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A Journey into Palliative Care and Reflections on EOL/Prognosis Communication

Introduction

This summer at Terence Cardinal Cooke (TCC), I had the opportunity to pursue a project and learn about palliative care. Through various learning exercises and regular interactions with patients, I learned much about the dynamic nature of the discipline. Described by some as “just good medicine,” I saw firsthand the vast amount of individualized attention patients needed and the effective communication required from the team to the patient to the family, creating an intricate web in which cracks could exist at multiple points. This paper aims to highlight some of those experiences, my personal reflections on them, and suggestions for improvement – more specifically, I gravitated towards observing and improving efforts at what is arguably the most pivotal juncture in a patient’s care: communication at the End of Life (EOL).

Palliative Care Experiences:

Specialized Punchcard:

In my journey, I found that to provide the highest quality of work within palliative care’s goal to alleviate pain and manage symptoms, it is intuitively necessary for all fronts to understand exactly what each patient’s needs are. However, this was found to be a major area of concern. We (the interns) saw the issue to be a lack of resources to paint an accurate picture of a patient without already having spent significant time with them. To compound this, there was no formal communication in which C.NAs familiar with a patient could pass on patient-specific information to other C.NAs, with no note of these things found on SigmaCare either. Especially at crucial times, such as changing of shifts, large amounts of care knowledge were falling through the cracks and directly causing preventable issues such as falls. We spoke with a nurse manager on 5H, who explained to us the protocol for changing of shifts. She then acknowledged that particularly in the mornings, this protocol was not always followed, citing potential improvements for communication of patient needs and events that happened overnight. One example of this was a patient who had a routine of getting herself dressed early in the morning.

However, because the C.NA looking after her was never told this during the changing of shifts, the patient never received assistance, attempted to do it herself, and fell.

It is for such issues that we created specialized punchcards for each patient highlighting medical, spiritual, existential, and family needs. Ideally, this serves as a tool to give everyone a more guided direction to taking good care of a patient, but also to have a better way of monitoring the progression a patient's most acute conditions - potentially raising an alarm for a state of decline and helping the team to maximally know who, when, and how to employ palliative care. An example of a punchcard reflecting a patient during a week of acute changes and team/family adjustments is found in the Appendix. We believe that finding a sustainable way to incorporate these punchcards into the day-to-day operations at TCC would bridge the gaps in communication that prevents patients from getting not only the high quality and individually tailored attention they need, but also the consistent care they deserve.

HIV QI

As part of our internship, we also helped assess the quality of current work through a QI for HIV patients, keeping consult orders orderly, ensuring Form 4 on MOLST forms were properly filled out for appropriate patients, and an EOL review checklist for patient deaths. The MOLST and consult audits, as well as checking on the status of call bells, bathtubs, and other areas of the facility, were part of an effort for a successful survey.

However, as part of a quality assessment for HIV patients, I was asked to do a randomized check on the CD4 count and whether Hepatitis B and C screenings had been done on admission for 35 patients. This helped educate me on what kind of care and testing for the patients on these floors entailed. It also helped in ensuring quality of care by reporting notes and performance outcomes for the physician's reference and possible improvement, but more importantly, ensured that the patients who were found not to have received tests or screenings received them, addressing possible health concerns that could have gone overlooked.

EOL Evaluation

In addition, we reviewed the deaths of 12 patients using a physician self-evaluation form and a form reviewing what various measures were taken leading up to death. (found in the Appendix.) Having turned in the reviews to the medical director, it was unsure whether these

deaths were “good deaths” and how conclusive our findings were. There was issue of bias, which was doubly raised by one of the physicians while evaluating herself. There was also some conflict between how the physician evaluated certain metrics and how the medical director would have evaluated them based on his understanding of the case. Furthermore, I found that a review of measures taken (2nd form) fell into the same pitfall as other attempts to paint a picture of a given patient. Much like care plans found on SigmaCare, a list of descriptions and medications fractionated into many sections failed to give a realistic depiction of the patient leading up to death. On further reflection, I found this evaluation to be an important experience not in how conclusive our findings were, but raising an important question of palliative care: in attempts to evaluate a team’s performance in quality of death, how can we even know what a good death is?

Reflections and Suggestions:

Of these exercises, the punchcard and EOL checklist motivated most of my reflections. The punchcard helped me develop a personal understanding of the definition of palliative care as one that alleviates suffering, especially because suffering can manifest in so many personalized ways. Thus, I realized the need for even more significant efforts to be placed into ways for each patient’s needs to be known better to everyone; we cannot help patients if we do not know them.

Furthermore, reflecting on the EOL review and the large discrepancy it created between its picture of a patient and the picture of a patient drawn up by through personal interaction, I had a heightened sense of how important the human aspect of medicine was. Advancing technology and protocols in palliative care are scientific and logical tools for improvement of care – however, to be able to provide good care for a patient at all, human interaction and a full understanding of that person’s existence and pain is absolutely necessary.

Most importantly, it raised the question in my mind, what is a good death exactly? Is it the physician’s opinion, the family/patient’s opinion, or is there some overlap? This quote resonates with what I found my belief to be: “The match between a patient’s goals and the care received should be the gold standard for quality palliative care.” (Emanuel et al.) In the end, I feel that it is difficult to corral a standard metric for death. If we have established that good care in living is so uniquely personalized, why should that not be the same case for death? Rather than trying to work towards giving the “best” death in any scientific or medical context, I feel that a

good death should instead be one focused on having all parties in satisfactory agreeance. This places a high importance on prognosis and EOL communication and the need to establish and maintain “consensus,” which pushed me towards my personal project.

Consequently, a suggestion to improve measuring quality of death is to incorporate a patient’s personalized punchcard as a metric by reviewing extensive and in-depth notes particularly for the symptoms and issues found on it. It seemed as though the biggest failure of the forms we used were that they were no more personalized or clear as notes on Sigma. Because we aim to personalize care, even when looking in retrospect, we should base death on how personalized it was. The goal: specifically reviewing a patient’s alleviation for major sources of suffering – which is likely the goal of care that all parties would have had consensus on at that point - will give us a more accurate insight into how the case was handled. We hope to understand and care for our patients better through the punchcard, and we can also aim to remember them better through the personalized scope of the punchcard rather than a generic lens.

Summer Project:

At Dr. Lechich’s recommendation, the other interns and I read a Perspectives article, “Uncertainty - The Other Side of Prognosis,” which emphasized the need to give equal attention to communicating the uncertainty of prognosis as to attempts to find more accurate models. Ultimately, “by normalizing uncertainty and attending to the affective response to living in the face of an uncertain future, [physicians] may help patients and their families enjoy the time they have now” (Smith et al.). The article was strikingly in accordance with the recurring theme of TCC’s need to improve physicians’ comfort and effectiveness in initiating and holding EOL conversations. Thus, I sought to find to better understand the dynamics of this communication, to study how the conversations currently take place, and to shed further light on and improve these efforts through a combination of physician feedback (via questionnaire, found in the Appendix), literature, and personal reflections.

Methodology:

To gather information, I prepared a short questionnaire and interviewed 6 physicians at TCC. The goal of the questionnaire was to have each physician answer questions about their

preferences and tendencies in communication, give their own feedback on what needs improvement and how it can be done, and through speaking out loud, to have them be self-aware of what the issues within prognosis conversations are. The summary of their responses can be found in the Appendix. Combining this with other literature on the topic of effective communication in nursing homes, I hope to provide a culmination of information to address what could be improved and propose how to do so.

Understanding prognosis at TCC:

In this context, prognosis can be understood as any communication about life expectancy, time frame of death, progression of the illness, potential future symptoms, or expected outcomes.

At TCC, there were some notable trends in how the conversation was generally approached. Every physician noted that after scheduling a meeting with the family, he/she would consult the interdisciplinary team and review old charts, labs, and notes to provide the most accurate and updated picture of the patients' status. Out of the 6, only 2 noted that they would prefer to have the meeting with the family alone due to conflicting information coming from different perspectives and/or team members themselves not being comfortable with being there, while 1 physician noted that having her team present was particularly crucial to her comfort level. However, all noted the importance of consulting the full team before the meeting.

Most physicians took a systematic approach, finding a step-by-step approach to be the best way to be consistent and normalize the emotions of a potentially difficult conversation. These steps were generally to ask the patient and/or family what their knowledge of the illness was, fill in the gaps of knowledge, and then to follow up by asking how they feel about the situation. There was also a trend in ideal setting, to find a private room without interruptions and placing an emphasis on having enough time for the conversation.

Most doctors commented that their comfort zones were their abilities to be sympathetic and to be knowledgeable in the medical processes. Discrete doctors noted their abilities to provide thorough details and to stress the importance of compliance to help patients and families understand the situation. Other doctors mentioned their abilities to understand families and to engage with them by using methods such as relating the situation to personal experiences and putting themselves in the families' shoes.

Challenges at TCC and addressing them:

There were also recurring challenges, most commonly:

- having family agree to come in for a meeting
- the family being reluctant to make a decision or disagreeing on plan of action
- cultural or language differences causing difficult family dynamics or expressions of sympathy being diluted when passing through a translator
- lack of education or health literacy
- family wanting patients continue to live despite his/her best interest for young patients especially, but also occasionally because of distrust in medical service.
- Further physician challenges and suggestions found in interview summary.

Having established what some of the issues are, it seemed necessary to understand what the roots of these issues are before finding a way to resolve them. In a study regarding barriers to communication regarding end-of-life care, 20 of the top challenges were listed by care provider teams and categorized into patient, system, dialogue, and provider barriers. (list found in the Appendix) The study found that recipient and system barriers were the most common (Anselm et al.). Juxtaposition of that list with the list provided by TCC physicians suggests that this may also be the case at TCC, especially recipient barriers. In a poorly developed provider-recipient relationship (which may stem from pressures within the healthcare system), it can be difficult for providers to understand the nuances of recipient factors such as family tensions, appropriate timing, readiness for such discussions, and cultural differences (Anselm et al.). Thus, finding ways to improve the relationship can help to overcome some of these major problems posed by the conversation, ultimately helping the patient receive better care and potentially a better death.

Why:

There are other reasons why this is an issue that should be considered an important target for improvement. A survey of 360 seriously ill patients regarding EOL care conducted by Steinhauser et al. showed that 96% of patients wanted to know what to expect about their physical condition and 86% wanted to know that their physician was comfortable talking about death and dying (Clayton et al.). And although patients and carers are often afraid to talk about the process of dying, they are relieved when the topic is finally discussed. The suggestion that

patients find it important that doctors be comfortable in talking to them about death, even if they may find it potentially uncomfortable to listen to, is alone a justifiable reason for this area to be improved. As a patient approaches EOL, assisting the transition into that stage of life as smoothly and supportive as possible is crucial, not only for patients who often need help accepting their prognosis, but also for families who must plan accordingly. It is well-noted by physicians at TCC that they do not feel entirely comfortable with or do not want to tell a patient that he/she is dying, and the 86% figure from the study shows how important the issue is.

In fact, few physicians, including specialists, receive formal training during residency about communication, and even doctors who routinely deliver difficult news admit they are unsure of their ability to properly perform this task (Barclay et al.). This was reinforced at TCC, where two physicians commented that they received no training in medical school, having to rely only on repetition and experience, and one mentioned that physicians are unsure of their abilities because they are “constantly told that they are bad at it.” A third physician also emphasized having/exuding confidence in their ability to perform, suggesting that sometimes the style is more important than content, as having confidence helps the family to trust what they are being told. This was something that the physician believed he and his colleagues could improve on. This is significant because patients’ perceptions of doctors’ inadequacy in communication are often noted as arising from what the doctors communicate as well as how they communicate (Russell et al.). Thus, improving in this area is not only for the health of the patients, but also for the physicians to become better at their jobs.

Some physicians feel discomfort because death is a sensitive topic. Other times in a physician-patient relationship, physicians have difficulty discussing issues or painting a full picture because they want to protect the patient. However, a study shows that if info is not honest/detailed, patients may perceive that potentially frightening information is being withheld (Russell et al.). Although physicians may believe introducing a topic is difficult and may unnecessarily upset a patient, evidence suggests that patients can still engage in discussions and maintain hope even when prognosis is poor (Russell et al.). This further supports the importance of a physician discussing bad news and being comfortable doing so, and the idea that patients want their doctors to be able to do so.

Additionally, this desire to protect patients with whom they have a relationship with manifests in other ways. This quote from “Uncertainty - The Other Side of Prognosis” summarizes and highlights the importance of physicians being aware of their own tendencies:

“Physicians' generally optimistic bias is well documented. In one study, physicians overestimated the likely duration of survival of terminally ill patients by a factor of five, and the longer the duration of the patient–physician relationship, the more optimistic the estimate...Others, ignoring the uncertainty inherent in prognostication, do more and more tests in the futile hope of improving their prediction. We believe that physicians need to recognize their reaction to uncertainty and how these reactions may influence their conversations with patients...By normalizing uncertainty and attending to the affective response to living in the face of an uncertain future, we may help our patients and their families enjoy the time they have now.” (Smith et al.)

Thus, it is not only patients and families who need to acknowledge the uncertainty of prognosis, but also the physicians. It is important for them to be self-aware of their relationship with a patient so that they are fully willing and able to not withhold important information, advise and make medical decisions in the best interests of the patient, and ultimately be strong in communication, considering it holds a direct tie to a patient’s quality of life.

Suggestions: Time, Be Repetitive, Hospice, A Different Model of Progression, Delivery

In my findings and observations, it seems that at TCC, the basic framework of the conversation and the importance of it is well understood. Every physician interviewed placed an importance on dialogue, asking what the family knows and would like answered, teamwork among all disciplines, and having a step-by-step procedure while simultaneously attempting to “play by ear” to tailor the conversation towards specific needs.

Thus, I believe the real improvement to be made comes within the mindset and attitude of the physicians themselves. This was reflected in the interviews, as one physician commented that “there’s nothing else done by someone else that can help; it is on the doctors” and most suggestions for improvement were for their colleagues to be more patient, know patients better, improve delivery, allot for more time, etc. Understanding better what kind of implications having an early and successful (or prolonged/unsuccessful) conversation would have for all parties involved could actually be the best incentive for physicians to improve personal efforts on this front:

Time

Time is a fundamental part of the conversation. For the physician and family (and/or patient) to be in a comfortable setting, sufficient time must be given. One physician remarked that “the family must not feel as though they are rushed, or under a time constraint to give a response or make a decision.” This was a common response given among all physicians who were interviewed, and while everyone understood the importance of time, several also noted that a barrier to having this conversation was the fact that they were busy and did not have much of it. In particular, one physician noted that Mondays are difficult because of the amount of emails and tasks accumulated over the weekend, and Fridays are difficult because there are many tasks to be completed before leaving for the weekend. Consequently, this physician said he tries to arrange meetings for in the middle of the week, and recommended his colleagues do the same - this way, they put themselves in the best position to avoid the pressures and temptations to cut meetings short due to emails or paperwork.

Be Repetitive

Often times, physicians go into conversations thinking that bad news interactions focus on one central piece of information (Wittenberg-Lyles et al.). However, repeating bad news could actually serve to be beneficial, especially in terminal prognoses. Redundancy of the prognosis reiterates the message, provides transitions to other care decisions, and helps the deliverers gauge the patients’ understanding of prognosis. (Wittenberg-Lyles et al.) First, repeatedly relaying the message in different manners helps to ensure that at least one form is understood by the patient.

Second, expressing the prognosis multiple times also allows the patient to respond multiple times, and the physician is able to gauge the patient’s understanding. (Does he/she repeatedly deny the prognosis? Or do they seemingly understand at the first or second attempt? Or do they first deny or not understand, but progressively seem to acknowledge and accept what they are being told?) This ultimately will help the physician guide the flow of the conversation, and when to progress forward or move back.

Third, usually after the patient understands the prognosis, talking about it also provides a segue into future options of care. Once given a terminal prognosis, patients or family will wonder what their options are if they cannot be cured, and this provides physicians a smooth

transition into how to move forward; this can be especially helpful in a transition between primarily offering curative care to primarily providing palliative care. Especially in a setting such as TCC, where based on the demographic, health literacy and education level has been raised as an issue, keeping this in mind could provide to be effective.

Use Hospice

Hospice is another sensitive topic that is potentially sensitive because of the implication that a family member is imminently close to death. And often times, the option of hospice is not even discussed until just before it is necessary for a patient to be placed on it. Even at TCC, we have encountered families resistant to EOL care plans because of the connotation of the name. Furthermore, one doctor stated that they are extremely hesitant to talk about or place a patient on hospice or EOL care plan simply because patients often outlive expectations. However, seeing that hospice can act as an active tool in conversation, not a death sentence, can help to overcome this; talking about hospice reinforces prognosis and provides an assessment of where the patient stands in terms of either understanding or accepting a terminal prognosis.

Talking about hospice does not entail aiming to place a patient on it, and often they may not feel ready for it. However, simply asking the patient's understanding of what hospice is and what purpose it serves as a catalyst to open the topic of advance care planning (Wittenberg-Lyles et al.). It tells the patient that based on their prognosis, they are at, or approaching, a point in which plans for the future need to be discussed. And much like repetition of prognosis, for patients who understand their prognosis, hospice serves as a reinforcement, and for those who do not understand or have a hard time acknowledging it, explaining hospice and having them see that it is seen as a possibility for them can help them to see their terminal status from a different perspective.

Effectively, even if not placed on hospice, talk about hospice care often facilitates a shift to a more positive interaction and effective conversations about advance care planning. It appears that open discussion of these topics gives the patient and family permission to start the process of discussing the planning for end-of-life and to achieve control over the last period of life (Wittenberg-Lyles et al.).

A Different Model of Progression

Another opportunity for improvement comes from what can be viewed as either a system change in operations at TCC or a perspective change from the physicians' end. Currently, there exists a linear model in which the amount of palliative care increases while curative care decreases as time since prognosis and approaching death passes. Bern-Klug et al. propose a refinement of the model which may be applicable for the patient demographic at TCC (Graphs found in appendix). The basis of the modification is that specifically in chronic illness, the reality of transition between the two types of care is not linear as the current model makes out. Rather, it occurs abruptly at pivotal points in which either an acute issue occurs, or when there has been a gradual change in status and the family/medical staff "catch up" to the slow changes that have transpired (Bern-Klug et al.). This staircase model places an emphasis on the need for more frequent meetings for updates and a higher importance on consensus on goals of care and care plans.

Two major barriers to reaching this consensus have been identified in literature: ambiguity about the appropriate time to make transitions to palliative care, and lack of emotional preparedness (Bern-Klug et al.). Knowing when the right time is a difficult challenge, but an important point to continuously keep in mind is to ask yourself and the family, is the patient currently unlikely to benefit from further curative medical inventions – and could they possibly even be harmed? Another barrier is that families – and even physicians – are not ready to forego these options. Again, it becomes important to review the medical information and to realize that at a certain stage when aggressive treatment is objectively not the best viable option, plans should be made for the relief of pain and suffering. And to do this, as aforementioned, physicians must take a moment during conversation to give a conscious effort not only in gauging a family's awareness, but their own as well.

In other types of patients, those with progressive cognitive impairment such as dementia, they may seem stable or be missing the sudden medical status changes that chronic illness patients have which would force physicians and families to periodically review the goals of care. In this case, an update is likely to occur in the late stages, when a patient's decline enters a "crossing of the threshold" (Bern-Klug et al.). Again, because the goals of care are most likely not being updated and adapted continuously, it is not only important to reach a consensus when the time comes, but also especially important to *maintain* it once reached. Because once the

threshold is crossed, there is a significant switch from curative to palliative care, as seen in the 3rd figure of the graphs. And because this is a change in the goals of care at the end stages of life, it is imperative that everyone is on the same page when it comes to preparing for caring for the patient and planning for death.

For this type of progression, barriers to maintaining the consensus are typically staffing issues and rehospitalization. Staffing does not seem to be an issue that can be addressed by physicians. However, rehospitalization has been brought up as a key issue at TCC. Two doctors claimed that they struggle to move forward with patients because of a distrust of medical care at TCC. Often, patients go to the hospital and agree to DNR directives, but on return to TCC, they rescind it. The doctors attributed this to believing hospital care was better, and sometimes after being treated for an acute issue, families believe the patient is on the mend. This highlights further just how important it is to relay prognosis sustainably, not to just get families “on the same page” by agreeing to what a doctor’s recommendations are, but to actually reach a “consensus” so that there is a shared understanding and prolonged agreement. Thus, reducing rehospitalization not only lowers costs, but also decreases the barriers present between the care providers and potential chances of maintaining consensus. This gives the current initiative to decrease rehospitalization at TCC even more of a mission to do so.

Understanding how to balance curative-palliative care using a more realistic model adapted to different types of patients may help physicians better conceptualize or visualize (potentially already existing) thoughts and methodologies for how to take care of their patients. But more importantly, it will help them more clearly relay to families the importance and “process” of finding a mutually agreeable course of action in the context of preparing for the loss of a life. This is crucial because often as families want to continue aggressive treatments, the lack of consensus prevents the amount of palliative care and quality-of-life measures from being given to the patient, while both the time towards death and progression of illness continues. However, if families understood the ramifications of failing to establish consensus quickly and efficiency, the frequency of that may decrease.

Thus, looking at the graph, if the vertical shifts (the time at which the graph goes straight up) that increase the amount of palliative care are continuously delayed at each pivotal point or at the point of crossing the threshold, once point of death is reached, the amount of palliative care provided (had this not been the case) would be less than what ideally could have been. This

raises the question of how well the patient's death was handled and clearly affects how comfortable the patient could have been at death, since palliative care prioritizes comfort. As mentioned, if families understood this better, they could become more amenable and diligent to coming in for meetings or trying to work with the physician to resolve differences in opinion for the sake of the patient. And if physicians understood this, they could be incentivized to schedule more frequent family meetings for chronic patients, helping to build that physician-family trust as a patient nears a more critical stage, and they could also be aware of placing emphasis on reaching a particularly sustainable consensus for progressive cognitive illness patients once at the threshold.

Delivery in Patient-Driven Conversation

Physicians have many tools to try and gauge a patient's understanding and to identify what they look for. However, the quality of responses they receive from patients is often questionable, and this causes confusion as to why patients seemingly contradict themselves and change their goals of plan or rescind prior advance directives. In some ways, it is only natural for people to often change their minds about their life when faced with death. However, it is still possible to try and glean as much of a truth as possible when talking to patients about what they are looking for in their care.

In research done by Brandt et al., they found that when patients were asked about what their goals for care are using open-ended questions and then closed-ended selection questions, there was a high level of discrepancy between the two responses they received to the same question. This suggests that it may be difficult to accurately identify patients' (or families') goals of care based only on their interpretation of responses to one type of question or the other (Brandt et al.).

As to why this is the case, it may be that an initial question may not reflect the response that would be given upon further reflection. If the closed-ended question was asked second, it may be that case that that represented more considered judgments. Another issue may be that in open-ended questions, a physician may look for key words that indicate a patient's desires, such as "get infection out" or "cancer free," while their closed-ended responses indicated not care-related goals, but goals such as "comfort" or "achieve life goals" (Brandt et al.).

Thus, the most effective way for a physician to understand the patient may be not to necessarily look for key words, or focus on one type of questioning, but rather to alternate between open ended and closed ended questions to probe at what they truly desire. As much as the patient and family should understand the medical perspective of a physician, because it is a relationship, it is imperative that the physician makes the effort to understand the patient beyond their medical status as well.

For example:

Physician: “Could you please tell me what your goals of care are so we can know how best to take care of you?”

Patient: “I want to get back to 100%”

Physician: “So I can be sure I understand, can you tell me more about what it means for you to get back to 100%?”

Patient: “I want my health to get back to normal”

Physician: “Are you saying your goal is to be cured of your heart problem or that you want to get back to the level of function you had before coming here?”

(Brandt et al.)

In this scenario, using open-ended questions and then a closed-ended question allows the physician to narrow down what he/she perceives as the patient’s goal, but also reaffirms it by making the patient iterate in their own words what they are looking for. This ultimately leads to a more patient-driven and accurate course of action, increasing the chances of sustainability.

Case Study:

Through the monitoring of several patients, I had the opportunity to see how palliative care initiatives were designed and how they were being carried out. Through this I was able to track different facets of the discipline that each patient embodied. However, there was one particular case where I was able to observe and review, through the lens of my project, the concepts of goals of care and plan of action for a patient.

Importance of being on the same page at EOL:

CD is a Huntington’s Disease patient, age 54, whom I picked up after it was brought to notice that various attempts to cease her regular vomiting were unsuccessful. Because of her persistent condition, she was at high risk for potential aspiration. Due to this risk, I began to

monitor her daily, with a personalized scorecard (found in Appendix). In this case, goals of care and being on the same page were a crucial factor. The patient had DNR, DNI, and DNH, all established at her prior wishes. Her care was primarily focused on attempts to prevent vomiting through changes in medicine and diet, body positioning to prevent aspiration, and making sure that all parties were in consensus, considering she had several family members who were closely involved. After multiple dietary and medicine adjustments failed to take effect, a family meeting was called.

The meeting was a full team meeting, with the medical director, physician, social work, pastoral care, nursing, and a hospice team from Calvary Hospital all present. The doctors began by establishing and confirming with the family that they knew the main issue at hand was the managing of her vomiting and the aspiration risk. The family members (2 sisters, 1 brother), quickly made it clear that they did not want extraordinary measures. The physician recommended an endoscopy to try and isolate the cause of her vomiting, or for her to see a G.I. specialist because of previous unsuccessful efforts. The family strongly reiterated that they did not want such measures, but did want to know what other solutions existed, because they were under the belief that they did not exist.

This presents a valuable opportunity to reflect on how effective the conversation turned out to be. After some time of being at odds between asking about other options, but not wanting heroic measures, the medical director asked, “if she refuses food, do you want us to stop feeding her?” They quickly agreed to this, asking for it to take place immediately if the patient was to ever communicate that she did not want to eat. The family also wanted to ensure that her pain would be taken care of, to which they were assured that morphine could be administered to the patient.

Hospice was also brought up, with the family’s understanding of what hospice is being probed and further explained on behalf of Calvary’s team. This opened up the conversation to what the goal of care was moving forward, which was evidently to take away all of her discomforts, even if addressing the vomiting meant to discontinue feeding. There was also some family background to their desires, as they (including the patient) had significant experience with the disease within the family and had a clear understanding that they wanted a comfortable death rather than prolonging an uncomfortable life. With this, the patient was placed on hospice just before the meeting concluded.

I found this to be an example of good EOL communication. The patient's condition as well understood by all parties, and the family seemingly knew what they wanted. The meeting itself ran smoothly, and sufficient time was given (the meeting lasted slightly over an hour). The meeting seemed long because for a period of time, the discussion was quite circular. However, in retrospect, the time spent was not redundant. The repetition reflected a successful conversation; the family attempted to relay in several ways that they wanted to stop feeding their sister by repeatedly citing that they did not want measures taken, did not believe there were alternative solutions, and that they were concerned for their sister's comfort – they had seen looks of fear in her sister when it came to food and vomit, and if she could not keep food down and causes her discomfort to vomit, why should she be forced to eat? The team also made a valiant attempt to relay to the family in different forms that it may still find the solution if they were to take certain measures such as an endoscopy or specialty consult.

Ultimately, this standoff was resolved through tactful usage of open-ended and closed-ended questions by the medical director. The discussion began by asking the family open-ended questions about their concerns and what they wanted, and responding to them, but admittedly progress of the conversation began to stall. However, at that point, the medical director explicitly asked the closed-ended question of whether what the family wanted was to stop feeding. This seemed to be the moment in which the medical director and the team brought to the table what they believed to be the family/patient's wishes, and this was confirmed by the family.

The hospice team then smoothly transitioned the discussion and planning even further, catalyzing a discussion of EOL in a positive manner. In fact, even if the family had not been willing to resort to hospice at that time, I believe that having talked about what it is and how it pertained to the patient would have opened up the gate to talk about EOL care planning in general. The timing and understanding of the progression of the illness was well-done as well. The vomiting was a change in medical status that called for a readjustment of goal of care/care plans, and a meeting was called before the medical staff had exhausted unnecessary efforts in hopes of finding a potential solution which may have gone against the patient or family's wishes. Had there not been a consensus reached on that day, the increase in palliative care that was needed (taking away medication, agreeing to stopping food, assurance of pain medication being provided, family visits becoming daily, hospice) would not have been accomplished, while time and illness continued. Luckily, because appropriate measures were able to be agreed on, and in a

timely fashion, the patient is more comfortable than she had been. In fact, due to the increase in palliation provided, I have noticed that her condition has improved, and the patient seems strong.

However, that is not to say it was handled perfectly either. From the medical director's description, there had been a lengthy conversation prior to this one that had seemingly aligned all parties' goals. But coming into this conversation, it was as though something had changed and what the family came in wanting was different from what the team's perspective was. I believe that having brought up the idea of hospice earlier – before the patient definitively needed it – would have helped to find a sustainable consensus during the previous encounter, rather than one that was established but seemed to dissipate. This raises the question of how well the previous conversation had been executed or whether there was a gap in communication that should have been addressed in between those times. Because Huntington's Disease is a progressive disease, as mentioned previously, having a sustained consensus is important. Although the family may not have been ready for hospice quite yet, it would have opened the doors earlier to EOL and possibly given permission to take other measures, or at least help clarify what the goal was.

Also, upon further check-in, I asked the patient if she was hungry and thirsty and if she had wanted to eat. She said yes to all, and I have given her cups of water on a few occasions after the meeting happened. This indicated to me that this patient may still have a strong desire to live. It also came up that a different sister who was not present at the meeting was still feeding the patient. This made me wonder if something prevented the execution of the plan or if the family truly knew what they wanted; and if not, could the physician have done anything to help better educate them on they wanted? Or was there a family dynamic that went undetected? Should the team have tried to have more family present at the meeting to reach a stronger consensus, or if the family was not in consensus amongst themselves, should the team have tried to encourage or facilitate it within the family? In conclusion, this experience showed me how an effective prognosis/EOL conversation could occur, but also highlighted both the work still needing to be done within it to truly improve a patient's quality of life, and the importance of trying to address these issues.

Conclusion

In speaking with the doctors at TCC, I have come to see that the mission is clear among all of them. Physicians have a standard protocol in which they try their best to balance sympathy

with medical advice. They also normalize uncertainty by attempting to keep a consistent protocol. They also acknowledge that the responsibility to communicate well is theirs. Therein lies the initiative to improve. Understanding just how far reaching the effects of this conversation have should provide the incentive to prioritize it. And seeing these ideas, such as topics of hospice, more personalized curative-palliative balances, and being repetitive, as a toolbox of interrelated instruments they can use to their advantage rather than a checklist of independent factors, could be sufficient for change.

The importance of this goal cannot be emphasized enough. I found myself working and learning about this topic because I saw how this could very well directly “make or break” a good death. From my own perspective, I found EOL to be important partly because of the peak-end bias, the idea that people judge experiences largely based on how they were at their peak and at their end, while other information such as duration or net (un)pleasantness is not used. If this is true in humans, we serve our patients best by offering as “good” of a death as we possibly can. As a fitting culmination of all this, I found a quote from Dr. Robert Pollack’s recent talk, “A Biologist Looks at the Human Soul,” which Ashley, Kerstin, and I had attended, to be extremely powerful:

“Each of these people has a soul, but we cannot tell much about that soul until we know more about the people closest to each of them. If they are loved and cared for, then of course their soul is well no matter how ragged their mind, or brain, or body. And if they are abandoned, mocked, written off as if already dead, then their soul must be in the Other World already, even though their body, or their brain, or their mind may still be present.”

If we can collectively improve the quality of palliative care provided to our patients at the end of their lives by improving communication and prognosis conversations, we can consequently give them a mutually unified and personalized death. In this, we offer them an ending with a healthy soul and ultimately a “good death.” This way, we can all do our part to serve TCC’s mission.

Appendix:

Figures:

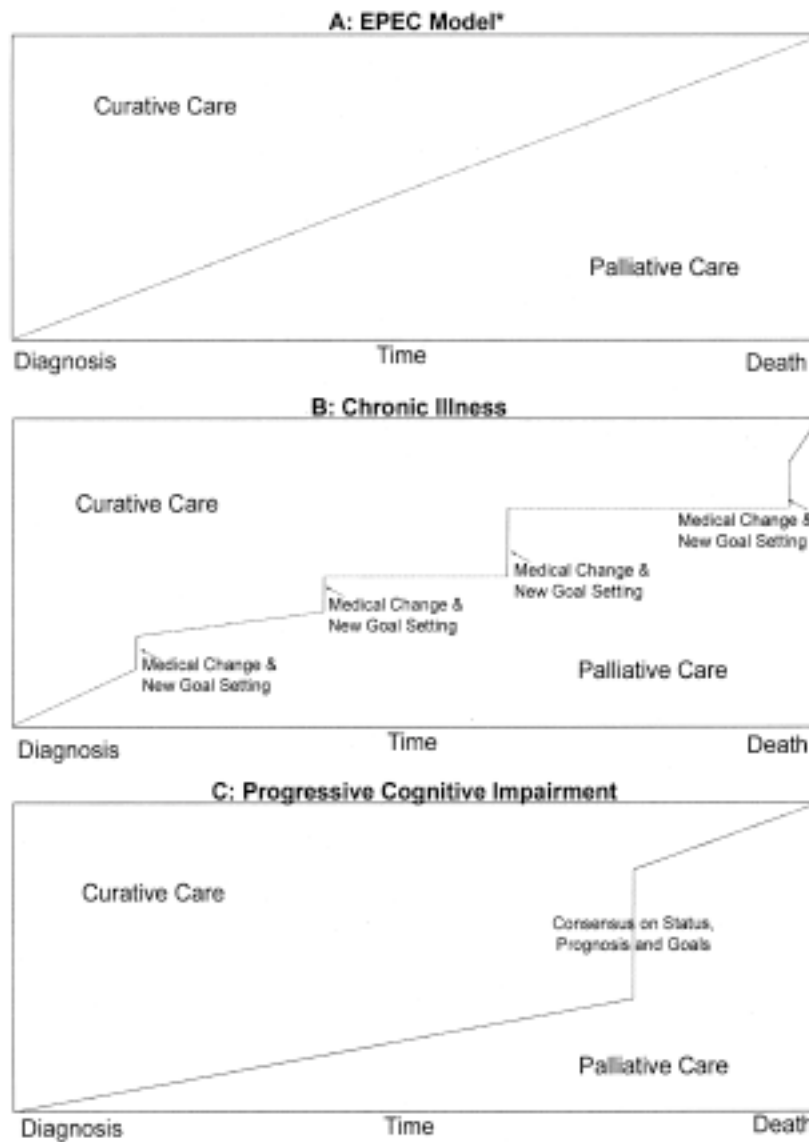


FIG. 1. Curative care to palliative care—transition. (Fig. 1A reproduced with permission from *The Education for Physicians on End-of-Life Care (EPEC) Curriculum* by L.L. Emanuel, C.F. von Gunten, and D.F. Ferris (eds): © The EPEC Project, The Robert Wood Johnson Foundation, 1999).

Box 1: Recipient barriers**1. Exclusion by family of patients or their wishes**

Families sometimes prefer to shield patients from these discussions and/or disregard patients' previously expressed wishes.

"I've had a couple of instances where the patient himself/herself was very calm and could appreciate the discussion and could carry on a reasonable conversation but the family didn't want this discussion with the patient. Quite often, we tell them that that's inappropriate because where they can, the patient is still in charge of his or her own decision making. On occasion the family is the biggest barrier."

2. Difficulty in *designating* a decision maker or reaching consensus

Families have difficulty either determining who the decision maker is, or what the family's consensus is regarding the desired level of intervention.

"[When] it is really unclear as to who the designated family member is that can be really bothersome because one family member will make a decision and then another family member will disagree. Obviously the family members themselves have not communicated with each other when that happens. . . You feel sometimes as though you're caught in the middle. . . and the danger there is you tend to favour the decision that you think is more appropriate."

3. Family *tensions*

Coping mechanisms of individuals increase family tension and make it difficult to establish communication. These include feelings of intense guilt, relieving stress through confrontation, and distancing themselves from the discussions.

"The family wanted us to do everything despite realizing that it was futile and that this patient was going to suffer, and so we felt that there was some inner guilt in the family members. They just wouldn't let the patient pass on and they wouldn't let us use the right to make the decision to not resuscitate."

4. Differences in *culture* or values

Certain cultures, religions, or other sources of deeply held values (which may conflict with those of providers) inhibit discussion.

"Unfortunately, our concepts of patient autonomy and about decisions about treatment are very Anglo-Saxon based ideologies where it is a little more open in terms of dialogue among family members. In other cultures it just doesn't work that way. The idea is you're the doctor. The presumption is that the doctor makes all the decisions, not the family. I think that western Anglo-Saxon cultures are more used to making decisions for themselves. This ideology is not as ingrained in other cultures. Often patients say to you, 'Well, you're the doctor, so you decide,' or 'Whatever you say, doctor.' Some people from other cultures expect you to make that decision for them."

5. Variable *capacity* to understand and appreciate discussions

Patient or family incapacity to understand or appreciate these discussions limits communication.

"Quite often the family is confused and although you have an idea about how you want to manage the patient and what would be appropriate actions, the family doesn't necessarily understand you."

6. Appropriate *timing*

A poorly timed discussion may raise anxiety in or alienate patients who are relatively well, young, insufficiently informed about their condition, afraid of death, unprepared for death, or who have not achieved closure in personal relationships.

"It's difficult when people are very sick and are approached at a moment of high stress. This is not the right time to broach the topic for the first time. Everybody is confused and nobody knows what to say and what to think."

7. Temporal *lability* of appropriateness of resuscitation

The appropriateness and desirability of resuscitation might be different at different times for either the patient or the provider.

"Therein lies the difficulty with those people who are "fine"—the durability of a DNR decision. If you ask a person about DNR and a DNR is signed, once out of the hospital and some time in the near or distant future, how definite was that decision made 5 months, 10 months, or 10 years ago?"

Box 2. System barriers

8. Suboptimal *coordination* of information exchange

Providers in teaching hospitals do not communicate optimally with each other or with other institutions regarding end-of-life discussions, even if these have occurred previously. The system for sharing information is inefficient. The resultant uncertainty regarding optimal management can delay initiation of communication.

"There could be better communication among health care personnel...These are things that get people into trouble, not discussing with family ahead of time, not communicating among medical personnel, somebody else making a decision. It's difficult for families because they see multiple doctors."

9. *Impersonality* of large teaching hospitals

Teaching hospitals are large impersonal institutions; care is typically short-term, with minimal involvement of community providers.

"It's not easy. Decisions for us are different than those made by long-term care physicians...Our usually short-term relationship with patients can pose a barrier...My willingness is reflected by my not really knowing the patient on a long term basis."

10. Providers unskilled in discussions as a result of *specialization* in certain areas

In teaching hospitals, care is specialty based; certain specialties are unskilled at conducting (or recognizing the need for) these discussions.

"Certain specialties are better at discussing issues like that. Oncologists tend to be better, infectious disease specialists for HIV tend to be better, but other disciplines seem to forget that their patients can die. Cardiologists are very poor communicators of this discussion. I think also, people who are nephrologists tend to forget that their patients can die from terminal conditions."

11. *Scheduling* difficulties

Busy work schedules of providers and the physical environment of hospitals make it difficult to arrange for private discussions.

"We are very busy and by definition if you are going to discuss this you have to be prepared to do it very slowly and patiently and wait for questions, answer questions. That's the biggest barrier for me. The absence of time that this sort of thing merits."

12. Lack of *external support*

External factors work against providers to create barriers to discussion: fear of legal action, lack of effective policy documents, and lack of institutional resources including education programs, better staffing, or 24-hour support for ethical decision making by resource people.

"We don't have good legal or institutional backup when we get into situations like this...It stems back to our training for codes. Our training starts with the ACLS course and there we're thrown in with nurses and other health care attendants and we all sit around learning algorithms. There's no integration of that whole process so you leave the course saying to yourself that you'll run the code for 20 minutes and consult the algorithms but what you really need is to have policy to back us up."

13. Risk of *abandonment* for "DNR" patients

"DNR" labels the patient and leads to abandonment or less aggressive care by others.

"One of the problems that I've come across is that when you do put a DNR on a patient's chart they frequently do not get the same care that they should get up until the point where they have to be resuscitated. It does brand them...That's one barrier that I have to the idea of DNR."

Box 3. Provider barriers**14. Inadequate *expertise* in prognosticating and leading discussions**

A lack of expertise due to inadequate training or inexperience makes providers feel uncomfortable about leading these discussions.

"No one teaches us how to do these things. There's no course on this and quite frankly our role models for this are few... a lot of this is learned at the bedside. I think there is a role to be had for educating physicians in an approach."

15. Discomfort with *emotion* involved

Identification with the patient, and/or other emotions, makes these discussions difficult.

"Some doctors have difficulty... we had 2 physicians recently who, no matter how hard we tried, they never would talk with the patients and family about this... They themselves had difficulty dealing with it... They couldn't come to grips with it."

16. Role *ambiguity*

Providers' roles and responsibilities in this domain are not well outlined; they fear reprimand due to overstepping the boundaries of their position.

"I think overall we need the development of clear definitions of roles... What's the role of the physician, the role of the nurse?"

17. *Prognostic uncertainty*

Providers prefer not to discuss end-of-life care until they are certain that the patient's prognosis is dismal.

"Often you don't know with 100% certainty that there's no hope... It's awkward, but I guess you can say that the chance is unlikely or less likely. However, people often want you to be more specific and that's hard because again, you just don't know."

Box 4. Dialogue barriers**18. *Nature of "DNR"* that may be perceived as nonsensical or defeatist**

Discussing or ordering "DNR" is either nonsensical (because it specifies things not to do, which is unique), or inappropriate, because it is seen as being defeatist.

"So many of our doctor's orders are written in the negative. For instance, "Do Not Resuscitate, No CPR, No This, No That." If things were written out in a more positive manner, it wouldn't be construed by the persons reading the chart as a "negative" thing, and in many cases as a Do Not Treat situation. We need to change the way we chart things and then you won't get that sort of confusion or misunderstanding."

19. *Societal values* surrounding death

Society does not generally recognize or appreciate death as a natural and acceptable part of life. This is reflected in expectations of unrealistically high survival rates from CPR, due to media portrayal.

"Another barrier is the perception of the general public and the perception of the families in terms of the success of a resuscitation effort... and how it's altered by the media and television shows like ER and Chicago Hope... That's the ER ward that I want to go to because all of those patients live through their resuscitation!"

20. Lack of *trust* in providers commitment or competence

Recipients of care lacked trust in providers. They questioned providers' commitment or competence by charging that issues such as resource allocation were interfering with acting in their interest, or by simply not believing their diagnosis and/or prognosis.

"Often if we aggressively seek DNR status on patients who may not be that ill or may not be that old, it undermines the trust that they have in you especially when they believe that your job is to provide them with excellent care. This is particularly important in the current status of the health care system with all the cutbacks and bed closures. They may misinterpret your intentions as 'killing them' to make way for someone who 'needs' their bed."

Forms:

Pre-Exercise Questionnaire:

Physician: _____

1. What do you feel your comfort zones are (consoling, delivering difficult prognosis, cultural barriers, projecting death, etc.) and where do you feel not as comfortable?
-specifically any strategies or keywords you use?

2. General impressions of peers - what do you think they could improve on or what do you think they do well?

3. What is your ideal setting you prefer to have the conversation? (time, place, environment, as a team or alone, etc.)

4. How do you feel and prepare beforehand and how do you feel and cope afterwards?
-What information do you feel must be relayed in an "effective" conversation?

5. Would it help if you had backup from another physician?

6. Personal strategies to normalize uncertainty/best educate families on what their goal of care is?

7. Difficulty or barriers you face in having the conversation - TCC-specific and general? (General: hard to talk about death to a family, too busy - not on list of priorities. TCC-specific: hard to find a quiet location, difficult to get family in to have the discussion)

8. 2 particularly difficult conversations of prognosis or prognosis-uncertainty you've faced or has tested you?

9. What would be helpful/How could I help?/Suggestions for improvement? (Ex: role playing exercise, self reflection session, collective discussion)

Patient: [REDACTED]	Medical										Family		Existential/Other
	Vomiting	Nausea	Hospice	Ability to communicate	Positioning	Diet/Food/Drink	Family Visitation	Family Understanding	Comfort				
C.NA/Volunteer Notes	Usually after each meal	Due to medicine	Started on 7/18	Enunciation, eye contact	Elevated to prevent aspiration, should not be lying flat	Track changes, what diet consists of, ask if shes hungry/thirsty	Important due to very involved family	Consensus on care planning	Ask patient				
Date													
7/15/2013	1x at lunch	Self-rated 2 out of 10, a lot better than last week		No difficulties understanding	Okay, not in danger	Removed warm, meaty foods, but vomit continues	Visited on Saturday	Had family meeting recently according to Dr. Lechich, appear to be on same page				When asked about airconditioner improving conditions, replied "Absolutely," but was exhausted - asked to be left to sleep	
7/16/2013	Claims no vomit, notes say 1x	1 out of 10		No difficulties understanding <i>was way more difficult communicating, hard time understanding due to enunciating problems, was able to give thumbs up however</i>	In chair on incline position	Same	Sister present	No updates				Seemed comfortable, no pain or discomfort noted	
7/17/2013	1x	Claims same as usual			In chair, safe	Same, potential stop feeding	Not there at time, but daily visits to begin	Had long family meeting, hospice care, placed on hospice, potential stop feeding				Had a look of fear while trying to communicate, as if about to vomit	
7/18/2013	No vomit as of yet	No nausea (because taken off meds?)	Began, patient is on hospice	Same	In chair, safe	Soup, though was planned discontinued food	Daily, sister present	Food was to be discontinued, but sister claims soup was given				Seemed comfortable with sister	
7/19/2013	No vomit as of yet	No nausea	Hospice nurse present	No issues, though seems though abilities definitely declined since prior	In bed, elevated	Soup, says is hungry and thirsty	Daily	Unsure, family was not present at time				Claim she is "doing good"	

-Patient not seen by pastoral care, thus not included in punchcard

TERENCE CARDINAL COOKE HEALTH CARE CENTER

End of Life Care Interdisciplinary Assessment Tool

Resident's Name: _____ Unit: _____ MR#: _____ Date: _____
 Discipline: _____ Date of Death: _____

Please indicate your response based on the following numerical scale. Note that the response of N/A will indicate that services were not applicable, not available or not answerable due to lack of information.

0 – Poor 1 – Fair 2 – Good 3 – Very Good 4 – Excellent

Statement

Response

1. If the patient experienced pain, management of the pain was: _____
2. If the patient experienced other symptoms, control of them was: _____
3. Medical communication with the family of the patient's condition and treatment options was: _____
4. Nursing response to the patient's needs and symptoms was: _____
5. Timeliness of receiving medications, especially for pain, was: _____
6. Nursing monitoring for new symptoms and needs was: _____
7. Discussions with the patient and/or family regarding advance directives were: _____
8. Discussions with patient and/or family regarding social service entitlements were: _____
9. Family counseling services were: _____
10. Discussions of spiritual belief issues with patient and/or family were: _____
11. Bereavement and spiritual support services for the family were: _____
12. Any psychiatric and/or psychological assessments or counseling for patient and/or family were: _____
13. Dietary assessment and any change to a more palatable diet regimen were: _____
14. Any rehabilitation assessments and interventions resulting in better comfort were: _____
15. Any recreation assessments or interventions resulting in better comfort were: _____
16. Considering the responses to the above statements, your overall assessment of the quality of the patient's end of life care is: _____

END-OF-LIFE CHECKLIST

Patient Name: _____ MRN: _____ Pt. ID: _____
 Identified as EOL: Yes _____ No _____

Advance Directives:

DNR: Yes _____ No _____
 Living Will: Yes _____ No _____
 HC Proxy: Yes _____ No _____

Assessments:**Comments**

Pain : Yes _____ No _____

Rx: _____

Symptoms: Yes: _____ No: _____

Dx/Rx: _____

Psychological: Yes: _____ No: _____

Social: Yes: _____ No: _____

Spiritual: Yes: _____ No: _____

Family Counseling: Yes: _____ No: _____

Bereavement: Yes: _____ No: _____

Rehabilitation: Yes: _____ No: _____

Dietary: Yes: _____ No: _____

Consultants: Yes: _____ No: _____

Outcome

Death at TCC: _____ Death at hospital: _____ Home hospice: _____

Physician Notes

Physician 1

-Comfortable in all aspects because he makes it a step-by-step process:

1. Assess what their knowledge of their situation is
2. Fill in gaps of knowledge with what you know as physician
3. Follow up on how they feel about it

-Hears colleagues have discomfort with conversation, particularly on discussing topic of how much time a patient has left to live based on potential of being wrong about prognosis, and because families put heavy weight on what they're told, and because physicians are continuously told that they are not good at the conversation

-Believes families don't look for specific dates, just enough knowledge to plan accordingly, important to provide reassurance.

-Ideal Setting: Private room, comfortable, no interruptions

-Prior to discussion:

1. Review chart to give not only accurate, but also updated information on disease progress
2. Speak with relevant specialists to know what they've been saying

-No coping methods

-Would find helpful to have a 2nd voice who agrees on the information you provide

-To normalize uncertainty:

1. Just be systematic
2. About you frame the information – language
3. Key phrases – “We're not good at predicting, especially at EOL, but from what we do know from observations of other patients with similar illnesses, we have a general impression that this is what you can anticipate.”

-Difficulties at TCC: finding a room, demographic, health literacy

-General difficulties: Not necessarily based on fear of being wrong, but more about having to deliver bad news

-On educating families on what their goal of care is: sometimes families simply are not ready or don't trust the system/information – act by what they feel is true. Can only be supportive in that case. However, there does come a point when those people don't act in best interest of patient that physician get take more of an active role through measures.

Physician 2

- Feels strong in speech involving compliance and importance of compliance
- Does not feel comfortable discussing time. Tries to convey message of impending death without be explicit, because feels families often understand what is trying to be said.
- Explains what would happen if patient does not take medication
- How quickly he/she would improve if she did
- Helps if done when alert and oriented
- Did not have enough information to comment on colleagues, only been here for 4-5 months, but presumes colleagues have more experience than she does in conversation
- Strongly prefers conversations with the team (Social Work, Head Nurse, Case Manager) involved, for documentation and knowledge of case purposes
- Does it in meeting room on units, just asks for meeting when seeing relative in patient room. Sometimes makes calls if needed
- Read discharge summary in order to compare from then to point of discussion, weight loss to explain cause and what they're doing about it, recent labs, and whether meds need to be changed, working well, or what the plan is if patient is not on meds
- Calls colleagues if they need advice, does not feel they need to be in the room for each conversation
- Believes families generally understand implications of EOL prognostication, agreeable to hospice care
- Had one patient whose patient's family in Albany, are afraid to make a decision, want everything even if they know patient was going to die
- Thinks it would be best to bring in more people when trying to educate on goal of care, especially if they struggle to understand
- In difficult situations, would prefer to call ethics committee
- No real barriers faced yet, only had 2-3 patient conversations thus far which were straightforward
- Believes team needs to be efficient and arrange conversations as soon as possible
- Physicians should know the patient well (effectiveness correlate with knowledge of patient) and the effects of things such as medication. Improvement on shoulders of physicians, no particular way they could be helped

Physician 3

-Discomfort: anytime patient is young, no contacts, no capacity, having to involve getting into psyche of family members

-Strength: describing medical processes and status

-Strategies: be thorough in giving as much information as possible (gets compromised if physician is in rush), don't prejudge their ability to understand/knowledge, giving more information helps them to make better judgment

-Avoid Monday/Friday, try to coordinate time with team beforehand

-Feels most variation in colleagues based on not competence, but confidence in what they know about the patient, which leads to confidence in delivery and how much trust the patients/family have in the physician. And having patience

-Ideal: private, high number of family members, having sufficient time, team members input or presence (but not always, because they may not feel comfortable, or it may not benefit the conversation to have them there)

-Prepare on how to deliver and what to say, prepare in advance for what you expect their response to be

-They have backup frequently (medical director, colleagues) but also call each other for assistance/advice

-Educating families: be forward, give them as clear a picture as possible by giving every detail of information so you come off as more confident about your prognosis. Focus should be on how you tell them, not necessarily being right.

-Barriers: young -> want to live, or family wants them to live. Lack of trust in medical service, complexity of medical issues in discrete patients. Can only overcome distrust by being close to them, passing information to families and having them understand/follow recommendations.

-If team here fails and ultimately they get rehospitalized, asking hospital team to discuss plan with family helps as well, as often patients trust hospital care more. (example, DNR, DNI at hospital, but full code when returning to TCC)

-Feels better knowing if hospital could not do it either; simply means they could not identify something. (could be guilt..didn't spend time with mother, disapproving of lifestyle, gets HIV and now feels responsible if lets mother die)

-Would not rush for meeting because he feels getting close to the patient to have them trust the physician and to be sure of their circumstances is best

-Bring ethics committee involved if all fails

-Suggest to colleagues: be patient, keep trying, involve others, have your own steps

Physician 4

- Strength is delivery/empathy (“putting myself in their shoes, relating to my own experience with mother”)
- Weakness: being asked when is ____ going to die?
- Routine: sit down, ask how they feel and what their understanding is. Allows them to sense that he is concerned about they will handle the news, and acts as warning sign of bad news coming
- Does in sun room, at least one other person from team, prefers to schedule on convenience of family
- Believes more important prep is knowing facts, no coping necessary
- Does not believe backup from another physician would necessarily help, but stressed importance of having someone else from the team present
- Normalizes uncertainty by first giving range, then “most people who have this condition live ____, but plenty live longer and shorter”
- Challenges: hard to get family in for discussion, cultural differences and language differences – interpreter diminishes amount of empathy relayed
- Doctor delivery as biggest issue
- Believes educational video highlighting difficult situations and emotional family members would be most helpful

Physician 5

- Strength: being sympathetic (uses father experience) and anticipating their feelings
- Would like to improve on technical aspect, delivering difficult prognosis. Does not like giving time frame due to chance of being wrong. Struggles with balancing because one could compromise the other
- Feels Dr. Lechich is good at being frank, but with compassion. Would like to learn
- Likes phrase “we can give her a good death”
- Also likes phrase “ER will be like such, but here we can do such”
- Prefers meeting alone because of potential conflicting information coming from different perspectives
- Prepares by talking to nurse, updating medical knowledge of patient, reviewing whether patient is eligible for hospice, and deciding whether to recommend hospice

- Play by ear rather than preparing step-by-step process. Easier to respond to what's given and adjust to give more or less information to family and patient
- Would not want physician backup, but believes pastoral care overcomes many religious barriers, acknowledged their benefit
- Normalizes uncertainty/educates families by giving different scenarios of both sides of the range rather than a set point. Tries to give maximum and minimum time frames of a certain condition.
- Religious barriers noted as biggest issue, then multiple relatives having conflicting feelings, and lack of education
- Addresses these by having group meeting urging family to come to consensus, and refrains from using medical terms
- Helpful to have a handout for a given disease to hand patients/families immediately after diagnosis explaining likely progression and future symptoms
- Hand out something to explain DNR, as patients believe it means giving up on a patient
- Tape a session with a real family, show to physicians and peer critique/evaluate

Physician 6

- Easiest to deliver difficult prognosis
- Difficulty in consoling (tears up often)
- Prefers using vague words
- Does not like placing or discussing EOL/hospice with patients because they outlive expectations
- DNR discussion key words: "Not easy to make this decision, but do you want to remember your loved one as you remember them? Or in a potentially vegetative state?"
- Emphasized desire to have medical director more involved with the team
- Does not push for answers, encourages further discussion between patient and family to weigh pros/cons
- Tell them they are allowed to rescind any decision
- Coping mechanism mostly simply to leave work at work the moment step out of building
- Finds being truthful and direct most effective
- Does not see major benefit from having backup from other physicians

-Challenges are that patient/family gets mad, would refer them to support systems such as pastoral care or psych, small % will never listen, always ask to do everything or act against recommendation

-Finds conversations easier to handle because the end result is always the same without adherence to medical recommendations: death

-Suggests using language patients can understand, need to have them ask questions to reiterate information because they often do not process what they are being told, establish trust and relationship with them, do not lie, maintain eye contact

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