Frequency of high-quality communication behaviors used by primary care providers of heterozygous infants after newborn screening

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Abstract

Objective—To examine the quality of communication likely to be experienced by parents when being first informed about how newborn screening identified heterozygous "carrier" status for cystic fibrosis or sickle cell disease.

Methods—Primary care providers (PCPs) of infants found to have carrier status were telephoned over a 48-month period, and asked to rehearse with a standardized patient how they would inform the infants' parent(s). 214 rehearsal transcripts were abstracted using explicit criteria methods to measure the frequency of five categories of high-quality communication behaviors.

Results—Overall, PCPs used large amounts of jargon and failed to use high quality communication behaviors. On average, PCPs used 18.6 total jargon words (8.7 unique words), but explained 2.4 jargon words. The most frequent assessment of understanding was the close-ended version, although it was only seen in 129 of 214 transcripts. The most common organizing behavior was importance emphasis (121/214). Precautionary empathy was rare; the most frequent behavior was "instruction about emotion" (33/214).

Conclusions—The limited use of high-quality communication behaviors in rehearsals raises concern about parental understanding, decision-making, and psychosocial outcomes after newborn screening.

Practice Implications—Measurement of specific behaviors may help PCPs to improve communication, and thereby improve the patient experience.

1. Introduction

Newborn screening (NBS) is a population-scale public health program which includes testing of infants' blood specimens that are applied to a special filter paper, dried, and tested at a centralized laboratory for a panel of genetic and metabolic diseases [1]. Cystic fibrosis (CF) and sickle cell disease (SCD) are included on NBS panels because the diseases' risk of death and disability can be reduced if identified before becoming symptomatic [2-5]. Both CF and SCD are autosomal recessive conditions, and heterozygous "carrier" infants are identified in far greater numbers than infants with the actual diseases [6]. Unfortunately,

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many families of carrier infants develop psychosocial complications after NBS, ranging from clinical levels of parental anxiety or depression to impaired parent-child bonding and the vulnerable child syndrome [1-3, 7, 8]. Some authors have referred to these carrier conditions as "Nondiseases," [9] although there is increasing interest in people being aware about some carrier states [10-12]. In the United States, NBS programs typically provide carrier results to the child's primary care provider (PCP) for disclosure to the parent. NBS programs have developed educational and support materials for families, but it is also important to work on PCPs communication because first conversations can be critical for understanding [13], and because the quality of PCP's communication has been criticized by parents and NBS officials [8, 14-16].

Psychosocial problems after carrier identification have been cited by bioethicists and others as grounds for delaying or discontinuing some NBS activities [17-20]. In contrast, we see psychosocial risks as a matter of NBS safety. To manage safety and allow NBS to expand, we have been developing techniques for assessing and improving PCPs' communication. We adapt methods from traditional Quality Improvement, so that the methods will be affordable and feasible for use on the same population scale that is covered by NBS [7, 21-31]. A key part of this effort has been to develop "communication quality indicators" that operationalize important communication behaviors for quantitatively reliable, objective measurement [21-28].

In this paper, we describe communication quality indicator data from a 48-month statewide sample of PCPs' "rehearsals" with a standardized patient prior to informing an actual parent about a NBS result showing carrier status for CF or SCD. We have previously used patient simulations in other studies of communication quality [22-27] and patient simulations are known to be an effective tool for physician education and assessment [32-36].

2. Methods

2.1 Context

This analysis was done as part of the "Wisconsin Project on Improvement of Communication Process and Outcomes after Newborn Screening" (hereafter called the "Project") [7, 29, 30]. The Project is a statewide research study and quality improvement effort by the NBS program of the Wisconsin State Laboratory of Hygiene and the Department of Health Services, with the Medical College of Wisconsin as a contracted project agent. Project methods are approved by Institutional Review Boards at the Medical College of Wisconsin and University of Wisconsin, Madison. The phase of the Project that this analysis covers ran over the 48 months from December 1, 2007 through November 30, 2011. A previous manuscript goes into more detail about the complex methodology for the Project's recruiting methods, as well as the acceptability of the methods to the PCPs and parents [30].

As one part of the Project, we telephoned PCPs of infants found by NBS to be carriers for SCD or likely carriers for CF, and invited the PCPs to rehearse over the telephone how they would inform parents about the results[30]. Parents were called during another part of the Project; these results will be reported elsewhere.

2.2 Participants

All participants for this analysis were PCPs, recruited by a multi-step process that was designed to function within the usual practice of the NBS laboratory [30]. The Project focused on two NBS results: the presence of fetal, adult, and sickle hemoglobin (the F-A-S result), or an elevated immunoreactive trypsinogen (IRT) followed by a single CF-associated mutation. The hemoglobin F-A-S result is 100% specific for the most common

type of SCD carrier status. Infants with an elevated IRT and a single mutation are said by the Project to be "likely CF carriers" because they have a 2-5% chance of having CF due to a mutation that was not included on the NBS panel [3]. Thus, infants with the likely CF carrier result require sweat testing to confirm that they are actually carriers [37, 38].

During the 48 months of the Project reported in this paper, when an infant was found to have either of these results the NBS laboratory faxed the result to the Project team at the same time it contacted the clinician listed on the NBS card. When the listed clinician was not the correct PCP [39], the Project team telephoned the birthing hospital and used other search techniques to identify the responsible PCP. At any point during this process, exclusion criteria could be applied: (a) NBS lists more than one abnormality, (b) gestational age < 35 weeks, (c) >5 days in neonatal intensive care, (d) hospitalization after nursery discharge, or (e) evaluation for some other medical abnormality. We also excluded infants by asking the PCP to identify any other contraindications to contact by asking, "Can you think of any reason why it would not be appropriate to contact this family later this year?"

Finally, we excluded PCPs and infants from the entire Project when the PCP informed us that the parents require a translator. We were concerned that we would not have the sample size to analyze the effect of a language barrier on communication outcomes. We also did not have the resources to conduct parent interviews in other languages.

2.3 Data collection

After the infant's actual PCP was located and the lack of contraindications was verified, PCPs were asked if they have any questions about the NBS result, and when they planned to inform the parent. PCPs were then invited to rehearse over the telephone how they would inform the infant's parent(s) about the result. For this rehearsal the interviewer pretended to be the infant's parent, following the protocol for our Brief Standardized Communication Assessment (BSCA) method [40]. Interviewers were instructed to maintain neutral vocal tone and avoid leading questions. Some artificiality is inevitable with the BSCA, but analysis is standardized and reduces confounding effects of patient variation.

PCPs were not asked to rehearse if they had previously rehearsed for another infant in the Project, or if they had declined to rehearse in the past. PCPs recorded only one rehearsal for analysis even if they had more than one patient in the project, both to save resources and also to avoid double-counting those PCPs who have a greater volume of patients. If the PCP had previously expressed interest but was unable to participate (e.g. because of time limits) then the PCP was invited to rehearse again.

Rehearsals were digitally audio-recorded, transcribed, and de-identified. To facilitate abstraction, transcripts are subjected to a parsing procedure to separate them into individual "strings" of text, each of which has a single subject and predicate that give the string a distinct meaning.

2.4 Measures (Communication quality indicators)

Transcripts of the PCP rehearsals were abstracted for communication quality indicator data using techniques that we previously demonstrated with smaller samples [21-28, 31]. As outlined elsewhere [21-28, 31], communication quality indicators operationalize important communication behaviors into specific, measurable targets for clinicians to improve. Indicators are independent of each other, so that clinicians may perform well on one indicator, but poorly on another [41].

2.4.1 Abstraction procedures—Our abstraction procedures are adapted from techniques used in traditional Quality Improvement, with abstractors reviewing transcripts in much the same way that hospital records are abstracted [41]. An explicit-criteria data dictionary is derived from published evidence and guidelines [13, 42-46], and contains detailed explanations and examples to reduce need for subjective judgment. Abstractors read though transcripts one string at a time, searching for strings that meet criteria outlined in the explicit-criteria data dictionary. To focus abstractors' attention, abstraction is done for one group of communication quality indicators at a time. Abstraction is facilitated by our self-developed software application, Transcript Abstraction System (TAS), and is done twice for one third of the transcripts for quality control and reliability (following the suggestion by Feinstein [47]).

In this manuscript we focus on four out of our five previously-described groups of communication quality indicators: jargon [23, 24], assessment of understanding [21, 22], precautionary empathy [25], and organizing behaviors [28]. The fifth group of indicators (which focuses on content messages) [26, 27] is complex enough that data from that portion of the Project will be presented in another manuscript [48].

2.4.2 Communication behavior group #1: Jargon and explanations—"Jargon" refers to medical, scientific, or other words that may be unknown or misunderstood by the patient [23, 24]. Patients are known to complain about the amount of jargon used by health care providers (in NBS and elsewhere) [42-46]. Since jargon may sometimes be necessary for a full explanation, this group also includes criteria for jargon word explanations.

The number of jargon words was counted via a previously described, automated search procedure that we adapted from corpus linguistics [23, 24]. Abstractors then verified the automated results, with an amendment process allowing abstractors to propose or ratify additions to the jargon list. When such a word was identified, an electronic search of previously abstracted transcripts was used to verify that the newly designated jargon word was not missed in previous abstractions [23, 24].

During abstraction, jargon explanations were also identified by following the abstraction procedure described above. This group of communication quality indicators also includes the ratio of explained to unexplained jargon words and the explanation lag, defined as the number of concepts (measured in strings) between the first use of the word and its explanation [23, 24].

2.4.3 Communication behavior group #2: Assessment of understanding—
Assessment of understanding (AU) refers to behaviors where the PCP seeks to gauge the effectiveness of his or her counseling about the NBS result. AUs are especially important for communication about NBS because, as with other complex topics, shock or intimidation may inhibit parents' questions or reduce the chance of a confused facial expression [49]. As described elsewhere [21, 22], our data dictionary includes definitions and examples for four types of AUs: close-ended, open-ended, request for a teach-back, and the relatively ambiguous "OK?" Ideally, the PCP will include a new AU periodically throughout longer conversations [22]; if a PCP moves on to new information before verifying understanding, evidence suggests the patient may puzzle over statements and miss the new information as it is presented [21, 22, 50].

2.4.4 Communication behavior group #3: "Precautionary empathy"—We coined this term to refer to behaviors in which the physician addresses emotion that may be present, but which is not apparent in the parent's speech, facial expressions, or body language [25]. Communication about "hidden" emotions is important because patients' facial expressions

do not always correlate with their emotional states for cultural reasons or because of a sense of shock [51, 52].

Abstraction for the precautionary empathy group was done following the procedure described above. As described elsewhere [25], our data dictionary for precautionary empathy includes eight behaviors, one of which (anticipate/validate) is a subgroup of two behaviors merged to increase reliability. Illustrative examples will be provided in the Results section's Table 4.

2.4.5 Communication behavior group #4: Organizing behaviors—Organizing behaviors refer to verbal cues in a physician's speech that help the patient keep up with the conversation, which influences the degree to which patients comprehend and retain verbal information [28, 53], or use the information in subsequent medical decision-making [54-56]. Organizing behaviors may be especially important for NBS because organization may help patients with the mental demands of simultaneously processing new information, experiencing emotions, and holding several unfamiliar concepts in mind [50, 57]. In contrast, disorganized speech may lead to confusion, recall problems, annoyance, or problems with the patient-provider relationship [54].

As described elsewhere [28], our data dictionary for organizing behaviors includes three subgroups of behaviors that have been grouped together to increase reliability: opening behaviors, structuring behaviors, and importance emphasis.

Abstraction for the organizing behaviors group was also done following the procedure described above. In contrast to the other four groups in this analysis, the data dictionary for organizing behaviors was derived exclusively from general communication and public speaking guidelines and training materials [50, 53-56] because they have not previously been studied in a health care setting.

2.5 Analysis

Data were archived using Access and SQLExpress software (Microsoft, Redmond WA). JMP software (SAS Institute, Cary, North Carolina) was used for statistical comparison with t-tests, Wilcoxon rank-sum, Cohen kappa comparisons, and the Chi-squared test, depending on the characteristics of the data being compared.

3. Results

Over the 48 months described in this paper, we logged 1642 infants with the hemoglobin F-A-S result, and 686 infants with the likely CF carrier result. After exclusion criteria and other sources of lossage were applied, we were able to reach 537 PCPs in time to invite a rehearsal, who together were responsible for 2075 of the infants we logged (89%).

Of the 537 PCPs invited to rehearse at least one time, 217 agreed (40.4%) and another 162 PCPs (30.2%) deferred participation to an interview about a future patient, but never had the opportunity to record a rehearsal. The remaining physicians declined to rehearse, but agreed for us to contact their patient's parent at 3 months of age (29.4%). Since many PCPs are responsible for more than one infant, the PCPs who recorded a rehearsal corresponded with 442 of the logged infants (19%).

Three recorded rehearsals were excluded from analysis because of technical issues with the audio recording. Further details about rehearsal enrollment and associated factors are reported elsewhere [30]. Descriptive characteristics of the enrolled PCPs are in Table 1.

3.1 Communication behavior group #1: Jargon and explanations

In this sample, PCPs used a large amount of jargon and failed to explain much of the jargon they used (Table 2).

There was no difference in jargon use based on PCP gender, provider race, years since graduation, months since last discussing an NBS result, or type of PCP (physician, physician assistant or nurse practitioner). PCPs discussing SCD trait results included significantly more unique jargon words (t-test, $p<0.05$) and significantly fewer jargon explanations (Wilcoxon, $p<0.05$).

3.2 Communication behavior group #2: Assessment of understanding

While many PCPs attempted assessments of understanding, they tended to use close-ended questions rather than the more effective open-ended assessment (Table 3). Only 2 PCPs (1.0%) used the most effective assessment, the request for a teach-back. Some additional comments about these two PCPs' transcripts are included in section 3.5.

There were no significant differences in use of this behavior based on NBS result, PCPs' gender, race, years since graduation, months since last discussing an NBS result, and whether the PCP was a physician, nurse practitioner, or physician assistant.

3.3 Communication behavior group #3: Precautionary empathy

As shown in Table 4, very few PCPs in this sample communicated about the potential for emotion. The most common type of precautionary empathy (15.4%) was the diverse behavior we group under the term "instruction about emotion." It is unclear, however, whether statements like "don't cry" or "I wouldn't worry about this" are helpful for parents.

There were no significant differences in use of precautionary empathy behaviors based on NBS condition, PCPs' gender, race, years since graduation, months since last discussing an NBS result, and whether the PCP was a physician, nurse practitioner, or physician assistant.

3.4 Communication behavior group #4: Organizing behaviors

Use of organizing behaviors was variable in this sample (Table 5). Slightly less than half of the transcripts included an opening behavior, and slightly more than half included at least one importance emphasis. Structuring behaviors (e.g. outlining, and summarizing) were rare.

There were no significant differences in use of this behavior based on NBS result, PCPs' gender, race, years since graduation, months since last discussing an NBS result, and whether the PCP was a physician, nurse practitioner, or physician assistant.

3.5 Examination of PCPs' overall performance

The variability of the PCPs' behavior on the rehearsals led us to do some further analysis, looking for patterns. The two transcripts that included a request for teach-back were studied closely, since this type of assessment of understanding may require unusual insight and skill. We hypothesized that the presence of a request for teach-back might prove to be a signal for a greater degree of skill. Although there was insufficient power for such a hypothesis to be tested, we did note qualitatively that one transcript included an importance emphasis and a close-ended assessment of understanding, and the other included an opening behavior, 3 importance emphases, and 3 close-ended assessments of understanding. Neither transcript included a precautionary empathy behavior.

We then used nonparametric correlation and Cohen kappa comparisons to determine if the absence or inclusion of any given behavior predicted the probability of absence or inclusion

of another behavior. There was a weak but significant correlation between the absence of organizing behavior and absence of assessment of understanding (r=0.286, p<0.001). Even so, detailed inter-behavior comparisons using Cohen kappa failed to find any other associations. Inter-observation comparisons are limited when the instances are rare, but even without correction for random chance it appeared equally likely that a given behavior would appear when another was present. A reasonable statistical interpretation of this finding is that communication behaviors were, quantitatively speaking, randomly-occuring phenomena in this sample.

4. Discussion and Conclusions

4.1 Discussion

The purpose of this paper was to comment on two important issues. First, we further demonstrated the feasibility of our explicit-criteria approach to communication for a population scale [30]. Second, and most importantly for NBS and patients, our findings point to likely widespread problems with the quality of communication likely to be experienced by parents after NBS identifies carrier status for CF or SCD.

Many of our findings were consistent with the results of our previous, smaller studies which found that PCPs tend to use too much jargon [23, 24] and may fail to assess understanding [21, 22], organize their communication [58], and discuss emotion [25]. PCPs' attempts to explain jargon suggest that some PCPs are aware that words can be confusing and they knew they should attempt to explain those words [23, 24] . Likewise, the inclusion of some assessments of understanding, organizing behaviors, and precautionary empathy behaviors suggests that PCPs may be aware of the need for these behaviors, but they may not be aware of the most effective techniques for including them. We are therefore optimistic about the potential for behavior-specific interventions with PCPs. That there were no differences in communication quality based on physician gender, ethnicity or years since graduation demonstrates that it is appropriate to target communication interventions to physicians at all stages of training and practice.

The current analysis does not provide data about the PCPs' actual communication or parents' psychosocial outcomes after the PCPs' rehearsals. Future analyses from this data set will examine physician communication quality and subsequent parental anxiety. Even so, there have been many studies of associations between outcomes and various aspects of communication [8, 59-64]. Since these more subjective measures are associated with benefits for patients, we anticipate that communication quality indicators will also benefit patients.

We acknowledge several limitations for the current analysis and for our methods in general. A significant limitation is that our data come from rehearsals with standardized patients, instead of recordings of actual PCP-parent encounters. Simulated patient encounters may reduce generalizability because of artificial circumstances or because a sense of observation may prompt research **participants** to greater efforts [65, 66]. On the other hand, the Hawthorne effect helps our Quality Improvement goals because the resulting ceiling on performance helps us to identify targets most in need of improvement. We included patient simulation in our data collection methods because of our aim to develop techniques that can be immediately, affordably disseminated to settings where communication improvement has not previously been feasible. Patient simulation is also an effective mechanism for assessing physician communication skills because many physicians cannot tell the difference between real and simulated patients in practice [67]. Finally, simulation avoids practical barriers (e.g. logistics, privacy, and consent), which otherwise would pose tremendous challenges for routine Quality Improvement professionals [68]. With Quality Improvement methods also

come a track record for improving other clinician behaviors on population scales, as well as concrete methods that are transparent to clinicians and easy to implement by Quality Improvement professionals with typical training [69]. Finally, the standardization that is possible with simulation allows for comparisons across clinicians to be made fairly and equally without confounding effects of variation in patients' medical risks and communication challenges [32].

It is also worth pointing out that the current manuscript only reports data from four groups of communication quality indicators, and that here are many other facets to communication "quality" [26, 27, 41]. Indeed, content messages are some are of most important quality indicators [26, 27], but had to be removed from this manuscript because the combined analysis was too long for a single journal article. We want to emphasize for providers, that even if they explain jargon, assess understanding, talk about the potential for emotion, and begin with an outline and end with a summary – even then, there still may be a long way to go to achieve high-quality communication. As with more traditional quality measures, the inclusion of these behaviors can be taken to "indicate" high-quality communication.

4.2 Conclusions

The implications of these communication problems are troubling. Since many psychosocial complications after NBS are a result of misconceptions or emotional distress [7, 70-73], then NBS may be less safe than it needs to be. Where some bioethicists might interpret our findings as an argument against the viability of genetic NBS, however, we see an opportunity for risk management. As we wrote in 2003, straightforward techniques like those in this study may be used to manage psychosocial risk, so that NBS can result in "more good than harm" over entire populations [74]. High quality physician communication may be an effective technique to manage the risk of psychosocial complication after newborn screening. With an effective way to manage the psychosocial risk, by measuring and improving the quality of physician communication, researchers can continue to pursue future innovations in newborn screening. Further research is testing how targeted feedback tools adapted from Quality Improvement can be used at a lower cost than would be needed for traditional training programs [29, 75]. If psychological problems and misconceptions can be addressed after NBS identifies carrier status for SCD and CF, then we have hope for addressing many of the ethical, legal, and social implications of forthcoming genetic tests [76].

4.3 Practice Implications

Helping physicians to improve the quality of their communication may help to improve patient understanding of test results and treatment options, and allow patients to actively participate in their care.

Acknowledgments

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Table 1

Participant characteristics

Characteristics	No. responding	
	n	*(%)*
Gender		
Male	88	41.1
Female	126	58.9
Ethnicity (self-reported)		
White	179	83.6
Black	13	6.1
Asian	11	5.1
Latino	2	0.9
South Asian or Pacific Islander	6	2.8
Middle Eastern	1	0.5
Other	1	0.5
Unknown or not reported	1	0.5
Years since graduation		
10 years or less	80	37.4
11-30	118	55.1
Greater than 30	16	7.5
Provider type		
Physician	203	94.8
Nurse practitioner	9	4.2
Physician Assistant	1	0.5
Lay midwife	1	0.5
Last time discussed a NBS result		
One year or less	116	54.2
More than a year	63	29.4
Unknown or not reported	35	16.4

Table 2

Use of jargon and jargon explanations

Indicator	Average	(SD)
Total jargon words	18.5	(9.8)
Unique jargon words	8.7	(3.4)
No Jargon words explained	2.4	(3.2)
Jargon explanation ratio	0.33	(0.44)
Jargon explanation time lag	2.4	(3.8)

Table 3

Transcripts with definite Assessment of Understanding behaviors.

		Transcripts	
Indicator	**Example**	**n**	**(%)**
Closed-ended assessment of understanding	*Do you have any questions?*	**129**	**60.3**
Open-ended assessment of understanding	*What questions for you have for me?*	**21**	**9.8**
Request for teach-back	*It would be helpful to me if you could repeat back that last point in your own words.*	**2**	**1.0**
OK?	*OK?*	**43**	**20.1**

Table 4

Transcripts with definite Precautionary Empathy behaviors

		Transcripts	
Indicator	**Example**	**n**	**(%)**
Assess for prior emotion	*How have previous experiences with screening tests made you feel?*	**0**	**(0.0)**
Anticipate/ Validate emotion	*Many people get sad when they hear this kind of news.*	**14**	**(6.5)**
Assess for emotion (closed)	*Are you feeling sad about this news?*	**2**	**(1.0)**
Assess for emotion (open)	*What feelings are you experiencing right now?*	**0**	**(0.0)**
Instruction about emotion	***Don't worry about this. Don't cry.***	**33**	**(15.4)**
Assess for possible future emotion (closed)	*Are you going to worry about this after you get home?*	**0**	**(0.0)**
Assess for possible future emotion (open)	*Based on your past experience, what emotions might you experience when you think about this later?*	**0**	**(0.0)**
Caution about future emotion	*When you think some more about the implication of this, you might get more worried.*	**10**	**(4.7)**

Table 5

Transcripts with definite Organizing Behaviors.

		Transcripts	
Indicator	**Example**	**n**	**(%)**
Opening behaviors	*I called you today to talk to you about your baby's test results.*	**104**	**(48.6)**
Structuring behaviors	*First we'll go over what newborn screening is, then we'll talk about your baby's results.*	**17**	**(7.9)**
Importance emphasis	*The most important thing to remember is that your baby is healthy.*	**121**	**(56.5)**