a more nationally representative sample. Eligible professionals for inclusion were staff physicians, residents, and nurses who cared for seriously ill patients and their families in the acute medical inpatient ward setting, which are patient care units where patients with non-surgical serious illness are admitted when they cannot be managed in the outpatient setting. The acute medical inpatient wards typically have 35-45 ward beds (nurse to patient ratios 1:4 to 1:8 depending on the complexity of patient care needs) and a small close-observation or telemetry unit for acute continuous vital signs monitoring (Nurse to patient ratio 1:2). An interprofessional team cares for patients with acute medical conditions, often stemming from a wide range of complex medical problems including diabetes, stroke, pneumonia, COPD, heart failure, sepsis and multi-system failure. Patients on such units may receive inpatient intermittent hemodialysis or noninvasive mechanical ventilation (continuous positive airway pressure CPAP) via face or nasal mask, however unstable patients may be transferred to intensive care unit for more intensive management. Participant recruitment took place in parallel with and aided by the DECIDE quantitative (questionnaire-based) study. Professionals received an email about the study and indicated their willingness to participate in a subsequent individual interview in the quantitative DECIDE survey. We selected participants to ensure balanced representation amongst the three hospital centers, between nurses and physicians, men and women, and amongst clinicians with

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diverse levels of experience. We obtained research ethics board approval at each participating

site; all participants gave informed consent before taking part.

**Data Collection**

Individual interviews at all sites were conducted by the same experienced qualitative

interviewer in a location of the participant's choice (a private room located close to the hospital

ward or in their home). Each participant provided one audio recorded interview lasting between

27-91 minutes (mean 47 minutes). The interviewer used a standard introduction and set of

questions, and the research team added additional prompts as the interviews progressed (Figure

1). During the in-depth interviews, participants were invited to describe specific encounters with

patients and families in the acute medical inpatient ward setting in which discussions about the

use or non-use of life-sustaining technology went particularly well and unwell (i.e. critical

incidents). We further explored participants' perceptions of professional roles and the context

and challenges encountered by healthcare professionals, patients, and their families. The

interviewer wrote detailed field notes, to record what stood out for her, immediately after each

interview. We transcribed audio recorded interviews verbatim and audited transcripts for

accuracy. Both transcripts and field notes were organized in NVIVO 10 to facilitate data

management.

**Analysis**

The team developed a codebook by reviewing critical incidents to code them inductively

into themes. We coded the data, and met frequently to discuss, challenge and make decisions

about codes and to interpret emerging findings. We further refined interview questions and

prompts for subsequent interviews using synchronous distance technology (Skype) after each set

of two or three interviews. We integrated all passages into the coding framework in their native

language. In particular, two bilingual investigators analyzed French interviews. Translation of

specific representative quotes into English, preserving the participants meaning, was done by the

researchers only to communicate results in written English communication/publications. We

worked together in an analytic process that involved synchronous and asynchronous meetings to

reflect on the evolving conceptual framework in light of new interview data and increased

immersion in the data. The draft code book evolved throughout the study and included key

themes, sub-themes, and their definitions. The names and descriptions of key themes changed,

collapsed and expanded based on new data, and considering the context of previous data. The

four factors presented here represent key themes in the interview data, sub- themes are described

as they relate to each of the key themes. We found that while participants' accounts reflected

their different perspectives based on their different levels of experience and professional

identities, certain key themes were prominent across participant categories (12 nurses, 9 residents

and 9 staff physicians).

Saturation in is achieved when adding 100 critical incidents to the sample contributes

only 2 or 3 more themes to the analysis[19]. In our study, a total of 30 interviews conveyed data

about 120 critical incidents (mean 4, range 2 – 9 critical incidents). We considered the data

categories had reached saturation since the first 4 interviews provided 18 critical incidents and all

but two themes to the description of factors influencing communication and decision-making

process; the remaining 26 participants described a further 102 critical incidents. We did not add

new themes to the analysis in the last 20 interviews.

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In summary, we used constant comparative methods combining independent and then group analysis. Auditing by a team member external to original analysis ensured themes fit with data. We continued until analysis indicated we had reached saturation.

**RESULTS**

A total of 30 individuals participated, 10 from each of three in-patient medical teaching units (Quebec, Ontario, Alberta): 9 staff physicians, 9 residents, and 12 nurses (Table 1). Participants were 25 to 63 years (mean 39 years), and mainly female (73%) - a distribution skewed by the high representation of female nurses (11 out of 12 in the study).

We found several key factors influenced communication and decision-making about life-sustaining technology. The overarching factor was how people conceptualized the goals of medical practice. Other factors related to how a patient or family's choice was shaped by their relationships, particularly how people worked towards 'making sense of the situation', how physicians and nurses approached the inherent and systemic tensions in achieving consensus with families, and how professional work regarding end-of-life issues was conducted within acute medical unit teams (Table 2). These contextual elements influenced the engagement of healthcare professionals, patients, and families and had significant implications for the quality of communication and decision-making about the use of life-sustaining technology. Participants described incidents in which these factors interacted in dynamic and unpredictable ways to influence decision-making for any particular patient and family.

**Factor 1: Conceptualizations of medical practice as '*saving lives and warding off death*'**

Death and dying were spoken of as largely a culturally taboo topic in hospitals. Participants' attitudes towards end-of-life communication and decision-making reflected a

dominant cultural, economic construction of hospitals, doctors, medicine as primarily about

saving lives: warding off death, <u>not</u> overseeing the dying (Table 2). Participants' descriptions

reflected a general assumption on their part and the part of patients and families that patients

were admitted for hospital care to regain health, not to die. Care continued under this assumption

until death was imminent. Importantly, participants described a norm of discussions being

avoided until doctors (and sometimes nurses) recognized that life-saving interventions were

increasingly futile and that death could not be postponed. Physicians and nurses characterized

communications with patients or more often families as difficult and stressful when they felt the

urgency to communicate with families primarily to prevent delivery of futile care. Discussions

about life-sustaining technology at such late points in the patient's life (or illness) focused on

*"getting the DNR [do not resuscitate]" (Resident Physician)*, and writing it in the chart.

Throughout the interviews, many participant accounts conveyed existential issues with

regards to witnessing suffering and managing the dying patient, and the perceived failure of

medical expertise. Mainly, since such discussions were equated with death and dying, healthcare

professionals often waited to have these decision-making conversations until there was, in their

words, '*nothing to be done'* for the patient. When this happened, the timing of communication

resulted in disclosure that the patient was almost certainly dying.

**Factor 2: Work towards '*making sense of the situation*'**

We found that *'making sense of the situation'* was work and a process that was essential

to advancing decision-making (Table 3). Participants described progress in decision-making as

contingent on having been able to make sense of a patient's situation. Work towards *'making*

*sense of the situation'* involved a process of establishing a relationship, knowing them over time,

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and integrating information about the patient's health and treatment options with (ideally the patients') illness beliefs and (ideally the patients') goals of care. In cases that went well, dialogue with patients and/or families created opportunities to construct a shared understanding of the patient's situation and the use of life-sustaining technology. A perceived failure to be emotionally ready for discussions or to make sense of the situation caused patients, families and/or healthcare professionals to '*get stuck'* and be unable to progress towards a decision. This contributed to delays in even initiating decision-making, and was perceived by nurses as a missed opportunity to ease patient and family suffering.

In their examples of discussions that went well, both physicians and nurses saw it as their role to facilitate this process. They described work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. When physicians struggled to make sense of the situation, often due to uncertainty about prognosis or the reversibility of the patient's condition, they delayed initiating the decision-making process. Both physicians and nurses reported experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering.

**Factor 3: Inherent and systemic tensions in achieving consensus about the goal of care**

An important contextual factor was that, in the face of patient suffering and imminent death, participants perceived that patients and families were emotional, even irrational at times. Patients and families were defined as 'difficult' based on what physicians and nurses saw as their inability to understand or accept the situation. Further, being difficult was linked to a failure to come quickly on board with the plan the physician saw as ethically and clinically appropriate. Engaging such patients and families in the decision-making process could be particularly

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challenging. Nurses who were left behind with patients and families in the wake of heated discussions between physicians and patients wanted more strategies for managing their stress and for speaking to stressed families.

In addition to the stress and challenges that are inherent to achieving consensus among patient, family and their healthcare team about the use of life-sustaining technology (Table 4), our data points to systemic limitations to consensus building and shared decision-making with patients and families. Achieving consensus is intricately interwoven with '*making sense of the situation'* (described above). Making sense of a situation requires some reflection and processing of information. The invitation to patients and families to make sense of dying is routinely occurring when active care has already been determined by healthcare team members to be futile; this can be very late. As noted above (Factor 1), situations described as challenging revealed that healthcare professionals tended to flag patients as urgently requiring goals of care discussions when patients were beyond rescue and often facing imminent death.

In cases where participants described a team-based approach to communication and decision-making, participants prioritized *"getting on the same page"* to establish agreement within the team, before engaging patients and families.  Team discussion focused on ensuring all relevant information was gathered before a discussion with family, and was emphasized as important to avoid patients and families being exposed to conflicting messages. The problem is that where goals of care communication and decision-making is occurring within such a compressed time frame, as seems to be the norm at study sites, patients and families may have even less time than healthcare team members to make sense of circumstances and thus meaningfully engage in decision-making. Such conditions could render patients and families emotional, irrational, or 'difficult'. Moreover, one can presume it would be more difficult for

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healthcare team members to defuse stressful communications when they are themselves feeling

pressure to adjust the patient's care plan before the patient dies and/or is exposed to futile

measures.

What seems to be key here, is that when communications with families did not go well,

most nurses and physicians did not have the experience and skill set to unblock tense

disagreements, nor did they have much time to do so. Not surprisingly, participants defined as

easy those decisions where both healthcare professionals and the patient and their family had

constructed the same meaning about the situation before a patient arrived in hospital or before a

discussion: *"It's easy when everyone is thinking the same thing"* (Staff Physician).

Factor 4: **Approaches to professional work within teams**

In their examples of critical incidents, participants contrasted a '*team-based approach*'

with the '*solitary nature*' of professional work. The Overall, the institutional/practical

construction of communication and decision-making about life-sustaining technology was

solitary and physician-centered (Table 5). While some participants described instances of a team-

based approach for a specific individual patient, a majority of participants perceived

communications as the physicians' responsibility as opposed to a team responsibility.

Participants described physicians who largely worked alone and asynchronously from other team

members to prepare, inform, and guide patients and families through decision-making. Leading

emotional end-of-life discussions alone placed a great deal of pressure on physicians, especially

residents.

Descriptions of nursing work were largely absent in physicians' narratives, even when

invited to reflect on nurses and other health professionals' roles. For most participants, work

done by nurses was not recognized as contributing to communication and decision-making about life-sustaining technology (even for nurses themselves). Nurse participants described their work as happening asynchronously around physicians' encounters. They described preparing the groundwork for physicians' discussions about life-sustaining technology, as well as "*picking up the pieces*" after physicians delivered unexpected prognostic news and decisions.

Most participants highlighted their recognition of the value of team-based approaches to goals of care communication and decision-making. Nurses and residents continue to feel isolated in the work they did connected to goals of care discussions. Where residents acknowledged the importance of more training, a number of nurses felt it would be beneficial to patients for nurses to be more fully informed and even included in physician-led goals of care discussions with patients and family. Mentorship, modeling, and support to develop the necessary skills to engage patients and families in productive discussions were frequently raised by participants. Most physicians are well prepared for 'breaking bad news', but less so for 'breaking bad news' to patients and families who were too distressed to listen to a 15-minute presentation and recommendation of care. More experienced physicians shared strategies to help patients and families be ready for these discussions. For example, two physicians in different cities advocated for a "step-wise" approach. They gently planted the seeds that a decision would soon need to be taken by commenting on the patient's declining health. They emphasized to their residents that patients and families needed time to adjust to a prognosis. Another physician stressed the importance of being present for these conversations: turning the phone off, putting time aside for this serious conversation, and listening to what the patient or family had to say. Many senior physicians explicitly included junior residents in discussions about the use or non-use of life-

sustaining technology. They knew that residents experienced more stress in these conversations

and required particular abilities to listen to, and respond to, families.

## DISCUSSION

The evolution of decision-making about life-sustaining technology for any particular

patient were influenced by social constructions of medical practice as life saving, an existential

and practical need to 'make sense of the situation' together, inherent and systemic tensions in

achieving consensus, and the solitary nature of professional practice in the medical teaching unit.

Indeed, it seemed that three conditions were present for a decision that "went well": 1) the

patient needed to be beyond rescue, 2) the "correct" option needed to be clear to healthcare

professionals, patients and families, who also needed 3) to agree about goals of care and the

interventions that should be used to achieve those goals. Unfortunately, these three conditions

are rarely present in the medical ward setting. Prognosis is hard to establish for seriously ill

patients[22], and physician perceptions of prognostic certainty affect the timing of decision making

[23].

The social construction of medical practice as *'saving lives and warding off death'*

reported by participants in this study, has significant implications for the quality of

communication about life-sustaining technology. First, the presumption within such a

construction of medical practice is that a life-saving focus is logical and by default in the

patient's best interest.  This is contrary to evidence that shows that at the end-of-life, palliative

care approaches result in the same or better quality of care and better health outcomes than high

intensity and costly life-sustaining technology care[24]. Essentially, what is important to note is

that with an equation of medical care as life-saving care, warding off death dominates decision-

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making in the hospital ward. Only when death cannot be warded off, is communication with patients and families about goals and end-of-life care needed, and this is communication aimed primarily at preventing life-sustaining care, which at that point is considered futile[25]. Preventing delivery of futile care is a provider centered problem, and is intensified for healthcare professionals for whom death becomes personal and uncomfortable.

Our findings echo other studies that have found that while patients and families desire involvement in decision-making[26,27], they are seldom presented with alternatives to life-sustaining technology[28]. Framing alternatives as '*there was nothing to be done*' corresponds to the social construction of medical practice as '*saving lives and warding off death*'. Such wording perpetuates the assumption that non-lifesaving care is equivalent to failure or abandonment[29]. We caution that language such as '*nothing to be done*' is unhelpful in that it frames non-aggressive healthcare, including nursing care, pain management, and palliative care, as nothing. This leaves little room for strategizing, valuing, and improving the work that is involved in comfort care. Reframing this message to what *we can provide* is critical to conveying to patients and families that we will not abandon them.

While clinicians felt it was crucial to know a patient's code status to prevent futile care, this may be a low priority for patients/families. A focus on more meaningful and productive dialogue with patients and families is needed. We found that work towards "*making sense of the situation*" was central to the decision-making process and was most effective (i.e. incidents that went well) when dialogue occurred with others. Establishing relationships with patients and families is a key element of the process, and occurred alongside the process of meaning making. Participants' narratives described the search for meaning in the situation by healthcare professionals, patients and families. Individual understandings of circumstances and

opportunities for health were developed in dialogue with patients and families and their

healthcare professionals (or between healthcare professionals). We suggest that work '*getting*

*everyone on the same page*' should fully involve patients and their families. The quantitative

survey results of the larger DECIDE mixed method study[18], which highly ranked patient/family-

related barriers as impeding communication and decision-making, are reflected in the stories of

patients and families who struggled to make sense of the decision and context they were facing.

And, since it is likely that patients and families will experience grief and loss with changing

health status[30], we should expect that for patients and families, making sense of illness will

require time and support from their healthcare team. In contrast, we found that the heavy result-

oriented agenda inherent in "*getting the DNR*" seemed to abbreviate communication and

minimize the engagement of patients and families. This important dialogue should not be rushed

or hurried to 'get a code status', especially when the box checked on the order sheet has such

enormous implications for the patient's future well-being. We suggest that an organized

approach to supporting early dialogue between healthcare professionals, patients, and their

family members is needed; shared decision making facilitate the integration of information about

options with the patient's values and preferences [31,32]. We know that such dialogue occurs in

complex environments, where listening to the patient and their family is essential to providing

care that fits best for each person at the end-of-life [13,33-39]. While some of the findings are known

from research in critical care settings (eg. the importance of supporting team-based approaches

or structured family involvement)[40-45], the acute medical ward setting is very different (eg. lower

nurse patient ratios, more daily admissions and discharges). Additionally, patients are more

likely to be able to participate in decision-making than patients in critical care settings. Taken

together, features of the acute medical ward setting may necessitate different strategies to

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optimize patient and family engagement.

Overall, there was an impoverished understanding of the potential for interprofessional practice. While our earlier survey findings described the perception that everyone *could* get involved[18], qualitative findings suggest that this is not yet happening. Participants described usual conditions in which they tended to work in isolation from other professionals and were unclear about each others' roles. While other professionals roles were invisible to most participating physicians, nurses could articulate related nursing work. Overwhelmed physicians believed that they worked alone with patients and families throughout the decision-making process, which is consistent with other research in the medical teaching unit setting[46]. However, interprofessional collaboration can decrease professionals' distress[47], and therefore it is possible that interprofessional collaboration in decision-making could maximize the opportunity to share the emotional burden of providing care, and to receive support from colleagues. Identifying optimal team roles may be an important first step in developing an intervention tailored to the clinical setting that would support patients, families and health providers in navigating this necessary, yet emotionally challenging territory.

A number of key factors speak to the importance of better supporting resident physicians in the acute medical ward setting. Medical residents experience varying levels of supervision for a whole range of clinical activities (not just for DNR orders) from one staff physician or one institution to the next, and depending on personal / local practice patterns. Further, their competence is assessed on a continuum as they become more autonomous to make important decisions; there is not a "gold standard" criteria for declaring a junior resident as being "competent" to lead decision-making about the use of life sustaining technologies. A combination of these and other factors may lead to situations where relatively inexperienced

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physicians are having end-of-life discussions on their own. Strategies that better support resident

physicians (and others) in the acute medical ward setting were welcomed and suggested by

participants in our study.

Participants shared some strategies that worked more effectively to engage patients and

families - for example, making time, sharing support roles, explicitly helping families make

meaning and progress in decision-making. In their stories of what went well, participants

engaged with and managed conflict within interprofessional teams and during challenging family

situations. In such situations, the team proactively supported patients and their families to make

sense of the situation, to understand recommendations, and supported them to make decisions.

Such support requires excellent communication skills, therefore like others[44,45,48], we advocate

for improved communication training for healthcare professionals. We also recognize that the

clinical teaching unit needs an organizational culture that supports decision-making processes

that will work under the conditions of usual practice. Institutional guidelines or standard

operating procedures with linked quality indicators might be helpful to promote an effective

team-based approach to communication and decision-making for the acute medical ward setting.

Several factors may limit the transferability of this research. First, not all perspectives of

healthcare professionals in the medical ward setting are represented by this work. Further

research should include the views of social workers, clinical ethicists, and others who work with

patients and families in the hospital. Second, our results may not be transferable to other

healthcare settings or other countries. We provide quotes to help readers decide whether our

experience resonates with their settings.

**CONCLUSIONS AND RELEVANCE**

An integrative approach to decision-making about the use of life-sustaining technology, that acknowledges and supports the non-curative role of healthcare and hospitals, is needed. We must strengthen the interprofessional team's capacity to cope with and communicate about uncertainty to patients and families, discuss related existential issues, and support patients and families who are suffering as they make decisions about care in advanced serious illness. The qualitative component of the mixed method DECIDE study adds depth to the understanding of contextual elements that influenced the engagement of healthcare professionals, patients, and families. This understanding about context is key to developing improvement strategies that harness the potential and actual roles of healthcare professionals.

**Authorship Statement**

JK and PHS designed the qualitative study, analyzed and interpreted data, drafted and revised the manuscript and approved the final version for publication. EN conducted interviews and analyzed and interpreted the data, revised the manuscript and approved the final version for publication. JJY contributed to the design of the study, obtained funding, and both JJY and JD audited the analysis and interpreted the data, revised the manuscript and approved the final version for publication. JK, PS, and EN had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Data Sharing Statement**

No additional data available.

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**Competing interests**

The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript. No financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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**TABLES**

**Table 1**. Participant demographics

| Characteristics | Staff physicians (n=9) | Residents (n=9) | Nurses (n=12) | TOTAL (n=30) |
|---|---|---|---|---|
| Female | 6 (67%) | 5 (55%) | 11 (92%) | 22 (73%) |
| Experience | | | | |
| <5 yrs | 2 (22%) | 9 (100%) | 4 (33%) | 15 (50%) |
| 5-10 yrs | 0 (0%) | 0 (0%) | 3 (25%) | 3 (10%) |
| 10+ yrs | 7 (78%) | 0 (0%) | 5 (42%) | 12 (40%) |
| Hospital | | | | |
| Ontario | 3 (33%) | 3 (33%) | 4 (44%) | 10 (33%) |
| Alberta | 3 (33%) | 4 (44%) | 3 (25%) | 10 (33%) |
| Quebec | 3 (33%) | 2 (22%) | 5 (42%) | 10 (33%) |

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**Table 2**. Conceptualizations of medical practice as '*saving lives and warding off death*'

| Description | Examples |
|---|---|
| Dominant cultural, economic construction of hospitals, doctors, medicine as being officially about saving lives: warding off death, not overseeing the dying. | "I think one of the things that's important is we go into this profession and, you know, doctors it's all about we need to fix things, and we need to, you know, cure things. That's kind of the mindset we have. And we sometimes lose sight of the fact that we can't actually fix everything." (Staff Physician) |
| | "It's as though for the physicians it's always life at any cost. Always. They are always focused on saving lives. Death is like a failure. It's not something we talk about." (Nurse) |
| | "One of the daughters was angry. She was saying we were abandoning her mother. That we weren't allowed to do that. That we had to keep it up until the end." (Nurse) |
| Discussions avoided until life-saving was not possible, or death occurred | "It's usually a pretty clear next step. Like the person is probably hours from dying and they change them to comfort [care]. Often it's that close." (Nurse) |
| | "A lot of times when the physician is having that conversation on a medical unit, it's when things have gone badly, when things have changed, when the patient is doing poorly so the family is really distressed about how their family member is doing." (Nurse) |
| Discussions focused on 'getting the DNR' | "I think we get task oriented. We want to get to a goal of care because we think it's appropriate, and we just want enough from the patient to justify in our own minds that they're in agreement with that. And I'm not sure, in an informed consent way, that that's enough." (Staff Physician) |
| Professionals' identity wrapped up in ideas of saving lives | "The residents say 'She's really sick, and she's not doing well.' 'Yeah, but we're doing everything. We are doing everything, and the rest is because the person is failing. It's not because we're failing.' So changing that mindset from we should be able to cure everybody all the time, and nobody should ever die which is crazy, right? Doesn't make sense." (Staff Physician) |

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**Table 3**. Work towards '*making sense of the situation*'

| Description | Examples |
|---|---|
| Focus on getting to know the patient and their personal life story | "We know everything medically about them, but we don't know their story and we don't know what informs the decisions they've made to this point and sometimes it can be as simple a thing as they had a really bad illness when they were young, and they got better, therefore they're going to get better this time." (Resident Physician) |
| Recognizing that the patient has a unique interpretation of what is happening, and what a 'correct' course of action might be is individual | "We're not the patient and although we have our own opinion about what is the best thing to do but regardless that's... you know, the goal should be to try to make the patient make the decision with our help in terms of trying to choose the best thing" (Resident physician). |
| Work helping patients and families understand the complex situations they were facing, helping them make sense of responses to treatments, and clarifying messages given by other members of the team. | "They've just been told something potentially devastating. So you've got to ask how much they actually retained. So that's usually the best place. So gleaning a bit of an insight into what they understand, what they retain, what this means to them, or what they're understanding it means, is probably the biggest step for the nurse to take after they've had that change. (Nurse) |
| Experiencing moral distress related to different perspectives about the importance of prognosis or the value of suffering | "I went in, and I saw the patient and I literally had tears in my eyes. It's like oh my gosh, I cannot believe that this body still has a soul living in it because it was terrible. And yet I wanted to be very respectful of the decision maker who I thought had a very valid perspective. So there's that conflict sometimes of perspective. I think I realize people just need time to absorb things." (Staff Physician) |
| To make a recommendation for care, healthcare professionals also needed to establish meaning. | "Sometimes it's denial; sometimes it's that we don't have time, or sometimes it's about us, we're not comfortable making that decision either. If we aren't… if I am not sure of the prognosis, if I think they might get better through some intervention, but at the same time there's other factors, like the intervention is pretty invasive, then in those cases [we delay the decision]." (Resident Physician) |

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**Table 4.** Inherent and systemic tensions in achieving consensus

| Description | Examples |
|---|---|
| Easy decisions were preceded/accompanied by work 'making meaning' together | "It's easy when everyone is thinking the same thing" (Staff Physician) |
| Perceived failure to progress towards meaning making or be emotionally ready for discussions led to delays in (initiating) potentially supportive discussions and decision-making. | "I had numerous conversations with the family, the husband particularly; it was his wife that was sick and very ill. He made a lot of comments that this person was his life and he couldn't live without her and all these things and so I started to wonder if we were more treating him instead of her for her symptoms. Anyway there was never any discussion over the next few weeks of goals of care, and they kept treating her and treating her and treating her. And I understand then, maybe two or three weeks after, then she coded, and she died later that day. I had had some struggles talking to the doctors that I worried if we hadn't broached the subject ahead of time then we weren't really helping to treat or ease this man's grief or the patient's suffering." (Nurse) |
| Holding strong opinions contributed to less discussion and dialogue, ultimately making it harder to reach agreement | "It becomes more problematic when people are demented, and you've got, I think it's less common now, but I ran into a public guardian once who would not change the level of care in those days and I resigned from the case, told them to get another doctor because I thought it was inhuman keeping an absolute vegetable alive, you know." (Staff Physician) |
| Working at cross purposes with patient's priorities and goals | "There was one time when neither the family nor the patient wanted any aggressive care. She was really not doing well. She had spoken clearly, as had her family. I had to call the physicians back in because we had been told to kick off a battery of antibiotics, take blood, get tests, this, that, and the family was not happy. And the physicians told them that it was pneumonia, that it was reversible which is why they were proceeding the way they were. But the family and the patient didn't want that." (Nurse) |

Factors Influencing Communication

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**Table 5**. Approaches to professional work within teams

| Description | Examples |
|---|---|
| Working alone to prepare and inform and guide patients. | "Everybody [patient and family] went with me to the quiet room… And I just spoke to all of them, like giving a speech." (Resident physician) "… I was sort of leading the meeting and the neurologist was just somewhat of a Silent Sam, just allowing me to lead the discussion and not offering a whole lot in the way of support or guidance, which was frustrating because patients who have this condition, this is how the condition goes. By and large this is how their life ends." (Staff physician) |
| Reacting to (non) decision-making discussions, rather than working together to support and create conditions for dialogue. | "Often we are picking up the collateral damage of non-decision-making, of non-discussions. Now things are really not going well. A decision needs to be taken right now. So we are more often in that mind frame. It's rare that we are ahead of the ball." (Nurse) |
| Feeling unprepared for challenging discussions about existential issues and end-of-life. | "And I can say this with certainty, that there are people, and I've seen it with colleagues as well as students, who are afraid of this: who are afraid of talking about anything related to end of life with people." (Staff physician) |
| Nurses remain in the background, behind the scenes. | "I will usually stand behind the curtain and not go on the other side of the curtain and be present with the conversation that's happening. I'll just listen. I won't be a contributor in that conversation. I don't know why I do that. (Nurse) "It's usually always been the physician that has that conversation and then we just, reinforce the conversation afterwards." (Nurse) "It's out of my hands whether or not it's taken into consideration or not. You can tell residents all they want but if they have something set in their mind that this is going to happen then that's going to happen. Most of the times we can't change their minds. But you never know." (Nurse) |

**Figure 1. Interview guide with prompts**

Interview introduction: *"Communication and decision-making about goals of care includes decisions about the use of life sustaining technologies at the end of life, such as cardiopulmonary resuscitation, ventilators, dialysis, or intensive care unit admission.*

*Can you tell me of an experience you have had with a patient or their family in which communication and decision-making about goals of care and the use of life-sustaining technologies went particularly well?*

*Can you tell me of an experience you have had where communication and decision-making about goals of care and the use of life-sustaining technologies did not go well?"*

**Examples of prompts**

1. About critical incident: What in particular defines this experience for you as a good/bad one? What made it easy/difficult? Where was this happening? What happened in this case? What was the outcome?
2. About participant role: What was your role in any meetings with the patient or their family? Is it normal for you to play this role? Did you do anything to get yourself, other members of the medical team, the family or the patient ready for discussing or deciding on goals of care? Is this normal?
3. About others' roles: What other members of the medical team were involved in the discussion(s) of goals of care and the use of life-sustaining technologies in this case? What were their roles? How did they become involved? What role does the nurse or do the nurses play, in your experience? Are nurse usually informed of upcoming family meetings?
4. About factors influencing decision –making: Are there certain circumstances that make discussions about goals of care of life-sustaining technologies particularly difficult, either for you or for the patient or their family? What makes it easier for families or patients to be actively involved in communication and decision-making about goals of care and life-sustaining technologies?

Figure 1. Interview guide with prompts
179x186mm (300 x 300 DPI)

Appendix 1. Consolidated criteria for reporting qualitative research (COREQ)

Submission to BMJ Open

Title: Factors influencing Communication And Decision Making About Life-Sustaining Technology during Serious Illness: A Qualitative Study

Authors: J Kryworuchko, PH Strachan, E Nouvet, J Downar, JJ You

| Item | Criteria | Location in manuscript | Response |
|------|----------|------------------------|----------|
| 1. Interviewer/ facilitator | Which author/s conducted the interview or focus group? | | Kryworuchko and Strachan led the study, Nouvet completed interviews. Downar, You audited analysis. All contributed to final analysis. |
| 2. Credentials | What were the researcher's credentials? *E.g. PhD, MD* | | Kryworuchko and Strachan: PhD Nursing. Nouvet: PhD, Anthropology. Downar: Master's degree in Bioethics, physician. You: Master's degree in Science, physician. |
| 3. Occupation | What was their occupation at the time of the study? | | Kryworuchko, Strachan, Downar, You: Research faculty at Canadian universities. Nouvet: Research Coordinator |
| 4. Gender | Was the researcher male or female? | | 3 female, 2 male |
| 5. Experience and training | What experience or training did the researcher have? | | Kryworuchko and Strachan are registered nurses with extensive experience in the medical ward and critical care settings. Nouvet had no previous experience in the clinical setting. All had qualitative research training and experience, and have published qualitative research. Downar is a researcher and physician with expertise in Internal Medicine, Critical Care Medicine, and Palliative Care Medicine. You is a hospital-based general internist and researcher. |
| 6. Relationship with participants | Was a relationship established prior to study commencement? | | No |
| 7. Participant knowledge of interviewer | What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research* | | Informed of general research goal: to identify barriers and potential solutions to improve communication and decision- |

| Item | Criteria | Location in manuscript | Response |
|---|---|---|---|
| | | | making about goals of care, focusing upon the perspectives of hospital-based physicians and nurses.. |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic* | | Participants knew Nouvet was a research coordinator, and that she was not a clinician. |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* | p. 7 | Interpretive thematic analysis, Critical Incident Technique |
| 10. Sampling | How were participants selected? *e.g. purposive, convenience, consecutive, snowball* | p. 7 | Purposive sampling to ensure balanced representation amongst the three hospital centers, between nurses and physicians, men and women, and amongst clinicians with diverse levels of experience |
| 11. Method of approach | How were participants approached? e.*g. face-to-face, telephone, mail, email* | p. 7 | Email, prior involvement responding to quantitative survey |
| 12. Sample size | How many participants were in the study? | p. 7 | n=30 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | | More people agreed to interviews that the number selected. All people approached agreed to participate in the study. |
| 14. Setting of data collection | Where was the data collected? e.g. *home, clinic, workplace* | p. 8 | In a location of the participant's choice (a private room located close to the hospital ward or in their home) |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | | Participants were interviewed individually |
| 16. Description of sample | What are the important characteristics of the sample? *e.g. demographic data, date* | p. 9, 24 | Professional role and years of experience, site, gender, age, |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | p. 8, 23 | Standard interview guide was developed, piloted and evolved as interviews progressed |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | p. 8 | No |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | p. 8 | Audio recorded |
| 20. Field notes | Were field notes made | p. 8 | Nouvet wrote detailed field |

| Item | Criteria | Location in manuscript | Response |
|------|----------|------------------------|----------|
| | during and/or after the interview or focus group? | | notes directly after each interview. |
| 21. Duration | What was the duration of the interviews or focus group? | p. 8 | 27-91 minutes (mean 47 minutes) |
| 22. Data saturation | Was data saturation discussed? | p. 7 | Yes – data collection ended when saturation was achieved |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | p. 8 | No. Transcripts were reviewed by researchers who listened to the audio recordings to verify their accuracy. |
| 24. Number of data coders | How many data coders coded the data? | p. 9 | 2 analysts coded each transcript independently (Kryworuchko, Strachan, Nouvet) |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | p. 9 | Not explicitly, major themes presented. |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | p. 9 | Derived from the data |
| 27. Software | What software, if applicable, was used to manage the data? | p. 8 | QSR NVivo version 10 |
| 28. Participant checking | Did participants provide feedback on the findings? | p. 8 | No. Auditing of analysis provided by two team members external to the initial analysis (Downar, You) |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number* | p. 9, 25-28 | Quotes presented throughout results and in Tables 2-5. Participants identified by professional role. |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | p. 9 | Yes |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | p. 9 | Yes |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | p. 9 | Yes – word count restrictions did not permit more extensive theme discussion. |