

The Implementation and Feasibility of a Patient/Family Satisfaction Survey at a Growing Pediatric Palliative Care Program

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Background

- Many pediatric palliative care (PPC) programs remain in their infancy.
- It is important to develop sustainable and efficient standardized operating procedures, with minimal participant burden, in order to best assess patient and/or family satisfaction, elicit feedback about PPC services, and identify improvement opportunities.

In-person

- In-person visit if hospitalized and frequently at bedside
- If unsuccessful after 3 attempts, proceeded with email or telephone contact.

Email

- Email with survey link sent if email address within the electronic medical record.
- Follow up telephone call within 24 hours.
- Email reminders sent to non-responders at 1- and 3-week intervals.

Telephone

- Initial telephone call to obtain email address
- Email with survey link sent
- Email reminders sent to non-responders at 1- and 3-week intervals.

Figure 1. Three initial recruitment methods with subsequent workflow.

Methods

- An anonymous, online survey was developed using the Pediatric Palliative Improvement Network's Patient/ Family Satisfaction Survey tool in addition to several program-specific questions.
- Eligibility criteria:
 - Patient is followed by the PPC team
 - Participants had at least one PPC interaction in the past 6 months, speak English or Spanish and are not in emotional distress
 - Patient participants are at least 13 years of age and capable of completing the survey.
- Eligible participants were contacted via 3 initial methods: in-person, email, or telephone with subsequent email (Figure 1).

Results

- Sixty-two eligible participants for 48 patients were identified.
- Three were excluded due to unsuccessful telephone contact and an inability to obtain an email address.
- The overall survey response rate was 55.9% (Table 1).
- In-person contact was most effective (100%) followed by telephone with subsequent email contact (46.7%), and lastly by initial email contact (40%).
- Each communication attempt resulted in increased responses except the 3-week email reminder.
- Sixteen participants, including all four patient participants, shared an email address with another participant/ family member, and of these, only four completed the survey.

Contact Method	Eligible participants	Participants successfully contacted*	Surveys completed	Completion rate for eligible participants	Completion rate for those successfully contacted
In-person	14	14	14	100.0%	100.0%
First Visit	14	11	11	78.6%	100.0%
Second Visit	3	2	2	66.7%	100.0%
Third Visit	1	1	1	100.0%	100.0%
Initial Email	32	30	12	37.5%	40.0%
Email Sent	32	30	5	15.6%	16.7%
24h Telephone Call	18	18	3	16.7%	16.7%
1 Week Email Reminder	22	22	4	18.2%	18.2%
3 Week Email Reminder	14	14	0	0.0%	0.0%
Initial Telephone Call	16	15	7	43.8%	46.7%
Email Obtained & Sent	15	15	5	33.3%	33.3%
1 Week Email Reminder	10	10	2	20.0%	20.0%
3 Week Email Reminder	5	5	0	0.0%	0.0%
Total	62	59	33	53.2%	55.9%

Table 1. Initial contact methods and their respective outcomes.

*Successful contact is defined as the ability to talk to a person face-to-face or via telephone, leave a voicemail, and/or ensure survey delivery via email.

Conclusions

- Patients and families were receptive to providing feedback.
- Participants were more likely to respond to the survey when approached in-person. If unable to approach participants in-person, programs may consider telephone and/or email.
- Participants who are likely to respond will do so following a 1-week reminder; further contact does not seem beneficial.
- Several barriers were identified including availability of interpreter services as well as the sharing of contact information amongst several family members. Increased effort should be made to obtain individualized contact information for each participant.
- We hope these findings will guide PPC programs in implementing their own assessments to include the family's voice in PPC program development and ensure the provision of high-quality care.