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Parental Information Seeking Following a Positive Newborn Screening for Cystic Fibrosis

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Abstract

This investigation focused on the information-seeking behaviors of parents ($N = 38$) whose newborn had received a positive screening result for cystic fibrosis. Roughly half of the participants actively sought information about their child's potential disease prior to the clinic visit. The most common sources of information were the internet, pediatricians, and family physicians. Analysis of behavior during the clinic visit showed rates of question asking that were judged as low, but comparable to the results of other studies. It was observed that parents would occasionally collaborate in the production of a single question. More educated parents tended to produce such questions more frequently. Importantly, frequency of collaborative questions was positively correlated with enhanced knowledge of cystic fibrosis six weeks after the clinic visit and with apparent dissatisfaction with the counseling interaction.

Patients who are informed about their medical conditions make better medical decisions and have more positive health outcomes (Waljee, Rogers, & Alderman, 2007). Nonetheless, many patients do not make efforts to acquire health information. Even when they do, the frequency of those behaviors – for example, in the form of patients' self-initiated questions – is low (e.g., Cegala, Marinelli, & Post, 2000). This study examines the information-seeking behavior of parents who are informed that their children received positive newborn-screening results for cystic fibrosis (CF). Parents in this circumstance have two periods during which they can acquire or avoid information concerning CF: Prior to and during the clinic visit. This article describes parents' information-seeking behaviors during both periods and examines their association with in-clinic communication and health outcomes, respectively.

The research reported herein is exploratory for two reasons. First, very little research has been done on audio/video records of parents' communication during *actual* genetic counseling sessions. Second, whereas the bulk of previous research on question asking has focused on single *patients* in *primary-care* settings, little is known about information

seeking during medical visits in which physicians interact with more than one adult client, neither of whom are patients.

A theoretical framework is provided by uncertainty management theories (e.g., Brashers et al., 2000), all of which focus on (a) information seeking versus avoidance, (b) sources of information, and (c) the precursors, correlates, and outcomes of specific behaviors that are intended to manage uncertainty. These issues guided our thinking as we sought to understand information management in the specific context created by a positive newborn screening for CF.

Procedures Surrounding Screening

In Wisconsin, blood samples are drawn within 48 hours of birth and tested for genetic diseases including CF. When screening results are positive, parents are contacted and instructed to make an appointment for further testing. The sweat test takes approximately 30 minutes to complete, and the analysis of its results takes an additional 30-60 minutes. During that time, parents, and other family members, meet first with genetic counselors then a healthcare professional to learn the test results.

Pre-Visit Information Seeking

One recent survey found that 76 percent of respondents *actively* seek health information from their physicians, 53 percent from friends and family, 57 percent from the internet, and 73 percent from various media (McKillen, 2002). Although these percentages vary from study to study (cf., Baker, Wagner, Singer, & Bundorf, 2003), available research shows that a substantial proportion of people actively seek health information, and have the opportunity to do so from different sources. But, insofar as a positive screen for CF presents parents with the possibility that their newborn has a life-threatening genetic disease, parents likely consider such information to be distressing, uncontrollable, and undesirable, all of which promote the avoidance of related health information (Brashers et al., 2000; Ramanadhan & Viswanath, 2006). Information avoidance is one strategy for maintaining psychological well-being (Brashers et al., 2000; Pakenmam, 1998). From this, we propose the following research question:

RQ1 Prior to clinic visits, from what sources and with what frequency do parents *actively* seek CF information?

It is also the case that people can *passively* receive health information. For example, medical practitioners can provide information along with newborn screening results even when individuals do not expressly seek it out. Thus, we also asked:

RQ2 From what sources and with what frequency do parents *passively* receive CF information (i.e., independent of their own information-seeking behavior)?

In-Clinic Information Seeking

Patients often have the goal of gaining medical information from physicians, and this goal is arguably more central and important when visits revolve around life-threatening diseases (for review, see van der Molen, 1999). The main vehicle for patients' active information seeking, and the main component of patients' communicative participation, is their question asking (e.g., Street & Gordon, 2008). By far the most common type of question that patients ask deal with biomedical topics (vs. psychosocial; Timmermans et al., 2005). Patients' question asking has been found to be positively associated with physicians' information giving (Gordon et al., 2005). Studies suggest that physicians provide more information in

multi-client visits (Labrecque et al., 1991), possibly because companions ask a relatively large number of questions. From this, we asked:

RQ3 What types of direct questions do parents ask genetic counselors and with what frequency?

Correlates of Pre-Clinic and In-Clinic Information Seeking

Level of formal education is positively associated with active information seeking in a variety of ways, including usage of cancer support/counseling services (Eakin & Strycker, 2001), seeking extra-clinic information about cancer (Ramanadhan & Viswanath, 2006), and in-clinic question asking (Eggly et al., 2006). We asked:

RQ4 Is education associated with pre-clinic and/or in-clinic parental information seeking?

There is evidence for a positive association between pre-clinic and in-clinic information seeking (Bass et al., 2006). Alternatively, patients may not seek info because they lack knowledge, and thus the language, with which to pursue their interests (Korsch, Gozzi, & Francis, 1968). Thus:

RQ5 What is the association between levels of pre-clinic and in-clinic information seeking?

As noted earlier, both pre-clinic and in-clinic health-information seeking tends to lead to an increase in related health knowledge (Heisler et al., 2002). We asked:

RQ6 Is pre-clinic and in-clinic parental information seeking associated with higher levels of CF-related knowledge?

Research suggests that patients' in-clinic levels of information seeking are positively associated with patients' post-visit satisfaction with (i.e., evaluations of) physicians (Anderson, et al., 1987), perhaps because patients' question asking is positively associated with physicians encouraging patients to discuss their opinions, express their feelings, ask questions, and participate in decision making (Street & Millay, 2001). Hence:

RQ7 Is in-clinic parental information seeking associated with judgments of the involvement and expertise of the medical staff?

RQ8 Is in-clinic parental information seeking associated with evaluations of the importance, quantity, rate, and clarity of the information provided by the medical staff?

Method

Participants

From April, 2002 through June, 2003, 20 families who lived in and around Madison, Wisconsin enrolled in our study. Participants were parents or grandparents of infants who tested positive for CF and had come to UW Hospital for a sweat test and counseling. There were 38 individuals including 20 mothers, 17 fathers, and 1 grandmother (19 dyads). Twenty six described their relational status as married, 6 as engaged, and 6 as single. The average age was 30 (SD = 8). Participants identified themselves as white/Caucasian (35), American Indian/Alaskan Native (2), or chose not to answer the item (1). In terms of education, 2 had formal education of less than high school, 18 completed high school, 8 vocational or technical training, 7 college, and 3 a post-graduate or professional degree.

Procedures

Upon arrival at the clinic, the research was described and individuals were invited to enroll. Participants received a questionnaire on their knowledge of CF-related genetic risk information and their information seeking behaviors. The counseling session was video recorded, transcribed, and coded. Equipment failure resulted in the loss of one videotape. Participants completed a brief post-counseling survey on their perceptions of the genetic counseling session. Two families, whose child's sweat test result was positive, did not complete the post-visit survey. Approximately six weeks later, participants were contacted by telephone, at which time knowledge was assessed again with the same questions.

Survey Measures

Pre-clinic information seeking—The survey asked participants: “Prior to arriving at the clinic today, did you read, hear, or see any information about cystic fibrosis?” Persons who answered yes were instructed to indicate from a list which sources had provided them with information and from which sources they had actively sought information.

Educational attainment—An item in the clinic survey asked “What is the highest level of education that you have completed?” The five-point response scale was anchored as follows: 1 = Less than high school, 2 = High School, 3 = Vocational or technical degree, 4 = College, and 5 = Professional/post-graduate.

Post-visit perceptions of the medical staff and in-clinic communication—Study participants responded to items to measure their perceptions of communication with the medical staff and the information with which they were provided. Items regarding personnel began with “The medical staff” and were answered on 5-point Likert scales anchored at the endpoints only where 1 = Strongly Disagree and 5 = Strongly Agree. Items to measure *involvement* were “seemed rather distant” (reversed), “was actively engaged with us,” “were very involved with us,” and “were withdrawn” (reversed) ($\alpha = .79$). Two items were used to assess *perceived expertise*: “were highly competent” and “seemed very knowledgeable” ($\alpha = .69$).

Participants provided data on five aspects of the information they received. *Importance* was assessed with: “I learned some important information today.” Two items assessed *quantity of information*: “We did not receive as much information as we would have liked today” and “The amount of information given to us today was overwhelming.” Because the correlation between them was low ($r = .49$) and the two showed a different pattern of associations with other variables, the two items were treated as separate variables. *Rate of presentation* was also captured with two items that were treated as separate variables for same reason ($r = .28$): “The rate at which information was presented was too fast” and “The rate at which information was presented was too slow.” *Clarity* was assessed with “The way that the medical staff presented the information was difficult to follow” and “The way that the medical staff presented information was very clear,” which were also examined as two distinct variables ($r = .49$).

Knowledge of CF—Table 1 presents the questions used to assess CF knowledge. The first four questions focus on genetic information about CF, while the next ten items concern CF symptoms. Participants were provided with three response options: True, False, and Unsure. The last two questions asked about the odds of a child getting CF given a particular situation. The participants were given six choices: about 1 in 100; about 1 in 10; about 1 in 4; about 1 in 2; no chance; and unsure. Correct answers were scored as 1; Incorrect or uncertain responses were scored as 0, yielding a potential range of 0 to 16. The mean scores

at the beginning of the clinic visit and six weeks later were 8.72 (SD=4.29) and 12.40 (SD=2.61) respectively.

Interaction Coding

We coded transcripts for parents' self-initiated (vs. solicited), direct (vs. indirect) questions that were designed to acquire discrete pieces of medically relevant information (vs. non-medical information, such as social forms of *How are you?*). We coded for two types of questions: Individual and collaborative. Individual questions were the product of a single participant. For example, see Example 1:

Example 1:
 325 MOM: So what happens if she does have cystic fibrosis?
Example 1:
 224 --> MOM: If, okay, if he tested for the gene abnormal, now if the
 227 test for cystic fibrosis comes back negative or whatever
 228 GC: The sweat test.
 229 MOM: The sweat test.
 230 GC: Okay.
 231 --> MOM: What does the abnormal gene, does it, is there more
 232 testing done?

In some cases, individual questions spanned multiple turns of talk:

Example 1:
 224 --> MOM: If, okay, if he tested for the gene abnormal, now if the
 227 test for cystic fibrosis comes back negative or whatever
 228 GC: The sweat test.
 229 MOM: The sweat test.
 230 GC: Okay.
 231 --> MOM: What does the abnormal gene, does it, is there more
 232 testing done?

At line 228, in the middle of the mother's question, the physician clarifies what she means by 'test,' whereupon she resumes her question at line 231.

We also coded for collaborative questions, which were discrete questions jointly constructed by two participants. In some cases, the clients negotiated the question between themselves prior to asking the counselor:

Example 3: [21005]
 01 MOM: Okay, so we were saying ((gazing at DAD))
 02 DAD: What is it? ((gazing at MOM))
 03 MOM: Hi, so we were saying what are the
 04 symptoms...
 05 DAD: ((how what)) [are the symptoms that's what I mean]
 06 GC: ((What are the symptoms...))
 07 GC: (the first symptom...)

At line 1, the mom gazes at the dad and prompts him to resume a prior topic: "so we were saying..." In response, while gazing at the mom, dad provides a candidate question (that might be asked of the counselor) for mom to (dis)confirm: "What is it?" (referring to CF). The mom disconfirms, "No" (line 3), then corrects the dad by asking a different question: "we were saying what are the symptoms" (lines 3-4). At line 5, dad accepts mom's correction and accounts for his error as a misspeaking: "that's what I mean"

In other cases, the questioning turn was itself collaboratively constructed:

Extract 4: [21006]
 01 GMA: Because the number is is is so high the 119 is
 02 so high compared to what might be nor[mal]
 03 GC: [Right
 04 GMA: You know I'm wondering if tha[t
 05 MOM: [Does his chance
 06 increase on having it
 07 GMA: Yeah.
 08 GC: Sometimes it does.

The grandmother begins the first component (Lerner, 2004) of her questioning turn at lines 1-2, then begins to ask her question at line 4: "You know..." Before the grandmother completes her question, the mother produces what Lerner (1991) described as a collaborative completion: "Does his chance increase ((pause)) on having it" (lines 5-6).

Using materials from a previous investigation, two coders were trained to identify questions and their individual/collaborative nature. When coders observed a question (individual or collaborative), they were instructed to mark its beginning and end on the transcript. For each question, coders were considered to be in agreement if any part of their transcript segments overlapped. Of the 335 questions identified by this procedure, the coders disagreed only once.

Results

Pre-Clinic Information Seeking

RQ1 focused on the frequency of information seeking as well as the sources of information. The most common source of information was the Internet (31%) followed by Pediatricians and Family Physicians, which, together accounted for 30% of the information-seeking attempts (Table 2). Next was Other (11%), followed by Family Members (6%), Friends (6%), and Medical Books (3%). RQ1 also asked about the number of different sources from which parents' sought information. In a subset of the data ($N = 36$), 44% did not engage in information seeking, 25% sought information from one source, 25% from two sources, 3% from three sources, and 3% from four sources. Thus, roughly half of the participants were active information seekers and half was non-seekers.

RQ2 focused on instances in which the parent was not engaged in active seeking, but nonetheless received information. Family physicians and pediatricians were the most common sources with each of them providing information to 31%. The Other category was the next most frequently mentioned (23%). Family members and the UW Hospital both provided information to 18% of the sample, with friends following at 12%.

In terms of the number of different sources, 29% of the sample received no information from any of the sources included in our study; 41% received information from one source; 18% from two; and 12% from three. An analysis which crossed the number of sources sought with number of sources provided revealed that 24% of participants reported that they neither sought nor received information about CF from any source.

In-clinic Information Seeking

RQ3 focused on the frequency with which parents asked independent and collaborative questions. For independent questions, we based the calculations on $N = 38$. This form of question was fairly common with an average of 9.16 ($SD = 11.29$, $N = 38$) per parent per session. The range of 0 to 40 showed that there was wide variation. Given that collaborative questions were the product of dyads, we counted a single collaborative question as one occurrence *for each parent*. This yielded a mean of .84 ($SD = 1.03$) and a range of 0 to 3.

Correlates of Information Seeking

In light of the modest sample size and a desire to balance the odds of Type I and Type II errors, we set α at .10. Power to detect small, medium, and large effects with $N = 38$ was .16, .58, and .95 respectively. We report exact probabilities whenever possible.

RQ4 focused on the possibility of a relationship between education and pre-clinic or in-clinic information seeking: $r(34) = .36$, $p = .04$, for active pre-clinic information seeking; $r(34) = .27$, $p = .12$, for information acquired passively prior to the clinic visit; $r(38) = .18$, $p = .27$, for the number of independent in-clinic questions, and $r(38) = .30$, $p = .07$, for frequency of collaborative questions.

For RQ5 we correlated the number of sources from which parents sought information with the frequency of independent and collaborative questions ($r_s = .01$ and $-.10$, both $p > .50$). We also correlated the number of sources from which parents were provided information with independent and collaborative questions ($r_s = -.01$ and $-.02$, both $p > .90$).

For RQ6 the number of sought-after pre-clinic information sources was correlated with pre-counseling CF knowledge: $r(33) = .26$, $p = .13$. An analysis using number of sources that provided information showed $r(33) = .40$, $p = .02$. Partial correlations of question frequency with CF knowledge at time 2 and controlling for knowledge at time 1 yielded $r(31) = .01$, p

= .94) for independent questions. The analysis for collaborative questions revealed a positive and significant association, $r(31) = .41, p = .02$. Whereas independent questions appeared to be unrelated to post-clinic knowledge, it seems that parents who made frequent use of collaborative questions learned more than those who did not.

RQ7 examined the relationship between question asking and judgments of the medical staff and the interaction (Table 4). For independent questions, no significant associations were observed. However, a more robust pattern was evident for collaborative questions. Higher frequencies of collaborative questions were consistent with perceptions of low staff involvement and low staff expertise. Similarly, the use of more frequent collaborative questions corresponded negatively with perceptions of information importance, too little information, information that was presented too quickly, and presentational clarity. In other words, persons who judged the information they received as unimportant and low in quantity produced more collaborative questions. Persons who believed that the information was presented clearly and not too quickly tended to produce fewer collaborative questions.

Discussion

Pre-Clinic Information Flow

Some persons in this study sought information about CF, whereas others did not. Seekers were observed was roughly equal in number to non-seekers (56% vs. 44%). These findings mirror those of a larger study ($N = 6,133$), which found a 50-50 split of persons who sought or did not seek information about cancer (Ramanadhan & Viswanath, 2006). Although our sample size does not permit strong conclusions about the population frequencies, it establishes that there are substantial numbers of parents whose child receives a positive screen for CF who do not actively pursue the acquisition of information. A better understanding of the motivations of seekers and nonseekers has the potential to improve parental decision making and psychosocial health.

Among seekers, the most common sources of information were the internet and pediatricians/family physicians. The high percentage of internet seekers raises the question of the quality of information in this medium. We conducted Google searches during the study and when drafting this manuscript. For both periods, the first hit returned by searching on “cystic fibrosis” was the Cystic Fibrosis Foundation, which is a reliable source of information. Given widespread knowledge of CF in the medical community, we suspect that the 30% of persons who contacted their pediatrician or family physician also received precise and veridical information. This leaves 39% of our sample who received information from other, possibly less reliable sources. This large remainder, in combination with the fact that 44% of our sample was composed of nonseekers, underscores the need to intensify outreach efforts to parents prior to the clinic visit. We reiterate the recommendation offered by Jedlicka-Köhler, Götz, and Eichler (1996): “Repeated interviews with both parents and the provision of audiovisual materials should be mandatory” (p. 204).

Other social entities provided information to parents regarding CF irrespective of the parents' own behaviors. Physicians, pediatricians, and the hospital were the most frequent sources. These numbers probably reflect the fact that mandated procedures in Wisconsin call for the State Hygiene Laboratory to inform the physician of record of the screening result, who then informs the parents. When these doctors cannot be reached or prefer not to deliver the screening news themselves, the hospital steps in to contact parents.

In-clinic Information Seeking

Most research on in-clinic question asking has focused on doctor-patient dyads in primary care settings (e.g., Cegala et al., 2000). The work reported here differs from previous

investigations in several ways. First, the interactions took place between parents, not patients, and a genetic counselor, not a physician (cf., Ellington et al., 2006). Second, the context is particularly stressful in that the possibility of a fatal genetic disease looms large (cf., Arora, 2003). Third, the communication setting involves three persons rather than two (cf., Eggly et al., 2006).

The data show that parents average 9 independent questions per session and .84 collaborative questions. To the extent that question asking indicates active participation in the medical encounter (Street & Millay, 2001), a total of 10 ($= 9 + .84$) questions over the period of an hour may be cause for concern. However, these numbers are comparable to Eggly et al. (2006) in which cancer patients asked an average of 9.9 questions per interaction, while their companions averaged 16.89 questions. Given the scripted nature of the counselors' communication and the fact that parents of newborns are typically sleep deprived, this level of participation may be all that can be expected.

Of greater consequence is the fact that there were large differences across parents in the degree of information seeking. The range for independent questions ran from 0 to 40 and for collaborative questions from 0 to 3. This degree of variability was also observed in Eggly et al. (2006) where the number of questions per interaction ranged from 3 to 65. Perhaps more knowledgeable parents felt a lesser need to seek information during the counseling session? When we correlated pre-clinic CF knowledge with the frequency of independent and collaborative questions there was no hint of support for this explanation ($r_s = .06$ and $.12$, both $p > .47$). A different interpretation, and one that we cannot test in our current data, is that of individual differences in the desire for health information. Maibach et al. (2007) describe four types of individuals that vary with regard to their level of activity and dependence on their physician.

Pre-clinic and In-clinic Information Seeking

We observed no evidence that pre-clinic information seeking predicted in-clinic information seeking. Of the 24 correlations computed, none approached significance using our decision rule of $p < .10$. Although these results were surprising to us, they may simply reflect the fact that our measures of information seeking were comparatively gross. Those measures focused on the number and type of information sources and number of questions. More nuanced analyses that capture the content and sequential aspects of the interaction may be necessary to see an effect of prior behavior on subsequent information seeking.

Communication Disparities and Knowledge

Prior research in the cancer context shows that education is positively associated with information seeking (Eakin & Strycker, 2001). The current results describe a similar phenomenon among parents whose child has been shown to be at risk for CF. More educated parents actively sought information from a greater number of sources prior to the clinic visit and they asked a greater number of collaborative questions relative to their less-educated counterparts. However, there was no observable effect for education on frequency of independent questions.

The findings for number of information sources and number of collaborative questions both suggest a disparity in communication equality that arises from group membership (Ramanadhan & Viswanath, 2006). The pre-clinic difference in information seeking (i.e., number of sources) may be attributable to the research skills that are part and parcel of advanced education. We speculate that more educated individuals have more practice doing research and greater faith in their ability to carry out research-related behaviors.

We suspect that the in-clinic behavior, that is, frequency of collaborative questions as a product of education, is the result of a different mechanism. To the extent that status is a function of education, persons with higher levels of education are more similar to the nurses and genetic counselors (M.A. degrees) with whom they are interacting. Presumably, same-status social actors feel more free to assert themselves when they are dissatisfied or unclear about some aspect of the medical interaction than are low-status parents speaking with high status medical personnel.

The data also suggest the potential for downstream effects. The number of pre-clinic sources sought and number of pre-clinic sources provided were both positively correlated with knowledge of CF at time 1, though only the sources-provided variable was significant ($r_s = .26$ and $.40$). The latter coefficient is particularly notable insofar as it suggests a concrete means of reducing the communication disparity described above. When parents receive information from multiple sources prior to the clinic visit, they are more knowledgeable about CF and, presumably, better able to absorb new information. By implication, it appears that less-educated parents could especially benefit from pro-active medical institutions that provide CF-related information via multiple sources. Hence, we return again to the recommendation that multiple interviews with parents should become normative.

Collaborative Questions

Relative to the literature on patient/companion information seeking (for review, see Street & Gordon, 2008), the present article may be the first to distinguish between individual and collaborative questions; That is, discrete questions that are constructed by a single client, or jointly by two clients (e.g., mother and father) (but see Seibold, McPhee, Poole, Tanita, & Canary, 1981 on tag-team questions). The most striking set of findings in this research concerns collaborative questions. On the one hand, in post-clinic surveys, parents who used higher levels of collaborative questions judged genetic counselors more negatively regarding their involvement and expertise, and evaluated the clinic interaction more negatively in terms of quantity, clarity, and rate. This finding has some affinity with that of Street and Gordon (2008), who found that, when patients and companions had comparable (vs. asymmetrical) degrees of active participation, patients reported significantly less satisfaction. Street and Gordon speculatively suggested that their finding might be explained in terms of patients and companions struggling over their respective roles and control. On the other hand, six weeks after the clinic visit, parents who used higher levels of collaborative questions had more knowledge of CF (controlling for pre-visit knowledge). Insofar as asking a question involves paying attention to both the construction of the question and to its answer (Sacks, Schegloff, & Jefferson, 1974), collaborative questions are an index of clients' joint attention to a medical topic. From other research, we know that post-visit, patient-companion communication can improve patients' understanding of visit-based information (Schilling et al., 2002). Collaborative questions may index clients' levels of involvement and attention, which may positively affect their own, and each others', understanding.

Limitations

The most obvious limitation is the small number of participants. Additionally, because the data were drawn from a single site, it is difficult to know the extent to which our results generalize to other locations and institutions. It is also important to bear in mind that the features that make the study unique – the sample of parents and genetic counselors, the threat of CF, the number of persons taking part in the interaction – also constrain the generalizability of the findings.

Conclusions

Despite these limitations, the investigation makes a contribution to our understanding of information seeking by identifying empirical regularities in parental behavior as well as areas in need of further inquiry. Two issues are of particular importance. The first concerns the meaning and causes of collaborative questions. To the extent that they are genuinely indicative of perceived problems with genetic counseling, it will be important to train counselors to spot this behavior, understand its implications, and adjust their actions accordingly. But, further research is needed to establish that the phenomenon is veridical in the CF context and beyond. The second issue is the wide variability observed in information seeking behavior. In both pre-clinic and in-clinic settings some parents were active seekers while others were, at best, reactive. Understanding the motivations that underlie these different approaches to uncertainty is crucial to matching information with parent needs. The medical establishment needs to take a more active role in the dissemination of information to parents at this critical moment in their child's life.

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Table 1

Items for the Assessment of CF Knowledge

Topic	Item
Genetic Knowledge	A child can get CF when only one parent has the gene for it. (F)
	CF does not run in families, since it is not a genetic disease. (F)
	If a couple has a child with CF, both of them must have the gene for it. (T)
	If a couple has no relatives with CF, they cannot have a child with CF. (F)
CF Symptoms	Failure to grow at a normal rate (T)
	Normal intelligence (T)
	Cough, frequent pneumonia, shortness of breath (T)
	Weak vision (F)
	Clumsiness or trouble walking (F)
	Need for pills to help digestion (T)
	Large stools (i.e., bowel movements) with a bad odor (T)
	Seizures or fits (F)
	Kidney problems (F)
CF Odds	Very salty sweat (T)
	If both of you (parents) are carriers of the cystic fibrosis gene, what are the chances that a future child of yours would have CF?
	If only one of you (parents) is a carrier of the cystic fibrosis gene, what is the chance that a future child would have CF?

Table 2

Sources from which Parents Actively Sought Information (N = 36)

Information Source	Proportion
Internet	31%
Pediatrician	19%
Family Physician	11%
Other	11%
Family members	6%
Friends	6%
XX Hospital	6%
Medical Books	3%
Encyclopedia	0%
Midwife	0%

Table 3

Sources that Provided Information Regardless of the Parents' Behavior (N = 34-35)

Information Source	Proportion
Physician	31%
Pediatrician	31%
Other	23%
Family Members	18%
XX Hospital	18%
Friends	12%
Midwife	0%
Medical Books	0%
Encyclopedia	0%
Internet	0%

Table 4

Correlations between In-clinic Information Seeking and Outcome Variables (N = 25-26)

Outcome Variables	Independent Questions	Collaborative Questions
Perceived Involvement	-.12	-.54 *
Perceived Expertise	-.20	-.40 *
Importance of Information	-.22	-.46 *
Quantity (too little)	-.13	-.39 *
Quantity (too much)	.11	-.19
Rate (too fast)	-.08	-.50 *
Rate (too slow)	.09	-.13
Clarity (difficult)	.06	-.21
Clarity (clear)	-.01	-.39 *

*
 $p < .10$.