

TITLE PAGE

Title: Personal Health Information Needs and Practices for Maternal Fetal Care

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STRUCTURED ABSTRACT

Purpose: The research examined characteristics, information needs, and information-seeking strategies to inform health information technology (HIT) design for pregnant women and caregivers.

Scope: Pregnancy is a common health condition and time of increased health-related needs.

Methods: Pregnant women and caregivers were recruited from the Fetal Center at Vanderbilt (FCV), Expect with Me (EWM) group prenatal care, and genetic counselors. Participant characteristics, information needs, and management practices were assessed using surveys, semi-structured interviews, home visits, journaling, and technology usage. A cross-sectional study involved one research visit with surveys and an interview during pregnancy. A longitudinal study comprised three research visits, a home visit, and analysis of journaling, social media, and portal use during and after pregnancy.

Results: One hundred participants (71 pregnant, 29 caregivers) were enrolled in the cross-sectional study, and 109 (82 pregnant, 27 caregivers) in the longitudinal study. Cross-sectional study participants reported 1054 health-related needs: 22.4% met, 49.4% partially met, 28.2% unmet. Need types were 66.2% informational, 15.9% logistical, 8.9% social, 8.6% medical, and 0.3% other. For pregnant women, unmet needs focused on being healthy/a good mother, childbirth, and infant care; caregivers' needs involved caring for the mother, the natural course of pregnancy, and life after pregnancy. Caregivers' activities most commonly involved searching for information (articulation work) and accompanying patients to appointments (illness work). At home, pregnant women struggled with mobility and desired more assistance; caregivers often did not know how to help. Technologies formed substantial portions of participants' support systems.

Key Words: consumer health informatics, information needs, pregnancy

PURPOSE

The overall goal of this project was to create an extensive knowledge base of healthcare consumer characteristics, information needs, and management strategies to inform the design of consumer health information technologies (HIT) for pregnant women and their caregivers.

SCOPE

Background

Pregnancy is one of the most common health conditions, and a time of increased questions, not only for the mother, but also for all individuals involved in the care of the mother or newborn baby. For women who have been healthy, pregnancy and delivery can be the first significant interactions with healthcare providers as an adult. When complications arise, pregnant women and their caregivers may be faced with uncertain outcomes, difficult decisions, and evolving information needs. Numerous questions arise, and health information must be processed as conditions are identified through prenatal testing. Pregnancy, childbirth, and the transition to parenthood are some of the most dramatic and stressful developmental changes. 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 his or her health. Meeting health-related needs is particularly important during pregnancy as appropriate prenatal education improves maternal and fetal outcomes.

Context / Settings

In 2011, the AHRQ recognized the need for robust studies of consumer health needs to improve the design of HIT and solicited grants for research in this area. 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 HIT for pregnancy.

Participants

This research examined the health-related needs, information-seeking behaviors, and information management practices of pregnant women and their caregivers. The research examined the needs of both pregnant women and a wide variety of caregivers, including spouses, siblings, parents, and friends of the expectant mother. We recruited participants from diverse settings including a group prenatal care practice and an advanced maternal-fetal center to capture a range of experiences from normal, uncomplicated pregnancies to pregnancies involving fetuses with severe congenital anomalies.

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. Studies that have analyzed the information needs of caregivers during pregnancy have mainly focused on the child's father. 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. Expectant fathers sometimes describe feeling "invisible" during pregnancy appointments and express a desire to be more involved. Other pregnant women's caregivers, including parents, siblings, extended family, former significant others, and friends, are rarely addressed in pregnancy-related health information literature or online pregnancy resources.

Incidence / Prevalence

In the United States, there are almost 6.5 million pregnancies and 4 million live births each year. In 2011, the Healthcare Cost and Utilization Project (HCUP) of the AHRQ reported that up to 94% of childbirths had complications, including both maternal and fetal conditions. Approximately 3% of all children born each year have birth defects, many of which are diagnosed antenatally.

METHODS

Study Design

A comprehensive investigation of the personal characteristics, information needs, and information management practices of pregnant women and their caregivers in the maternal fetal care setting was conducted. Pregnant women seen at the Junior League Fetal at Vanderbilt (FCV), the Expect with Me (EWM) group prenatal care program, or by genetic counselors (GC) were enrolled. The FCV is an advanced maternal-fetal care setting that incorporates a clinical program in fetal diagnosis and therapy. Multi-disciplinary teams bring a group of expert medical providers from different specialties to deliver care at one location. Most patients seen at the FCV are experiencing a pregnancy with a fetal anomaly or other complication of pregnancy. EWM is an innovative group prenatal care program that combines the components of traditional prenatal care with health education and support delivered in a group setting. Small groups of pregnant women (i.e., 8 to 12 individuals) with similar gestational ages and their caregivers meet for 10 group sessions during pregnancy. Each pregnant subject was permitted to invite up to three caregivers to participate in the study. Caregivers were defined as any individual who would participate significantly in the care of the mother or her baby. Participant characteristics, information needs, and

information management practices were assessed during and after pregnancy using five techniques: (1) survey instruments, (2) semi-structured interviews, (3) home visits, (4) analysis of participant journals, blogs, and micro-blogs, and (5) usage data from the My Health at Vanderbilt (MHAV) patient portal.

A cross-sectional study recruited from participants from FCV and EWM, and subjects participated in a single research visit to complete the survey instruments and a semi-structured interview. A longitudinal study recruited from FCV, EWM, and GC, and these participants took part in up to three research visits with surveys and semi-structured interviews, a home visit, and analysis of their use of journaling, blogs, micro-blogs, and MHAV during their pregnancy and immediately after delivery. The study protocols were approved by the Vanderbilt University Institutional Review Board.

Data Sources/Collection

Adult pregnant women and their caregivers were approached at all recruitment sites for participation in the two studies. Eligibility criteria included age ≥ 18 years, pregnancy with gestational age < 36 weeks, and home within 100 miles of Vanderbilt University Medical Center (VUMC). The cross-sectional study included participants with the ability to speak English or Spanish; the longitudinal study included only English-speaking subjects. Pregnant women enrolled in each study were allowed to invite up to three caregivers, defined as any individual who would be significantly involved with the care of the mother or child, to participate in the study. All participants provided written informed consent. Participants in the cross-sectional study were excluded from participation in the longitudinal study, and vice versa.

For Spanish-speaking participants, all research materials were translated into Spanish, and a Spanish interpreter was present for the entire research visit. Participants were compensated for their time with a \$25 gift card and reimbursement for their travel to and from VUMC for each research visit completed (i.e., one for the cross-sectional study and up-to three for the longitudinal study). Longitudinal study participants who took part in a home visit were provided with a \$25 gift card.

Interventions

This research project did not involve interventional studies.

Measures

Surveys

Participants completed a demographic questionnaire assessing age, race, ethnicity, home location, marital status, parity, employment status, individual and household income, education, and self-reported technology usage, including use of popular online pregnancy resources and the MHAV patient portal. We recorded the gestational age of the pregnancy at the date of the interview and the relationship between the pregnant woman and any participating caregivers. In English-speaking participants, health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM), a well-validated and widely used measure of health literacy. In Spanish-speaking participants, health literacy was assessed with the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), which is based on and highly correlated with the REALM. Numeracy was measured by the General Health Numeracy Test (GHNT) a 6-item validated questionnaire for assessing general health numeracy. Stress was determined using Cohen's Perceived Stress Scale, a widely used psychological instrument for measuring the perception of stress that has demonstrated high reliability in pregnant populations. The Multidimensional Health Locus of Control (MHLC), a survey based on social learning theory and designed to measure beliefs surrounding sources of health-related behaviors, was measured in all participants. The MHLC contains 18-items with 6-items for each of its three subscales: Internal, Chance and Powerful Others. A technology usage questionnaire asked

participants if they had access to or had used MHAV and if they had used which of the following resources: BabyCenter.com, TheBump.com, FitPregnancy.com, WhatToExpect.com, Pregnancy.com, Text4Baby.org, or other, with an option to describe other sources.

All 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. We constructed descriptive distributions and summary statistics of demographics and survey responses. Continuous variables were summarized with medians and inter-quartile ranges (IQR). Categorical variables were summarized as counts and frequencies.

Semi-structured Interviews and Home Visit

Study subjects 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. As part of this interview, participants were asked questions about technology use and preferences for five different forms of technology: text messaging, automated telephone calls, FaceTime/Skype, social media, and online discussion forums. The following questions for each form of technology: 1) Do you use [technology]? 2) Have you used [technology] to communicate with your healthcare provider(s)? 3) Have you used [technology] for your health in any other way? 4) Would you be willing to use [technology] to communicate with your healthcare provider(s)? 5) Would you be willing to use [technology] to support your health? After responding to each binary (yes/no) question, follow up questions addressed the details of their current use, willingness to use, nature of use, advantages, and disadvantages of each form of technology. Interviewers focused specifically on any barriers to use or ideas for future applications of these forms of technology related to health. Interviews were designed to last approximately one hour. Pregnant women and their caregivers completed research activities separately, with each providing individual responses to survey and interview questions.

Cross-sectional study participants participated in a single interview, which was done at the time of enrollment. Interviews with Spanish-speaking patients were conducted with an interpreter. Individuals in the longitudinal study took part in up to three semi-structured interviews: one at enrollment usually in early to mid-pregnancy, one approximately one to two months prior to delivery, and one approximately one to two months after delivery. In addition, participants in the longitudinal study were given the opportunity to participate in an optional home visit, a research interview done at the participant's home, either prior to or after delivery. At this home visit, two research team members conducted a semi-structured interview including questions on living situation, the physical home, neighborhood and community, daily activities, changes in routine since conception, technology use and preferences, and information needs. 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. One caregiver in the cross-sectional study refused audio recording, and thus, detailed interviewer notes were taken and de-identified prior to analysis.

Health-Related Needs Analyses

Health-related needs of pregnant women and their caregivers were manually extracted from interview transcripts by research team members. The research team employed an expanded concept of "health-related need" as described by Diana 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. Expressions of emotional needs or the desire for support were also recorded, as these needs are prevalent and understudied concerns during pregnancy.

Each health-related need was classified by semantic type and the degree to which the need was met (i.e., met, partially met, or unmet). Semantic types were chosen from a taxonomy of consumer health-related needs or communications developed by the research team. 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. The taxonomy provides a comprehensive schema dividing consumer health-related needs into five 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 medical attention. Social needs include those involving emotion or a request for support, and the other category includes needs not otherwise represented in the taxonomy. At least two 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 (i.e., need of the same semantic type and focused on the same topic) expressed at multiple places in an interview were merged into a single need for that interview. For the longitudinal study, needs identified at each first research visit were entered into a REDCap database and assigned a unique identifier. Duplicate or identical needs that were addressed at more than one interview were recorded separately but labelled with the appropriate unique identifier to track their expression and whether the needs were met over time.

For the cross-sectional study, training of the researchers on the taxonomy was performed by group analysis of 500 needs, with the remaining needs classified independently. Discrepancies in category assignments were discussed to achieve consensus. Inter-rater reliability with Cohen's kappa was measured for the remaining needs to evaluate reproducibility of the taxonomy category assignments. For the longitudinal study, at least two research team members extracted and categorized information needs from all interviews over time, and discrepancies were discussed to achieve consensus. Health-related needs were summarized by source (i.e., pregnant patient or caregiver) and whether they were met. Those reported needs were qualitatively compared for differing themes between pregnant patients and caregivers.

Caregiver Analysis

Interviews from caregivers in the cross-sectional study were analyzed to describe the actions and roles of caregivers during the pregnancy with emphasis on how caregivers attempt to meet the needs of both themselves and the expectant mother. Research team members extracted information about caregiver actions and roles from transcripts of the semi-structured interviews by creating excerpts that were subsequently coded with labels that reflect a patient work framework. Based on the scholarship of Corbin and Strauss, patient work is defined as "exertion of effort and investment of time on the part of patients or family members to produce or accomplish something." Three major types of work are involved: 1) illness work includes tasks directly related to the illness (e.g., taking medications, monitoring blood pressure); 2) everyday life work includes all of the other activities that must go on, regardless of the illness (e.g., meal preparation and child care); 3) biographical work includes strategic activities to reposition oneself or the family in the face of illness (e.g., training for a new type of career or planning a budget for hiring a professional caregiver). Other relevant concepts include articulation work, coordination across actors, tasks, artifacts, and spaces (e.g., arranging for time off from work to attend a medical appointment), and invisible work, the activities that are often overlooked, yet essential (e.g., being available to talk to a patient after she gets test results). Two interview transcripts were coded by five team members to develop and refine the coding scheme. Two of the team members then applied the coding scheme to the remaining transcripts. Two different team members reviewed the coding for accuracy and consistency.

Home Visit Analysis

Home visit interview transcripts were analyzed an iterative, inductive coding approach, with two research team members first reviewing every interview for common themes before creating a codebook for analysis.

After discussion the derived codes in a group setting, the research team agreed on five major themes to include in the codebook: physical home, help in the home, neighborhood and community, the virtual home, and biggest concerns. Subsequently, all interviews were reviewed independently by two researchers to extract relevant excerpts for each code. Discrepancies were discussed to reach consensus.

Social Network Assessment and Analysis

Participants' support networks were assessed by giving participants a sheet of paper with a face in the center, representing the participant, and the following instructions: "Draw or list your support system and indicate the key people/sources that you have relied on as resources during this pregnancy. The most important people should be closer to you or indicated with an *. Also, tell us who these people are. For example, they might be a member of your family, friend, healthcare professional, or internet resource (e.g., contacts from blogs, social networking sites, or other web or mobile application resources)."

From each social network drawing, research team members extracted the total number of elements and number of individual people, groups of people, technologies, and other elements. The role of each person (e.g., husband, sister, or mother), the name or type of each group, and the types of technologies were recorded. Subtypes of technologies were categorized as general Internet search engines (e.g., Google), educational or informational resources (e.g., WebMD), apps (e.g., BabyBump), or social media (e.g., Facebook). For continuous characteristics, we summarized the data using mean and standard deviation, and we compared these variables between pregnant women and caregivers with the use of Wilcoxon rank sum test. For categorical characteristics, we reported the percentages of each category and compared between roles using Pearson Chi-square test. Associations among support system size, components, and stress were examined with Spearman correlation for continuous variables and Pearson's Chi-square test for categorical variables. The 95% confidence interval (CI) was constructed for Spearman correlation coefficient based on 5,000 bootstrap samples. Two-sided p-values < 0.05 were considered significant.

Limitations

The research was performed at a single large academic medical center in the southeastern United States, and most participants were recruited from FCV, an advanced maternal-fetal practice. Only a small number of Spanish-speaking participants were enrolled. Thus, the results may not generalize to other settings and all pregnant families. For the analyses of health-related needs, the determination of whether a need was met was made by the research team in retrospective review of the interview. This limitation is partially mitigated by the fact that the interview 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 two researchers, with research team members discussing all discrepancies. Study participants were aware that the research personnel were not their clinical providers, and thus, they may not have expressed medical needs. In addition, many research interviews were often done before or after clinic visits, and thus, participants may have received answers to their questions or knew they would be answered by their providers. For these reasons, the actual number of needs in this population may have been underestimated by the findings. Technologies evolved significantly between the time of writing the grant proposal, receiving funding, and completing the research project. Thus, the findings may not include contemporary consumer health technologies or reflect current use and preferences for the technologies studied.

RESULTS

Principal Findings / Outcomes

Cross-Sectional Study Population

One hundred participants were enrolled in the cross-sectional study, including 71 pregnant patients and 29 caregivers. Eighty-three participants (57 pregnant women, 26 caregivers) were recruited from FCV and 17 (14 pregnant women, 3 caregivers), from EWM. For the participants recruited from FCV, fetal diagnoses included gastroschisis, spina bifida, congenital heart disease, cardiac arrhythmia, twin pregnancy, placenta previa, placenta accreta, cytomegalovirus infection, and cleft lip and palate. Pregnant participants had an average age of 27.6 years, whereas caregivers were significantly older with an average age of 33.9 years. Twenty percent of participants identified as Black or African American; 71% as White; 1% as Native Hawaiian or Other Pacific Islander; and 8% as Other. Five participants (4 pregnant women, 1 caregiver) were Spanish-speaking. Of all participants, the involved pregnancy was in the second trimester for 19% and the third trimester for 81% at the time data were collected. 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 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.

Longitudinal Study Population

One hundred nine individuals (82 pregnant women and 27 caregivers) were enrolled in the longitudinal study, 69 (63.3%) from FCV, 10 (9.2%) from EWM, and 30 (27.5%) from genetic counselors. Ninety participants (82.6%) were female, and 19 (17.4%) were male. Mean age of participants was 31.0 years, with a range of 18 to 59 years. The reported races of participants were White (83, 76.1%), Black or African American Asian (3, 2.8%), and Other (9, 8.3%), and the reported ethnicities were Hispanic or Latino (11, 10.6%) and Not Hispanic or Latino (93, 89.4%). For the 27 caregivers, the relationships to the pregnant participant were spouse (13, 11.9%), significant other (5, 4.6%), mother/father (4, 3.7%), friend (2, 1.8%), child (2, 1.8%), and other (1, 0.9%). All participants completed first interviews; 70 (64.2%), completed second interviews, and 76 (69.7%) participated in the third interview after delivery. Fifty-nine (59, 54.1%), study subjects completed the home visit. Seventy-one (65.1%) participants had a pregnancy with a fetal diagnosis, 104 (95.4%) a maternal diagnosis, and 32 (29.4%) a diagnosis requiring surgical intervention.

Health-Related Needs Analyses

The 100 participants in the cross-sectional study 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. 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 research team members. The inter-rater reliability for classification of the health-related needs showed almost perfect beyond chance agreement with a Kappa's coefficient of 0.95 ($p < 0.001$).

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 (e.g., placenta previa for the mother or spina bifida of the fetus), with the subcategories of clinical presentation (77, 24.8%), natural history/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 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 three needs were classified as other, all of which pertained to needs regarding naming of the baby.

Both women and caregivers reported needing information on specific pregnancy symptoms, appropriate medications to take, and upcoming tests throughout pregnancy, and both reported using Internet websites and smartphone apps to try to meet these 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 towards future interventions for 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.

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. 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. 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.

Caregiver Analysis

Twenty-nine caregiver interviews from the cross-sectional study were analyzed. Twenty one of the caregivers were male between the ages of 18 and 50 years, and 8 were female between the ages of 23 and

53 years. The gestational age of the baby at the time of the interview was between 20 and 35 weeks with a mean of 30.6 weeks.

Caregiver actions during pregnancy were identified and most commonly involved searching for information, accompanying the patient to medical appointments, planning for the baby, asking questions, and listening and/or providing emotional support. Over 50% of caregivers reported each of these actions, and 98% of caregivers reported searching for information. Approximately 10% of the actions indicated prior experience with caregiving, either from assisting other people (5%) or from caring for other children (5%). Caregivers in this study performed administrative work that included articulation among tasks, technologies, and other people. Many other tasks were classified as articulation work because of the caregiver's role as the mediator between the patient and a variety of entities (e.g., insurance companies, medical providers, and even physical artifacts such as car seats and paint for baby's room). Caregivers spoke at length about providing emotional support for the pregnant woman, listening to her, and collaboratively making sense of aspects of the pregnancy with her. This work is classified as invisible work because it draws on tacit knowledge of the relationship between two people, and it is easily overlooked in an assessment of "tasks." Finally, the caregiver's intimate role in the pregnant woman's life (e.g. spouse, mother, housemate) led to documentation of a substantial amount of everyday life work. There were many examples of household tasks (e.g., care of an elderly parent or meal preparation) that the caregiver performed and may have performed even if the woman were not pregnant. However, many caregivers did report taking on tasks that the pregnant woman would have otherwise normally performed.

We found that the caregivers performed a wide variety of actions, with the majority reporting that they accompanied the patient to medical appointments, planned for the baby, and searched for information on topics such as diagnosis, child care, and other questions. These findings indicate that some of the caregiver actions involve specific, sometimes sequential steps (e.g., making phone calls or searching for information on the Internet). Other actions are less specified (e.g., providing emotional support or caring for children). Still others are difficult to classify as actions because they represented the caregiver holding a "role" rather than performing a task. Examples of such roles include being the source of health insurance and having experience with a disease or with infant care. Many of the activities identified can be supported by consumer health informatics (technologies and innovative educational interventions).

Home Visit Analysis

Fifty-nine individuals (48 pregnant women and 11 caregivers) completed the home visit in the longitudinal study. Two home visit interviews were conducted jointly with the pregnant woman and caregiver while the remaining interviews were conducted individually. Of the 50 participants in the longitudinal study who did not complete a home visit: 21 did not initially consent to a home visit, 4 consented but later declined participation, 5 delivered prior to scheduling a home interview, 5 were hospitalized prior to delivery and did not want to do the home visit after delivery, 6 withdrew from the study before scheduling a home visit, 6 encountered conflicts in scheduling their home visit, and 3 were lost to follow up. Forty-three home visit interviews were completed prior to delivery and 16 were completed after delivery. For those interviews conducted prior to delivery, the interview was done an average of 53 days before delivery (range of 1 day to 135 days before delivery). All participants in this study had pregnancies resulting in a viable live birth. For those interviews done after delivery, the interview was done an average of 67 days after delivery (range of 26 days to 135 days after delivery).

The pregnant participants who did home visits had a mean age of 21.3 years (range = 18 to 42). Most pregnant participants were White (83.7%, n=63), with the remaining participants being Black or African American (4.1%, n=2), Asian (2.0%, n=1), and Other (10.2%, n=5) – specified as Hispanic (n=4) and "Irish/Mexican" (n=1). The caregivers who did home visits were 90.9% male and 9.1% female and had a mean age of 32.8 years (range= 24 to 53). The caregiver study population were White (81.8%, n=9), % Black or African American (9.1%, n=1), 0% Asian (n=0), and Other (9.1%, n=1) specified as Hispanic. Of

the pregnant participants, 23 were recruited from FCV, 21 participants were recruited from EWM, and 4 participants were recruited from genetic counselors. Of the caregivers, 9 were recruited from the FCV, 1 participant was recruited from the EWM program, and 1 participant was recruited from a genetic counselor.

The analysis of home visit interviews identified themes about health management, including the physical home, help at home, community, the virtual home, and biggest concerns. One consistent theme that emerged was ways in which the physical home was hindering or assisting pregnant women and their caregivers. Within the home space, challenges included mobility, accessibility, education, and access to technology. Over three-quarters of participants (46, 78.0%) discussed desired changes in their home to accommodate the physical challenges of pregnancy. Participants suggested adding a ramp to aid in mobility, specific adjustments to appliances such as raising the height of the washer and dryer, changes to the layout of their home such as moving the nursery downstairs, a desire for more space in their kitchen or garage, and a home without stairs. Approximately half of participants (32, 54.2%) noted the ways in which their home was accommodating or helpful in their pregnancy. The common themes that arose were the location of the home in relation to healthcare providers, the proximity of a supportive family member, having easy access to internet and technology in the home, specific items such as TempurPedic® mattresses, a favorable layout of the home, the size of the home, and owning the home. The major themes emerging from discussion of the physical home were functional needs and limitations during and after pregnancy.

Another recurring theme found within the home visit interviews was help in the home. All but 5 pregnant participants reported receiving help in the home from various sources including a nanny, grandparents, aunt, brother, other children, mother, sister, father, and husband or partner. Many participants reported a desire for more help in the home. The most common areas of desired help included: cleaning, childcare, medical help, physical tasks in the home, cooking, and personal care. Many pregnant women discussed a general lack of proactivity in their caregivers, reporting that their husband or partner would “take orders” but were often unsure how to initiate help. Caregivers often acknowledged their lack of initiative. Some pregnant participants described teaching their husbands or partners new skills such as doing laundry, feeding pets, and cooking. One caregiver adjusted appliances to limit lifting for the pregnant woman, and one pregnant woman set alarms on her caregiver’s phone to remind him to feed their animals, a new and non-routine task for the caregiver. Several participants noted that they received help from their older children with cleaning and everyday household activities. Fifteen participants reported receiving support from their neighborhood or community. Such help included answering questions, care of pets or children, emotional support, housework, and medical advice. Many participants found a lack of routine help from their immediate neighborhood but noted they could rely on neighbors in an emergency. Several participants reported that they trust and rely on women in their community that have recently had a baby as opposed to older women, as they felt pregnancy, healthcare, and resources have changed drastically over the years. Participants were asked how the community could be more supportive of pregnant women, and one of the most common responses was more expectant mother parking at shopping centers. Online resources for pregnancy were discussed as part of the “virtual home,” or online community, of pregnant women and caregivers. Several themes emerged regarding the advantages and disadvantages of online forums, support groups, and social media pages. Approximately one-third of participants discussed being actively involved in forums, online support groups, or social media pages and finding them useful for finding answers and avoiding isolation during pregnancy. Another one-third of participants perceived forums and social media support groups as unhelpful and unreliable.

Nearly half of participants (n=24) discussed having at least one biggest concern pertaining to the home. The most common biggest concern involved other children, with other common sources of apprehension being sleep, preparing the home, lifestyle changes, relationships, and pet interactions with the baby.

Social Network Analysis

The social network diagrams of participants in the cross sectional study were analyzed as described above. The 100 participants reported a total of 680 support system components. Individual persons were the most common support system elements, comprising 60.3% (408/680) of the support system for all participants, 58.4% (307/525) for pregnant women, and 57.7% (90/156) for all caregivers. Among individuals cited, first-degree relatives such as spouses, parents, or siblings were the most common, although many individuals also included specific healthcare providers or named friends. The next most common support component was groups of people, making up 19.3% (132/680) of the support system for the entire sample, 21.0% (110/525) for pregnant women, and 21.2% (35/156) for caregivers. Friends, especially those with children, were one of the most common groups in support networks. Other commonly mentioned groups included colleagues, healthcare practices, and members of one's church.

Both groups identified technologies as parts of their support system: 16.2% (112/680) for all participants, 16.8% (88/525) for pregnant women, and 16.0% (25/156) for caregivers. Google (17.9%, 20/112 technology components), Internet searches (18.8%, 21/112), and BabyCenter (12.5%, 14/112) were the most common support network components, but a wide variety of health information technologies were identified, including blogs, online support groups, and online journals. Finally, other resources comprised the smallest part of the support system: 4.2% (28/680) of the system for all participants, 3.8% (20/525) for pregnant women, and 5.1% (8/156) for caregivers. In this category, magazines and books, most notably the book *What to Expect When You're Expecting*, were the most common elements.

Male and female caregivers showed a similar proportion of persons in their support system, but differed in their proportions of groups, technology, and other elements. Female caregivers' support systems included a greater percentage of groups (32.1%, 9/28) than did the support systems of males (18.8%, 24/128), and males reported a greater proportion of technology in their support systems (18.8%, 24/128) than did females (3.6%, 1/28). Males also showed a greater mean number of support elements in every category. The most notable differences between the sexes were within the categories of persons and technology. Male caregivers' support systems, on average, included 3.52 support persons and 1.14 technology elements, while females' support systems consisted of 2.00 persons and 0.13 technology elements.

Among all participants, informational websites were the most popular form of technology support resources (42.1%, 45/107), followed by general Internet search engines (37.3%, 40/107), social media tools (11.2%, 12/107), and apps (9.3%, 10/107). Among pregnant women, informational websites are the most popular form of technological support (41.9%, 36/86), followed by general Internet search engines (33.7%, 29/86), social media tools (12.8%, 11/86), and apps (11.6%, 10/86). Caregivers more frequently reported general Internet search engines (50%, 11/22) as part of their support systems, followed by informational websites (40.9%, 9/22), social media tools (9.1%, 2/22), and then apps (0%, 0/22). Only one female caregiver reported a technology support element (general Internet search engine), whereas males reported support using general Internet search engines (47.6%, 10/21), informational websites (42.9%, 9/21), and social media tools (9.5%, 2/21).

We examined whether the participant characteristics, including the social network size and components, were associated with levels of stress. Stress was not found to significantly correlate with age (Spearman's $Rho = -0.176$, 95% CI: $-0.361, 0.021$, $P = 0.08$), race ($P = .93$), household income (Spearman's $Rho = -0.196$, 95% CI: $-0.395, 0.008$, $P = .06$), or education level (Spearman's $Rho = -0.111$, 95% CI: $-0.286, 0.07$, $P = .27$) within the entire sample. In addition, none of the support system components significantly correlated with stress; among all participant data, pregnant women subset data, and caregiver subset data, there was no significant correlation between stress and the number of persons, groups, technology, and other resources in an individual's support system. The composition of an individual's support system (i.e., percentage of support system distributed across persons, groups, technology, and other support components) also did not correlate significantly with stress. Only individual income, correlated with stress level (Spearman's $Rho = -0.229$, 95% CI: $-0.425, -0.026$, $P = .027$).

Technology Usage Analysis

Technology use and willingness to use questions for text messaging, automated phone calls, FaceTime/Skype, social media, and online discussion forum were summarized for cross-sectional study participants. Most had used all five forms of technology, with text messaging (109, 100%) and social media (99, 90.8%) being the most frequently used. To communicate with healthcare providers, most people had used automated phone calls (57, 52.3%) and some had used text messaging (39, 35.8%), while the other three forms of technology were only used by a small minority of participants for this purpose. However, most participants reported being willing to use several of these forms of technology to contact their healthcare providers, especially text messaging (99, 90.8%) and Skype/FaceTime (81, 74.3%). About one-third of the participants had used text messaging (34, 31.2%), social media (42, 38.5%), and online discussion groups (33, 30.3%) to support their health in other ways. A smaller proportion of the study participants had used automated phone calls (19, 17.4%) or Skype/FaceTime (2, 1.8%) to support their health. However, most participants were willing to use all five forms of technology to support their health, except for automated phone calls (48, 44%).

From the qualitative responses to the questions about technology use and preferences, two codebooks of themes were created. The first codebook described the ways in which participants used the five forms of technology. Three major themes arose in this codebook: 1) personal use, 2) healthcare use, and 3) business/professional use. The second codebook described the preferences related to these forms of technology, including any advantages, disadvantages, or barriers to use. Five major themes arose in this codebook: 1) professionalism, 2) convenience, 3) interpersonal communication, 4) technology issues, and 5) content characteristics.

Most participants reported personal use of several technologies for communicating to family/friends, with this being the most common use of text messaging. The second most popular reason for text messaging was healthcare appointment reminders. When asked how they would be willing to use text messaging for their health, most participants responded they would like to use it for asking provider questions and notifying provider about issues. Most responses about text messaging were positive and commented on convenience, most fitting into the themes of easy to respond and saving time. There were some negative comments about text messaging being unprofessional, not serious, and lacking security. Most participants reported using automated phone calls for healthcare appointment reminders. The overwhelming majority of the responses about automated phone calls were negative, with the most common responses being that participants prefer to talk to a person, automated phone calls takes too much time, and the calls are not personalized.

Skype and FaceTime, like text messaging, had mostly been used by participants for communicating with family and friends, but participants reported limited use for health-related purposes. Many participants, however, were willing to use Skype or FaceTime to communicate with their providers or support their health, and most of the comments about this form of technology were positive. Participants discussed the convenience of using Skype or FaceTime to communicate with healthcare providers because it would allow them to show physical symptoms and could potentially replace an in-person encounter with video messaging. Participants also commented on better interpersonal communication with providers because of the ability to see facial expressions and reactions with video chat technologies.

Most participants reported using social media regularly for communicating with family/friends and getting news/information. While many people used social media for personal purposes, participants discussed worries about social media lacking privacy and security when asked about using this form of technology to contact their healthcare providers or support their health. Lastly, many participants discussed using online discussion forums but noted that they typically only read and did not share their own information. While participants often commented on the volume of unique and different opinions as a positive aspect of online discussion forums, they also noted the lack of transparency about participant qualifications on these forums. Many commented that reading them can take too much time.

MHLC Analysis

Mean MHLC scores were calculated for all participants in the cross sectional study. Average MHLC scores and standard deviation (SD) for participants in the cross sectional study were Internal - 26.9 (4.2), Chance - 15.9 (5.0), and Powerful Others - 17.9 (4.5). Pregnant women's scores were: Internal - 26.4 (4.0), Chance - 17.7 (4.7) and Powerful Others - 15.6 (4.5). Caregivers on average had higher scores on all three subscales: Internal - 27.9 (4.7), Chance - 16.8 (5.8), Powerful Others - 18.2 (4.6). Scores on the Internal subscale were found to be independent of scores on the Chance and Powerful Others subscales. Scores on the Chance and Powerful Others subscales were significantly positively correlated with each other ($p=0.004$). Internal scores were negatively correlated with Chance scores and positively correlated with Powerful Others scores but these relationships were not significant ($p=0.49$ and $p=0.47$, respectively).

Regression analyses examined the relationships among MHLC scores, information-seeking behaviors, and health-related needs. Higher Chance scores were associated with fewer information seeking behaviors ($p=0.002$). Neither Internal nor Powerful Others scores were predictive of number of resources sought. These relationships remained constant when controlling for whether the current pregnancy was the participant's first child. Regression analyses looking at specific websites accessed by pregnant women and caregivers revealed that lower Chance scores associated with MHA V use, regardless of whether this was the participant's first child ($p=0.007$, 0.02). Higher Chance scores were significantly associated with accessing FitPregnancy ($p=0.02$).

MHLC scores were not significantly correlated with the number of health-related needs reported by participants. Internal score was positively correlated with number of logistical needs, and this relationship approached significance ($p=0.06$). In modeling relationships between MHLC scores and subcategories of health-related needs, the Powerful Others score was associated with management and test categories. Informational management needs were positively correlated Powerful Others scores ($p=0.01$) and informational test needs were negatively correlated with Powerful Others score ($p=0.008$). There was no significant relationship between MHLC scores and whether health-related needs were met.

Additional Analyses

This research study generated an enormous amount of consumer health data. Analyses of health-related needs, patient portal usage, and social media usage from the longitudinal study are ongoing and are expected to produce additional results and publications.

Discussion

The reported research revealed that pregnant women and their 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. 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.

The actions and roles of caregivers in pregnancy fit the patient work framework, including the following types of work identified by Corbin and Strauss: illness, everyday life, biographical, articulation, and invisible. Compared with other health conditions (e.g., diabetes or heart conditions), pregnancy seemed to demand fewer traditional forms of illness work, such as medications and monitoring. Even in cases that involved a fetal diagnosis, the pregnant patients in these studies rarely required medications or therapies. However, caregivers reported attending medical appointments, obtaining medications from the pharmacy, and measuring the pregnant woman's blood pressure. To support this work, electronic health records might

be extended to store caregivers' identities and roles to allow performing tasks for the patient or providing patient-generated health data.

Everyday life work involved performing tasks, maintaining and engaging with the environment (especially the home), and interacting with other people. These activities were frequently social, suggesting an opportunity for intervention or education using remote conferencing and social media tools. Childcare was an important activity for many caregivers, including taking over tasks that the pregnant participant had performed previously. Much of the household and caregiving activities of women is typically "invisible" to other members of the family. A useful consumer health tool for pregnancy might support pregnant women in defining these everyday tasks so caregivers can assume responsibility to accomplish them.

Biographical work involved reflection on one's life trajectory, which primarily involved planning the future of the family and taking on new roles. Caregivers discussed financial planning, arranging time to be with the baby, managing the childcare workload for the new baby and other children, and planning for a child who was expected to have a disability. Education and other interventions may assist with these types of biographical work by providing access to information. Invisible work primarily involved providing emotional support to the patient, and collaboratively making sense of a diagnosis with the patient or others. A unique challenge in all pregnancies is dealing with uncertainty. In our study, caregiver participants described coping through religion and spirituality, understanding scientific interpretations of the likelihood of an event, and practices such as meditation. Numerous online support groups and blogs are available to support pregnant women for both uncomplicated pregnancies and a wide range of specific prenatal diagnoses. Fewer such resources are available to the caregivers with similar as well as unique concerns and stresses. Support groups specifically oriented toward pregnancy caregivers could help them become informed about ways to cope with difficult diagnoses and uncertainty.

Articulation work was often required when the caregiver coordinated with other actors, interacted with technologies, or served in a role such as the source of insurance. Articulation work is the often-overlooked investment of time and effort to make sure other activities take place (e.g., coordinating calendars for an appointment). Many activities that we classified as articulation work could be performed by a variety of people. For example, we distinguished between "driving the patient" and "accompanying the patient" to medical appointments. The former can be performed by a taxi driver, but the latter is a task only for specific individuals. This category is especially amenable to application of existing technologies such as delivery and rideshare apps, and coordination tools such as calendaring apps and messaging.

This research project is among the first to examine the concept of health management in the home for pregnancy, and the findings from this analysis have several important implications. Specifically, pregnant women and caregivers identified numerous physical challenges in the home during pregnancy. Pregnant women expressed a consistent need for help with everyday household activities, for which caregivers were sometimes ill-prepared, emphasizing a need for caregiver education. Those caregivers who were able to help took on new roles, often with direction. Personal assistants such as Google Home or Amazon Alexa might be employed support patients with everyday activities such as checking the doorbell, setting timers, turning the lights on, and communicating with others. The most consistently reported deficiency in neighborhoods and community was the availability of parking spaces for pregnant women, which might be addressed in the future with increasing adoption of online ride services such as Uber and Lyft. Such services might be expanded to include assistance with heavy bags, car seats for other children, or additional safety protections for vulnerable pregnant women. Many participants reported receiving support towards their health from individuals residing both near and far including family a few steps away to across the country. The latter connections, made possible through social media, forums, and support groups formed a "virtual home." Participants in this study noted that individuals with recent pregnancy experiences provided more valuable information, and peer-matching programs pairing pregnant women and caregivers with individuals with similar gestational age, pregnancy diagnoses, geographic locations, or delivery sites might support pregnant women and their caregivers in obtaining reliable information during pregnancy. Finally, nearly half of participants reported biggest concerns pertaining to their home. Common concerns were other children,

lifestyle changes, sleep, home location, relationships, and pets. Pregnancy information resources addressing these common concerns might decrease the stress associated with pregnancy and care of a newborn.

This study is also one of the first to examine technologies as part of the support systems of pregnant women and caregivers. We observed that both pregnant women and a diverse set of caregivers reported technologies as a substantial component of the support systems for pregnancy. Pregnant women more frequently cited medical informational sites rather than broad Internet search engines as components of their support system, with social media and apps identified less frequently. Caregivers more often included general Internet search engines in their support networks, followed by informational websites, social media, and apps. These differences suggest that pregnant women may have more specific questions regarding their own pregnancy and the medical conditions of both themselves and of the fetus. Therefore, they seek more specific advice from reputable informational websites like hospital or government sites rather than search broadly using sites like Google. We also noted that male caregivers reported more individual and technology support system components than female caregivers did. This finding provides evidence of the important need for pregnancy-related technology and resources specifically designed for male caregivers, as most pregnancy resources are likely tailored for expectant mothers and a female audience. Overall, pregnant women had larger support systems than their caregivers, suggesting that expectant mothers seek larger and broader support networks during the vulnerable life stage of pregnancy. Pregnant women identified more persons, groups, and technologies as parts of their support systems than did caregivers. The distributions of support systems' components were similar between pregnant women and caregivers, with both groups identifying technologies as substantial parts of their support networks. Unlike prior studies, we did not see any relationship between the size or nature of the support system and stress. The breadth of our pregnant women's and caregivers' support systems may have offered the emotional and informational support that could counter stress. Our only variable that did significantly correlate with stress, individual income, is an external variable that is not easily stabilized or impacted by a support system.

This research project explored the distribution of MHLC scores in both pregnant women and their caregivers and the relationships among MHLC scores, health-related needs, and information seeking-behaviors in this population. We found that pregnant women and caregivers had MHLC scores consistent with published norms, but relationships among the subscales were unique to this population. Powerful Others and Chance scores were significantly, positively correlated; however, there was no significant association between Internal scores and Chance or Powerful Others scores. Prior studies have performed analyses on healthy, undergraduate students and not adult patients currently experiencing the stress and unpredictable nature of pregnancy. Our study participants might have been more likely to view health as a result of multiple sources.

Our findings were not consistent with prior work that found Internal Health Locus of Control to be positively correlated with information-seeking behaviors. Previous studies examining these relationships were completed using either healthy volunteers or mothers of children with disabilities. In these studies, the participants were not themselves experiencing a health condition. In contrast, our sample was composed of pregnant women and caregivers, a majority of whom were experiencing complicated pregnancies. The correlation of Internal scores with information seeking behaviors might be stronger in individuals who are healthy and weaker in those intimately connected to the illness, such as a mother pregnant with a fetal anomaly. Our study demonstrated that feeling like health is a result of fate or luck (i.e., higher Chance scores) was associated with reduced use of resources to obtain health-related information. In particular, individuals with higher Chance scores were less likely to report using MHAV, Vanderbilt's patient portal. Utilization of patient portals or Internet resources is an active process that provides patients the opportunity to take ownership of their health and participate actively in their care. It would follow that individuals who feel their actions have no impact on their health status would be not be as likely to engage in such activities.

Conclusions

This research 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. Most needs are informational in nature, but substantial numbers of medical, logistical, and social needs exist. 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 prognosis for a prenatal diagnosis, 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.

This research reveals that caregivers perform a rich set of activities that support pregnant women to benefit the health and well-being of both mother and child. These activities take place in the deceptively complex context of “everyday life.” Our analysis of caregiver activities revealed that much of the work performed by caregivers is invisible or administrative, work that is frequently unacknowledged. Using a patient work lens to describe context and the work required to navigate them helps one empathize with and more fully understand the experiences of patients and caregivers, and such understanding can be translated into better-designed education and HIT interventions for support.

The home visit component of this research had several interesting findings, which emerged during interviews in the home environment. Most expectant mothers encountered everyday problems with mobility and household management. Pregnant women desired more assistance from caregivers, who often did not know how to help. Caregivers who provided help took on new roles. Many expectant families did not trust advice found online. Almost half of expectant families had biggest concerns that involved the home.

This study is one of the first to demonstrate that technologies formed a substantial component of the support networks for pregnant women and their caregivers. Pregnant women more frequently cited specific medical informational or educational resources, whereas caregivers more commonly reported general Internet search engines in their support networks. Male caregivers more frequently had access to technologies and identified them in their support networks more frequently than did female caregivers. Female caregivers’ support networks during pregnancy included more individuals and groups of persons.

This research project examined technology use and willingness to use for pregnancy and found important gaps between reported use and willingness to use various technologies. Most pregnant women had used text messaging, automated phone calls, Skype/FaceTime, social media, and online discussion forums. To communicate with healthcare providers, most were willing to use text messaging and had not, but desired to use Skype/FaceTime. Fewer were willing to use social media or online discussion forums due to concerns about privacy and security. Most were willing to use text messaging, Skype/FaceTime, or online discussion forums to support health in other ways, but few had done so. About half were willing to use automated phone calls, but most did not like them due to the impersonal nature and time required.

This study is one of the first to measure MHLC scores in pregnant women and caregivers and to determine relationships between the MHLC scores, information-seeking behaviors, and health-related needs in the perinatal setting. MHLC scores in pregnant women and caregivers were consistent with published norms, but their relationships differed from prior studies. Powerful Others and Chance scores were significantly and positively correlated, but there were no significant correlations between Internal scores and Chance or Powerful Others scores. Similar to other studies, Internal MHLC scores were positively correlated with information-seeking behaviors in pregnant women and caregivers. Expectant mothers and caregivers with higher Chance scores were less likely to access pregnancy websites or a patient portal, regardless of whether they had other children. The exception to this trend was that individuals with higher Chance scores were significantly more likely to access FitPregnancy.com, an entertainment-style site with short articles. Pregnant women and caregivers who feel their health outcomes are due to chance may prefer the less formal resources. MHLC scores were not significantly correlated with the total number of health-related needs expressed or whether needs were met.

Significance

As almost all pregnant women and many caregivers in these research studies utilized online resources for guidance and support perinatally, the observed unmet needs in this population represent an important opportunity for the development of improved HIT for pregnancy. Caregivers play an important role, and they have unique needs that are not well met by most resources for pregnancy, which are designed for mothers and/or women. Better support for caregivers can have ripple effects to improve the experience of the mother and baby. In studying health-related needs and management practices, several unique themes emerged in the research interviews done in participants' homes. This finding suggests that comprehensive studies of consumer health-related needs might include studies done in the home, where a significant amount of information-seeking and health management are done. Additional research is needed to understand how technologies function as part of the support system for families during pregnancy and the effects that use of HIT might have on pregnancy outcomes. Pregnant women and their caregivers expressed strong preferences for their use of HIT in communicating with providers and managing their health. Such preferences should be re-assessed as new technologies emerge and technology adoption changes. The MHLC may offer an alternative way to identify individuals not likely to actively seek information to maintain or improve their health. Future research should focus on the best strategies to engage these individuals in health-related activities.

Implications

The findings of this research have several implications for the design of HIT, which may render technologies more 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. 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. Future studies should evaluate the effectiveness of HIT in addressing these unmet needs of expectant mothers and their caregivers and their ability to improve maternal and fetal outcomes.

The caregivers participating in this research described activities that aimed to manage stress and uncertainty and to provide emotional and cognitive support to the pregnant woman. These goals suggest an opportunity to supplement a caregiver “boot camp” with educational interventions that help participants with the following tasks: developing coping and stress management strategies, helping the pregnant woman develop coping and stress management strategies, making sometimes difficult lifestyle changes to accommodate a baby in the household, and planning for incorporating the new baby into family life, and for the future. Our findings align with previous studies that emphasize the importance of the role of the caregiver and suggest that providers encourage pregnant women to identify helpful caregivers and include them in as many aspects of the pregnancy as possible. Caregivers are actively involved in the pregnant woman's life, and they should be included in health care interactions with the approval of the pregnant woman, including not only the administrative aspects such as appointment-making, but also the care-related decision-making and engagement with the provider when questions arise. Many consumer health technologies such as patient

portals offer caregiver access to appointment, information and messaging functions for patients, but they are infrequently utilized for caregivers in pregnancy. This research highlights the rich and frequent activities of pregnancy caregivers, which could be supported by consumer health tools. With an understanding of such activities, healthcare providers could be sure to encourage adoption, not only by pregnant women, but also by the caregivers that accompany them to appointments or are mentioned in interactions.

The findings of home visit analyses have several implications for the design of consumer health technologies or educational resources for pregnant women, caregivers, or individuals planning to have children. Pregnancy poses physical challenges to everyday activities in the home, suggesting the need for supportive home assistants, additional planning, and online tools with information about optimizing the home environment for the limitations of pregnancy. Pregnant women consistently express an unmet need for additional help in the home, reporting that caregivers are under-resourced and unprepared. Thus, this component of the study reaffirmed our findings from other analyses that dedicated resources for caregivers are needed. Neighborhoods can better support pregnancy with additional expectant mother parking or enhanced online ride services addressing the special needs of pregnant women. Some pregnant women find support and community through a virtual home in online forums and social media sites, but improvements are needed enhance the quality of information available. Significant concerns related to the home are common during pregnancy, and resources to support needs related to other children, sleep, relationships, home location, and pets should be incorporated in perinatal education.

Both pregnant women and their caregivers reported technologies as a substantial component of the support systems for pregnancy, and male caregivers noted more support system components than female caregivers. This finding highlights the need for pregnancy-related technology and resources specifically designed for male caregivers, as most pregnancy resources are likely tailored for expectant mothers and a female audience.

The analysis of technology use and willingness to use in pregnant women and their caregivers has several important findings to guide the design of HIT for pregnancy. Many pregnant women and caregivers had used automated phone calls for personal and healthcare purposes and stated they would be willing to continue doing so, but with significant reluctance. Organizations wanting to optimize patient satisfaction should consider abandoning this impersonal form of interaction. In contrast, text messaging and video chatting technologies, such as Skype/FaceTime, had rarely been used to interact with healthcare providers or support health, but many pregnant women and their caregivers would be willing to use them for these purposes if privacy and security issues were addressed. Lastly, social media and online discussion forums were frequently used by pregnant women and their caregivers for communicating with other people and getting information, but they are wary of using these forms of technology to manage their health, often citing lack of privacy and security as major concerns. Developers of future HIT may employ the findings of this study to design future technologies with patient satisfaction and trust in mind. As healthcare consumers gain experience with emerging technologies, their willingness to use them for health may change, and such preferences should be re-examined at periodic intervals.

MHLC scores may provide an assessment to identify individuals unlikely to seek information and to guide designers of HIT in tailoring content for pregnant women and caregivers who are likely to express certain types of informational needs.

LIST OF PUBLICATIONS and PRODUCTS

Manuscripts

1. Dorst MT, Shilo H Anders SH, Chennupati S, Chen Q, Jackson GP. Health information technologies in the support systems of pregnant women and their caregivers: mixed-methods study. *J Med Internet Res.* 2019 May 9;21(5):e10865. doi: 10.2196/10865. PMID:31094327.

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3. Anders S, Aaron H, Jackson GP, Novak L. Supporting caregivers in pregnancy: a qualitative study of their activities and roles J Patient Exp. 2019 Jun;6(2):126-132. doi: 10.1177/2374373518785570. Epub 2018 Jul 16. PMID: 31218258.
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Abstracts and Posters

1. Carpenter SR, Dudek ME, Chen Q, Hurst CB, Jackson GP. Health literacy effects on health-related needs of pregnant women and caregivers. *Poster presentation at National Society of Genetic Counselors 37th Annual Conference in Atlanta, GA, November 14, 2018.*
2. Huth HB, Skeens R, Herzberg S, Anders S, Simpson C, Novak L, Jackson GP. Health management in the home: a qualitative study of pregnant women and their caregivers *Poster presentation at the Research Experiences for Undergraduates Symposium, Alexandria, VA, October 29, 2018.*
3. Anders S, Aaron H, Jackson GP, Novak LL. Designing technologies for caregivers in pregnancy. *Poster presentation at the 2018 International Symposium on Human Factors and Ergonomics in Health Care, Boston, MA, March 27, 2018.*
4. Danko ME, Robinson JR, Skeens RK, Jackson GP. Health-related needs of pregnant women and caregivers with prenatal surgical fetal diagnoses. *Oral presentation at the 13th Annual Academic Surgical Congress, Jacksonville, FL, February 1, 2018.*
5. Dudek M, Grabarits C, Slamon J, Danko M, Robinson J, Novak L, Simpson C, Anders S, Jackson G. Evidence for the crucial role of psychosocial counseling in addressing unmet patient information needs. *Oral presentation at the National Society of Genetic Counselors 36th Annual Conference, Columbus, OH, September 15, 2017.*
6. Chennupati S, Dorst M, Anders S, Jackson GP. Technology usage and preferences during pregnancy. *Poster presentation at the AMIA 2016 Annual Symposium, Chicago, IL, November 14, 2016.*
7. Dudek M, Grabarits C, Slamon J, Dorst M, Chennupati S, Ivory C, Jackson G. Information needs of patients and their caregivers: utility of genetic counselors. *Poster presentation at the National Society of Genetic Counselors 35th Annual Education Conference, Seattle WA, September 28 – October 1, 2016.*
8. Anders S, Novak L, Simpson S, Ingram E, Jackson G. A qualitative analysis of pregnant women and their caregivers' information needs. *Poster presentation at the Academy Health 2016 Annual Research Meeting, June 26 – 28, 2016.*
9. Robinson J, Huth H, Jackson GP. Systematic review on the effect of health information technology in surgical patient care. *Oral presentation at the 2016 Academic Surgical Congress, Jacksonville, FL. February 2 – 4, 2016.*
10. Huth H, Anders S, Jackson GP. Information seeking behaviors of pregnant women and their caregivers: technology usage and preferences. *Poster presentation at the AMIA 2015 Annual Symposium, San Francisco, CA, November 14 – 18, 2015.*
11. Anders S, Novak LL, Simpson C, Ingram E, Davis SA, Jackson GP. A qualitative analysis of pregnant women and their caregivers' information needs. *Poster presentation at 2015 AHRQ Research Conference, Crystal City, VA, October 4 – 6, 2015.*