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Audio-Recorded Discharge Instructions for Limited English Proficient Parents: A Pilot Study

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Abstract

Background—Parents with limited English proficiency (LEP) demonstrate lower comprehension of discharge instructions.

Objectives—(1) Determine the feasibility of providing a greeting card with language-specific, audio-recorded discharge instructions to LEP parents; (2) Describe use of and satisfaction with the cards; and (3) Evaluate card effect on instruction comfort with home care and comprehension.

Methods—LEP parents of children undergoing day-surgery from April to September 2016 were eligible. Participants were randomized to usual discharge instructions, or usual instructions plus a 3-minute card with language-specific audio instructions that could be replayed repeatedly. Parents were surveyed by telephone 2-7 days post-discharge to assess card use and satisfaction, comfort with home care, and discharge instruction recall (medications, home care, follow-up, and return precautions). Parent-reported instructions were compared to instructions in the medical record; concordance was determined by 2 blinded reviewers. Due to difficulty achieving recruitment goals, analysis focused on feasibility and acceptability.

Results—Of 83 parents enrolled, 66 (80%) completed the follow-up survey. Most had not completed high school (61%) and spoke Spanish (89%). Parents reported high satisfaction with the card (4.5/5 for ease of use, helpfulness, and understandability). Ninety-four percent shared the card with others, and 45% reported listening >5 times. Besides reviewing the care instructions generally, parents reported using the card to review medications and engage others in the child's care.

Conclusions—Providing language-concordant, audio-recorded discharge instructions was feasible, and parents reported high satisfaction with and frequent use of the cards with multiple caregivers.

Keywords

Quality improvement; language barriers; healthcare disparities

Background

Over 15% of US children live with a parent who has limited English proficiency (LEP).¹ Language barriers in the medical setting have been associated with lower quality care, including worse comprehension and adherence,^{2–5} increased risk of adverse events,^{6–9} and increased readmission rates.^{10,11} Low health literacy in the LEP population,^{12–14} along with failure to provide language-concordant discharge instructions, likely contributes to these worse outcomes. Provision of language-concordant, audio-recorded discharge instructions could improve parent comprehension and may improve child safety and outcomes.

Recordable cards are paper-based cards with a built-in recordable audio chip, similar to a greeting card that plays a music or personal message. They represent a “low-tech” solution to addressing disparities based on communication and comprehension. They are inexpensive, readily available, and do not require that the family have a mobile phone capable of making recordings. The recordable card can be shared with multiple caregivers, which is beneficial for caregivers who cannot be present during hospital discharge. The cards are customizable and re-usable, so families can receive up-to-date, personalized instructions. In initial pilot-testing with 12 families, all caregivers found the card “helpful” or “very helpful,” and nurses noted that the 3-minute recording time limit required them to distill the discharge teaching down to the most important messages. However, the feasibility, acceptability and effect of implementing recordable cards for discharge instructions in a busy unit are unknown. Therefore, the primary aim of this study was to determine the feasibility of and utilization patterns for language-specific audio-recorded discharge instructions for pediatric day-surgery patients with LEP parents. Our secondary aim was to determine whether receipt of a card with audio-recorded discharge instructions in the parents’ preferred language for care improves parent comprehension of discharge instructions and parent-reported confidence in caring for the child after discharge.

Methods

Setting and participants

We conducted this prospective pilot study at a freestanding children’s hospital between April and September 2016. We enrolled LEP parents of day-surgery patients who endorsed a preferred language for care for which a staff interpreter was available (Spanish, Somali, Russian, Ukrainian, Vietnamese, Mandarin, or Cantonese). Language preference was assessed at hospital registration and recorded in the medical record. Eligible parents were those receiving condition-specific discharge instructions that included at least 2 of the following: a new medication, home care instructions (e.g., wound care or diet advancement), return precautions, or follow-up appointments. Parents were ineligible if the child was not discharged to home from the recovery room. This study was reviewed and approved by the Western Institutional Review Board. It was registered with clinical trials.gov ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study?term=NCT03195842) Identifier: NCT03195842).

Study design

This study was designed as a pilot randomized trial, assessing both feasibility and outcomes. We sought to compare usual discharge care alone to usual discharge care plus provision of the recordable card with language-specific discharge instructions. Due to substantially lower-than-expected eligibility and enrollment, we were underpowered to test our hypotheses related to randomization. Therefore, the majority of our analyses focus on feasibility and acceptability.

Approach and recruitment—Potentially eligible families were approached by the research assistant (RA) about the study in several ways: by telephone several days before the surgery, in the pre-operative anesthesia clinic in the week prior to surgery, or on the day of the child’s surgery. The RA was bilingual in English and Spanish, and used a professional

interpreter for other languages. Families who consented to participate were then randomized to receive usual care or usual care plus recordable card. Contact information, demographics, and some baseline family data were collected at enrollment. Reasons for declining to enroll in the study were collected in a de-identified manner. Participant incentive was added part way through the study to enhance enrollment, after which point participants received a \$40 gift card for completing the study.

Usual discharge care—Discharge instructions were communicated to LEP families through a variety of methods. A member of the surgical team (attending or resident) talked to the family after the surgery, generally with an in-person interpreter, and reviewed some elements of discharge instructions. Written instructions were generated from *condition-specific* patient education handouts that the PACU nurse selected based on the child's diagnosis, and *patient-specific* instructions that the surgeon entered into the electronic medical record. Many of the diagnosis-specific handouts were available in multiple languages and were provided in those languages if the nurse selected them; the patient-specific written instructions were only provided in English. The amount of patient-specific instructions provided varied, but was typically not more than 3-5 sentences. The nurse reviewed all of the discharge information with the parents through a professional interpreter.

Recordable card—The recordable cards resembled greeting cards, and played a prerecorded message when the play button on the inside was pushed. Each card can record up to 3 minutes of audio, be recorded and erased up to 50 times, and be played >100 times. For parents randomized to the card, the interpreter worked with the nurse to identify which of the written instructions to record. Patient-specific instructions were always recorded, but because the diagnosis-specific handouts could sometimes add up to more than 10 pages, the instructions felt to be most important for a given family were identified and recorded, rather than all content from the handouts.

The interpreter then recorded the identified information in the family's preferred language for care. The interpreter was able to record and re-record the information until they were satisfied that they had effectively conveyed the meaning onto the card. They then reviewed how the card worked with the family. Each card had the patient's name and date of surgery on it, along with information for contacting the hospital language line if they had questions. Parents who received a card also received usual discharge instructions.

Data collection—Parents were called 2-7 days after the surgery to complete a telephone survey. The survey was administered in Spanish (using a professionally translated version) or through a telephone interpreter for other languages. We used a variety of measures to ascertain satisfaction, comfort, and comprehension. We asked families who received a card how often they referred to it and how satisfied they were with the instructions received. These questions were adapted from a previous study of recordable cards for children with asthma.¹⁵ We also asked for open-ended feedback about the cards, which was added part way through the study. To assess parental comfort in caring for the child post-discharge, we used 7 of Berry *et al*'s care transition measures, in which parents rated a series of statements using a Likert scale from strongly disagree (1) to strongly agree (5).¹⁶ We selected *a priori* measures focused on comfort in caring for the child, which we had hypothesized might be

influenced by receipt of the card. Parents were also asked to report the discharge instructions they received, using Engel *et al*'s approach.^{17,18} Documented discharge instructions, used to determine concordance with parent-reported instructions, were abstracted from the electronic medical record by a blinded abstractor.

Child, family, and encounter characteristics were collected from hospital administrative data and via the enrollment and follow-up surveys.

Analysis—Patient and family characteristics were compiled by study group. Intervention acceptability was examined using descriptive statistics based on questions related to card satisfaction and use. Open-ended feedback about the cards was reviewed by two bilingual team members and grouped by theme. Intervention feasibility was determined based on ability to successfully deliver a recorded card to families randomized to that group.

For the care transition measures, mean Likert scale scores (1-5) were compared by study group using the t-test, using an intention-to-treat approach.

To determine instruction comprehension, we compared parent-reported and documented instructions for medications, home care, follow-up, and return precautions, and rated the degree of concordance.^{17,18} Two authors (KCL and CG) blinded to study group compared parent survey responses to documented instructions, within each of the 4 instruction domains. Parent report was considered *not concordant/wrong* if it was missing all relevant components of discharge education within the category, or included information that was wrong and could lead to negative health consequences; *minimally concordant* if it included few elements of the discharge instructions, but no information that was actively incorrect; *partially concordant* if it included some or most of the relevant information, but was missing at least one important element; and *mostly or totally concordant* if it included all clinically important elements of the discharge education. For medications, we did not ask parents to specify the dose or dosing interval, but asked that they correctly name oral medications. For topical medications, including ear drops, we accepted a description of the medication that included location of application and/or indication (e.g., cream to prevent surgical site infection, ear drops) as concordant. Distribution of comprehension responses were evaluated by assigned study group within each domain using Fisher's exact test. A summary percent concordance, across domains, was calculated by assigning 1 point for each "totally concordant" domain, divided by the number of domains for which instructions were provided. Families provided with instructions in fewer than 2 domains were excluded from the summary calculation (n=4).

Given that our groups were unbalanced with respect to several important baseline factors, we also conducted an exploratory multivariate analysis of outcomes. For this analysis, we modeled summary percent concordance using linear regression, and modeled comfort with home care using logistic regression, after converting responses to dichotomous top-box responses, with the most positive option as a 1 and all other options as zero. We controlled for medical complexity using PMCA, and post-procedure acuity based on procedure category. We considered endoscopy, cardiac catheterization, and dental procedures to fall in the low post-procedure acuity category, and all others into the high post-procedure acuity

category. While groups were also unbalanced with regard to receiving written instructions in their preferred language, this was determined by procedure type and therefore highly collinear with post-procedure acuity. Consequently, we did not also include it in the models.

Power calculations—In the year prior to our study, there were 734 day-surgery patients with potentially eligible LEP parents (14 per week). Assuming 70% eligibility, 80% consent, and 80% retention,¹⁹ we expected 164 completed surveys in 6 months, or ~82 per group, to provide >80% power to detect a 0.5 point difference (on 5-point scale) in scores on each home-care comfort metric,¹⁶ and a 23% difference in discharge instruction comprehension.^{19,20}

Results

Enrollment and retention

Over the 7.5 months of study enrollment, there were 197 potentially eligible participants, which was 57% lower than expected based on surgical volumes in prior years. Over the entire study period, 82% percent of eligible families were approached (n=162), and 52% of approached families consented to enroll (n=83; Figure 1). Eighty percent (n=66) of enrolled families completed the follow-up survey. Due to low eligibility and enrollment with our initially planned strategies (approaching and consenting families primarily on the day of surgery, and not offering participant incentive), after 5 months of recruitment we were able to add a phone-recruitment approach prior to surgery and a \$40 participant incentive for completing the survey. With these changes, consent for enrollment increased from 42% (48/115) to 80% (35/44), and survey completion increased from 71% (34/48) to 91% (32/35).

Lower-than-expected eligibility was attributable to several factors. Day-surgery volumes were down compared to previous years due to staffing shortages. In addition, due to staff turnover, we were unable to enroll Somali-speaking families (our second-most-common language) for half of the study period.

Among the parents who were approached and declined to participate, the most common reasons reported were feeling the card to be unnecessary (because, for example, the adolescent patient was English proficient, or the discharge instructions seemed straightforward; n=29), feeling too stressed about the child's surgery (n=13), being too busy for the follow-up phone survey (n=12), or not liking that they might be randomized to not receive a card (n=5).

Child, family, and encounter characteristics

Among the 83 families enrolled, most preferred Spanish for care (89%), and the majority of caregivers reported speaking English not well (55%) or not at all (28%) (Table 1). Sixty percent of parents had less than a high school degree. Nearly all of the children were insured by Medicaid (95%), and about half had undergone a previous surgery. Most parents reported receiving at least some written discharge instructions in their preferred language for care, although this was more common in the group randomized to receive a recordable card (90%) than among those randomized to usual care (67%). The usual care group also had far more

children whose procedure was a GI endoscopy, with very straightforward discharge instructions (20% vs 2%; see Table 1 and Appendix 1). Other child, family, and procedural characteristics appeared evenly distributed between groups.

Intervention Acceptability

Among the 31 parents who received a card and completed the follow-up survey, all reported that at least 1 person listened to the card after discharge (Table 2), and most reported the card being listened to by multiple individuals, including the patient. Nearly half (45%) reported that the card was listened to more than 5 times. All caregivers endorsed listening to the card to review the child's care; additional, open-ended reasons that were volunteered included curiosity or for fun, wanting to share the information with others, wanting to be sure they hadn't missed something, and wanting to specifically review the medications (Sidebar). Satisfaction scores were high, with mean Likert scores of 4 or above (out of 5) on all 8 measures. The 4 measures related to overall card satisfaction (the card was easy to use, easy to hear, helpful, and the information made sense) each had a mean Likert score of 4.5 out of 5. Regarding the specific domains, medications were rated as most helpful (mean 4.4, SD 0.5), and follow-up appointments as least helpful (mean 4.0, SD 0.9).

Open-ended feedback

Open-ended questions eliciting what parents who received a card liked most, liked least, and would recommend improving were added near the end of recruitment and were collected from 13 participants (Sidebar). Major themes regarding likeability included that the card had all of the information they needed to care for their child, it was audio-recorded rather than written, it was easy to use, and it was in their preferred language. When asked what they liked least, 9 of the 13 parents said they had no complaints; the remainder reported not having understood something about how the card worked, that it was too easy to accidentally erase, and that more information should be recorded. When asked how to improve the card, major themes included recording more individual details and including what the surgeon actually said rather than the information from the written discharge paperwork.

Intervention feasibility

During eligibility screening, 18 families (out of 197) could not be approached for enrollment because an in-person interpreter was not available to make the recording for a card in their language that day. Of the 42 families randomized to receive a card, only 3 did not receive one due to logistical challenges with recording and card delivery. In one case, the interpreter was too busy, and in 2 cases, the family did not feel they could wait for the recording to be completed.

Comfort caring for the child

Overall, parent-reported comfort was high in both groups, with mean Likert scores of greater than 4 on all 7 measures (Table 3). We were underpowered to examine statically significant differences between assigned groups.

Comprehension

Recall of follow-up appointments was high in both groups, with over 70% of parent's answers rated as completely concordant (Table 4). About half of parents in both groups reported medication names in a fully concordant manner, with most of the rest providing partially concordant information. Fewer parents provided concordant responses for home care or return precautions. Overall, on average, parent instruction recall was low, with summary concordance percentages across domains of 40% for families who received a card and 42% for families who did not. We were underpowered to examine statically significant differences between assigned groups.

Exploratory multivariate analysis

In multivariate analyses, controlling for post-procedure acuity and medical complexity, we found no between-group differences in instruction concordance or comfort with home care measures, with estimates and confidence intervals similar to those in unadjusted analyses. However, we were underpowered to detect even moderate-to-large differences in outcomes.

Discussion

In this pilot trial of language-concordant, audio-recorded discharge instructions, we found that families who received a card were universally satisfied with the card, and believed that the card was helpful in caring for their child after discharge from a day-surgery procedure. We found that it was feasible to record and deliver these cards to families in a range of languages during discharge from a busy post-anesthesia care unit. However, due to challenges with eligibility and enrollment, we were underpowered to detect differences in outcomes. In addition, in this population of children undergoing relatively uncomplicated day-surgery procedures, we found high levels of parent confidence with and moderate comprehension of instructions across both groups. All participants received in-person interpretation as part of standard care; coupled with straight-forward instructions, this may also have contributed to difficulty in identifying between-group differences.

This study achieved its primary aim of determining that it was both acceptable and feasible to deliver discharge instructions to LEP families via a recordable card. Families were universally satisfied with the card and the information included on it, and nearly half of families reported listening to it more than five times. In the majority of families, multiple individuals listened to the card, which would be expected to improve understanding of the child's care across more of the people who might be involved. Even when the card was being listened to primarily due to its novelty, improved awareness of the instructions would be a likely result. Parents particularly liked that the card included much of the most important information, and therefore made them feel safer in how they were caring for their child. Given that we know that LEP patients and families are at higher risk for poor discharge instruction comprehension and medication administration errors,^{21,22} providing instructions in a format that improves accessibility and promotes frequent review seems promising. In addition, the enthusiasm of the open-ended responses suggests that overall satisfaction scores, of the kind tracked and reported by many hospitals and healthcare systems, may well be improved with such an intervention. It could therefore be valuable to

organizations, with or without measurable improvement in other outcomes; overall hospital satisfaction should be assessed in future work.

We also determined that providing language-concordant, audio-recorded discharge instructions in real time was feasible. Given that accurate medical translation (from written text to written text) is a time-consuming process that often cannot be accomplished prior to patient discharge and is not available at many hospitals, having interpreters audio-record the instructions is a potentially promising option. In designing the intervention, we found that it was important that recording be done in a way that allowed the interpreter adequate time to generate a product they were satisfied with, and time to review it with the family to be sure they understood it. On three occasions during the study, we were unable to record the card within the timeframe that the family was willing to wait prior to discharge, but the majority of the time, we were able to get the cards recorded and explained to the family without delaying discharge.

A previous randomized study of audio-recorded instructions found that an asthma action plan, delivered via recordable greeting card at pediatric clinic visits, was associated with improved asthma control and high parent satisfaction.¹⁵ The participants in this previous study were all English-speaking, but the authors noted the cards' ability to overcome literacy barriers. In our sample, in addition to addressing the language barrier, we were also likely addressing literacy barriers, which often co-occur with LEP.¹⁴ In our sample, for example, 38% of our enrolled families did not complete more than an 8th grade education. Interventions to improve understanding among LEP populations that rely on reading skills or technology such as smart phones have the potential to worsen disparities, by improving understanding among the least disadvantaged in the group (those with strong literacy skills and ready access to mobile technology), while leaving the most disadvantaged further behind.²³

During the course of this study, we encountered several challenges that led to important learning and should inform future work. To begin with, prior to adding participant incentives, we experienced low rates of enrollment in the study. We had not initially budgeted to include participant incentive, based on a previous study that achieved high levels of enrollment in the emergency department with LEP participants and no incentive.¹⁹ In the previous study, while families were randomized to different methods of interpretation, the randomization was occurring at the level of the emergency department rather than at the level of the individual. In this study, with randomization at the level of the individual, families perceived the potential to be randomized to usual care as a drawback, and some were unwilling to participate without compensation for their time in filling out the survey. Once we added participant incentive, enrollment increased markedly, showing that the initial low enrollment is unlikely to reflect a negative attitude towards the intervention itself.

We also encountered difficulty in demonstrating differences in outcomes between groups, due both to a low sample size and a ceiling effect with some of our outcomes. As mentioned previously, we did not achieve our intended sample size due to lower than expected eligibility and low enrollment prior to the addition of incentive. With our final sample of 66 completed surveys, we had 53% power to detect a moderate difference in comfort with home

care, and 35% power to detect a moderate-to-large difference in comprehension. We also encountered universally high scores related to parent confidence caring for the child at home, in both groups. While this may reflect excellent discharge teaching and universal use of in-person interpreters as part of usual care, this may also reflect that the discharge instructions themselves were straightforward, and the children essentially healthy at the time of discharge. This was particularly true in the control group, with a disproportionately high number of the children being discharged home following GI endoscopy. Staffing shortages in the OR not only contributed to low eligibility, but also led several of the surgical service lines, including General Surgery, to redirect many of their day-surgery patients to a different location, to which we were unable to expand recruitment. As a result, the children who were enrolled represented a less complicated and variable mix of procedures, with less complicated discharge instructions. A wider, more complicated breadth of discharge instructions would likely allow for a greater ability to demonstrate a difference between groups.

In addition to the issues mentioned above, the generalizability of our findings was also somewhat limited by the fact that this study was conducted at a single institution, and with a largely Spanish-speaking population. Moreover, we had access to in-person interpreters to make the recordings, which is not always possible in many locations. Strategies to increase disseminability of the intervention could include providing standardized, pre-recorded instructions, and using telephone or video interpreters to make the recording. Nonetheless, this pilot study provides important acceptability and feasibility information for future larger studies, in which more generalizable strategies and outcomes can be better assessed.

In conclusion, we demonstrated that it was feasible to provide families with language concordant, audio-recorded discharge instructions following a day surgery procedure, and caregivers that received such instructions reported high satisfaction and frequent use of the card across multiple caregivers. We were unable to demonstrate a difference in outcomes due to sample size constraints; choosing a higher acuity population for future studies would also likely improve the ability to identify differences. Recordable cards are a feasible and promising approach for delivering time-sensitive discharge instructions to families facing language or literacy barriers. Future studies are needed to determine what impact they might have on outcomes and in what populations they are most effective.

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Appendix 1: Specific surgery types of enrolled participants, by assigned study group

Surgery type	Usual care (N=41)	Rec card (N=43)
Otolaryngology total	14	16
Adenoidectomy and ear tubes	0	3
Tonsillectomy and adenoidectomy	2	5
Tonsillectomy	2	0
Cochlear implant	1	0
Tympanomastoidectomy	0	1
Reduction of nasal fracture	0	1
Ear tubes	1	2
Excision mass—head and neck	2	1
Tympanoplasty, myringoplasty	0	1
Ear repair/reconstruction	4	1
Ear repair, adenoidectomy	1	0
Laryngoscopy w laser	0	1
Cleft lip repair	1	0
Urology total	6	7
Circumcision	1	1
Excision mass—urology	1	1
Hydrocelectomy	1	0
Suprapubic catheter insertion	1	0
Patent processus vaginalis repair	1	2
Orchiopexy	1	1
Orchiopexy, hernia repair, circumcision	0	1
Buried penis, circumcision	0	1
Orthopedics total	3	5
Bone biopsy	0	1
Trigger thumb release	1	2
Open reduction and internal fixation	1	0
Humerus implant revision	1	0
Osteotomy, finger	0	1
Finger tendon repair	0	1
General surgery total	5	7
Port insertion/removal	1	1
Toenail excision	0	2
Excision of mass	3	4
Gastrostomy closure	1	0
Hardware removal	0	1
Ophthalmology total	2	5
Cataract removal	0	2
Lensectomy, vitrectomy	0	1

Surgery type	Usual care (N=41)	Rec card (N=43)
Strabismus repair	2	2
Other		
GI Endoscopy	8	1
Cardiac catheterization	1	0
Dental extraction	2	0

Sidebar: Open-ended feedback from participants who received a card, grouped by theme, regarding additional reasons for listening to the card, what they liked most, what they liked least, and what they would do to improve the cards.

Category	Example caregiver quotes
Additional reasons for listening to card (N=14)	
For curiosity, to show off, or to play	To show off how it works, the novelty. Everyone was really impressed. For my daughter to play with. It's something new, like, what is this? Out of curiosity.
To share information	So that my daughter would know the instructions for her own care. To explain to another person how to care for the baby.
To make sure they were not missing something	To see what it had in the card, in case we missed something. To learn, see if we missed any further information. The older sister who helps to care for him listened.
To review medications	To be sure about how to give him his medicines. I listened to it every time I gave him his medicines. To remember the medications well.
What people liked most (N=13)	
Audio rather than written	Really remarkable, how you can put all the information in audio! Really good. I didn't have to read everything about caring for my child, it made it easier for me to do it this way than to read. I just pushed and listened to the voice of the interpreter
Can be listened to repeatedly	If you forget you have it right there, as a reminder. You get to keep it forever, like a memento
In preferred language	That it was in Spanish There are still times that I listen to it, and my husband too. He was really happy and said that he hopes they offer these very soon. Basically the language, you have it right at your fingertips—you don't have to go searching through papers. It closes and it stops, easy, practical, really good.
Nice for future appointments	That it can be used for other appointments, that it can record 100 times It would be useful in the future as well, easy to understand and easy to use, they tell me exactly when, where, and how everything with my child
Generally satisfied	It's a good idea, it seems to me like a really good idea, especially for people having their first surgery, you forget.
Specific content	The instructions about the medications, and how to take care of him. It reminds you what you have to do if you have an emergency and it gives me the number.
Easy to use, practical	That it is easy to record it or to listen to it, it's good, it's not complicated, it's easy to know about him. It was very important, practical, very specific, very easy to listen to, very useful.
Helped child with self-management	That he can listen to it himself and take care of himself.
What they liked least (N=13)	
Technical difficulties	That sometimes it doesn't work when it opens That it won't record again

Category	Example caregiver quotes
Easy to erase	That it can be erased – easy to erase. After 2 times the other child erased it.
Wished for more content	That it only had a little bit, so, it would be good if you could put more.
No complaints	Maybe the color, which is white – a joke! Everything is very good, there was nothing I did not like. I liked everything, the person who came up with this was very smart.
What to improve (N=13)	
No changes, liked as is	I liked everything, I don't know what more you could put. For me, it seemed perfect.
More specific patient information, including medications	The only thing I would say is to basically record everything about the patient, including how to give the medication because that part is missing, to give the whole complete, detailed information for the patient.
Summary from MD, not written paperwork	I don't know how to make it better. A summary from the doctor, what he says when he talks with us after the surgery in place of what's written on the paper that they give us? Record more time? There isn't enough time to record what the doctor says when he is with the interpreter, if it could record more.
Pause button	A pause button.
A way to save the information	A file to save it.
Colors, music	I don't know, I think for example if it is for children, colors or drawings for children, background music would grab your attention more, relaxing music. I don't know if they'll think I'm crazy, or what?

Abbreviations

LEP	limited English proficiency
SCH	Seattle Children's Hospital

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Figure 1. Study enrollment and retention

This figure shows study eligibility, enrollment, randomization and retention, following Consolidated Standards of Reporting Trials (CONSORT) guidelines.²⁴

Table 1

Study participant characteristics, based on assigned study group

	No card	Received card
	N=41	N=42
From administrative data		
Male	18 (44%)	25 (60%)
Age (mean, SD)	8.1 (4.9)	7.3 (5.0)
Public insurance	39 (95%)	41 (98%)
Language		
Spanish	36 (88%)	38 (90%)
Somali	3 (7%)	3 (7%)
Mandarin	1 (2%)	0
Vietnamese	1 (2%)	0
Russian	0	1 (2%)
Pediatric Medical Complexity		
Algorithm		
Complex Chronic	9 (22%)	6 (14%)
Non-complex chronic	10 (24%)	15 (36%)
Non-chronic	22 (54%)	21 (50%)
Surgery type ^a		
Otolaryngology	14 (34%)	16 (38%)
Urology	6 (15%)	7 (17%)
General surgery	5 (12%)	8 (19%)
Orthopedics	3 (7%)	5 (12%)
Ophthalmology	2 (5%)	5 (12%)
GI Endoscopy	8 (20%)	1 (2%)
Other	3 (7%)	0
From enrollment survey	N=41	N=41
Child had previous surgery	20 (49%)	22 (54%)
Same type of surgery	10 (24%)	10 (24%)
Parent born in Mexico	30 (75%)	33 (81%)
Years in US	13 (5.9)	13(6.3)
English proficiency		
Not at all	10 (24%)	13 (32%)
Not well	24 (59%)	22 (54%)
Well	7 (17%)	6 (15%)
Parent highest grade		
8 th or less	16 (39%)	15 (37%)
Some high school	9 (21%)	10 (24%)
High school graduate	8 (20%)	9 (22%)
Some college/2 year degree	4 (10%)	3 (7%)

	No card	Received card
From administrative data	N=41	N=42
Bachelor's degree or higher	4 (10%)	4 (10%)
From follow-up survey	N=35	N=31
Income		
<\$15,000	4 (11%)	2 (6%)
\$15-30,000	11 (31%)	10 (32%)
\$30-50,000	9 (26%)	7 (23%)
>\$50,000	3 (9%)	0
Decline to answer	8 (23%)	12 (39%)
Called healthcare provider after discharge with question or concern	4 (11%)	4 (13%)
Received help from family member or friend to read instructions	5 (14%)	4 (13%)
Received at least some written instructions in preferred language	24 (67%)	28 (90%)

^aSee Appendix 1 for full list of procedure names by study group

Table 2

Use of and satisfaction with the cards, among those who received them

Follow-up survey responses	N=31
Did anyone listen to card?	
Yes	31 (100 %)
Who listened?	
The parent being surveyed	30 (97%)
The other parent	22 (71%)
The child (patient)	17 (55%)
Another caregiver	4 (13%)
Other family members or friends	17 (55%)
How many times was it listened to?	
1-5	17 (55%)
6-10	10 (32%)
11-15	3 (10%)
16+	1 (3%)
Reasons to listen	
To review child's care	31 (100%)
Some other reason (see Appendix)	14 (45%)
Card was easy to use *	4.5 (0.5)
Card was easy to hear *	4.5 (0.5)
Information made sense *	4.5 (0.5)
Card was helpful *	4.5 (0.5)
Medication information helpful *	4.4 (0.5)
Home care information helpful *	4.4 (0.6)
Follow-up appointment information was helpful *	4.0 (0.9)
Return precaution information helpful *	4.3 (0.7)

* mean and SD Likert response, scale 1-5

Table 3

Parent-reported comfort in caring for their child at home based on Likert scale responses (1 to 5), by assigned study group^a

	No card (N=35)	Card (N=31)	P-value
I had enough information	4.33	4.39	.73
I knew the warning signs	4.19	4.39	.20
I understood how to manage my child's care	4.37	4.35	.89
I knew who to call	4.34	4.35	.92
My child was healthy enough to go home	4.06	4.29	.16
I had an easily understood plan for healthcare for my child	4.26	4.39	.34
I had an easily understood list of appointments	4.11	4.39	.09
I understood why my child needed each medication	4.34	4.35	.92
I understood how much and how often to give each medication	4.31	4.42	.41

^aT-test

Table 4

Instruction comprehension, based on 2 coders comparing parent report to written discharge instructions abstracted from the chart

	No card	Card	P-value
Medications			
No concordance/wrong	1/27 (4)	0	.50 ^a
Minimal concordance	0	0	
Partial Concordance	11/27 (41)	15/29 (52)	
Complete concordance	15/27 (56)	14/29 (48)	
Home care			
No concordance/wrong	3/36 (8)	1/31 (3)	.59 ^a
Minimal concordance	6/36 (17)	9/31 (29)	
Partial Concordance	12/36 (33)	10/31 (32)	
Complete concordance	15/36 (42)	11/31 (35)	
Follow-up			
No concordance/wrong	4/28 (14)	3/25 (12)	.69 ^a
Minimal concordance	1/28 (4)	0	
Partial Concordance	2/28 (7)	4/25 (16)	
Complete concordance	21/28 (75)	18/25 (72)	
Return precautions			
No concordance/wrong	2/30 (7)	2/29 (7)	.96 ^a
Minimal concordance	4/30 (13)	4/29 (14)	
Partial Concordance	22/30 (73)	20/29 (69)	
Complete concordance	2/30 (7)	3/29 (10)	
Domains Completely Concordant ^b			
(%, 95% CI)	42% [34, 50]	40% [30, 49]	.76 ^c

^aFisher's exact test

^bCalculated for caregivers given instructions in >3 of the domains above (n=32 for no card, 31 for card)

^cT-test