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Evaluation of Physician and Nurse Dyad Training Procedures to Deliver a Palliative and End-of-Life Communication Intervention to Parents of Children with a Brain Tumor

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Abstract

When a child's prognosis is poor, physicians and nurses (MDs/RNs) often struggle with initiating discussions about palliative and end-of-life care (PC/EOL) early in the course of illness trajectory. We describe evaluation of training procedures used to prepare MD/RN dyads to deliver an intervention entitled: Communication Plan: Early Through End of Life (COMPLETE) intervention. Our training was delivered to 5 pediatric neuro-oncologists and 8 pediatric nurses by a team of expert consultants (i.e., in medical ethics, communication, and PC/EOL) and parent advisors. Although half of the group received training in a 1-day program and half in a 2-day program, content for all participants included 4 modules: family assessment, goal-directed treatment planning, anticipatory guidance, and staff communication and follow-up. Evaluations included dichotomous ratings and qualitative comments on content, reflection, and skills practice for each module. Positive aspects of our training included parent advisers' insights, emphasis on hope and non-abandonment messages, written materials to facilitate PC/EOL communication, and an MD/RN dyad approach. Lessons learned and challenges related to our training procedures will be described. Overall, the MDs and RNs reported that our PC/EOL communication-training procedures were helpful and useful. Future investigators should carefully plan training procedures for PC/EOL communication interventions.

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Keywords

palliative care; end-of-life care; parents of children with a brain tumor; palliative and end-of-life communication training

Parents of children with a cancer diagnosis have expressed increased satisfaction with the care they receive following effective health care communication. Also, delivery of clear and timely palliative and end-of-life care (PC/EOL) communication is essential to equip parents of children with life-threatening illness and a poor prognosis to make informed decisions about their child's medical care (Slort et al., 2011; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). Without clear information, parents may not acquire enough foundational knowledge and understanding about the offered oncology treatments and PC/EOL options to form an opinion or preference about them (Ammentorp, Kofoed, & Laulund, 2011; Aschenbrenner, Winters, & Belknap, 2012). Bereaved parents have reported dissatisfaction when receiving unclear information about their child's prognosis and PC/EOL options, even as their child's death grew near (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Davies & Connaughty, 2002; Hendricks-Ferguson, 2007; Maynard, Rennie, Shirliffe, & Vickers, 2005; Meyer, Burns, Griffith, & Troug, 2002; Monterosso & Kristjanson, 2008; Widger & Picot, 2008). Parental dissatisfaction with unclear information can also trigger a sense of anger toward the child's health care providers (HCP) and of regret about decisions made during the child's PC/EOL trajectory (Levetown, 2008).

Multiple barriers are associated with delivery of PC/EOL information to parents of children with cancer and a poor prognosis (Levetown, 2008). A primary barrier is the limited training of practicing pediatricians and pediatric oncologists in PC/EOL communication with parents and children (Baker, Torkidson, Barlargeon, Olney, & Kane, 2007; Galushko, Romotsky, & Voltz, 2012; Kersun, Gyi, & Morrison, 2009; Roth, Wang, Kim, & Moody, 2009). Furthermore, medical education does not focus on the importance of using interpersonal techniques (e.g., listening skills, empathy, and open-ended interviewing) (Levetown, 2008). Barriers to the delivery of effective PC/EOL information to parents are associated with physicians' beliefs and attitudes about the best time to discuss a bad prognosis, uncertainty about how to balance hope and honesty, and family resistance to receiving PC/EOL information (Hilden & Emanuel, 2001; Meert, Eggly, Pollack, Anand, & Zimmerman, 2008; Wolfe et al., 2007). In addition, an evidence-based curriculum has yet to be established regarding the most effective teaching method to train medical students, nurses, and physicians to competently and comfortably engage in difficult discussions about PC/EOL (e.g., prognosis), especially early in the illness trajectory when hope supports a curative effort and planning for comfort and quality of life may enhance the quality of care (Grainger, Hegarty, Schofield, White, & Jefford, 2010; Kersun et al., 2009).

Communication skills training programs (CSTPs) usually instruct medical students and residents in PC/EOL communication skills without the use of actual patients. Evaluation of these programs has focused on the acquisition of skills through simulation and role-play with trained actors, rather than through practice with real patients with a poor prognosis (Back et al., 2007; Back, Arnold, Tulskey, Baile, & Fryer-Edwards, 2003; Greenberg,

Ochsenschlager, O'Donnell, Mastruserio, & Cohen, 1999; Levetown, 2008; Tulsy, 2005). In a comprehensive review of studies focused on the evaluation of PC/EOL CSTPs, all 5 of the studies found included MDs with adult oncology patients (Moore, Mercado, Artigues, & Lawrie, 2013); no pediatric CSTP studies were reported in this review. None of these reviewed studies included an MD/RN dyad team approach, even though clinicians recognize that RNs are positioned to share patients' and caregivers' perspectives and questions about prognosis and PC/EOL options with the MD (Helft, Chamness, Terry, & Urich, 2011). Training MDs to engage in PC/EOL discussions without an RN present does not support the interprofessional collaboration between MDs and RNs that is believed to be important to delivering clear health care information and fostering satisfaction with received communication (Martin, Ummenhofer, Manser, & Spirig, 2010).

Purpose

This study, in which MD/RN dyads were trained to deliver the intervention, evaluated the efficacy of a new PC/EOL communication intervention, Communication Plan: Early Through End of Life (COMPLETE). The study targeted parents of children with a brain tumor and a poor prognosis during scheduled follow-up treatment evaluations in a clinical setting. This article describes our evaluation of the actual training procedures used to prepare MD/RN dyads to deliver the COMPLETE intervention, and it describes lessons learned. The MD/RN training was completed prior to enrolling eligible parents in the primary study. The evaluation of the delivery of the COMPLETE intervention to enrolled parents will be presented in a subsequent paper.

Background

Parents of children with life-threatening illnesses have often reported a need for compassionate, clear, and timely PC/EOL communication (Aschenbrenner et al., 2012). The primary factors contributing to HCPs' delay in engaging in discussions about PC/EOL options with parents of children with life-threatening illness and poor prognosis for survival are not clear. Two systematic reviews have provided evidence that the following factors may contribute to such delays: (a) MDs'/RNs' attitudes and beliefs about conducting PC/EOL discussions (e.g., fear of causing emotional distress and diminishing hope) and lack of use of basic communication skills (e.g., listening, establishing trust); (b) patients' and family members' beliefs and volatile responses; (c) limited PC/EOL communication training; and (d) lack of system support for HCPs to have protected time to engage in PC/EOL discussions and address concerns by patients and family members (Bluebond-Langner, Beecham, Candy, Langner, & Jones, 2013; Gysels, Richardson, & Higginson, 2004).

Widely recognized PC/EOL communication-training programs for oncology fellows (Oncotalk) and emergency department physicians (SPIKES) are in place to help these HCPs engage adult patients in PC/EOL discussions (Back et al., 2007). Existing communication-training programs are primarily focused on preparing future and practicing physicians to discuss PC/EOL topics with their adult patients (e.g., breaking bad news) (Back et al., 2003; Gysels et al., 2004; Kersun et al., 2009; Slort et al., 2011). However, similar programs have not yet been developed for use by pediatric oncologists in discussing PC/EOL options with

parents of their patients (Kersun et al., 2009). In addition, few studies have evaluated MDs' delivery of a PC/EOL communication intervention to adult patients with cancer during oncology treatments (Moore et al., 2013). In contrast, the national PC/EOL education program entitled End-of-Life Nursing Education Consortium (ELNEC) (Malloy et al., 2006) has provided education to enhance the knowledge and skills of RNs to provide competent physical care for pediatric and adult patients during PC/EOL and also psychosocial and bereavement support. Still, few studies have focused on evaluating training procedures for RNs to engage in PC/EOL communication with adult patients with cancer during cancer treatments (Wilkinson, Perry, Blanchard, & Linsell, 2008; Wilkinson, Roberts, & Aldridge, 1998). Also, no published studies were identified that presented an evaluation of training procedures for MD/RN dyads to deliver a PC/EOL communication intervention to parents of children with cancer (Tang, Chan, Zhou, & Liaw, 2013).

Wide variation exists in the delivery of PC/EOL communication-training programs to MDs/RNs (e.g., programs range in length from 3 hours to 5 days). Some investigators have evaluated training programs that include follow-up booster sessions. Limited formal education in pediatric PC principles and practices during medical school and residency has many MDs reporting a lack of confidence in their ability to initiate discussions about PC/EOL options (Galushko et al., 2012; Sheetz & Sontag Brown, 2008). Several national health care organizations (e.g., NIH, IOM) have advocated the use of patient-centered communication principles during PC/EOL communication training (Perocchia et al., 2011) as well as an interdisciplinary focus to ensure that effective and sensitive PC/EOL communication is provided to parents of children with a terminal illness (Levetown, 2008; Roth et al., 2009). In one descriptive study, pediatric oncology nurses conveyed a concern about not receiving sufficient educational preparation to initiate and engage in PC/EOL discussions with parents of children with a poor prognosis and during EOL (Hendricks-Ferguson, Dupree, Sawin, & Haase, 2009). Still, evidence-based guidelines for PC/EOL communication strategies to be used by MD/RN dyads during difficult discussions about pediatric patients and family members have yet to be established (Foster, Lafond, Reggio, & Hinds, 2010).

COMPLETE Study Overview

The COMPLETE study aimed to refine and pilot test a PC/EOL communication intervention. The intervention was designed to be delivered within routine clinic visits using (a) an MD/RN team approach to PC/EOL communication; (b) written decision maps and parent resource forms indicating both treatment and PC/EOL options; and (c) hope-sustaining and non-abandonment messages that the MD/RN team modified according to their own communication styles and according to the needs and preferences for information as expressed by the parents. We conducted a single-group, pilot exploratory-development study to evaluate the COMPLETE intervention in 2 phases. We carefully developed an innovative and comprehensive training program to equip our MD/RN dyads to be prepared to deliver COMPLETE according to our established protocol and to help ensure that future delivery of our intervention was according to protocol. In this article, we describe our evaluation of our training procedures designed for the MDs/RNs to deliver COMPLETE and also the lessons learned during our training procedures.

COMPLETE Intervention Training

Planning Process for Training

Our study team, composed of principal and co-investigators, PC/EOL communication and ethics expert consultants, and bereaved-parent advisors, collaborated during a 2-day face-to-face meeting to plan and develop MD/RN training procedures. The resulting training plan and materials included (a) didactic content on PC/EOL evidence-based best practices; (b) communication skills practice through role-playing with parent advisors; (c) COMPLETE study protocol policies and implementation procedures; and (d) a comprehensive resource manual. The manual included (a) MD/RN intervention session outlines; (b) scripted language and prompts to guide MD/RN discussions during parent sessions; (c) role-specific checklists for team members to review prior to scheduled parent sessions; (d) copies of protocol documents (e.g., parent-session and data-collection forms, quality assurance checklists); and (e) study policies and protocols for training and for MDs/RNs to follow during intervention delivery to parents.

Training Implementation

Setting and Sample

The MD/RN interventionists, trained to deliver the COMPLETE intervention and participate in study-related activities, were recruited from 3 tertiary pediatric children's hospitals located in urban areas and affiliated with the Children's Oncology Group: IU Health Riley Hospital for Children, Indianapolis, Indiana; SSM Cardinal Glennon Children's Medical Center, St Louis, Missouri; and St Jude Children's Research Hospital (SJCRH), Memphis, Tennessee. Eligibility criteria for participating HCPs included (a) pediatric neuro-oncologists and registered nurses currently caring for children with a brain tumor; (b) willingness to work as a collaborative team (i.e., MD/RN dyad) to conduct the intervention and willingness to participate in planned training activities; and (c) willingness to deliver COMPLETE according to the protocol. Prior to the study, the MDs/RNs at each site indicated that they did not routinely integrate early PC/EOL communication into treatment-decision discussions with all patients/families. Instead, PC/EOL discussions were sometimes delayed until close to the child's death. According to institutional review board policies, participating MD/RN interventionists were considered research-study participants during the training; following training, they were considered study staff. We established a psychosocial support plan in the event that any participants experienced significant emotional distress during training. During small-group reflective discussions and after role-playing activities, we scheduled protected time for the parent advisors and MD/RN interventionists to debrief and to express how they were feeling. A bereavement counselor was available for phone consultation by the parent advisors throughout and following the training.

Description of Planned Training

The MD/RN training program was conducted twice. In year 1, a 2-day training was done for personnel from 2 sites: IU Health Riley Hospital for Children in Indianapolis and Cardinal Glennon Hospital in St Louis. Participants attending this training included 3 MDs, 5 RNs, 3 investigators, 2 consultants, and 3 bereaved-parent advisors (1 married couple, 1 single

mother). In year 2, SJCRH was added as a study site. After considering both the feedback from the year 1 cohort and the concerns over the limited availability of SJCRH's staff to attend, a decision was made to shorten the year 2 training to 1 day. The itinerary was adjusted to assure the topics covered were the same, and to compensate for less time, the MD/RN participants were instructed to review independently the study protocol materials and didactic PC/EOL communication modules prior to training. Participants attending the year 2 training included 2 MDs, 4 RNs, 2 investigators, 1 consultant, and 3 parent advisors (1 married couple, 1 single mother).

Training for both year 1 and year 2 groups included 2 components: training on the COMPLETE intervention and training on the research study implementation. Modules for the intervention training component included (a) establishing a therapeutic alliance with the parents (i.e., eliciting and understanding parent perspectives); (b) offering meaningful choices (i.e., assessing parents' preferences to receive PC/EOL information); and (c) reaching a shared understanding of the child's diagnosis and treatment options (e.g., goal-directed treatment planning, anticipatory guidance). Didactic and experiential learning strategies were used. The MDs/RNs (1) received evidence-based information about recommended PC/EOL communication skills, (2) practiced intervention delivery with parent advisors in 4 role-playing sessions, and (3) participated with the parent advisors in PC consultant-facilitated debriefing and reflective discussions. At the end of the 1- and 2-day training sessions, MD/RN participants completed an evaluation form about the training they received.

Data Collection and Analysis

To evaluate the MD/RN perspectives about the training and to determine MD/RN receptivity and perspectives regarding the usability of COMPLETE prior to study activation, participants completed an evaluation form immediately post-training. The investigator-developed form included 5 dichotomous items (agree/disagree format) and 8 open-ended questions (Table 1). Approximate completion time was 10 minutes. Descriptive statistics were used to evaluate the dichotomous items. Content analysis of the open-ended questions was completed by 2 of the study investigators, and 100% agreement was reached on the final themes.

Results

Description of Sample

Thirteen interventionists (5 neuro-oncology MDs and 8 pediatric oncology RNs) consented to participate and completed the training. Four (80%) of the 5 MDs were male. The MDs' years of experience with providing care to children with a brain tumor ranged from 4 to 8 years (mean = 4.5 years). All of the participating RNs were female. Years of experience of the RNs working in pediatric neuro-oncology ranged from 5 to 15 years (mean = 7.5 years). Among the 13 interventionists, 11 (84%) were Caucasian and 2 (15%) were Asian. No data were obtained on age of participating MD and RN interventionists.

Participants' Post-training Evaluation Outcomes

Quantitative responses—Evaluation of training activities by the 3 MDs and 4 RNs at IU who received the year 1 training program indicated 100% positive agreement with the 5 dichotomous (agree/disagree) comments (Table 1). The 2 MDs and 4 RNs at SJCRH who received the year 2 training program indicated 100% agreement on 4 of the 5 positively worded items on the post-training evaluation form. One of the SJCRH trainees disagreed with the positively worded statement regarding appropriateness of time to learn what was necessary for training.

Qualitative written responses—Participants described their perspectives about our training procedures by responding to the open-ended questions (Table 1). From their comments, 5 major themes were identified: (a) benefits of training as a means to learn, (b) benefits of expert mentor and practice skills, (c) meaningful PC/EOL communication tools to use after training, (d) receptivity to implementing the intervention in own practice, and (e) recommendations for future training procedures (Table 2).

Theme 1: Benefits of training as a means to learn—The MD/RN responses provided evidence that our training approaches helped them acquire additional PC/EOL communication knowledge and skills: “Information was useful. Data presentation and observing consultant interviewing parents were helpful” (MD #1). Participants also indicated that didactic content (i.e., review of the protocol and the modules) provided specific and useful examples of PC/EOL language to participants that could be incorporated into the delivery of COMPLETE. They also indicated that the didactic content and practice skills had bolstered their confidence and comfort in integrating hope and non-abandonment messages into discussions: “Helpful that hope and non-abandonment was emphasized” (MD #2). And, they felt that information about ways to assess parents’ goals would be meaningful and helpful during the difficult discussions they have with parents about their child’s condition, prognosis, and treatments: “Goal directed care planning ... is meaningful to our practice” (MD #3).

Theme 2: Benefits of expert mentors and practice skills—The MD/RN participants reported that having fully engaged PC/EOL expert consultants providing feedback during role-playing and debriefing was useful: “... very useful to have the opportunity to listen and observe spoken and unspoken language [during role plays]” (RN #1). They believed the faculty fostered a comfortable and trusting learning environment that was a safe place to dialogue and practice communication skills. The participants also indicated that they valued the opportunities to hear parent advisors’ feedback regarding their communication skills during role-play conversations: “... very helpful to incorporate what we heard or observed into our language of the interview process. The skills practice was very helpful. Reflections after role play excellent for learning” (RN #2).

Theme 3: Meaningful PC/EOL communication tools to use after training—Participants indicated that they had gained awareness that their previous PC/EOL communication skills were inadequate and they highly valued the training: “This opportunity [training for the study] has given me the piece of my career I have so longed

for” (RN #3). Specifically, they appreciated learning about communication tools (e.g., use of hope and non-abandonment messages and anticipatory guidance using visual aids) that could easily be incorporated into difficult discussions with parents and other clinicians: “Helpful in learning new/better technique of communicating with each other as a team and with families” (RN #4). In addition, participants found that the debriefing sessions after role-play offered constructive feedback that fostered self-reflection on perceived gaps in their PC/EOL communication skills: “Discussions during/after role-playing were helpful—the intent was to redirect/improve [by] role-playing” (RN #5).

Theme 4: Receptivity to implement the intervention in own practice—

Participants identified several ways that COMPLETE could be implemented into their practice. They thought that COMPLETE training materials (e.g., hope-focused text and sample prompts to use with parents to open dialogue) would be helpful during and beyond this study: “Starting points for conversations with parents/patients ... useful in my clinic visits with families in my conversations. I can further pinpoint their goals and try to align what we are doing with their goals” (RN #6). They also thought that COMPLETE skills would be helpful in discussions with families and when mentoring other health care providers on ways to have difficult PC/EOL conversations with parents: “This training gave me some insight & tools—i.e., language and approach to use for intro of palliative care. Not only are we learning with our families [in the study]. I will have the opportunity to also teach other co-workers” (RN #7). Participants thought that use of COMPLETE skills would enhance dialogue with parents and patients in our study, and they identified benefits of routinely using the COMPLETE PC/EOL skills to assess parents’ care goals for their child and integrate parents’ preferences into the child’s plan of care: “The slide on communication responses [other families’ experiences] will be very helpful to open the lines of communication” (RN #8).

Theme 5: Recommendations for future training—Although the majority of participants responded with an “agree” rating on survey item #5 in Table 1 (i.e., The format of training was an appropriate amount of time to learn what I needed to know to conduct the COMPLETE intervention well), there were a few RN participants who conveyed the concern that the training time for MD/RN dyads to implement a PC/EOL intervention should be longer: “Definitely needed 2 days. This was intense, one day is inappropriate” (RN #4). They also recommended that role-playing scenarios be expanded: “Change scenarios to include baseline MRIs with stable results” (RN #6). Lingering concerns about implementing the study in a busy clinic setting were also expressed: “Perhaps add content as to how this may be implemented in a timely manner in a real busy practice” (MD #5).

Process Evaluation

On the first day of the year 1 training, we encountered the following challenges related to the role-playing activities. The RNs were hesitant to engage as equals with MDs in protocol discussions with the parent advisors. The MD participants were reluctant to engage in the role-playing necessary to learn the intervention, expressing that they already had much experience conducting bad-news conversations and discussing treatment options. This MD reluctance to engage was also related to hesitation about being observed by other team

members during role-play activities with the parent advisors. The MD participants were very skilled at conveying medical information about the child's condition in a caring, complete approach; however, when parent advisors displayed strong emotions, the MDs' use of listening and empathic responses decreased and use of medical terms and teaching increased. Because these challenges raised concerns about ability to deliver the COMPLETE intervention according to protocol, we abbreviated the planned day 2 study implementation training (e.g., recruitment, measurement, and quality assurance procedures) considerably and focused on addressing participants' concerns around role-play, having additional role-play sessions, and debriefing and encouraging reflection on delivery of the protocol. We also modified the written case-study scenarios and language prompts to make them easier to follow. To ensure that the trained MD/RN participants had the knowledge and skills to deliver COMPLETE as proposed, the core investigators provided post-training intervention-skill coaching and post-intervention delivery debriefings during review of the transcribed summary of the parent sessions (which were audiotaped). After the study was activated, phone conferences were also conducted between the MDs/RNs and the PC/EOL communication consultant and the core investigators.

Discussion

Summary of Lessons Learned during Training

Several lessons were learned from the training. One related to the difficulty in scheduling and planning training meetings with a large group of trainers (e.g., PC/EOL expert consultants) and trainees (MD/RN dyads) who may hold full-time positions. Based on the authors' review of published PC/EOL training studies, our challenge with scheduling training dates for our trainers and trainees has not been previously reported in the literature. One explanation for this gap in the literature is that the majority of published research reports on PC/EOL training programs have been focused on physicians who were in training roles (e.g., medical students, fellows, residents) that provided protected time for the lead investigator to schedule dates for the trainees to participate in planned PC/EOL educational programs (Back et al., 2007; Back et al., 2003; Fischer & Arnold, 2007; Fryer-Edwards et al., 2006; Furman, Head, Lazor, Casper, & Ritchie, 2006; Han, Keranen, Lescisin, & Arnold, 2005). Hence, we recommend that investigators consider adding extra time to their study timeline to allow for scheduling training dates for practicing health care providers.

A second lesson was that we had allowed insufficient time for training to cover both the intervention and study implementation. One explanation for our observation of insufficient time to deliver our training procedures to our MD/RN dyads is that evidence-based guidelines to plan PC/EOL training programs for health care providers have yet to be established (Fellowes, Wilkinson, & Moore, 2005; Roth et al., 2009). We purport that the communication skills necessary for PC/EOL discussions and related ethical principles related to protocol processes are complex and difficult to teach in a single session, without follow-up. And, although we provided a comprehensive research study manual describing all policies and procedures, participants also needed more training time on protocol processes for implementing and tracking the study-related activities. We recommend that research on PC/EOL communication interventions include a minimum of 3 training days, so that the

intervention training and research policies and procedures training can be adequately addressed. We also recommend scheduled follow-up feedback on intervention delivery to ensure intervention fidelity of the protocol. Last, we recommend that training should emphasize a clear distinction between (a) skill mastery needed to deliver an intervention and (b) research team responsibilities for intervention delivery, measurement, and study fidelity (e.g., scheduling sessions; timely completion of study forms).

A third lesson is related to the role of bereaved-parent advisors in training. As the parents engaged in the role-play sessions using memories of their child's and their own cancer journey, they expressed strong emotions, especially by crying. We provided time for debriefing of emotions during training and opportunities to "step out" of their role. Still, all the parents expressed a desire to continue participating in the role-playing activity. In addition, parents declined available post-training counseling when contacted after training by our trained bereavement consultant. After the training, the parent advisors (a) reported that their involvement had served their desire to help future parents and (b) expressed a strong desire and willingness to participate in similar studies in the future. However, the strong emotions expressed by some parent advisors seemed to produce heightened anxiety and distress for some of the MDs and RNs, decreasing their ability to engage in the communication skills training. Also, some of the MDs' and RNs' open-ended comments indicated a belief that role-playing with the parents did not seem authentic because they were at a different place from that of parents of newly diagnosed pediatric patients. Still, debriefing sessions with the bereaved parents after role-playing were perceived as helpful by the MDs and RNs for receiving feedback on what parents perceived as preferred communication (e.g., clear wording, caring behaviors). In light of both the parent and MD/RN responses, we recommend that bereaved parents be involved in training only to provide the parent perspective on provider/parent communication and that trained actors be used as simulated parents for role-play. Based on the authors' review of published PC/EOL training studies, we have not identified any studies that included bereaved parents or real patients as participants in simulation-type role-playing activities for PC/EOL communication training of practicing or future health care providers. To date, the majority of published PC/EOL training programs with health care providers have documented use of role-playing activities with either a faculty member or a standardized patient (Back et al., 2007; Back et al., 2003; Fischer & Arnold, 2007; Fryer-Edwards et al., 2006; Moore et al., 2013; Torke, Quest, Kinlaw, Eley, & Branch, 2004; Wilkinson et al., 2008).

A unique feature of our study was the use of an MD/RN dyad team approach to prepare our dyads to collaboratively work together to deliver a PC/EOL communication intervention to future parents of children with a brain tumor. To date, few studies have included an MD/RN approach to train health care providers in working as a team to foster a collaborative approach to deliver PC/EOL information to patients and family members (Tang et al., 2013). A fourth lesson related to this study feature was that training for the dyads should include training on team science (i.e., understanding their unique professional roles), especially regarding ways to collaborate and feel comfortable working together, with both dyad members contributing fully. A recent literature review focused on the need to improve collaboration of MDs and RNs during delivery of patient care to ensure that quality of care is fostered to all patients supports this lesson (Tang et al., 2013).

In summary, the pilot training for the COMPLETE study was designed for pediatric MDs/RNs to learn ways to initiate early and ongoing PC/EOL discussions with parents of children with brain tumors and a poor prognosis. The development, implementation, and evaluation of a comprehensive provider-training plan were essential to the validity of the study outcomes. Another important goal of this study was eliciting MDs' and RNs' evaluation of whether the training procedures provided the necessary skills to deliver COMPLETE according to the study protocol.

In response to the goal of developing and evaluating a standardized training procedure, the MD/RN participants' responses to the questionnaire and their open-ended comments represented in the qualitative themes indicate that, overall, the participants were receptive to the training procedures and recognized their potential usefulness in practice. The pediatric oncology neuro-oncologists (MDs) and pediatric oncology nurses (RNs) recruited for this study were all highly experienced HCPs; yet, they were very receptive to obtaining additional PC/EOL communication training to implement the COMPLETE intervention. After training, the MDs and RNs recognized that focused education on PC/EOL communication provided new competencies to conduct communication intervention research and integrate new communication skills into their practice. The identified major themes from the collected responses to the open-ended questions provide useful knowledge and contribute to best practices for equipping MD/RN dyads to implement PC/EOL communication interventions in future studies.

Limitations

The research reported in this article was planned as a small exploratory and feasibility single-group pilot study. Because no PC/EOL communication-training procedures have been published for pediatric oncology MDs/RNs and no PC/EOL communication interventions have been implemented with parents of children with cancer, we needed to first evaluate if implementation of the training procedures and intervention was perceived as acceptable and useful by the recruited pediatric oncology MDs/RNs. Still, several limitations must be considered. First, we recruited only a small number of pediatric oncology MDs/RNs to receive the training and to deliver the protocol to the target population. Second, the training procedures included only verbal communication skills and did not include nonverbal techniques. Third, we used an investigator-developed training evaluation form because no measures have been established to evaluate PC/EOL provider-training procedures. Fourth, we chose to conduct only post-training evaluations of the provider-training procedures rather than using a pre- and post-test evaluation format. Because we did not request the MD/RN to complete evaluations after each of the didactic modules, it is possible that collected evaluation data did not include a complete recall of the training content. Fifth, we provided different lengths of training for the 2 sites. At the SJCRH site, we chose to evaluate a 1-day format because of challenges related to scheduling a 2-day format and a limited timeframe before the study funding ended. Sixth, because this was a single-group pilot study, randomization procedures were not possible. Last, the intervention was developed for delivery by only a small number of pediatric neuro-oncologists and nurses at each site. The rationale was based on the need to include MDs and RNs who would have routine clinical contacts with eligible parents of children with brain tumors to discuss their child's response

to oncology tests and treatments. Another factor in this decision was related to the sensitivity of the intervention and the belief that parents would be more receptive to the intervention if delivered by their child's primary MD and RN rather than by an unfamiliar research team member. Therefore, the findings from this pilot study must be interpreted with caution when planning and evaluating future provider-training programs for communication interventions to be delivered by pediatric oncology MDs/RNs.

Conclusion

In summary, the results of our training procedures for pediatric oncology physicians and nurses to deliver a PC/EOL communication intervention to parents provide information for investigators to consider regarding PC/EOL training for intervention delivered as part of a research study. Our 4 main take-home recommendations for investigators who are planning training procedures for health care providers on delivery of a PC/EOL communication intervention include (a) a minimum of 3 days to adequately train MD/RN dyads for collaborative delivery of an intervention and comprehension of required study procedures; (b) use of trained actors as simulated patients/family members during training; (c) use of parent advisors as consultants during training and intervention planning; and (d) when conducting training for interdisciplinary teams, provide training on working as a collaborative team. We propose that integrating these recommendations into future training procedures for physicians and nurses to deliver a PC/EOL communication intervention will foster increased confidence and competence in these individuals.

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References

- Ammentorp J, Kofoed PE, Laulund LW. Impact of communication skills training on parents' perceptions of care: Intervention study. *Journal of Advanced Nursing*. 2011; 67(2):394–400. [PubMed: 20955186]
- Aschenbrenner AP, Winters JM, Belknap RA. Integrative review: Parent perspectives on care of their child at the end of life. *Journal of Pediatric Nursing*. 2012; 27(5):514–522. [PubMed: 22920662]
- Back AL, Arnold RM, Baile WF, Fryer-Edwards KA, Alexander SC, Barley GF, ... Tulsky JA. Efficacy of communications skills training for giving bad news and discussing transitions to palliative care. *Archives of Internal Medicine*. 2007; 167:453–460. [PubMed: 17353492]
- Back AL, Arnold RM, Tulsky JA, Baile WF, Fryer-Edwards KA. Teaching communication skills to medical oncology fellows. *Journal of Clinical Oncology*. 2003; 21(12):2433–2436. [PubMed: 12805343]

- Baker J, Torkidson C, Barlargeon JG, Olney CA, Kane J. National survey of pediatric residency program directors and residents regarding education in palliative medicine and end-of-life care. *Journal of Palliative Medicine*. 2007; 10:420–429. [PubMed: 17472514]
- Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. Preferred place of death for children and young people with life-limiting and life-threatening conditions: A systematic review of the literature and recommendations for future inquiry and policy. *Palliative Medicine*. 2013; 27(8):705–713. [PubMed: 23612958]
- Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Archives of Pediatric and Adolescent Medicine*. 2002; 156(1):14–19.
- Davies B, Connaughty S. Pediatric end-of-life care: Lessons learned from parents. *The Journal of Nursing Administration*. 2002; 32(1):5–6. [PubMed: 11802640]
- Fellowes D, Wilkinson S, Moore P. Communication skills for health care professionals working with cancer patients, their families and/or carers. *The Cochrane Database of Systematic Reviews*. 2005; 3:1–32.
- Fischer GS, Arnold RM. Feasibility of a brief workshop on palliative care communication skills for medical interns. *Journal of Palliative Medicine*. 2007; 10(1):19–23. [PubMed: 17298247]
- Foster TL, Lafond DA, Reggio C, Hinds PS. Pediatric palliative care in childhood cancer nursing: From diagnosis to cure or end of life. *Seminars in Oncology Nursing*. 2010; 26(4):205–221. [PubMed: 20971402]
- Fryer-Edwards K, Arnold RM, Baile W, Tulsy JA, Patracia F, Back AL. Reflective teaching practices: An approach to teaching communication skills in a small-group setting. *Academic Medicine*. 2006; 81(7):638–644. [PubMed: 16799286]
- Furman CD, Head B, Lazor B, Casper B, Ritchie CS. Evaluation of an educational intervention to encourage advance directive discussions between medicine residents and patients. *Journal of Palliative Medicine*. 2006; 9(4):964–967. [PubMed: 16910810]
- Galushko M, Romotsky V, Voltz R. Challenges in end-of-life communication. *Journal of Supportive and Palliative Care*. 2012; 6(3):355–364. [PubMed: 22871981]
- Grainger MN, Hegarty S, Schofield P, White P, Jefford M. Discussing transition to palliative care: Evaluation of a brief communication skills training program for oncology clinicians. *Palliative and Supportive Care*. 2010; 8:441–447. [PubMed: 20875208]
- Greenberg LW, Ochsenschlager D, O'Donnell RO, Mastruserio J, Cohen GC. Communicating bad news: A pediatric department's evaluation of a simulated intervention. *Pediatrics*. 1999; 103(6):1210–1217. [PubMed: 10353931]
- Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: A systematic review of effectiveness. *Support Care Cancer*. 2004; 12:692–700. [PubMed: 15258839]
- Han PKJ, Keranen LB, Lescisin DA, Arnold RM. The palliative care clinical evaluation exercise (CEX): An experience-based intervention for teaching end-of-life communication skills. *Academic Medicine*. 2005; 80(7):669–676. [PubMed: 15980083]
- Helft PR, Chamness A, Terry C, Uhrich M. Oncology nurses' attitudes toward prognosis-related communication: A pilot mailed survey of oncology nursing society members. *Oncology Nursing Forum*. 2011; 38(4):468–474. [PubMed: 21708537]
- Hendricks-Ferguson V. Parental perspectives of initial end-of-life communication. *International Journal of Palliative and Hospice Care*. 2007; 13(11):1–10.
- Hendricks-Ferguson V, Dupree C, Sawin K, Haase J. Perspectives of novice nurses regarding end-of-life communication [Abstract]. *Oncology Nursing Forum*. 2009; 36:1. L1.
- Hilden HM, Emanuel EJ. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. *Journal of Clinical Oncology*. 2001; 19(1):205–212. [PubMed: 11134214]
- Kersun L, Gyi L, Morrison WE. Training in difficult communications: A national survey of pediatric hematology-oncology and pediatric critical care physicians. *Journal of Palliative Medicine*. 2009; 12(6):525–530. [PubMed: 19508138]
- Levetown M. Communication with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics*. 2008; 121(5):e1441–1460. [PubMed: 18450887]

- Malloy P, Ferrell BR, Virani R, Uman B, Rhome AM, Whitlatch B, Bednash G. Evaluation of an end-of-life nursing education for continuing education and clinical staff development educators. *Journal for Nurses in Staff Development*. 2006; 22(1):31–36. [PubMed: 16465096]
- Martin JS, Ummerhofer W, Manser T, Spirig R. Interprofessional collaboration among nurses and physicians: Making a difference in patient outcome. *Swiss Medical Weekly*. 2010; 140(w13062):1–12.
- Maynard L, Rennie T, Shirliffe J, Vickers D. Seeking and using families' views to shape children's hospice services. *International Journal of Palliative Nursing*. 2005; 11(2):624–630. [PubMed: 16415754]
- Meert KL, Eggly S, Pollack M, Anand KJS, Zimmerman J. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*. 2008; 9(1):2–7. [PubMed: 18477906]
- Meyer EC, Burns JB, Griffith JL, Troug RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*. 2002; 30(1):226–231. [PubMed: 11902266]
- Monterosso L, Kristjanson L. Supportive and palliative care needs of families of children who die from cancer: An Australian study. *Palliative Medicine*. 2008; 22:59–69. [PubMed: 18216078]
- Moore PM, Mercado SR, Artigues MG, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *The Cochrane Library*. 2013; 3:1–98.
- Perocchia RS, Hodorowski JK, Williams LA, Kornfield J, Davis NL, Monroe MA, Bright MA. Patient-centered communication in cancer care: The role of the NCI's cancer information service. *Journal of Cancer Education*. 2011; 26(1):36–43. [PubMed: 20532726]
- Roth M, Wang D, Kim M, Moody K. An assessment of the current state of palliative care education in pediatric hematology/oncology fellowship training. *Pediatric Blood Cancer*. 2009; 53:647–651. [PubMed: 19449397]
- Sheetz MJ, Sontag Brown MA. Pediatric palliative care: An assessment of physicians' confidence in skills, desire for training, and willingness to refer for end-of-life care. *Journal of Hospice and Palliative Care Medicine*. 2008; 25(2):100–105.
- Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Ehteld MA, ... Deliens L. Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliative Medicine*. 2011; 25(6):613–629. [PubMed: 21273221]
- Tang CJ, Chan SW, Zhou WT, Liaw SY. Collaboration between hospital physicians and nurses: An integrated literature review. *International Nursing Review*. 2013; 60(3):1–12. [PubMed: 23406228]
- Torke AM, Quest TE, Kinlaw K, Eley JW, Branch WT. A workshop to teach medical students communication skills and clinical knowledge about end-of-life care. *Journal of Gerontological Internal Medicine*. 2004; 19:540–544.
- Tulsky J. Beyond advance care directives: Importance of communications skills at the end-of-life. *Journal of the American Medical Association*. 2005; 294(3):359–365. [PubMed: 16030281]
- Widger K, Picot C. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric Nursing*. 2008; 34(1):53–58. [PubMed: 18361087]
- Wilkinson S, Perry R, Blanchard K, Linsell L. Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: A randomized controlled trial. *Palliative Medicine*. 2008; 22:365–375. [PubMed: 18541641]
- Wilkinson S, Roberts A, Aldridge J. Nurse-patient communication in palliative care, an evaluation of a communication skills programme. *Palliative Medicine*. 1998; 12:13–22. [PubMed: 9616455]
- Wittenberg-Lyles E, Goldsmith J, Ragan S. The shift to early palliative care: A typology of illness journeys and the role of nursing. *Clinical Journal of Oncology Nursing*. 2011; 15(3):304–310. [PubMed: 21624865]
- Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel EJ, Weeks JC. Understanding of prognosis among parents of children who died of cancer. Impact on treatment goals and integration of palliative care. *Journal of the American Medical Association*. 2007; 15(19):2469–2475.

Table 1

Physician and Nurse Training Evaluation Form.

Dichotomous (agree/disagree) items	
1	The didactic training content to implement the COMPLETE intervention was appropriate.
2	The skills practice exercises, such as role-playing activities with the bereaved-parent advisors, were helpful.
3	Participating in small-group reflective discussions on PC/EOL communication was helpful.
4	The training I received during the study will enhance my ability to provide PC/EOL communication with my patients outside of the study.
5	The format of training was an appropriate amount of time to learn what I needed to know to conduct the COMPLETE intervention well.
Open-ended items	
1	To help us improve training in future studies, please provide your thoughts on what was most helpful and/or unhelpful about the didactic content.
2	Please provide details on aspects of the skills practice you thought were most helpful and/or not helpful.
3	Please provide details on aspects of the small-group reflective discussions you thought were most helpful and/or not helpful.
4	Please provide details on ways the training may or may not help you provide PC/EOL communication.
5	Please provide details on anything you would change, shorten, or lengthen during training.
6	Describe specific ways in which the PC/EOL communication content may be useful or helpful in your practice.
7	Provide comments related to the content on use of hope and non-abandonment messages.
8	Provide additional comments you think will be helpful to refining the training in the future.

Abbreviations: COMPLETE, Communication Plan: Early through End of Life; PC/EOL, palliative and end-of-life care.

Table 2

Themes and Sample Comments.

Data Generating Question Theme	Sample Comment
Theme 1: Benefits of training as a means to learn	
<ul style="list-style-type: none"> • Information and demonstration of communication skills by a PC/EOL expert were helpful 	“Information was useful. Data presentation and observing consultant interviewing parents were helpful.” (MD #1)
<ul style="list-style-type: none"> • Helpful communication strategies (i.e., hope and non-abandonment messages) to deliver the protocol 	“... very helpful reviewing communication responses to open the lines of communication. Helpful that hope and non-abandonment was emphasized.” (MD #2)
<ul style="list-style-type: none"> • Emphasis on the importance of assessing parents’ goals 	“Goal directed care planning ... meaningful to our practice.” (MD #3)
Theme 2: Benefits of expert mentor and practice skills	
<ul style="list-style-type: none"> • PC/EOL communication content, provided by a trusted PC communication expert 	“... very useful to have the opportunity to listen and observe spoken and unspoken language [during role plays].” (RN #1)
<ul style="list-style-type: none"> • An opportunity to practice and refine communication skills delivered to families 	“... very helpful to incorporate what we heard or observed into our language of the interview process. The skills practice was very helpful. Reflections after role play excellent for learning.” (RN #2)
Theme 3: Meaningful PC/EOL tools to use after training	
<ul style="list-style-type: none"> • Gaining new communication tools and opportunity to apply skills with team members 	“Information shared regarding hope, anticipatory guidance, therapeutic alliance will stay with my practice forever. I have gained tools that are invaluable.” (MD #4)
<ul style="list-style-type: none"> • Recognizing previous PC/EOL communication training was inadequate 	“This opportunity [training for the study] has given me the piece of my career I have so longed for.” (RN #3)
	“Helpful in learning new/better technique of communicating with each other as a team and with families.” (RN #4)
<ul style="list-style-type: none"> • Participating in debriefing during and after role-playing activities 	“Discussions during/after role-playing were helpful. And, the intent was to redirect/improve role-playing.” (RN #5)
Theme 4: Receptivity to implement the intervention in own practice	
<ul style="list-style-type: none"> • Planning to use the COMPLETE intervention in own practice 	“This training gave me some insight & tools—i.e., language and approach to use for intro of palliative care. Not only are we learning with our families [in the study]. I will have the opportunity to also teach other co-workers.” (RN #7)
<ul style="list-style-type: none"> • Recognition of how communication tools can be used to initiate PC/EOL discussions 	“The slide of communication responses will be very helpful to open the lines of communication.” (RN #8)
<ul style="list-style-type: none"> • Plans to use new skills to assess parents’ goals and integrate with child’s plan of care 	“Gives me starting points for conversations with parents/patients. It will be useful in my clinic visits with families in my conversations. I can further pinpoint their goals and try to align what we are doing with their goals.” (RN #6)
Theme 5: Recommendations for future training	
<ul style="list-style-type: none"> • Expand training time 	“Definitely needed 2 days. This was intense, one day is inappropriate.” (RN #4)
<ul style="list-style-type: none"> • Modify role-playing scenarios to be more clinically focused 	“Change scenarios to include baseline MRIs with stable results.” (RN #6)
<ul style="list-style-type: none"> • Develop strategies to implement in a busy clinic 	“Perhaps add content as to how this may be implemented in a timely manner in a real busy practice.” (MD #5)

Abbreviations: COMPLETE, Communication Plan: Early through End of Life; MD, physician; PC/EOL, palliative and end-of-life care; RN, nurse.