Virtual Family Meetings: A Novel Pediatric Palliative Care Teaching and Communication Tool

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Introduction

Family meetings are a cornerstone of pediatrics and palliative and hospice medicine and they are often referred to as the ‘procedure’ of palliative medicine. Palliative care specialists use family meetings to communicate a patient’s condition and prognosis, identify patient and family preferences, and determine an appropriate path forward that aligns the care plan with the patient’s goals of care [1]. In pediatrics, family meetings represent a quintessential opportunity to communicate clearly and empathically with parents and patients, provide answers to questions, correct misconceptions, and reduce parents’ and patient’s feelings of uncertainty. Family meetings have been also shown to improve concordance of end-of-life care with the expressed desires of patients and families as well as mitigate anxiety and depression in the bereaved [2]. Since the onslaught of the Coronavirus pandemic in the United States in 2020, social distancing has become a way of life, in and out of the workplace. In the healthcare system, social distancing presents new challenges to a field that depends on close personal interactions, whether it is direct patient care or close communication. To address patient care needs while still maintaining social distancing, our institution employed Webex Meetings (© 2020. Cisco Systems, Inc.) as a tool to create virtual meetings as a substitute to the physical meetings that were held prior to the social distancing restrictions. These virtual meetings were easy to integrate into faculty and staff transactions. However, the appropriateness of this tool for family meetings to discuss critical topics, such as goals of care, was uncertain. Herein, we present a case study illustrating an appropriate use of technology to conduct family meetings during the COVID19 pandemic. The aim of this report is to describe how we used this technology for a family meeting and learned about its utility as a communication and teaching tool.

Background

Health care providers leading family meetings require specific skills including the ability to communicate with both clarity and empathy while conveying complex and difficult information. In addition, they are tasked with keeping the meeting organized, attending to families’ questions, and synthesizing clinical information while also ensuring the meeting is not excessively long without it ever feeling rushed. Yet, pediatric oncology fellows have inconsistent training in communication skills needed for family meetings and many practicing physicians feel uncomfortable utilizing palliative care communication skills [3]. Simulated patient encounters using actors in the roles of patients and family members have emerged as a critical teaching tool to facilitate the acquisition of the communication skills needed to lead family meetings and to discuss changes in prognosis and goals of care [4]. While these add value to our educational process, they cannot replace the experience that is gained by real life scenarios.

In 2020, at our institution, in an effort to minimize the spread of Coronavirus, a directive is in place to limit all in-person gatherings to fewer than five participants, visitors are restricted to 1 (or in special circumstances, 2) family members, and face masks are currently mandatory for staff and patients and visitors. As a result of these measures, the intimate family meeting environment, which is meant to provide comfort to families during difficult conversations is being replaced by a heavy dependence on technology. The necessity of forging forward with palliative care-led family meetings for our critically ill, and sometimes terminal pediatric oncology patients has led to the use of video conferencing during the COVID-19 era.

A Virtual Family Meeting

Our first Webex family meeting was with the parents of
an 11-year-old boy with multiply relapsed, refractory acute lymphoblastic leukemia. His respiratory status was worsening due to fungal pneumonia and the medical team sought clarity on the patient’s goals of care and next steps should he develop respiratory failure. In addition the palliative care team wanted to address how the parents were communicating with the child and to offer practical tips, support, and reading material (including a story book about a dying tree) that could be read to the child. Under normal circumstances, multiple members of the interdisciplinary team would attend the family meeting, but usually no more than 3 or 4 in addition to the family in order to avoid the family feeling the pressure of an audience. These participants may include the palliative care attending physician and/or nurse practitioner, an intensive care physician and/or nurse practitioner, a social worker, a chaplain, the patient’s bedside nurse, and one or two members of the primary care team (oncologist or stem cell transplant physician). This practice often leaves people out, including other involved medical specialists, all levels of medical learners, additional nurses on the unit, child life specialists, psychologists, and other members of the interdisciplinary team. Yet the information that is shared and discussed in these meetings is invaluable to ensure alignment of all members of the team with the families’ goals of care.

As per our usual protocol, the parents were given a worksheet to guide them as they listed their questions and concerns (Appendix 1). In addition, the parents were asked if they would consent to having multiple staff members, all of whom they had met previously, join the meeting via Webex. The parents readily consented, and actually also asked if they could similarly add another family member to the Webex meeting. This request was allowed by providing the family member with the phone number and the meeting identification number.

The entirety of the medical team, including interdisciplinary staff from inpatient nursing, patient advocacy, pediatric oncology, palliative care, and intensive care, met via Webex without the family to address questions and concerns of all staff members. This preparatory meeting also served to align staff on the medical facts and areas in need of clarification by the family. Following the preparatory staff meeting, an inventory of the people remaining on the Webex was taken, and it included the family’s assigned social worker, bedside nurse, charge nurse, nurse manager, supportive care nurse practitioner, a representative from patient advocacy, and the patient’s primary oncologist. All staff on Webex were asked to mute their microphone unless called upon from the meeting facilitator to keep background noise to a minimum. Three key personnel, all physicians, including the oncology fellow, the palliative care attending physician, and the palliative care fellow who was also fluent in Spanish–the child and family’s native language–met with the family in a conference room on the hospital unit where the child was admitted. The choice to use a conference room was based on the need to socially distance (larger space) and to allow parents an opportunity to discuss their child’s care without him present.

The decision to include a child in these discussions is dependent on many factors (age and development of child, child and parent’s desires, etc.) but ultimately the decision lies with the parents. In our experience, when young children are involved, speaking with parents first allows a plan to be developed and parents to process difficult emotions. Following the meeting, parents and or staff can meet with the child and discuss the information and plan in a developmentally appropriate way. The family was introduced to the technology, which included a live-streaming video of the meeting. A projector screen clearly displayed the names of the attendees at the Webex meeting. The supportive care attending and fellow facilitating the meeting first identified all the staff members on the teleconference. The meeting proceeded as it normally would have with an allowing of the family to recapitulate their understanding of the medical facts, and to raise their questions and concerns, followed by information sharing, pointed questions by staff, informed decision-making, and negotiation of a care plan. Occasionally questions were posed to individual Webex participants as the need arose, and those participants would be called upon to answer. For the most part, however, participation was limited to the family and the 3 physicians in the room. The team and family’s concerns were addressed sufficiently during the meeting leading to a successful and agreed upon plan of care aligned with the family’s wishes.

Normally following a family meeting, the next step is to verbally communicate the results of the meeting to the most critical members of the interdisciplinary team and the remainder of the staff would read the family meeting synopsis in the electronic medical record. However, with this novel technology, the need for a formal verbal information handoff was mitigated as all parties in need of the information were already on the call and had heard it firsthand. In addition, medical learners, including a new nurse practitioner to the team, were able to witness a complex family meeting dynamic, how wishes of the family were identified, and the process of decision-making in real time. The nurses on the call reported feeling better informed regarding the families’ concerns and appreciated hearing the responses to those concerns in real-time, noting that sometimes the verbal and written hand-offs may lose some information in translation. Additional members of the care team commented on the utility of using this technology as a teaching tool for learners, including social work and psychology students, to enable them to witness a well-coordinated family meeting without being intrusive to the family. Additionally, it was reported by some that although in-person participation is preferred, this was a very useful alternative option. The family was appreciative that so many members of their care team could convene to create the best plan of care for their child even amid the Coronavirus-related restrictions and that their additional family member could participate by remote access to the meeting.
Conclusion

The virtual family meeting was considered a success because the family was satisfied with it, the staff was well-informed after it, and the learners were provided with modelling for how to conduct the meetings. This experience has led us to think that perhaps, even after the COVID-19 era of social distancing is behind us, that teleconference technology could be used in family meetings to enhance the learning of interdisciplinary trainees, and improve communication across interdisciplinary team members regarding the rationale underpinning patients’ plans of care, particularly in the palliative care setting. Future research should incorporate validated self-report survey instruments, semi-structured qualitative interviews, and clinical outcome variables to assess acceptability and impact of virtual family meetings on clinical care, staff communication, and acquisition of learning objectives for trainees.

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References