
Research and Applications

Consumer health-related needs of pregnant women and their caregivers

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Received 31 December 2017; Revised 2 May 2018; Editorial Decision 16 May 2018; Accepted 4 June 2018

ABSTRACT

Objectives: To build effective applications, technology designers must understand consumer health needs. Pregnancy is a common health condition, and expectant families have unanswered questions. This study examined consumer health-related needs in pregnant women and caregivers and determined the types of needs that were not met.

Materials and Methods: We enrolled pregnant women <36 weeks' gestational age and caregivers from advanced maternal–fetal and group prenatal care settings. Participant characteristics were collected through surveys, and health-related needs were elicited in semi-structured interviews. Researchers categorized needs by semantic type and whether they were met (ie, met, partially met, or unmet). Inter-rater reliability was measured by Cohen's kappa.

Results: Seventy-one pregnant women and 29 caregivers participated and reported 1054 needs, 28% unmet, and 49% partially met. Need types were 66.2% informational, 15.9% logistical, 8.9% social, 8.6% medical, and 0.3% other. Inter-rater reliability was near perfect ($\kappa=0.95$, $P<0.001$).

Discussion: Common topics of unmet needs were prognosis, life management, and need for emotional support. For pregnant women, these unmet needs focused around being healthy, childbirth, infant care, and being a good mother; caregivers' needs involved caring for the mother, the natural course of pregnancy, and life after pregnancy.

Conclusion: Pregnant women and caregivers have a rich set of health-related needs with many not fully met. Caregivers' needs differed from those of pregnant women and may not be adequately addressed by resources designed for mothers. Many unmet needs involved stress and life management. Knowledge about consumer health needs can inform the design of better technologies for pregnancy.

Key words: needs assessment, caregivers, pregnant women, consumer health informatics, consumer health information

BACKGROUND AND SIGNIFICANCE

This article describes a study of the health-related needs of pregnant women and their caregivers to inform the design of health information technologies for pregnancy. Pregnancy is one of the most common health conditions, and for many women, their first significant interaction with the healthcare system. In the United States, there are almost 6.5 million pregnancies and 4 million live births each year.^{1,2} The Healthcare Cost and Utilization Project (HCUP) of the Agency for Healthcare Research and Quality (AHRQ) reported in 2011 that up to 94% of childbirths had complications, including both maternal and fetal conditions.³ Approximately 3% of all children born each year have birth defects, many of which are diagnosed antenatally.⁴ When complications arise, pregnant women and their caregivers may be faced with uncertain outcomes, difficult decisions, and evolving information needs.⁵ Numerous questions arise, and health information must be processed as conditions are identified through prenatal testing. Pregnancy, childbirth, and the transition to parenthood have been shown to be some of the most dramatic and stressful developmental changes.^{6,7} Even couples with completely normal pregnancies—especially first-time parents—may have significant health-related needs during this time. Obtaining information is one of the most basic actions a person can do to be engaged in health and make informed decisions about care. Patients with a wide variety of health conditions are known to have significant unmet information needs, and addressing those needs can help them succeed in their roles and maintain well-being.^{1,8–10} During pregnancy, meeting health-related needs is particularly important as appropriate prenatal education improves maternal and fetal outcomes.^{11–14}

Several studies have examined the information needs of pregnant women, but most have been small, limited in scope, and did not include the needs of caregivers.^{15–20} Studies that have analyzed the information needs of caregivers during pregnancy have mainly focused on the child's father, without inclusion of other caregivers of the mother and child, such as grandparents, siblings, or close family friends.^{7,21,22} Consideration of other caregivers is especially important when over one in four children grow up in a home without a father, and one in 14 may live in a household headed by a grandparent.^{23,24} Hsieh et al.²⁵ examined the needs of pregnant women referred for genetic counseling, and most women reported information needs focused on interpretation of genetic testing, risks of genetic defects, and the health of the baby. Small studies of prenatal consultations for congenital anomalies have identified diverse information needs about the nature of the anomaly, treatment options, and prognosis, by both the pregnant women and their caregivers.^{26–28} One study of 16 pregnant women diagnosed prenatally with fetal congenital anomalies revealed 398 questions logged by these women through the course of their pregnancies. Questions identified from this study were predominantly about medical diagnoses, interventions, or disease management, and many needs remained unmet despite the patients receiving care in an advanced maternal–fetal center.²⁹ Research conducted using focus groups with 17 pregnant women in a Women, Infants, and Children (WIC) program revealed that standard prenatal care was not designed to address the many questions that arise in early pregnancy, and as a result, pregnant women turned to health information technologies to address their unmet needs.³⁰

Several recent studies have focused on the use of the Internet and other technologies for pregnancy-related information by expecting mothers.^{31–39} The Internet and smartphone applications, often termed “apps”, have become popular sources of health information

for pregnant women, with up to 95% of women using the Internet as a resource during pregnancy,^{32,34,38} and 60–75% of pregnant women reporting use of a pregnancy-related smartphone app.³⁸ In 2014, there were 1059 pregnancy apps available for Apple devices and 497 pregnancy apps for Android devices.⁴⁰ The overall quality of pregnancy-related Internet sources and apps have been questioned, and the majority of pregnancy-related apps and Internet sites are designed for the pregnant woman, with caregivers having fewer technology resources to meet their needs.^{37,41} A systematic review performed by Sayakhot et al.³¹ found 7 studies assessing the use of Internet health information by pregnant women, with the main types of information accessed being about fetal development, nutrition or medications in pregnancy, pregnancy complications, and antenatal care. While these studies characterized the information sought by pregnant women, they did not determine the needs that prompted the searches or whether needs were met.

OBJECTIVES

In 2011, the AHRQ recognized the need for rich studies of consumer health needs to inform the design of health information technologies.⁴² With support from this funding opportunity, we conducted a comprehensive study of the health-related needs of pregnant women and their caregivers. We sought to characterize the diverse health-related needs that arise during pregnancy, to highlight the differences between needs of pregnant women and their caregivers, and to determine the types of needs that are met and unmet to support the design of effective health information technologies for pregnancy.

MATERIALS AND METHODS

Study setting and population

This study was a cross-sectional examination of health-related needs in pregnant women and caregivers conducted at Vanderbilt University Medical Center (VUMC). Adult pregnant women (age 18 years or older) were recruited from the Vanderbilt Center for Women's Health group prenatal care program (Expect with Me) and the Fetal Center at Vanderbilt. Expect with Me is an innovative program in which small groups of 10–12 pregnant women with due dates in the same month meet together monthly during pregnancy for educational sessions facilitated by midwives. The Fetal Center at Vanderbilt is a multidisciplinary, advanced maternal–fetal care clinic that cares for pregnant women with a maternal or fetal concern. These sites were selected to capture health-related needs in both routine and complicated pregnancies. Both first-time expectant mothers and women with prior pregnancies along with their caregivers were included as their needs may differ. Enrolled pregnant women were given the opportunity to invite up to 3 adult caregivers, defined as any individuals who were expected to be significantly involved in the pregnancy and postpartum care of the mother or neonate, to participate in the study. Pregnant patients and caregivers who spoke English or Spanish were eligible for this study. Exclusion criteria included a pregnancy greater than 36 weeks' gestational age or home address over 100 miles from VUMC to assure sufficient time and feasibility to attend a research visit prior to delivery. All participants provided written informed consent, and caregivers were not included in the study without consent of the pregnant mother. The research protocol was approved by the Vanderbilt University Institutional Review Board (141813).

<p>1. Clinical Informational Needs or Communications</p> <p>A. Normal Anatomy and Physiology</p> <p>B. Problems (Diseases or Observations)</p> <ol style="list-style-type: none"> 1. Definition 2. Epidemiology 3. Risk factors 4. Etiology 5. Pathogenesis/natural history 6. Clinical presentation 7. Differential diagnosis 8. Related diagnoses 9. Prognosis <p>C. Management</p> <ol style="list-style-type: none"> 1. Goals/strategy 2. Tests 3. Interventions 4. Sequence/timing 5. Personnel/setting 	<p>D. Tests</p> <ol style="list-style-type: none"> 1. Definition 2. Goals 3. Physiologic basis 4. Efficacy 5. Indications/contraindications 6. Preparation 7. Technique/administration 8. Interpretation 9. Post-test care 10. Advantages/benefits 11. Costs/disadvantages 12. Adverse effects <p>E. Interventions</p> <ol style="list-style-type: none"> 1. Definition 2. Goals 3. Mechanism of action 4. Efficacy 5. Indications/contraindications 6. Preparation 7. Technique/administration 8. Monitoring 	<p>9. Post-intervention care</p> <ol style="list-style-type: none"> 10. Advantages/benefits 11. Costs/disadvantages 12. Adverse effects <p>2. Medical Needs or Communications</p> <ol style="list-style-type: none"> A. Appointments/scheduling B. Medical equipment C. Personnel/referrals D. Prescriptions E. Problems F. Follow-up G. Management H. Tests I. Interventions <p>3. Logistical Needs or Communications</p> <ol style="list-style-type: none"> A. Contact information/communication B. Facility/policies C. Insurance/billing 	<p>D. Medical records</p> <p>E. Personal documentation</p> <p>F. Health information technologies</p> <p>G. Tests</p> <p>H. Interventions</p> <p>I. Transportation</p> <p>4. Social Needs or Communications</p> <ol style="list-style-type: none"> A. Acknowledgment B. Complaints C. Emotional need or expression D. Relationship communication E. Miscellaneous <p>5. Other</p>
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Figure 1. Consumer health needs taxonomy.

Data collection

Study subjects completed surveys to assess demographic characteristics, socioeconomic factors, and technology usage, including self-reported use of popular online pregnancy resources and the Vanderbilt patient portal. They participated in semi-structured interviews, which included questions about health issues, prior pregnancies, information needs, biggest concerns, and resources used to access health information for pregnancy (Supplemental File S1). Interviews were designed to last approximately 1 h. Pregnant women and their caregivers completed research activities separately, with each providing individual responses to survey and interview questions. Survey data were entered into a Research Electronic Data Capture (REDCap) database by one member of the research team and verified by a second team member.⁴³ Interviews with Spanish-speaking patients were conducted with an interpreter. Each interview was audio recorded, transcribed into a word-processing format, translated to English for Spanish-speaking participants, and stripped of identifiers prior to analysis.

Consumer health-related needs collection

Health-related needs of pregnant women and their caregivers were manually extracted from interview transcripts by research team members. We employed an expanded concept of “health-related need” as described by Forsythe in characterizing physician information needs, to include any expression communicating a desire for information, whether general or specific to the patient, and involving both formal and informal or local knowledge.⁴⁴ We also included expressions of emotional needs or the desire for support, as these are prevalent and understudied concerns during pregnancy.⁷

Data analyses

Each health-related need was classified by semantic type and the degree to which the need was met (ie, met, partially met, or unmet). Semantic types were chosen from a taxonomy of consumer health-related needs or communications developed by the research team and shown in Figure 1. This taxonomy has been employed to categorize consumer health needs from various sources including questions from patient journals, patient portal messages, and a patient engagement consultation service, and it has been validated with inter-rater

reliability of its applications.^{45–49} The taxonomy provides a comprehensive schema dividing consumer health-related needs into 5 main categories: informational, logistical, medical, social, and other. *Informational* needs are questions that require clinical knowledge, such as information about the etiology or prognosis of a disease. *Logistical* needs are requests for practical information, such as how to contact a provider or whether a service is covered by a patient’s insurance. *Medical* needs express the desire for medical care, such as requests for the results of a patient’s test or a new problem that needs urgent medical attention. *Social* needs include those involving emotion or a request for support, and the *other* category includes needs that do not fit into the current taxonomy schema.

At least 2 research team members reviewed all needs to independently determine the need category and if the need was met at the time of the interview. Duplicate needs (ie, need of the same semantic type and focused on the same topic) expressed at multiple places in the interview were merged into a single need. Training of the researchers for use of the taxonomy on this data set was performed on 500 needs, with the remaining needs classified independently. Any discrepancies in category assignments were discussed to achieve consensus among the research team members. Inter-rater reliability with Cohen’s kappa was measured for the remaining needs to evaluate reproducibility of the taxonomy category assignments.

We constructed descriptive distributions and summary statistics of demographics of the pregnant patients and caregivers included in the study. Reported health-related needs were summarized by source (ie, pregnant patient or caregiver) and whether they were met. Those reported needs that were determined to be either met/partially met or unmet at the time of the interview were qualitatively compared for differing themes between pregnant patients and caregivers. Continuous variables were summarized with medians and interquartile ranges (IQR). Categorical variables were summarized as counts and frequencies. All analyses were conducted in R version 3.3.2.⁵⁰

RESULTS

Study population characteristics

One hundred participants were enrolled into the study, including 71 pregnant patients and 29 caregivers. Eighty-three participants (57

pregnant women and 26 caregivers) were recruited from the Fetal Center at Vanderbilt, and 17 (14 pregnant women and 3 caregivers) were recruited from Expect with Me. Demographic characteristics of the participants are described in Table 1. For the participants recruited from the Fetal Center, fetal diagnoses included gastroschisis, spina bifida, congenital heart disease, cardiac arrhythmia, twin pregnancy, placenta previa, placenta accreta, cytomegalovirus infection, and cleft lip and palate.

The majority of enrolled participants were white (71, 71%) and non-Hispanic (85, 85%). Of all participants, the involved pregnancy was in the second trimester for 19 (19%) and the third trimester for 81 (81%). The relationships of caregivers to pregnant women included spouses (10, 34.5%), parents of the mother (7, 24.1%), significant others (7, 24.1%), siblings of the mother (2, 6.9%), an adult child (1, 3.4%), a divorced husband (1, 3.4%), and father of the child without current stated relation to the mother (1, 3.4%). Fifty-three participants had other children, and 47 were experiencing their first pregnancy.

Eighty-seven (87.0%) study subjects used online resources to access information about their pregnancy, including 66 pregnant women (93.0% of all pregnant participants) and 21 caregivers (72.4% of all caregivers), $P = 0.009$. Among pregnant women, the most commonly accessed resources were BabyCenter.com (used by 50, 70.4%), WhatToExpect.com (27, 38.0%), TheBump.com (22, 31.0%), Pregnancy.com (17, 23.9%), FitPregnancy.com (9, 12.7%), Text4Baby.org (2, 2.8%), and other websites (35, 49.3%). For caregivers, self-reported usage included BabyCenter.com (used by 6, 20.7%), WhatToExpect.com (4, 13.8%), TheBump.com (2, 6.9%), Pregnancy.com (5, 17.2%), FitPregnancy.com (1, 3.4%), and other websites (11, 37.9%). The most commonly reported “other” resource accessed was “Google”, reported by 11 (15.5%) pregnant women and 6 (20.7%) caregivers. Fifty (70.4%) pregnant women and 6 (20.7%) caregivers reported using the VUMC patient portal.

Health-related needs of pregnant women and their caregivers

Health-related needs were extracted from transcripts of audio-recorded, semi-structured interviews. One caregiver refused audio recording, and needs were extracted from detailed interviewer notes; the exact duration of this interview was not recorded. For the remaining 99 participants, the mean interview duration was 39 min and 38 s with a range of 11 min and 37 s to 68 min and 35 s. The 100 participants reported a total of 1054 health-related needs. A median of 10 needs (IQR 6–14) were expressed by the pregnant women and 7 needs (IQR 5–11) by their caregivers. A total of 551 (52.3%) needs were expressed by pregnant women or caregivers without children, and 503 (47.7%) needs were from participants who had children. After 500 of the needs were classified jointly for training, 554 needs were coded independently by two members of the research team. The inter-rater reliability for classification of the reported health-related needs resulted in almost perfect beyond chance agreement with a Kappa’s coefficient of 0.95 ($P < 0.001$).

Table 2 shows the distribution of health-related needs across the major semantic categories. Six hundred ninety-eight needs (66.2%) expressed were informational, consisting of 553 needs reported by pregnant women and 145 needs expressed by their caregivers. Three hundred eighteen needs (45.6% of all informational needs) were in the problem category related to a maternal or fetal diagnosis (eg, placenta previa for the mother or spina bifida of the fetus), with the subcategories of clinical presentation (77, 24.8%), natural history/

Table 1. Demographics of pregnant women and their caregivers

	Pregnant patients (<i>n</i> = 71)	Caregivers (<i>n</i> = 29)
Sex, <i>n</i> (%)		
Male	0	21 (72.4)
Female	71 (100)	8 (27.6)
Race, <i>n</i> (%)		
White	50 (70.4)	21 (72.4)
Black	14 (19.7)	6 (20.7)
Native Hawaiian or Other Pacific Islander	1 (1.4)	0
American Indian/Alaskan	0	0
Other	6 (8.5)	2 (6.9)
Ethnicity, <i>n</i> (%)		
Hispanic	11 (15.5)	3 (10.7)
Non-Hispanic	60 (84.5)	25 (89.3)
Language spoken, <i>n</i> (%)		
English	67 (94.4)	28 (96.6)
Spanish	4 (5.6)	1 (3.4)
Age (years), median (IQR)	26 (22.5–32.0)	30 (23.0–43.0)
Highest education level completed, <i>n</i> (%)		
8th grade	0	1 (3.4)
High school	22 (31.0)	11 (37.9)
Some COLLEGE COURSES	17 (23.9)	8 (27.6)
2-Year college degree	6 (8.5)	2 (6.9)
4-Year college degree	14 (19.7)	5 (17.2)
Master’s degree	7 (9.9)	1 (3.4)
PhD or equivalent	2 (2.8)	0
Other	3 (4.2)	1 (3.4)
Individual income, <i>n</i> (%)		
\$15 000 or less	34 (50.7)	7 (25.9)
\$15 000–\$29 999	12 (17.9)	9 (33.3)
\$30 000–\$44 999	8 (11.9)	6 (22.2)
\$45 000–\$59 999	4 (6.0)	2 (7.4)
\$60 000–\$79 000	5 (7.5)	1 (3.7)
\$80 000–999 999	2 (3.0)	1 (3.7)
\$100 000 or above	2 (3.0)	1 (3.7)
Household income, <i>n</i> (%)		
\$15 000 or less	13 (19.4)	6 (22.2)
\$15 000–\$29 999	13 (19.4)	7 (25.9)
\$30 000–\$44 999	11 (16.4)	7 (25.9)
\$45 000–\$59 999	9 (13.4)	4 (14.8)
\$60 000–\$79 000	5 (7.5)	0
\$80 000–999 999	4 (6.0)	0
\$100 000–119 999	5 (7.5)	0
\$120 000–\$139 999	2 (3.0)	2 (7.4)
\$140 000 or above	5 (7.5)	1 (3.7)
Estimated gestational age (weeks), median (IQR)	31.6 (28.3–34.7)	31.4 (30.3–33.7)
Trimester of pregnancy, <i>n</i> (%)		
1st	0	0
2nd	15 (21.1)	4 (13.8)
3rd	56 (78.9)	25 (86.2)

pathogenesis (61, 19.2%), and prognosis (61, 19.2%) being among the most common. Of all reported informational needs, 203 needs (29.1%) were about interventions, such as epidural anesthesia or breastfeeding, with the most common subcategories being technique (76, 37.4%) and preparation (25, 12.3%) (Table 2). One hundred fifty-six needs (22.3% of all reported informational needs) were about general management of a medical problem; 20 needs (2.9% of

Table 2. Information needs of pregnant women and their caregivers

	All (<i>n</i> = 100), needs (<i>n</i> = 1054), <i>n</i> (%)	Pregnant patients (<i>n</i> = 71), needs (<i>n</i> = 825), <i>n</i> (%)	Caregiver (<i>n</i> = 29), needs (<i>n</i> = 229), <i>n</i> (%)
Informational	Total = 698 (66.2)	Total = 553 (67.0)	Total = 145 (63.3)
Normal anatomy and physiology	1 (0.1)	1 (0.1)	0
Problem	318 (30.2)	235 (28.5)	83 (36.2)
Management	156 (14.8)	119 (14.4)	37 (16.2)
Tests	20 (1.9)	18 (2.2)	2 (0.9)
Interventions	203 (19.3)	180 (21.8)	23 (10.0)
Logistical	Total = 168 (15.9)	Total = 122 (14.8)	Total = 46 (20.1)
Contact/communication	16 (1.5)	14 (1.7)	2 (0.9)
Facility/policies/personnel	48 (4.6)	36 (4.4)	12 (5.2)
Insurance/billing	14 (1.3)	8 (1.0)	6 (2.6)
Medical records	0	0	0
Personal documentation	0	0	0
Health information technologies	17 (1.6)	13 (1.6)	4 (1.7)
Tests	0	0	0
Interventions	12 (1.1)	9 (1.1)	3 (1.3)
Transportation	7 (0.7)	3 (0.4)	4 (1.7)
Life management	53 (5.0)	38 (4.6)	15 (6.6)
Undifferentiated	1 (0.1)	1 (0.1)	0
Medical	Total = 91 (8.6)	Total = 75 (9.1)	Total = 16 (7.0)
Appointments/scheduling	3 (0.3)	3 (0.4)	0
Medical equipment	14 (1.3)	13 (1.6)	1 (0.4)
Personnel/referrals	13 (1.2)	10 (1.2)	3 (1.3)
Prescriptions	0	0	0
Problems	24 (2.3)	21 (2.5)	3 (1.3)
Follow-up	1 (0.1)	1 (0.1)	0
Management	2 (0.2)	1 (0.1)	1 (0.4)
Tests	31 (2.9)	23 (2.8)	8 (3.5)
Interventions	3 (0.3)	3 (0.4)	0
Social	Total = 94 (8.9)	Total = 73 (8.8)	Total = 21 (9.2)
Acknowledgment	0	0	0
Complaints	4 (0.4)	4 (0.5)	0
Emotional	87 (8.3)	66 (8.0)	21 (9.2)
Relationship communication	0	0	0
Miscellaneous	3 (0.3)	3 (0.4)	0
Other	Total = 3 (0.3)	Total = 2 (0.2)	Total = 1 (0.4)

informational needs) were about tests; and one need was about normal anatomy and physiology.

Pregnant women and caregivers expressed 168 needs (15.9% of all) that were logistical. Within this category, participants most commonly requested information about general life management issues especially related to preparation for the baby (53 needs, 31.5% of logistical needs), hospital facility policies or personnel (48 needs, 28.6% of logistical needs), and contact information (16 needs, 9.5% of logistical) for their providers. Ninety-one needs (8.6% of all) were medical in nature, most commonly involving the need for the specific results of a test (31 needs, 34.1% of medical needs) or the expression of a problem needing medical attention (24 needs, 26.4% of medical needs). Ninety-four needs (8.9% of all) were social, with most common being the need for emotional support (87 needs, 92.6% of social needs). Only 3 needs were classified as other, all of which pertained to needs regarding naming of the baby.

In both pregnant women and their caregivers, 236 (22.4%) of all needs were met, 521 (49.4%) were partially met, and 297 (28.2%) were unmet. Table 3 provides examples of the common types of needs that were met and partially met for pregnant patients and caregivers, as well as some information about the resources accessed in attempts to meet those needs.

Both women and caregivers reported needing information on specific pregnancy symptoms, appropriate medications to take, and upcoming tests throughout the course of pregnancy, and both reported using Internet websites and smartphone apps to try to meet these types of needs. Although pregnant women and caregivers expressed similar semantic types of needs, the focus of common needs was often different. For example, needs for information on interventions by the pregnant women were more commonly focused toward future interventions of the newborn, while caregivers expressed more informational needs around the processes of labor and delivery. For general management, pregnant women had questions about what they could do to be healthy and take care of themselves during pregnancy, whereas caregivers sought information about what they could do to take care of the mother or themselves in the stressful context of becoming a new parent or parent of a child with a significant illness. Logistical needs for hospital or provider information were expressed by both pregnant women and caregivers, with Internet resources often used to help meet those needs. While online social networking groups were utilized, most pregnant women and caregiver needs for social and emotional support were met through person-to-person interactions, such as with family, friends, or social workers.

Table 3. Examples of met and partially met needs of pregnant women and caregivers

Pregnant women	Caregivers
<p>Problem presentation <i>Interviewer:</i> What kind of information have you been looking for or thinking about related to your pregnancy? <i>Pregnant patient:</i> So I would look up stuff like that and like the reason why I'm short of breath or why am I so hot or you know, why am I so tired. And it's just, but in your first trimester you usually experience these type of things. Any, any of my friends that have kids, I'll ask them. You know, how was their pregnancy? And they'll just be like, "Girl Google that stuff." I'm like okay. What do I need to Google? Google, just Google first trimester, da, da and such and such.</p> <p>Problem management <i>Interviewer:</i> Describe what, if any, technology you've used to assist you during the pregnancy. <i>Pregnant patient:</i> My Smartphone and my pregnancy app. It, well I just get it really. I don't really use it, but it tells me like what tests need to be done. Like it will pop up once a week and it will tell me what tests need to be done that week or what I should be expecting.</p> <p>Interventions <i>Interviewer:</i> At each visit, is that, do you feel like that that helps you when you get new information or more data about the baby or kind of? <i>Pregnant patient:</i> Oh, yes, it really does. We have had the papers drew out to how the surgeries going to go by the cardiologist. So, he was able to draw it out and everything and kind of explain step by step how the surgery is going to go. So that was really, really helpful. And he gave us a paper showing us, you know, step by step how the surgery would go and what the surgery was actually going to be like.</p> <p>Logistical <i>Interviewer:</i> Any newer activities that you can think of that are related to the pregnancy? <i>Pregnant patient:</i> Just been googling the crap out of stuff. Constantly checking, you know, the surgeons here, make sure they're up to par with the surgeries cause, you know, you always want to make sure the best person's operating on your child.</p> <p>Social and emotional support <i>Interviewer:</i> How have other people been involved in helping you out with the issues? <i>Pregnant patient:</i> You know, my mom, my sister, are just a great emotional support in terms of just, you know, let me know how it goes and checking in and, you know, just reassuring me that, you know, they're there for me if I ever need anything.</p>	<p>Problem presentation <i>Interviewer:</i> If you were developing a website, what would I like to see in it? <i>Caregiver:</i> I think they still ought to have something for like people who do go into a little depression or something after [they] have them babies. That they can read up on and see little warning signs.</p> <p>Problem management <i>Interviewer:</i> What kind of information have you been looking for or thinking about related to the pregnancy? <i>Caregiver:</i> Recently she was . . . having some back pain. So we were seeing like what she could take, everything like that. We did a Google search, everything like that. Contacted her doctor and that's how we pretty much get our answers. They've got a nursing line over at Gateway that's 24 h. So if she's got any questions we just dial them up if Google or anything didn't turn anything up.</p> <p>Interventions <i>Interviewer:</i> What kind of information have you been looking for or thinking about related to the pregnancy? <i>Caregiver:</i> Just mainly processes of like how is this going to work, going into it, just having no concept of labor and delivery and that kind of thing. So yeah, just trying to figure out what those processes mean. But the class, yeah, the class that we went to, we went to, I forgot to mention that. We watched birthing videos which was a new experience for me.</p> <p>Logistical <i>Interviewer:</i> So when you say texts, like phone text message? <i>Caregiver:</i> Yeah, we have [DOCTOR], when she texts us and we text her. I wouldn't say often, but as needed. And when we were on vacation last week, she texted just to make sure everything was okay cause we were in Alaska and we were nervous about being so far away and so she was just kinda checking in on us and, which was really nice, and gave us some doctors' names up there just in case so stuff like that. So we felt very comfortable leave the lower 48 to go on a trip.</p> <p>Social and emotional support <i>Interviewer:</i> Is there a way that people who want to help or the community or someone offering resources could do a better job of presenting what's available to make. . .it more acceptable during a stressful time? <i>Caregiver:</i> I can't remember the girl's name that had, you've got two social workers, and I can't remember her one name. She's still here. She really, I think had good insight on when a family needed a little extra hug.</p>

Two hundred ninety-seven needs (28.2%) were unmet. Most unmet needs expressed by the pregnant women and caregivers were informational (150 needs, 52.1%) or logistical (66 needs, 22.9%). Of the remaining, 13.9% were social and 11.1% were medical.

The distributions across types of unmet needs were similar for pregnant women and caregivers, although the topics and focus of needs were different (Table 4). For example, both pregnant women and caregivers expressed concerns about the overall prognosis of their children. However, the caregivers often reported concern for the prognosis of the mother. Pregnant women described unmet logistical needs around managing a newborn along with other responsibilities, such as work and care of other children, whereas caregivers were more broadly concerned with how life was going to be after the delivery. The reported emotional needs of pregnant women involved significant stress and fear about being a good mother. In contrast, caregivers frequently communicated the need to have a support person for themselves, such a mentor or

someone to talk to who may understand the pressure and role of the caregiver.

DISCUSSION

This article describes one of the largest qualitative studies of health-related needs in pregnant women and caregivers and is one of the first to categorize needs using a taxonomy specifically designed for healthcare consumer needs. The Internet is a widely-used source of health information for pregnant women,³⁰⁻³⁹ and the results of this study have several important implications for the design of health information technologies for pregnant women and their caregivers. The majority of the needs expressed were informational in nature, but a substantial number fell into medical, logistical, and social/emotional categories. These latter categories correspond to many concepts suggested by Forsythe and colleagues in assessing the

Table 4. Themes of unmet needs of pregnant women and their caregivers

Pregnant women	Caregivers
<p>Child’s medical problems and prognosis <i>Interviewer:</i> What is your biggest concern right now? <i>Pregnant patient:</i> They’re taking mine at 34 weeks so they’re taking him even early so now I’m looking at premature. Is the lungs going to be developed and all this other stuff?</p> <p>Birth plan <i>Interviewer:</i> What kinds of information are you looking for? <i>Pregnant patient:</i> What to expect during your pregnancy. Like, well not during pregnancy, but when you go to have, like when you have the baby. And what are your actual choices out there. Cause like, you know, there’s natural birth, epidural, is there anything else?</p> <p>Life management <i>Interviewer:</i> If you could have more help with your current pregnancy, what would that be? <i>Pregnant patient:</i> More help. I’m not really sure how to answer that. I’d love to have someone come clean my house. I don’t really know what, I think that’s the main thing is that you get so tired, you know. You’re trying to keep up with the household and a child and daily life.</p> <p>Problem prognosis and stress <i>Interviewer:</i> I guess how are you dealing with the fact that you don’t know exactly the extent of everything at this point [regarding child’s diagnosis]? <i>Pregnant patient:</i> Kinda got that in our heads about well, if you’re not gonna know, it’s gonna be when they find out. That’s hard to cope with, with just waiting.</p> <p>Stress and fear <i>Interviewer:</i> What is your single biggest concern at this point? <i>Pregnant patient:</i> Hmm, I guess probably the stresses of having two new babies at home and still caring for a five year old. . .it’s just the, the fear of going into labor early and that fear and anticipation and oh my gosh what do I do?</p>	<p>Disease descriptions and information <i>Interviewer:</i> What kind of information would you like to see on a website for pregnant women? <i>Caregiver:</i> If they have an easy user-friendly way of understanding anything that can potentially go wrong. Cause it, I mean it’d be one thing to say, here’s what you do when everything goes right, but what do you need to do really? Just ride it through. I think overall, just understanding more for the men about pregnancy. Women seem to understand most of it, the terminology or whatever. The terminology for me and most guys, it’s not, we’re not that smart when it comes to that.</p> <p>Life management <i>Interviewer:</i> What is your biggest concern right now? <i>Caregiver:</i> Being home with the other two kids and trying to figure out how we’re gonna be able to do it.</p> <p>Problem prognosis <i>Interviewer:</i> What kinds of information are you looking for? <i>Caregiver:</i> Kinda anything and everything to just learn about it, what’s gonna happen. What are the chances and what’s gonna be his life outcome and nobody really knows the life outcome, like we were talking to one doctor here, I guess there’s really nobody over like fifty years old with the heart defect, so [there is] limited information.</p> <p>Emotional support <i>Interviewer:</i> Is there anything else that you can think of that would help you more? <i>Caregiver:</i> Just talking to someone.</p>

information needs of physicians, and they are equally relevant to consumer health needs.⁴⁴ Further, they are topics that may not be addressed in existing online pregnancy resources. For example, some of the commonly reported unmet needs about hospital policies and provider contact information are easy to address, but require “local” or “informal” information. Technologies such as institutional patient portals would be well suited to provide such information, and studies of unmet consumer needs such as ours can identify high priority topics to inform the user-centered design needed to optimize the benefits of tools such as patient portals.⁵¹ Our research team interpreted health-related needs broadly, resulting in a greater understanding of the questions, concerns, and issues confronting families during pregnancy than seen in prior studies focused predominantly on clinical information needs.^{16,18,19} Of note, a significant number of needs were social and emotional concerns that have been also previously been shown to be common, especially among first-time parents, and seldom addressed by traditional “information needs” studies.⁷

To our knowledge, this study is one of the first pregnancy-related needs studies to include diverse types of caregivers, rather than the pregnant women’s partners only. These additional caregivers brought unique needs to this study. For example, the parents of a pregnant mother sometimes expressed more detailed concerns about the pregnancy or delivery, based on their prior experiences with pregnancy and childbirth. The focus of the needs overall differed with expectant mothers often expressing needs centered around the well-being of their children whereas caregivers were concerned broadly about the health of the mother, child, and also

themselves. The health-related needs for both expectant mothers and their caregivers were complex. For example, the commonly reported need for information about the prognosis of the baby was often accompanied by a social need for emotional support to cope with associated uncertainty. In clinical practice, providers tend to address both needs with information, rather than resources for support. The failure to identify this important emotional component can lead to needs being incompletely or inappropriately addressed. In our study, informational needs appeared well met by Internet websites and smartphone apps, but more personal resources were sought for social and emotional needs.

Over one-quarter of these needs were completely unmet, despite the fact that our participants were receiving care in advanced maternal-fetal care or intensive group prenatal care settings designed to address such needs. In our study, needs remained unmet even with the widespread availability of online resources for pregnancy and frequent use of these tools by our study population. Other consumer health informatics researchers have identified a wide variety of unmet needs of patients and their caregivers in the inpatient setting,^{49,52–55} and our study suggests that similar types of needs are unmet during pregnancy despite regularly scheduled ambulatory visits and extensive use of online resources. There were many unmet informational needs of pregnant women regarding the birth plan, type of anesthesia options, delivery technique, and advantages or disadvantages of each option. Such needs are commonly addressed in childbirth classes, which may be taken later in pregnancy. These findings suggest that pregnant women and their caregivers may be interested in this education earlier in the prenatal period.

Caregivers, on the other hand, did not frequently report the need for specific details regarding interventions for the mother or child, but instead expressed more needs about the natural history of pregnancy and overall disease process in pregnancies with a fetal diagnosis.

Logistical needs were commonly unmet among both pregnant women and caregivers, and addressing these easily-answered questions might have a significant impact on decreasing stress of the experience of pregnancy and delivery. For example, common logistical needs about contact information, personnel, and medical facilities can easily be met through design of websites, multimedia applications, or videos to allow pregnant women and their caregivers to easily visualize and explore healthcare institutions, their services, and staff. Such applications are well developed in the travel industry (eg, hotel websites), but less commonly implemented for healthcare organizations. General life management logistical needs and social or emotional needs were also commonly unmet. These understudied pragmatic and social needs are important as caregivers are at risk for physical, psychological, and emotional deleterious effects from providing care for another.^{56–58} Recognizing and addressing these needs may help mitigate such effects.

One important finding of our study was that while the overall distributions across semantic categories of needs among the pregnant women and caregivers were similar, the topics and focus were often different, especially among the unmet needs. Online pregnancy resources, prenatal clinical encounters, and pregnancy or childbirth educational classes typically focus on the needs of the pregnant women, with caregivers' unique and substantial needs often going unmet, even late in pregnancy. Our study found that fewer caregivers used online resources for pregnancy, and it is not clear whether those resources could have met their needs or were oriented toward the pregnant patient and would have failed to address the unique needs of pregnancy caregivers. Resources designed for caregivers and the nuances of their concerns are needed. Some needs, such as informal needs about prognosis, may never be met antenatally, due to the uncertainty about the exact diagnosis or severity of the disease process. As discussed above, logistical needs (eg, how to get to the hospital or where to park) which often become the responsibility of the caregiver, could be easily met through technology-based resources. The social and emotional needs that often accompany unmet information needs about prognosis and high risks interventions, such as surgery in a fetus or newborn, could be addressed through disease-specific social media sites and online support groups. Further, these disease-specific sites should be designed to support a wide variety of caregivers as well as expectant mothers. Few participants had used such online support resources for social needs, but those who did found them valuable.

This study has important limitations. The research was performed at a single large academic medical center in the southeastern United States, and the majority of participants were recruited from an advanced maternal–fetal practice. Thus, our results may not generalize to other settings. Second, our study population was also predominantly female, White, and English-speaking, and the majority of caregivers were male. Approximately 30% of our study subjects were non-White, and both Spanish-speaking and female caregivers did take part in the study. However, our findings might not fully represent the health-related needs unique to minority populations or those of female caregivers. Thirdly, the determination of whether a need was met was made by the research team in retrospective review of the interview. However, the transcripts included rich discussions of the expressed needs, usually with dialogue about whether the

need was met. In addition, this determination was made by at least 2 researchers, with research team members discussing all discrepancies. Fourth, participants were aware that the research personnel were not their clinical providers, and thus, may not have expressed medical needs. In addition, many research interviews were done before or after clinic visits or group meetings, and thus, participants may have received answers to their medical questions or knew they would be answered by their providers. For these reasons, the actual number of needs in the medical category may have been underrepresented in our findings. One participant did not allow audio recording of the semi-structured interview, and thus, the analysis of this person's needs and whether they were met was limited by the notes taken by the research team. Of note, 2 research team members conducted this interview, and therefore, one was able to ask questions while the other focused on the note-taking task. Lastly, the majority of our participants were in the second or third trimester, and thus the observed needs may not reflect those of early pregnancy. Our research team is currently completing a longitudinal study of health-related needs at multiple points during and after pregnancy with many participants being enrolled earlier in gestation.

CONCLUSION

This study demonstrates that pregnant women and their caregivers have a diverse set of health-related needs that arise during pregnancy and may remain unmet despite care in advanced maternal–fetal or intensive group prenatal care settings. The majority of needs are informational in nature, but substantial numbers of medical, logistical, and social needs exist, many of which could be easily addressed through health information technologies. Pregnant women and caregivers have similar semantic types of health-related needs, but their topics and focus differ. Many unmet needs reported by both pregnant women and caregivers involve the prognosis for a prenatal diagnosis, the general management of pregnancy, the process of and intervention options for childbirth, breast feeding, general life management during and after pregnancy, and the need for emotional support. As almost all pregnant women utilize online resources for guidance and support perinatally, unmet needs in this population represent an important opportunity for the development of improved technology resources for pregnancy.

Our findings have several implications for the design of health information technologies that are effective in meeting the health-related needs of pregnant women and caregivers. First, tools should be developed not only for pregnant women, but also for a wide variety of pregnancy caregivers, with special emphasis on addressing their unique and frequently unmet needs, including how to assist the pregnant mother to care for themselves during the stressful experiences of pregnancy and caring for a newborn. Robust online tools from the travel or retail industries with appropriate use of location information and user preferences should be replicated to address the common and often unmet logistical needs related to pregnancy experiences, such as finding directions to a hospital or clinic, learning about newborn nursery or delivery room policies, or identifying places to buy equipment for infants and children. Finally, designers of pregnancy tools should recognize that many types of informational, logistical, and medical needs—including questions about prognosis, caring for a newborn along with other children, and test results—are associated with typically unmet needs for emotional support. Our study participants expressed preferences for personal communications to meet such needs, so developers should consider employing technologies that support rich interactions, such as video chat tools

or social media groups. Our ongoing research includes a detailed qualitative analysis of how the available online tools were used by our study participants and why they failed to meet patient and caregiver needs related to pregnancy. Future studies should evaluate the effectiveness of health information technologies in addressing these unmet needs of expectant mothers and their caregivers and their ability to improve maternal and fetal outcomes.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

FUNDING

This work was supported by the National Institutes of Health National Library of Medicine [T15 LM007450], the Agency for Health Research and Quality [R01 HS021496], the National Institutes of Health National Center for Advancing Translational Sciences [UL1 TR000445], and the Surgical Outcomes Center for Kids at Monroe Carell Jr. Children's Hospital and the Section for Surgical Sciences at Vanderbilt University Medical Center.

CONTRIBUTORS

JRR participated in the acquisition and analysis of data, drafting, and revision of the article. SHA, LLN, CLS, and LEH participated in the acquisition and interpretation of data and revision of the article for important intellectual content. KAB contributed to the interpretation of data and critically revising the article. GPJ contributed to the conception and design of the study, analysis and interpretation of data, and drafting and revision of the manuscript. All authors provided final approval of the version to be submitted and agree to be accountable for all aspects of the work.

Conflict of interest statement. None declared.

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