Sharing Life-Altering Information: Development of Pediatric Hospital Guidelines and Team Training

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Abstract

Background: Despite parent and physician reports of inadequate skill development, there are few guidelines for training the pediatric care team in sharing life-altering information (SLAI), i.e., “breaking bad news.” The necessary skills for SLAI differ between pediatric and adult medical environments.

Objectives: We set out to establish evidence-based guidelines and multidisciplinary team training for SLAI in pediatrics, and to demonstrate an improvement in immediate self-efficacy of training participants.

Methods: A multidisciplinary task force, which included parent participation and feedback, and which received input from parents of patients in multiple pediatric subspecialties, crafted children’s hospitalwide guidelines for SLAI. A one-hour training module on the guidelines was presented to several multidisciplinary pediatric team audiences; 159 voluntary pre- and post-presentation self-efficacy surveys were collected. Responses were analyzed by paired t-test (within groups) and ANOVA (between groups).

Results: All evaluated groups of care team members reported significant improvements in self-efficacy among four learning objectives after the training. Medical trainees, newer physicians, and nonphysician (e.g., midlevel providers including nurses) team members reported the greatest improvements, regardless of whether they had received previous training in SLAI.

Conclusions: We propose pediatric-focused SLAI guidelines based on a modified SPIKES protocol. Focus on patient- and family-centered, culturally sensitive pediatric practices should be the basis for development of training that can be periodically reinforced. Future comprehensive training will incorporate experiential learning. SLAI requires a skill set that benefits from lifelong learning.

Introduction

WHEN FACED WITH THE RESPONSIBILITY of sharing bad news with patients and families, physicians have expressed fear of invoking and expressing emotion, not knowing all the answers, and taking away patients’ and families’ hope.¹ Recent evidence, however, suggests that patients and families do not experience these perceived negative effects after honest information is shared with them.² When communicating with pediatricians, parents have repeatedly expressed a preference for honest, clear information regarding their child’s condition.^{3–5} The pediatrician must convey details with sensitivity, since parents reported lasting emotional injury after bad news about their children was shared with them unskillfully.^{5,6}

Efforts to standardize the approach to the bad news conversation have historically come from the palliative care^{6–8} and adult oncology^{9–12} settings, although there is a documented need for these skills in pediatric settings, including the intensive care unit,^{13,14} newborn nursery,^{15,16} and general pediatrics practice.^{4,17,18} Fallowfield et al. described that medical trainees experience a “woeful lack of training” in how to do this well.⁵ In one study, primary care interns reported greater discomfort with breaking bad news to families of pediatric patients than to adult patients.¹⁹ Increased opportunities to develop and refine these important communication skills are needed in pediatrics.¹⁸

Alternatives to the phrase “breaking bad news”^{1,8,9,11} include “delivering,”^{8,15,18} “giving,”¹⁸ and “communicating”³ bad news. These terms all imply a one-way flow of

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information, limiting the emphasis on family-centered care,⁸ even subtly suggesting a paternalistic approach to this sensitive interaction. “Bad news” implies a value judgment by the physician, who may be unaware of the patient’s or family’s interpretation of the information in the context of their lives.²⁰ “Bad news” is repeatedly described as a subjective phenomenon, based on the perceptual, cultural, and personal environment of the patient.^{1,4,5,9,11,16} Parents can react negatively to being told that a diagnosis is not, relatively speaking, “bad” news, as that is theirs alone to judge.⁴ Therefore, we maintain that (1) two-way, collaborative, family-centered communication between the pediatric care team and the patient and family is essential; (2) the approach to and the content of the conversation are likely to have an impact on the patient’s or family’s sense of well-being; and (3) avoiding the appearance of paternalism is crucial to starting and maintaining a trusting relationship between the care team and the patient and family. To integrate these concepts, we have replaced “breaking bad news” with “sharing life-altering information” (SLAI), defined as any medical information that the patient or family might perceive as causing a significant change in the health or quality of life of the child and family. Hereafter in this study we will use SLAI to refer to our program and to other studies that have involved breaking bad news.

Our multidisciplinary task force has developed hospital-wide pediatric SLAI guidelines. Our initial training goals were to introduce the guidelines, to demonstrate their relevance and importance to pediatrics, to raise awareness of SLAI throughout the children’s hospital, and to provide tools and strategies to help care team members develop these skills. We then evaluated the impact of our brief training session on the immediate self-efficacy of care team members.

Methods

Development of pediatric SLAI guidelines and training

This work was conducted at the American Family Children’s Hospital in Madison, Wisconsin, a 61-bed free-standing children’s hospital with >3500 admissions and >130,000 outpatient pediatric subspecialty visits annually. A multidisciplinary task force, comprised of pediatricians (representing primary care, hospitalist medicine, hematology/oncology, and palliative care); pediatric nurse practitioners (representing hematology/oncology and general surgery); nurses (representing inpatient hematology/oncology and critical care); a social worker; health psychologists; a child life specialist; hospital chaplains; the pediatric emergency care coordinator; the hospital pediatric educational coordinator; and a parent advocate convened to formulate comprehensive guidelines for SLAI throughout our children’s hospital. Additional parent input was provided by parents of patients from four different pediatric subspecialties, who were videotaped as they recounted being informed of the initial diagnoses of their children. Each parent participant consented to the use and dissemination of this video content.

The SPIKES framework,⁹ which was designed for oncologists sharing diagnostic and prognostic information with their adult patients, was central to the development of our pediatric SLAI guidelines.^{11,18} (see Table 1). The original SPIKES components are S – Setting up the meeting; P –

establishing family Perceptions; I – soliciting an Invitation to discuss information with the family; K – providing medical Knowledge/information; E – expressing Empathic responses to family Emotions; and S – Summarizing and Strategizing the next steps. Baile et al.⁹ reported that training in SPIKES enhanced the confidence of physicians who share life-altering information with patients and families. We made several modifications to SPIKES for the pediatric setting based on recent literature (see Table 1), the consensus of our task force, and the experiences of the videotaped parents.

We then prepared a one-hour training module, “Offering Clarity, Compassion and Collaboration to Families: Sharing Life-Altering Information in Pediatrics,” and presented it at five different regularly scheduled educational conferences for pediatric care team members. The training consisted of a brief didactic session introducing the guidelines, videotaped parent recollections, and group critique of videotaped role-play scenarios demonstrating SLAI encounters. In the first scenario, a teen football player and his mother discuss with the physician a non-life-threatening diagnosis of a traumatic fracture. In the second scenario, the same patient and his mother learn that the fracture is due to a bone tumor. We also provided the guidelines on a pocket reference card (see Table 1). Participation in these sessions was voluntary, as was participation in the study survey (see below). A presentation of the module can be viewed at: <http://videos.med.wisc.edu/videoInfo.php?videoid=41210>.

Brief training programs such as ours have been employed successfully in medical student, resident and fellow curricula,^{14,21} some of which also include role-playing or standardized patient encounters^{22–25}. Our novel approach includes videotaped parent recollections of their SLAI encounters to emphasize key points in the guidelines. By observing scenarios showing successful and unsuccessful uses of the SLAI guidelines, participants had an opportunity to critique the performances and reconsider their own approaches to SLAI.

Evaluation of the training module

For initial validation of the guidelines we evaluated change in self-efficacy of our participants. An anonymous self-assessment survey was distributed prior to each presentation (see Table 2), in which respondents evaluated their ability to implement each of the four learning objectives of the module on a five-point Likert scale before and after the presentation. Double-sided surveys paired individual pre- and post-presentation responses. The four objectives were chosen based on previously identified needs in pediatric education relating to effective communication: (1) a strategy for approaching SLAI encounters;¹⁸ (2) a focus on patient and family-centered care;^{3,8,11,17,26} (3) utilization of a multidisciplinary team;^{6,25} and (4) sensitivity to patient and family emotional responses.^{1,2,5,9} This research was judged exempt by the Social and Behavioral Sciences Institutional Review Board at the University of Wisconsin-Madison.

Statistical analysis

Paired item response patterns were summarized by the mean increase in response and standard deviation (SD) for each of the four objectives listed in Table 2. Paired pre-presentation versus post-presentation response patterns

TABLE 1. SUMMARY OF PEDIATRIC GUIDELINES FOR SHARING LIFE-ALTERING INFORMATION^a

	<i>Recommendations</i>	<i>References</i>
Setting	<ul style="list-style-type: none"> • Determine who (e.g., family and team members) will be present; multidisciplinary team should reflect individuals most likely to have direct impact on the patient's care • Establish whether patient will participate in meeting. Arrange for child life or other coverage if patient will be separated^b • Be seated. Introduce all team members and describe their roles at the start of the discussion^b • Team discusses results, findings, and recommendations before meeting^b • Arrange for health interpreter if necessary^b • Manage personal interruptions (e.g., pagers off) 	18, 27, 28, 31, 35
Perception	<ul style="list-style-type: none"> • Explore what family already knows about child's medical condition: "What have you been told about your child's medical situation so far?" • Correct misinformation • Tailor information to family's level of comprehension 	11
Involvement^b	<ul style="list-style-type: none"> • Confirm meeting agenda • Encourage questions/comments, assure of other opportunities to meet/discuss • Be sensitive to family's culture, race, religious beliefs, & socioeconomic background^b 	7, 8, 11, 15, 16, 20, 26, 33, 34
Knowledge	<ul style="list-style-type: none"> • Warning shot: "I have some difficult news to share" • Connect new information with information family already has • Pace information, limit to a few key points • Check family's understanding as information is shared • Use visual aids or handouts • Avoid jargon, euphemism, excessive bluntness, or prognostication • Emphasize positive findings when possible^b • Discuss possible outcomes, acknowledge future can be unclear^b 	3, 6, 10, 17
Emotion, empathy	<ul style="list-style-type: none"> • Use empathic responses after observing family's emotional response: "I can see how upsetting this is for you;" "I can tell you were not expecting to hear this;" "I know this is not good news for you;" "I was hoping for a better result." • Use exploratory questions to clarify thoughts/feelings expressed by family: "What do you mean?" "Tell me more about it." "Could you tell me what you're worried about?" • Use validating responses for emotions and reactions: "I can understand how you feel that way." 	2, 44
Strategy, summary, self-reflection	<ul style="list-style-type: none"> • Ask if family is ready to discuss treatment plan or next steps; assure family they will participate in care decisions^b • Encourage discussion; offer recommendations for particular treatment based on medical judgment • Verify family understands the treatment plan; use "teach back" as necessary • Balance hope with realism & discuss palliative care, if appropriate: "There are always options." "We will be here to support you." ^b • Summarize mutual goals, time line • Offer help sharing information with others (e.g., patient, siblings, family)^b • Provide information about support services (e.g., social work, spiritual care, health psych, support groups, community resources)^b • Document meeting & plans in medical record • Team members distribute responsibilities for follow-up with patient/family^b • Reflect upon and process team members' emotions/reactions; discuss what worked, what could be improved^b 	2, 8, 11, 30, 33, 35, 38

^aGuidelines modified from the SPIKES framework of Baile et al.⁹^bModifications made to original SPIKES for the pediatric setting.

were evaluated using a paired t-test (p^1). ANOVA, two-sample t-test, was used to compare changes in response patterns between various subgroups (e.g., among age groups, years of experience, prior training, team role and gender; p^2). We set $\alpha=0.05$ as indicative of statistical significance.

Results

A total of 159 pre-and post-presentation surveys were returned; characteristics of respondents are summarized in Table 3. The session with the largest audience was the only one at which total attendance was recorded, with 69 of 70

TABLE 2. SURVEY QUESTIONS

<i>Demographics</i>
Team role, e.g., attending physician, resident/fellow, medical student, NP or PA, RN, other
Age
Number of years in present role
Gender
Have you had any prior teaching/training on breaking bad news to patients?
Please rate yourself and your clinical practice with each of the following statements.^a
<i>Likert scale 1–5 (1 = not competent, 3 = somewhat competent, 5 = fully competent)</i> I believe I am able to:
1. Incorporate effective strategies for sharing life-altering information into my practice.
2. Provide high-quality patient and family-centered care when sharing life-altering information.
3. Utilize a shared multidisciplinary team model to share life-altering information.
4. Personally, be sensitive to the patient and family needs and responses when sharing life-altering information.

^aThese questions were repeated on the post-presentation survey. NP, nurse practitioner; PA, physician's assistant; RN, registered nurse.

participants (99%) returning completed surveys. The survey results are presented in Table 4. The mean values reported indicate increases from pre- to post-training Likert scale ratings. All respondents in aggregate demonstrated statistically significant increases in the mean item responses for the four training objectives. Each individual group exhibited significant increases in most objectives, with medical trainees demonstrating the largest difference in all objectives. These differences among groups were significant in incorporating an effective SLAI strategy, patient- and family-centered care, and utilizing a shared multidisciplinary team model for SLAI, as indicated by ANOVA-generated p^2 values for between-group comparison in Table 4.

When stratified by years of experience and age, the most significant self-assessment increases were observed among respondents with fewer than 16 years of experience in their current role, and those less than 60 years old. Only the youngest respondents (less than 30 years old) demonstrated a significant increase in sensitivity to family needs and emotional responses.

There were significant increases on all objectives, regardless of previous training in SLAI. This difference was statistically indistinguishable except for objective one (incorporating an effective SLAI strategy): the magnitude of improvement in the “no prior training” group was significantly greater than in the “prior training” group. No significant differences were detected between male and female respondents (not shown).

Discussion

Based on our analysis of pediatric literature, the consensus of our task force, and parent feedback, we modified SPIKES for use in a pediatric population (see Table 1). We expect to reach all general and subspecialty pediatricians, medical trainees, and multidisciplinary care team members who interact with pediatric patients.^{5,18}

TABLE 3. CHARACTERISTICS OF SURVEY RESPONDENTS

<i>Role on team</i>	<i>N (%)</i>
Attending physician	54 (35)
Fellow or resident	32 (21)
Medical student	18 (12)
NP or PA	14 (9)
RN	15 (10)
Social worker	3 (2)
PT or OT	6 (4)
Other	11 (7)
<i>(did not specify, or N ≤ 2 of: speech and language pathologist, dietician, child life specialist, chaplain, research associate)</i>	
Total responses	153
<i>Years in current role</i>	
≤ 5	100 (65)
6–15	26 (17)
≥ 16	28 (18)
Total responses	154
<i>Age, years</i>	
20–29	48 (32)
30–39	46 (30)
40–49	21 (14)
50–59	27 (18)
≥ 60	10 (7)
Total responses	152
<i>Prior training in SLAI</i>	
Yes	86 (57)
No	65 (43)
Total responses	151
<i>Gender</i>	
Male	56 (38)
Female	93 (62)
Total responses	149

NP, nurse practitioner; OT, occupational therapist; PA, physician's assistant; PT, physical therapist; RN, registered nurse; SLAI, sharing life-altering information.

Unlike most adult settings, pediatric SLAI encounters must include the parents or guardians of patients. Not all pediatric patients are expected to participate in SLAI discussions, depending on individual factors such as age and cognitive status. Recent surveys of parents of children diagnosed with cancer revealed that while many parents wanted their children to be present at the initial diagnostic discussion, some retrospectively indicated that the child's presence was inappropriate.^{27,28} Pediatricians generally attempt to include patients in medical decision making.²⁹ Therefore, the “Setting” portion of our guidelines prompts the provider to inquire of parents whether the patient should be present during the discussion. The size and composition of the care team should also be considered, and the role of each team member should be explained to the family. Ultimately, the providers, trainees, and multidisciplinary staff expected to have the greatest impact on the patient's care should participate in the initial SLAI discussion.

In order to emphasize more explicitly patient- and family-centered care, we have redefined “I”—originally “Invitation” in SPIKES—to “Involvement.” Engagement of the patient and family is achieved by welcoming questions, comments, goals, and sentiments throughout SLAI

TABLE 4. SELF-ASSESSMENT CHANGES FROM PRE- TO POST-PRESENTATION

Respondents (N)	1. Implement effective strategy for SLAI		2. Patient/family-centered care		3. Use multidisciplinary team		4. Sensitive to family needs/responses	
	Mean ^a (SD)	p ¹	Mean ^a (SD)	p ¹	Mean ^a (SD)	p ¹	Mean ^a (SD)	p ¹
All (159)	0.7 (0.6)	<0.001	0.6 (0.6)	<0.001	0.7 (0.8)	<0.001	0.2 (0.6)	<0.001
Team role								
Attending physician (54)	0.3 (0.6)	<0.001	0.2 (0.4)	0.001	0.4 (0.7)	<0.001	0.1 (0.4)	0.008
Resident, fellow (32)	0.7 (0.5)	<0.001	0.8 (0.5)	<0.001	0.8 (0.8)	<0.001	0.3 (0.6)	0.060
Medical student (18)	0.9 (0.6)	<0.001	0.7 (0.7)	0.001	1.2 (0.5)	<0.001	0.4 (0.5)	0.020
NP, PA (14)	0.7 (0.6)	0.004	0.6 (0.5)	0.004	0.7 (0.8)	0.020	0.4 (0.6)	0.130
Other (36)	1.0 (0.6)	<0.001	0.7 (0.7)	<0.001	0.7 (0.7)	<0.001	0.4 (0.7)	0.008
	p ² <0.001		p ² <0.001		p ² =0.003		p ² =0.270	
Experience, years								
≤5 (100)	0.7 (0.6)	<0.001	0.6 (0.6)	<0.001	0.7 (0.7)	<0.001	0.2 (0.6)	<0.001
6–15 (26)	0.8 (0.8)	<0.001	0.6 (0.8)	0.001	0.9 (0.9)	<0.001	0.4 (0.6)	0.008
≥16 (28)	0.4 (0.6)	0.001	0.2 (0.5)	0.130	0.5 (0.6)	0.001	0.2 (0.5)	0.130
	p ² =0.090		p ² =0.005		p ² =0.210		p ² =0.350	
Age								
20–29 (48)	0.9 (0.5)	<0.001	0.8 (0.6)	<0.001	0.9 (0.7)	<0.001	0.4 (0.6)	<0.001
30–39 (46)	0.6 (0.6)	<0.001	0.5 (0.7)	<0.001	0.5 (0.7)	<0.001	0.2 (0.6)	0.080
40–49 (21)	0.8 (0.7)	<0.001	0.6 (0.8)	0.008	0.8 (0.8)	0.001	0.3 (0.7)	0.130
50–59 (27)	0.6 (0.5)	<0.001	0.3 (0.4)	0.02	0.6 (0.7)	<0.001	0.2 (0.6)	0.110
≥60 (10)	0.1 (0.6)	1.000	0.2 (0.4)	0.50	0.6 (1.0)	0.25	0.1 (0.3)	1.000
	p ² =0.005		p ² =0.007		p ² =0.090		p ² =0.330	
Prior training								
Yes (86)	0.6 (0.6)	<0.001	0.5 (0.6)	<0.001	0.7 (0.7)	<0.001	0.2 (0.5)	<0.001
No (65)	0.8 (0.7)	<0.001	0.6 (0.7)	<0.001	0.7 (0.8)	<0.001	0.3 (0.7)	<0.001
	p ² =0.007		p ² =0.190		p ² =0.820		p ² =0.520	

^aMean values are expressed as mean increase in score from pre- to post-training survey on each five-point Likert scale.

p¹=paired t-test for within group comparison; p²=ANOVA for between group comparison.

NP, nurse practitioner; PA, physician assistant; SD, standard deviation; SLAI, sharing life-altering information.

encounters. We also use “Involvement” to remind the care team that the preferences and decisions of families are heavily influenced by background, language, and culture.

To the final “S,” “Summary/Strategy,” we have added “Self-reflection.” We know that it is important for the care team to reflect on the conversation with the family, with an aim toward improving their skills and engaging in self-care after stressful, emotional conversations,^{2,8,20,30} particularly since direct feedback from families to physicians regarding their skills in this setting is rare.^{11,17,27}

Our guidelines therefore incorporate themes shown to be important in pediatrics, including (1) patient- and family-centered care,^{3,8,11,17,26} (2) the extent of the patient’s participation early in the SLAI process;^{27,28,31} (3) culturally sensitive conduct of SLAI encounters;^{7,8,15,16,20} (4) multidisciplinary care;^{20,25,27,32} (5) overcoming physician reluctance to recognize and validate the emotional responses of family;^{1,2,5,9} and (6) the value of self-reflection in improving the emotional well-being and professional growth of the provider.^{2,5,20,30,33}

Pediatric trainees (e.g., residents, fellows, medical students) have expressed a consistent desire for more SLAI training.^{22–24} In our study, medical students reported greater comfort with all four objectives after the training session; residents and fellows reported greater comfort with incorporating an effective SLAI strategy, patient- and family-centered care, and utilizing a shared multidisciplinary team model for SLAI, but not with sensitivity to family needs and

emotional responses (see Table 4). Participants with fewer than 16 years of experience (likely including medical trainees and newer physicians) reported significant improvement in all four objectives (see Table 4), versus participants with at least 16 years of experience, who did not report significant improvement in perceived sensitivity to patient/family needs and emotions. Possibly, our more experienced respondents already felt more comfortable with the sensitivity required in SLAI encounters before our training session. We also note the experiences of other authors, who describe that empathy is difficult to teach and master.^{6,12,18,21,33}

Since pediatric trainees often report insufficient teaching of SLAI skills,^{20–22,31,34} it is possible that today’s attending physicians feel insufficiently trained to provide appropriate mentoring and modeling to current trainees.^{25,31,35} We found that attending physicians (approximately one-third of the study population) collectively reported significant improvement on all four objectives (albeit to a lesser degree than trainees and students; see Table 4), suggesting that provider comfort with these skills can still be improved after one has completed formal medical training, additively with one’s own practical experience.

When participants were stratified by age, only those at least 60 years reported no significant improvement across the stated objectives (see Table 4). This age group had a relatively small sample size, which could explain this result. Alternatively, our most experienced participants may not fully recognize their own capacity for improvement: in one

study, senior oncologists were found to overrate their performance in SLAI encounters when compared with their patients' level of distress.³⁶ We propose that effective SLAI skills benefit from lifelong learning.¹⁸

Nearly one-third of respondents were nonphysician care team members (see Table 3). Advanced practice providers (e.g., nurse practitioners and physician's assistants) who also reported significant improvements in incorporating an effective SLAI strategy, patient-and family-centered care, and utilizing a shared multidisciplinary team model for SLAI. Other participants reported significant improvements on all four objectives (see Table 4). These findings are consistent with previous reports that team-based training in SLAI improves communication with families,⁶ and successful team-based training formulae have been utilized in the pediatric emergency and critical care settings.²⁵

Our training module positively impacted participants' immediate self-efficacy, which was our initial goal. Estimating one's own ability to succeed in a specific situation has been called self-efficacy by Bandura, who theorized that improved self-efficacy leads to better development and employment of new skills.³⁷

Little evidence has been published regarding the long-term retention of skills after a brief training such as ours, but it likely wanes over time if not periodically reinforced.¹⁴ To assist in long-term retention of SLAI skills, our training materials included a pocket reference card (see Table 1) stating the guidelines. Care team members may consult the card before any SLAI meeting. We anticipate using the training module to periodically reinforce the SLAI guidelines for all pediatric care team members, to facilitate lifelong learning. For our pediatric residents, we are developing an augmented training session emphasizing small group role-play scenarios, as experiential learning of SLAI skills is known to be especially beneficial for medical trainees.^{22,34,38} Evaluating long-term retention and use of the SLAI guidelines is a future goal.

Our findings have several limitations. This work was conducted within a single institution, and this specific educational program may not generalize elsewhere. While the effect of pediatric SLAI training experiences at other institutions may be different, the implementation of hospital-wide pediatric SLAI guidelines should nevertheless be an effective initial step toward skill improvement.¹⁸

Our training sessions and the self-assessment survey were voluntary. It is possible that individuals who elected to attend and participate in the survey were substantially different from those who did not, although we did note a 99% survey participation rate at our largest session. We therefore expect that our results are representative of total attendees, although we cannot speculate about individuals who did not choose to attend the training or participate in the survey.

Our self-assessment used single-item responses generated based on each of the four learning objectives. These allowed the benefit of being brief, and may have improved response rates, but their simplicity may have obscured more nuanced potential responses by participants.³⁹ Single-item self-assessments have been found to be valid and reliable in evaluating perceptions of dementia in the elderly⁴⁰ and workplace physical stressors,⁴¹ and in the current study provide initial validation to support intensifying our educational efforts.

While our ultimate goal is to have a beneficial impact on patients and families, asking them to evaluate the SLAI en-

counter immediately after it concludes presents ethical challenges.⁵ Nonetheless, it has been repeatedly suggested that improved provider education and confidence in SLAI leads to improved interactions with patients.^{24,33-35} In one randomized controlled study, internal medicine and family medicine interns randomized to an intensive psychosocial skills course reported improved self-efficacy in communication,⁴² and their patients reported increased confidence in their physicians and greater overall satisfaction than patients of control, nontrained interns.⁴³ This illustrates a direct correlation between physician self-efficacy and patient outcome. We expect that by raising care team awareness of and confidence in important SLAI skills, patient and family experiences will improve.

Conclusions

Our guidelines (see Table 1) offer an opportunity to develop hospital-wide, multidisciplinary pediatric training in SLAI. Participants in our training reported significant improvement in their self-efficacy, most demonstrably among trainees, young physicians, and other members of the multidisciplinary team. Skills in SLAI should be reinforced throughout a provider's career, although few resources exist—for training or practice—that are customized to the pediatric setting. Ideally, if pediatric care team members improve their communication skills, outcomes for patients and families will be better, including diminished emotional stress, increased understanding of the diagnosis, and greater understanding of information during early discussions of treatment options.

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References

1. Buckman R: Breaking bad news: Why is it still so difficult? *Br Med J* 1984;288:1597-1599.
2. Mack JW, Smith TJ: Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. *J Clin Oncol* 2012;30:2715-2717.
3. Krahn GL, Hallum A, Kime C: Are there good ways to give 'bad news'? *Pediatrics* 1993;91:578-582.

4. Strauss RP, Sharp MC, Lorch SC, Kachalia B: Physicians and the communication of "bad news": Parent experiences of being informed of their child's cleft lip and/or palate. *Pediatrics* 1995;96:82–89.
5. Fallowfield L, Jenkins V: Communicating sad, bad, and difficult news in medicine. *Lancet* 2004;363:312–319.
6. Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ: Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics* 2004;114:1248–1252.
7. Apatira L, Boyd EA, Malvar BA, Evans LR, Luce JM, Lo B, et al.: Hope, truth and preparing for death: Perspectives of surrogate decision makers. *Ann Intern Med* 2008;149:861–868.
8. Browning D: To show our humanness: Relational and communicative competence in pediatric palliative care. *Bioethics Forum* 2002;18:23–28.
9. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP: SPIKES: A six-step protocol for delivering bad news: Application to the patient with cancer. *Oncologist* 2000;5:302–311.
10. Leydon GM: "Yours is potentially serious but most of these are cured": Optimistic communication in UK outpatient oncology consultations. *Psychooncology* 2008;17:1081–1088.
11. Lee SJ, Back AL, Block SD, Stewart SK: Enhancing physician-patient communication. *Hematology Am Soc Hematol Educ Program* 2002;2002:464–483.
12. Maldonado M: Warning shot. *JAMA* 2012;308:2575–2576.
13. Aronson PL, Yau J, Helfaer MA, Morrison W: Impact of family presence during pediatric intensive care unit rounds on the family and medical team. *Pediatrics* 2009;124:1119–1125.
14. Nishisaki A, Hales R, Biagas K, Cheifetz I, Corriveau C, Garber N, et al.: A multi-institutional high-fidelity simulation "boot camp" orientation and training program for first year pediatric critical care fellows. *Pediatr Crit Care Med* 2009;10:157–162.
15. Abdelmuktader AM, Abd Elhamed KA: Egyptian mothers' preferences regarding how physicians break bad news about their child's disability: A structured verbal questionnaire. *BMC Med Ethics* 2012;13:14.
16. Al-Abdi SY, Al-Ali EA, Daheer MH, Al-Saleh YM, Al-Qurashi KH, Al-Aamri MA: Saudi mothers' preferences about breaking bad news concerning newborns: A structured verbal questionnaire. *BMC Med Ethics* 2011;12:15.
17. Sharp MC, Strauss RP, Lorch SC: Communicating medical bad news: Parents' experiences and preferences. *J Pediatr* 1992;121:539–546.
18. Harrison ME, Walling: What do we know about giving bad news? A review. *Clin Pediatr (Phila)* 2010;49:619–626.
19. Dubé CE, LaMonica A, Boyle W, Fuller B, Burkholder GJ: Self-assessment of communication skills preparedness: Adult versus pediatric skills. *Ambul Pediatr* 2003;3:137–141.
20. Phipps LL, Cuthill JD: Breaking bad news: A clinician's view of the literature. *Ann R Coll Physicians Surg Can* 2002;35:287–293.
21. Michelson KN, Ryan AD, Jovanovic B, Frader J: Pediatric residents' and fellows' perspectives on palliative care education. *J Palliat Care* 2009;12:451–457.
22. Greenberg LW, Oshsenschlager D, O'Donnell R, Mastriuserio J, Cohen GJ: Communicating bad news: A pediatric department's evaluation of a simulated intervention. *Pediatrics* 1999;103:1210–1217.
23. Towle A, Hoffman J: An advanced communication skills course for fourth-year, post-clerkship students. *Acad Med* 2002;77:1165–1166.
24. Morgan ER, Winter RJ: Teaching communication skills. An essential part of residency training. *Arch Pediatr Adolesc Med* 1996;150:638–642.
25. Farrell M, Ryan S, Langrick B: 'Breaking bad news' within a paediatric setting: An evaluation report of a collaborative education workshop to support health professionals. *J Adv Nurs* 2001;36:765–775.
26. Klassen A, Gulati S, Dix D: Health care providers' perspectives about working with parents of children with cancer: A qualitative study. *J Pediatr Oncol Nurs* 2012;29:92–97.
27. Johnston DL, Appleby W: Pediatric oncologists opinions on breaking bad news. *Pediatr Blood Cancer* 2011;56:506.
28. Parker TM, Johnston DL: Parental perceptions of being told their child has cancer. *Pediatr Blood Cancer* 2008;51:531–534.
29. Partridge BC: The mature minor: Some critical psychological reflections on the empirical bases. *J Med Philos* 2013;38:283–299.
30. Jellinek MS, Hirst J, Stein MT: Giving bad news: A 13-year old with acute psychotic symptoms and catatonia. *J Dev Behav Pediatr* 2007;28:241–244.
31. Rider EA, Volkan K, Hafner JP: Pediatric residents' perceptions of communication competencies: Implications for teaching. *Med Teach* 2008;30:e208–e217.
32. Pirie A: Pediatric palliative care communication: Resources for the clinical nurse specialist. *Clin Nurse Spec* 2012;26:212–215.
33. Stenmarker M, Hallberg U, Palmerus K, Marky I: Being a messenger of life-threatening conditions: Experiences of pediatric oncologists. *Pediatr Blood Cancer* 2010;55:478–484.
34. Brown CM, Lloyd EC, Swearingen CJ, Boateng BA: Improving resident self-efficacy in pediatric palliative care through clinical simulation. *J Palliat Care* 2012;28:157–163.
35. Kolarik RC, Walker G, Arnold RM: Pediatric resident education in palliative care: A needs assessment. *Pediatrics* 2006;117:1949–1954.
36. Ford S, Fallowfield L, Lewis S: Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer* 1994;70:769–770.
37. Bandura A: Self-efficacy mechanism in human agency. *Am Psychol* 1982;37:122–147.
38. Gough JK, Frydenberg AR, Donath SK, Marks MM: Simulated parents: Developing paediatric trainees' skills in giving bad news. *J Paediatr Child Health* 2009;45:133–138.
39. Loo R: A caveat on using single-item versus multiple-item scales. *J Manag Psychol* 2002;17:68–75.
40. Ayalon L: The IQCODE versus a single-item informant measure to discriminate between cognitively intact individuals and individuals with dementia or cognitive impairment. *J Geriatr Psychiatry Neurol* 2011;24:168–173.
41. Sabbath EL, Goldberg M, Wu Q, Descatha A: Can a single-item measure assess physical load at work? An analysis from the GAZEL cohort. *J Occup Environ Med* 2012;54:598–603.
42. Smith RC, Mettler JA, Stoffelmayr BE, Lyles JS, Marshall AA, Van Egeren LF, et al.: Improving residents' confidence in using psychosocial skills. *J Gen Intern Med* 1995;10:315–320.

43. Smith RC, Lyles JS, Mettler JA, Marshall AA, Van Egeren LF, Stoffelmayr BE, et al.: A strategy for improving patient satisfaction by the intensive training of residents in psychosocial medicine: A controlled, randomized study. *Acad Med* 1995;70:729–732.
44. Scrimin S, Axia G, Tremolada M, Pillon M, Capello F, Zanesco L: Conversational strategies with parents of newly diagnosed leukaemic children: An analysis of 4880 conversational turns. *Support Care Cancer* 2005;13: 287–294.

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