



Communication Study

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).

Conclusion: 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.

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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, 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].

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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 gives 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

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