

Application of a Consumer Health Information Needs Taxonomy to Questions in Maternal-Fetal Care

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Abstract

Pregnancy is a time when expectant mothers may have numerous questions about their unborn children, especially when congenital anomalies are diagnosed prenatally. We sought to characterize information needs of pregnant women seen in the Vanderbilt Children's Hospital Fetal Center. Participants recorded questions from diagnosis through delivery. Questions were categorized by two researchers using a hierarchical taxonomy describing consumer health information needs. Consensus category assignments were made, and inter-rater reliability was measured with Cohen's Kappa. Sixteen participants reported 398 questions in 39 subcategories, of which the most common topics were prognosis (53 questions; 13.3%) and indications for intervention (31 questions; 7.8%). Inter-rater reliability of assignments showed moderate ($\kappa=0.57$) to substantial ($\kappa=0.75$) agreement for subcategories and primary categories, respectively. Pregnant women with prenatal diagnoses have diverse unmet information needs; a taxonomy of consumer health information needs may improve the ability to meet such needs through content and system design.

Introduction

Pregnancy is a common health condition that generates a diverse set of consumer health information needs, not only for the mother, but also for all individuals who are involved in the care of the mother and child. In the United States, there are approximately 6.5 million pregnancies each year, resulting in over 4 million live births¹. Although the duration of pregnancy is limited, it is nonetheless a 40-week health condition with a variable and changing course that can be viewed within an illness trajectory framework². Pregnant women must adopt new health practices to support their developing baby, manage existing medical conditions in the context of pregnancy, and address maternal or fetal complications. For the numerous American women each year who are pregnant in addition to having one or more existing chronic illnesses, the concurrent management of these conditions can be quite challenging³. Even women with relatively "normal" pregnancies may have widely varied experiences influenced by their individual symptoms, degree of physical limitations, and effects of their lives.

Annually in the United States, approximately 875,000 women experience one or more complications of pregnancy⁴, and approximately 120,000 children are born with birth defects^{5,6}. When disruptions in the pregnancy trajectory, such as a maternal complication or fetal anomaly, are identified, the conceptualization and management of the pregnancy changes drastically, especially as more information is discovered and measures to affect maternal or fetal outcomes are initiated. Parents may be faced with difficult decisions about high-risk testing or treatments, pregnancy termination, or the withdrawal of support after the birth of a child with a poor prognosis. Maternal or fetal complications can result in newborns with chronic illnesses that will require lifelong management. During this time, the mother and her support network have increased interaction with the healthcare system and may experience significant physiological, psychosocial, and financial changes^{7,8}.

Obtaining information is the most basic and perhaps most important action one can take to manage a health condition and make informed decisions. Consumer health information needs have been studied across a number of patient populations⁹⁻¹², but little is known about the needs of pregnant women. Among those referred for genetic counseling, the most commonly expressed concerns were the risks of certain diseases and interpretation of genetic tests. Most questions in this population were prompted by uncertainty and the need for reassurance¹³. Studies of prenatal consultations for congenital anomalies identified diverse information needs about the nature of the anomaly, treatment options, and prognosis. They also highlighted the value of these consultations in reducing anxiety, preparing the families, and maintaining hope^{14,15}. Parental and caregiver information needs and information-seeking behaviors are notably dynamic over the course of a disease¹⁶ and as a result of interventions performed, such as surgery¹⁷.

Adequately addressing the information needs of parents and caregivers can improve prenatal care as well as maternal and fetal outcomes. It is well known that appropriate prenatal education and care reduces the risk of preterm birth, pregnancy complications, and congenital anomalies¹⁸⁻²⁵. Several long term studies of nurse home visits to educate pregnant women before and after delivery have shown dramatic improvements in a wide variety of social, economic, developmental, and other health-related outcomes for the mother, family, and child²⁶⁻³⁰.

Patients and families are increasingly turning to the Internet and other health information technologies (e.g., patient portals and mobile applications) to manage health-related information and answer questions. Complex social, economic, and cognitive factors are likely to contribute to the willingness to use such technologies and individuals' success in finding appropriate answers. Knowledge about information needs, information-seeking behaviors, and resource preferences are needed to guide the design and support the adoption of health information technologies with the goal of improving prenatal care and outcomes. In this study, we characterized the information needs of pregnant women seen in an advanced maternal-fetal care clinic using a taxonomy of consumer health information needs developed by our research team. We also evaluated the reliability of this taxonomy in describing consumer health information needs.

Methods

Population and data collection

We examined the quantity and nature of information needs of pregnant women evaluated for a pregnancy complication or congenital disorder at the Fetal Center of the Monroe Carell Jr. Children's Hospital at Vanderbilt University Medical Center. Patients who were 18 years of age or older were approached to take part in this study, and those women providing informed consent were enrolled. Data were collected between November 2007 and January 2009. The research protocol was approved by the Vanderbilt University Institutional Review Board.

Participants were given notebooks and asked to record questions that arose regarding the medical problems of their unborn children from the time of diagnosis through the end of their pregnancies. Questions were collected from the notebooks at the time of follow up clinic visits and at the end of the study.

Data analysis

Participants' journal questions were transcribed into text files with all identifiable information removed. Multi-part questions were separated into individual question segments for coding analysis. We categorized questions using a taxonomy we developed to represent consumer health information needs (Table 1). Model development started with a representation of *Clinical Information* needs, which are questions requiring clinical knowledge; this model of clinical information needs has been used to organize and facilitate search in online medical information resources³¹. This model divides clinical knowledge into four primary categories: *Problems*, ranging from non-specific findings such as fever to well-defined diseases such as stage 4 melanoma; *Management*, the general framework for addressing a clinical problem; *Tests*, encompassing any diagnostic modality; and *Interventions*, including any therapeutic modality from education to medications or surgical procedures. Subcategories, such as indications or contraindications for tests and interventions capture more detailed types of information.

A research team comprised of clinicians, medical students, and human factors experts expanded the taxonomy after analyzing a variety of consumer health communications, including journal entries, patient-provider messages exchanged via a patient portal, and patient and family interviews about informational needs. After independent and consensus review of these sources, three additional primary categories were added to the taxonomy: *Medical needs*, addressing desire for or delivery of medical care; *Logistical needs*, pertaining to the pragmatic and supporting aspects of care delivery; and *Social communication*, expressions of social interaction or an interpersonal relationship that is not directly related to care delivery. Subcategories were then enumerated to describe the specific question types identified in these primary categories. Our final taxonomy contains seven primary categories, 59 subcategories, and one category (*Other*) for content that cannot be categorized due to being incomplete or incomprehensible.

Two raters with clinical experience were trained to use the taxonomy on the first 200 questions collected. The remaining questions were independently coded by the two raters, with their responses used to calculate measures of inter-rater reliability. Cohen's kappa was used for this purpose as it estimates the beyond-chance agreement of two raters coding with mutually exclusive categories. A gold standard consensus for all messages in the corpus was developed through discussion between the two raters and the lead taxonomy author (GPJ).

Table 1. Consumer Health Information Needs of Pregnant Women with High-Risk Pregnancies

Category / Subcategory	Example Question (Participant #)	Count	Percent of Primary Cat.	Percent of All Questions
<i>Problems</i>		146	–	36.7
Definition	<i>What is gastroschisis? (52)</i>	4	2.7	1.0
Epidemiology	<i>How often are babies born with this defect? (52)</i>	11	7.5	2.8
Risk Factors	<i>Does holoprosencephaly increase the risk for sudden infant death syndrome? (20)</i>	23	15.8	5.8
Etiology	<i>What causes holoprosencephaly? (20)</i>	12	8.2	3.0
Pathogenesis / Natural History	<i>How does pregnancy with twins affect my blood sugar levels worse than a singleton? (31)</i>	11	7.5	2.8
Clinical Presentation	<i>How much intestine are usually outside? (45)</i>	23	15.8	5.8
Differential Diagnosis	<i>Why isn't baby moving legs very much? (13)</i>	4	2.7	1.0
Related Diagnoses	<i>Are there other abnormalities that we should be looking for after this? (37)</i>	5	3.4	1.3
Prognosis	<i>What is the chance of survival after birth? (18)</i>	53	36.3	13.3
<i>Management</i>		74	–	18.6
Goals / Strategy	<i>What's going to happen after baby is born? (52)</i>	12	16.2	3.0
Tests	<i>How common is genetic testing during pregnancy? (33)</i>	5	6.8	1.3
Interventions	<i>How can this [gastroschisis] be fixed? (52)</i>	21	28.4	5.3
Sequence / Timing	<i>Will circumcision be done during his first surgery or after? (32)</i>	21	28.4	5.3
Personnel / Setting	<i>Can we deliver at the hospital back home or do we need to come to [Hospital]? (56)</i>	15	20.3	3.8
<i>Interventions</i>		101	–	25.4
Definition	<i>What is a shunt? (19)</i>	3	3.0	0.8
Goals		0	–	–
Mechanism of Action	<i>[What's the drug] and what does it do? (35)</i>	1	1.0	0.3
Efficacy	<i>Is it proven that there is a better outcome by having the surgery before the baby is born? (19)</i>	3	3.0	0.8
Indications / Contraindications	<i>Is this a reason to abort my child and not give him a chance (33)</i>	31	30.7	7.8
Preparation	<i>Do I need to be NPO before my C-section? (17)</i>	2	2.0	0.5
Technique / Administration	<i>How long will his surgery take? (34)</i>	16	15.8	4.0
Monitoring		0	–	–
Post-intervention Care	<i>After his surgery, how long before he can have a bath? (32)</i>	20	19.8	5.0
Advantages / Benefits	<i>Will it be best to breastfeed or use formula? (23)</i>	4	4.0	1.0
Costs / Disadvantages		0	–	–
Adverse Effects	<i>Will my baby hurt after surgery? (52)</i>	21	20.8	5.3

Table 1 (continued)

<i>Tests</i>		23	–	5.8
Definition		0	–	–
Goals	<i>What does a chromosome test prove? (35)</i>	2	8.7	0.5
Physiologic Basis	<i>Amniocentesis shows lung development how? (35)</i>	1	4.3	0.3
Efficacy	<i>How many children are misdiagnosed [by genetic testing]? (33)</i>	1	4.3	0.3
Indications / Contraindications		0	–	–
Preparation		0	–	–
Technique / Administration	<i>Do you do a chromosome test off amnio? (35)</i>	2	8.7	0.5
Interpretation	<i>How do you come up with the baby's weight? (35)</i>	14	60.9	3.5
Post-test Care		0	–	–
Advantages / Benefits		0	–	–
Costs / Disadvantages		0	–	–
Adverse Effects	<i>Does having so many ultrasounds have any adverse effect on the baby or pregnancy? (18)</i>	3	13.0	0.8
<i>Medical Needs</i>		20	–	5.0
Scheduling	<i>How long before my next appointment? (38)</i>	1	5.0	0.3
Medical Equipment		0	–	–
Personnel / Referrals	<i>Should I get a second opinion? (34)</i>	2	10.0	0.5
Prescriptions		0	–	–
Problem	<i>My ankles and fingers stay swollen 24/7 now. (17)</i>	2	10.0	0.5
Follow Up		0	–	–
Management	<i>Is there anything I should do differently now for the remainder of the pregnancy? (33)</i>	4	20.0	1.0
Tests	<i>Should the doctors be checking my urine? (50)</i>	1	5.0	0.3
Interventions	<i>Is there a way to reduce pain of the labia? (17)</i>	10	50.0	2.5
<i>Logistical Needs</i>		33	–	8.3
Contact Information	<i>I need to get the emergency phone numbers. (38)</i>	2	6.1	0.5
Facility / Policies	<i>How old must you be to visit the NICU? (40)</i>	25	75.8	6.3
Insurance / Billing		0	–	–
Interventions	<i>Are there support groups that we can attend? (32)</i>	5	15.2	1.3
Medical Records		0	–	–
Pers. Documentation		0	–	–
Health IT	<i>What are some websites I can look at? (34)</i>	1	3.0	0.3
Tests		0	–	–
<i>Social Communication</i> [†]		0	–	–
<i>Other</i>		1	–	0.3

[†] All subcategories (Acknowledgement, Concerns, Relationship, and Miscellaneous) contained zero messages.

Results

Participants and journal questions

Sixty pregnant women were enrolled in this study. The age of the participants ranged from 18 to 38 years with a median age of 24.4 years. Fifty-five participants were Caucasian, two were black, and three declined to provide their race. The average gestational age at enrollment was 26 5/7 weeks with a median of 27 weeks and range of 14 to 37 5/7 weeks. The average time from enrollment to delivery was 67.1 days for all study subjects. There were 67 prenatal diagnoses in the fetuses of the 60 women who participated in the study. The most common anomalies were gastroschisis ($n = 13$), spina bifida (7), ventriculomegaly (7), and congenital diaphragmatic hernia (7). Other diagnoses included holoprosencephaly, Dandy Walker malformation, hydrocephalus, cleft lip or palate, hypoplastic left heart, hypoplastic right heart, transposition of the great vessels, congenital cystic adenomatoid malformation, pulmonary sequestration, multicystic or polycystic kidney, polyhydramnios, hydronephrosis, skeletal dysplasia, talipes, absent radius, anemia, thrombocytopenia, heterotaxy, trisomy, and conjoined twins.

Nineteen women returned notebooks for question analysis, and 16 of these participants submitted at least one question during the study period. The average age of patients returning notebooks was 24.6 years with a median age of 23 years. All patients returning notebooks were Caucasian. The average gestational age at enrollment for participants returning notebooks was 28 3/7 weeks with a median of 28 6/7 weeks. For the patients who submitted at least one question, the average time from enrollment to delivery was 58.3 (range of 1–130) days. Participants returning notebooks each reported up to three congenital anomalies associated with their pregnancies, including gastroschisis, ventriculomegaly, hydrocephaly, holoprosencephaly, microcephaly, heterotaxy, congenital adenomatoid malformation, congenital diaphragmatic hernia, trisomy 6, choroid plexus cyst, mosaicism, lemon sign (a fetal skull ultrasound finding), and hypoplastic left heart syndrome. The participants reported a total of 398 questions with an average of 21 questions per participant who returned a notebook.

Health information needs

The great majority (86.3%; Table 1) of questions submitted by participants concerned clinical information needs, with most related to Problems (36.7%), Interventions (25.4%), or Management (18.6%). Clinical information needs about Tests accounted for just 5.8% of all questions. The remainder of participants' questions addressed Medical Needs (5.0%) or Logistical Needs (8.3%). One question could not be categorized as it did not contain a question or expressed need (Other, 0.3%). No questions were identified as Social Communication.

Participants' questions most commonly addressed specific concerns about the prognosis of their fetus (13.3%), the indications or contraindications for performing particular interventions (7.8%), policies of the medical facility where the participant and their fetus was receiving care (6.3%), the clinical presentation of the problems affecting their fetus (5.8%), and the risk factors for the problem (5.8%). Sixty-six percent (39/59) of all subcategories in the taxonomy had at least one question meeting their criteria for coding.

Within primary categories, the most commonly identified subcategories were: fetal prognosis (36.3% of all Problem questions); recommended or available interventions and the sequence/timing of management plans (each 28.4% of all Management questions); indications or contraindications for particular interventions (30.7% of all Interventions questions); interpretation of test results (60.9% of all Test questions); requests for administration of interventions (50.0% of all Medical Needs questions); and facility policies (75.8% of all Logistical Needs questions).

Taxonomy reliability

Two raters independently assigned codes to a random sample of 198 questions that were distinct from those used to train the raters in the use of the taxonomy. The raters achieved 60.1% agreement with $\kappa = 0.57$ when using the subcategories only. This represents moderate agreement beyond chance, according to the widely used criteria proposed by Landis and Koch³². When the raters' subcategory codes were mapped to their respective primary categories, percent agreement improved to 82.3% with $\kappa = 0.75$, representing substantial agreement beyond chance.

Discussion

Health information needs of pregnant women

Through the application of a novel taxonomy of consumer health information needs, we have identified and categorized diverse needs expressed by women carrying high-risk pregnancies. The journaling process by which

participants generated and recorded their questions enabled participants to reflect and focus on the many clinical information concerns that arose as a result of their fetus's prenatal diagnosis, and greater than 85% of questions addressed such clinical information needs. Many women wished to understand the implications of the diagnosis, including the prognosis of their fetus, the clinical features of the congenital anomaly or syndrome, and the natural history of the problem. There was also significant concern about the frequency of and reasons why the problem arose and the likelihood that it would affect future pregnancies (i.e., epidemiology, risk factors and etiology).

With many of the fetuses likely to require interventions including surgery and/or medications, women wanted to know more about available management strategies and timing as well as specific details of the interventions that might be required. Among questions oriented to a specific intervention, most dealt with indications, contraindications, adverse effects, care for the infant after the intervention, and the technique by which the intervention is administered. These findings reinforce the key informational elements that should be included in both verbal discussions between clinicians and patients as well as electronic resources (e.g., patient portals, knowledge websites) developed to support this patient population. Despite the importance of testing in evaluation and management of most prenatal diagnoses, few questions addressed such information needs and most focused on the interpretation of test results that the participants had already received. This observation suggests that clinicians and genetic counselors providing support to this population may need to give additional attention to explaining the results of testing performed and the implications for problem management.

Most non-clinical information needs were logistical in nature, focused on either facility policies (e.g., restrictions on visitors to the neonatal intensive care unit) or the availability of services or equipment at a particular medical facility. These unanswered questions are an easily addressed category of unmet information needs, and providing such information may help decrease anxiety in a stressful time for the expectant mother. Few active medical needs were expressed, but these frequently included the need for maternal interventions, such as scheduling a Cesarean section, treating swollen joints, or enrolling in special birthing classes.

As the questions in our study were collected throughout a participant's pregnancy, we observed changing health information needs as the participants progressed toward delivery. This trend was demonstrated by Participant 32, who initially asked questions about future management of her fetus once an infant (e.g., "Should I make sure any kids he will be around aren't sick?"), but later asked questions about the impending surgery for her fetus once born (e.g., "After his surgery how long before he can have a bath?"). Such changes reflect a woman's evolving priorities and need for answers as more information is discovered and measures to affect maternal or fetal outcomes are planned or initiated¹⁶. Our ongoing research projects are evaluating patterns of information needs over time and expanding the illness trajectory framework for pregnancy.

Taxonomy development, reliability, and implications

In addition to describing consumer health information needs among women with complicated pregnancies, our study reports the preliminary evaluation of a novel taxonomy for their organization. Notably, our evaluation demonstrates our taxonomy's ability to comprehensively categorize a large number of questions with moderate to substantial reproducibility. Our study reports the distribution of self-reported information needs in pregnant women experiencing a problem with their pregnancies or unborn children. The types of questions identified in other patient populations and sources of consumer health information needs (e.g., patient portal messages) may differ significantly. While we did not identify questions for all categories in our proposed taxonomy in the current study, additional work by our group evaluating other sources of consumer information needs has shown a broad range of questions across the proposed categories and sufficient coverage to justify their inclusion³³. Additional validation on other sources of consumer health questions and an analysis of categories with high rates of disagreement between our raters will enable refinement of our taxonomy for future use.

Other researchers have proposed taxonomies for clinical questions asked by physicians, but these are complex and contain potentially overlapping categories^{34, 35}. Consumers' health information needs are more varied than physicians' and extend beyond the clinical information domain. Classifying consumer health information has been a research priority, and some studies have examined patient and caregiver needs in specific diseases^{9-12, 36-44}. However, comprehensive taxonomies to characterize broadly the semantic types of consumer information needs independent of domain or disease have not been proposed.

As clinicians, informaticists, and systems developers collaborate to build resources to support healthcare consumers, a comprehensive taxonomy of consumer health information needs may have several important applications. First, our taxonomy could be used to characterize the information needs of populations, as we have demonstrated here for

women carrying high-risk pregnancies. Such research may identify gaps in current sources of knowledge for consumers and guide content authors in producing resources that best address information needs. Our taxonomy could also be used to triage questions or map to appropriate information resources to provide answers. The broad classification of information needs into clinical information, medical, and logistical needs may guide selection of an appropriate resource type, and the specific subcategories in our taxonomy can provide filtering of content to meet the consumer's particular need. For example, clinical information needs might be answered by medical textbooks or corresponding consumer health knowledge resources, while logistical needs could be directed to appropriate pages on the healthcare institution's website. Medical needs might require urgent intervention by a healthcare provider, but social communications could be addressed during normal business hours.

Limitations

Our study was conducted in an advanced maternal-fetal care setting, and the information needs observed may not generalize to women with normal pregnancies. We did not collect information about whether the participants had been pregnant previously, and the median age of our participants of 23 years was slightly younger than the average age of first-time pregnancy in the United States of 26 years. Participants' age and parity are likely to have affected the types of questions reported. We had a relatively low response rate, as dedicated research personnel were not available to collect notebooks at all clinic visits. The questions collected likely reflect the needs of patients with more complicated pregnancies, as healthy mothers may not have returned to the Fetal Center or our tertiary care center for delivery. Although only 16 participants provided questions, we obtained 398 questions for analysis, which exceeds the quantity studied in other populations^{35,45} and provided coverage of two-thirds of our taxonomy.

The distribution across types of questions reported is likely biased by our method of collection and the prompts provided to participants. Our instructions most likely elicited greater numbers of clinical information needs, and pregnant women have many additional medical and logistical needs that were not captured in our study. Given the time-dependent nature of the latter types of needs, participants may have addressed them through telephone or online messaging communications rather than recording them in their journal for review at a later date. Participants were advised that questions were being collected only for research purposes. They were encouraged to use their notebooks to remind them of questions for their physicians, but explicitly instructed that their physicians would not review their questions unless asked to by the participant. The limited racial diversity of the participants providing questions in our study may also limit the generalizability of our content distribution to populations with greater racial heterogeneity.

We achieved only moderate inter-rater reliability of the taxonomy when using the subcategory codes. As compared to other studies categorizing medical content, our coding reliability is stronger, especially considering the limited training our raters received. For example, in a study of primary care doctors evaluating clinical questions from other primary care and family doctors, they achieved 55% overall agreement with $\kappa = 0.53$ ³⁵. Further, our substantial agreement using only primary categories suggests that these categories are well-defined and mutually exclusive. We expect that with additional training and experience using our taxonomy, inter-rater agreement will increase substantially.

Conclusions

In this study, we have proposed and evaluated one of the first comprehensive taxonomies of consumer health information needs and applied it to describe the information needs of women carrying high-risk pregnancies. Pregnant women with prenatally-diagnosed congenital anomalies or pregnancy complications have significant and diverse information needs, and the observed needs could all be categorized using our simple but comprehensive taxonomy. The unmet needs identified in this population were largely related to clinical knowledge about the prognosis, diagnosis, management, and intervention plans for the fetus. Additional easily addressed logistical needs about healthcare facility policies were identified. We achieved moderate to substantial coding reliability with our proposed taxonomy. By modeling the spectrum of consumer health information needs, our taxonomy may guide content development for healthcare consumer information resources and improve automated systems to intelligently process and answer consumers' questions.

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