Health Management in the Home: A Qualitative Study of Pregnant Women and Their Caregivers

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Abstract

With growth in consumer health technologies, patients and caregivers have become increasingly involved in their health and medical care. Such health-related engagement often occurs at home. Pregnancy is a common condition and, for many women, their first exposure to health management practices. This study examined how pregnant women and caregivers managed health in their homes. Participants completed sociodemographic surveys and semi-structured interviews about living situation, information needs, and technology use. Using an iterative, inductive coding approach, we identified themes about health management, including the physical home, help at home, community, the virtual home, and biggest concerns. 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. Over half of expectant families had biggest concerns that involved the home.

Keywords

health information technology, caregiving, challenges, environmental design

Introduction

With widespread availability of the Internet and proliferation of online tools, consumers have become increasingly active participants in health management. There is a movement toward self-service in almost every industry, with consumers buying clothes, booking travel, and banking themselves through online applications. In health care, patients seek information, interact with providers, and receive care outside the walls of the hospital, demanding more accessible and personalized online health services (1,2). As the home becomes realized as a landscape for active health management, patients and caregivers may manage and use health information, even developing specific strategies for storing the information for later use (3,4).

Moen and Brennan defined health information management in the home as work carried out by individuals to acquire, organize, and manage health information for both current and future use (4). Valdez et al further contributed a framework for considering the work that is done by patients and caregivers, including and beyond information management (5). Computers, tablets, and smartphones, and other consumer health information resources, are now ubiquitous, enabling a wide range of personal health information management to occur within the home setting. Although accessibility to such programs has increased, many consumer health platforms such as patient portals remain inherently designed to focus on care within the health care system and are most heavily used by patients with chronic illnesses who interact with the health care system frequently.

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At present, the literature on the health management of pregnancy in the home is primarily limited to the physiological monitoring and reporting of health conditions such as preeclampsia (6), leaving the barriers and facilitators to health management in the home throughout pregnancy widely unknown. Investigations on the self-management of other chronic conditions (7,8) have begun to understand individual aspects of health management activities in the home and have even developed consumer health information technologies to facilitate patient self-care outside health care institutions; however, little has been done to understand the efficiency and effectiveness of such applications or the role of others in one's health care management.

Although a deficit in health management continues to exist, organizations like the Veterans Health Administration are creating services, such as the Care Coordination/Home Telehealth program, to provide in-home health management solutions for veterans. The program has reduced hospital admissions by 19% and receives high-satisfaction ratings, one of the few programs to undergo a successful implementation. It is, however, uncertain if existing programs such as these offer solutions to relevant patient issues pertaining to health management (9). Given the lack of data regarding patient information technology and management within the home, others are attempting to use wearable technologies and applications to better understand such gaps.

Health management in the home is particularly relevant for pregnant women and their caregivers, as pregnancy results in physical, social, and medical changes that affect the need for pertinent information in the home. Pregnancy is a common health condition resulting in over 3.95 million births each year (10), and for many women, pregnancy is their first interaction with the health care system, resulting in the formation of new questions and a heightened need for answers. These information needs are often increased in high-risk pregnancies, making up 5% to 10% of all pregnancies annually (11). We sought to understand the management of a common health condition—pregnancy—in the home not only for pregnant patients but also for a wide variety of caregivers involved in care of the mother or baby. The objective of this study was to understand the health management needs, strategies, and practices within the home during pregnancy to inform the design of health information technologies for expectant families.

Methods

Study Design, Population, and Setting

This mixed methods study is an analysis of home visit data from a longitudinal study examining health-related needs and information management practices in pregnant women and their caregivers. The investigative team used a qualitative approach to capture the broad scope and variability of health management activities within the home that might otherwise be unrealized. Quantitative studies of this population have been published elsewhere (12). Pregnant patients were recruited from 3 sites at Vanderbilt University Medical Center (VUMC): The Fetal Center at Vanderbilt, an advanced maternal-fetal multidisciplinary clinic; genetic counseling; and Expect with Me, a group prenatal care program. The exclusion criteria for the study were non-English speakers, a gestational age greater than 36 weeks upon enrollment, patient age less than 18 years, and a home address greater than 100 miles from VUMC. Participants were compensated for each interview and gas mileage. Pregnant women enrolled in the study were given the option to invite up to 3 adult caregivers to participate in the study. A caregiver was defined as an individual substantially involved in the care of the mother or baby. All participants in the study provided written informed consent. The research protocol was approved by the Vanderbilt University Institutional Review Board.

Data Collection

Individuals in the study took part in up to 4 perinatal research interviews: 1 at enrollment usually in early-to-mid pregnancy, 1 approximately 1 to 2 months prior to delivery, 1 approximately 1 to 2 months after delivery, and 1 home visit, a research interview done at the participant's home. Sociodemographic characteristics including age, sex, race, gestational age, income, employment status, education, parental status, and recruitment site were collected by survey at the first research interview. This study also examines qualitative data gathered from all of the research interviews in the home from this longitudinal study. At this home visit, 2 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. Interview questions were created using the SEIPS 2.0 systems framework (13) to understand the configuration, engagement, and adaptation of the study participants in regard to health management in the home. Interviews were audio recorded, transcribed, and de-identified prior to analysis. Research data were stored in a Research Electronic Data Capture database (14).

Data Analysis

The researchers used an iterative, inductive coding approach (15), with 2 investigators first reviewing each interview in Dedoose, a qualitative analysis tool (16). Common themes surrounding the physical and social environment of everyday pregnancy care at home were identified and coded in Dedoose (16) for further analysis and discussion. Coding is the process is identifying phrases of interest, highlighting the desired text, and applying a categorical tag for easy retrieval during analysis. A detailed review of each extracted theme was completed by the full investigative team of 7 people and yielded 5 major themes which built upon prior research

(17,18) for inclusion 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 2 researchers to comprehensively extract relevant excerpts for each code or theme. Discrepancies were discussed to reach consensus.

Results

Study Population Characteristics

One hundred nine individuals (82 pregnant women, 27 caregivers) were enrolled in the longitudinal study, and 59 individuals completed the home visit. Two interviews were conducted jointly with the pregnant woman and caregiver while the remaining interviews were conducted individually. Of the 50 participants that did not complete a home visit: 21 did not initially consent, 4 consented but later declined, 5 delivered prior to scheduling the interview, 5 were hospitalized prior to delivery and did not wish 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 did not follow up. For those interviews conducted prior to delivery, the interview was done an average of 53 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. The characteristics of participants who completed the home visit are shown in Table 1.

The Physical Home

One consistent theme that emerged in the home visits was ways in which the physical home was hindering or assisting pregnant women and their caregivers in everyday management of their condition. Within the physical home space, health management of pregnancy as a health condition may include mobility, accessibility, education, and access to technology. Over three-quarters of participants (n = 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, raising the height of the washer-dryer, changing the layout of their home such as moving the nursery downstairs, and purchasing a home without stairs. Approximately half of participants (n = 32, 54.2%) noted the ways in which their home was accommodating or helpful in their pregnancy. Examples include the location of the home in relation to health care providers, the proximity of a supportive family member, having easy access to internet and technology in the home, specific items such as TempeurPedic mattresses (Tempur-Pedic North America, LLC), a favorable layout, and owning the home. The major themes emerging from discussion of the physical home were functional needs and limitations during and after pregnancy.

Table 1. Participant Demographics.

	Pregnant participants (n = 48)	Caregivers (n = 11)
Sex		
Male	0	10 (90.9%)
Female	48 (100%)	1 (9.1%)
Age, years		
Mean	21.3	32.8
Range	18-42	24-53
Race		
White	40 (83.3%)	9 (81.8%)
Black or African American	2 (4.2%)	1 (9.1%)
Asian	1 (2.1%)	0
Other	5 (10.4%)	1 (9.1%)
Household income		
Under US$15 000	5 (10.4%)	2 (18.2%)
US$15 000-29 999	4 (8.3%)	3 (27.3%)
US$30 000-44 999	5 (10.4%)	2 (18.1%)
US$45 000-59 999	2 (4.2%)	1 (9.1%)
US$60 000-79 999	6 (12.5%)	0
US$80 000-99 999	5 (10.4%)	2 (18.2%)
US$100 000-119 000	4 (8.3%)	0
US$120 000-139 000	7 (14.6%)	0
US$140 000 or Above	9 (18.8%)	1 (9.1%)
No answer	1 (2.1%)	0
Employment status		
Full-time	24 (50.0%)	9 (81.8%)
Part-time	6 (12.5%)	1 (9.1%)
Not employed	17 (35.4%)	1 (9.1%)
No answer	1 (2.1%)	0
Highest level of education		
High school	6 (12.5%)	5 (45.5%)
Some college courses	6 (12.5%)	2 (18.2%)
2-year college degree	3 (6.2%)	1 (9.1%)
4-year college degree	15 (31.3%)	1 (9.1%)
Master's degree	11 (22.9%)	2 (18.2%)
PhD or equivalent	5 (10.4%)	0
Parental status		
No other children	20 (41.7%)	8 (72.7%)
Have other children	28 (58.3%)	3 (27.3%)
Delivery status at interview		
Before delivery	37 (77.1%)	6 (54.5%)
After delivery	11 (22.9%)	5 (45.5%)
Recruitment site		
Fetal center	23 (47.9%)	9 (81.8%)
Expect with me	21 (43.8%)	1 (9.1%)
Genetic counselor	4 (8.3%)	1 (9.1%)

Roles and Help in the Home

Another recurring theme found within the home visit interviews was help in the home. All but 5 pregnant participants reported receiving help with health management in the home from various sources including a nanny, grandparents, aunt, siblings, parents, other children, and husband/ partner. Several pregnant participants (n = 14, 29.2%) reported receiving help from more than one person. Many participants reported a desire for more help in the home. The most common areas of desired help included: cleaning, childcare, medical help,

Table 2. Help in the Home.

Category	Excerpts
Spouse or partner	"I guess my husband. Like I have, he will, he will like take orders. He doesn't know, like he doesn't, he isn't very proactive, yeah or like, God bless him, but he will listen . . . And he, and he tries."
	"Well he was a lot of help in the first trimester. Doing his own chores, his own laundry. He learned how to use the washing machine. Yeah. I'm pretty domesticated, so yeah he had to learn how to cook and, well he knew how to cook."
Other children	"Usually if I can I'll try to do some kind of cleaning and have him help, I'm like, look [CHILD'S NAME] we're gonna wipe off the front of the refrigerator, he's a towel. We're gonna like actually the other day he helped me clean the baseboards . . ."
Friends and family	"My best friend will be here Monday, and she's a great wife when she's here. She's fantastic. And then, his mom will be here . . . So, that will give me like a month of assistance."

physical tasks, cooking, and personal care. Interview excerpts illustrating common themes emerging around help in the home during pregnancy are shown directly below (Table 2).

Many households developed strategies to provide more assistance to the pregnant woman in the home. The majority of 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. The majority of caregivers acknowledged their overall lack of initiative. Some pregnant participants described teaching their husband or partner new skills done by the pregnant woman before pregnancy 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 nonroutine task for the caregiver. Several participants noted that they received help from their older children with cleaning and everyday household activities.

Neighborhood and Community

Fifteen participants reported receiving support managing their pregnancy from their neighborhood or community. Such help included answering questions, care of pets or children, emotional support, housework, and medical advice. Representative quotations are shown below (Table 3). The majority of the participants found no help from others in their immediate neighborhood, but many noted they could rely on neighbors in an emergency.

Several participants noted that they trust and rely on women in their community that have recently had a baby as opposed to an older women, as they felt pregnancy, health care, and resources have changed drastically over the years.

Table 3. Neighborhood and Community Support.

Category	Excerpts
Questions (n = 1)	"The neighbors, I guess they helped out a little bit, maybe. Asked them questions and all that kind of fun stuff."
Pet care (n = 1)	"Yeah. We have some friends in law school, and one of the things they've done is regularly come by and pick up our dog because he's getting walked a lot less just because of other things."
Emotional support (n = 4)	". . . whether it's just emotional support or her being a resource but also a mom and having been through Vanderbilt, she got me fully set up. I didn't know even where to start when it came to getting ready."
Childcare (n = 4)	"My neighbor across the street help with my daughter in the morning, my older daughter, they take her to school since we've got so much going on its hard to get her in the care in the morning."
Housework (n = 1)	"So she always comes over and helps and random things, stuff like that, or invites us over to her house."
General (n = 1)	"My mom for the most part, she does live 12 steps away from us."
Medical Support (n = 3)	"I called my neighbor across the street who used to be a labor and delivery nurse at Vanderbilt so that was helpful . . . I have a couple of mom friends I speak with around the corner and an older woman who is a couple houses down that we're close with and we kinda share life with them."

Virtual Home

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 sources of information.

Biggest Concern

The majority of participants were asked what their "biggest concern" was and sometimes that involved the home. 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. Representative quotations are shown in Table 4.

Table 4. Home-Related Biggest Concerns.

Concern	Excerpts
Other children (n = 11)	"the fact that I'm not really able to cut back on activity the way that would make me feel most comfortable because I have kids and it's not like I can just go lay down in the bed and like get the pressure off and stuff like that."
Sleep (n = 7)	"Getting enough sleep. I know I won't be a functioning human if I don't get enough sleep."
Preparing the Home (n = 4)	"Other than like, I hope this construction gets done. I really don't want to have an infant in the house with like hoards of men coming through like working on the upstairs."
Lifestyle changes (n = 4)	"Like he [the baby] has full control over what's going to happen, what we're going to do, how our schedule's going to go. Is he going to heal properly? Like all of it's on him."
Relationships (n = 2)	"That's one of the hardest things. I think it's also not taking out any anger on my husband."
Pet and baby interactions (n = 1)	"My dog has had history, it's erratic, it's like once every seven months or something, but he gets aggressive and he'll bite . . . but it's one thing for that to happen to an adult and it's quite another thing for that to happen to a small child and that makes me really, really nervous."
Home location (n = 1)	"The drive out to Vanderbilt. It's about an hour and fifteen minutes and I thought, "Oh, there's definitely gonna be an accident on the way there because today is the day, and of course things don't work out.""
Moving (n = 1)	"Well, the pregnancy, no, but I was concerned about us selling our home and I'm like, "Where are we gonna live?" That was my concern."

Discussion

This study is among the first to examine the concept of health management in the home for pregnancy, and its findings have several important implications for the design of health information technologies for the management of chronic health conditions. While some investigations on home health care during pregnancy report on the monitoring, prevention, and remote reporting of the health conditions surrounding pregnancy (6), they do not address the gaps in our understanding of the everyday health management of pregnancy. As a result, other studies (7,19–21) have analyzed and even entered the home space to investigate the home as a "place of care" and understand health management practices for other chronic health conditions; however, little work has been done to analyze caregiver or greater community involvement in conjunction with self-management in the home. Although such extensive research exists surrounding this topic at large, little has been done to comprehensively how the many components of a patient's homelife impact the experience of health management during pregnancy. Using a qualitative, human factors approach, this study reports on the role of the patient, caregiver, community, and technology in the daily management of pregnancy as a chronic health condition and presents a unique set of information technology needs and behaviors.

Pregnant women expressed a consistent need for help with everyday household activities for which caregivers were sometimes ill-prepared to provide assistance, emphasizing a need for caregiver education. The majority of caregivers were, reportedly, uncertain on how to help their pregnant loved one, and those who were able to help took on new roles, often with direction. Although there is a wealth of online information about pregnancy (10), few resources are available and directed specifically at caregivers. Most focus on the medical aspects of pregnancy, childbirth, and child care, with little emphasis on health management and hindered daily activities. Future online resources for pregnancy caregivers should address these important and unmet caregiver needs to allow them to provide maximal support within the home. Additionally, it is possible that personal assistants (ie, Google Home or Amazon Alexa) can support patients with everyday activities such as checking the doorbell, setting timers, turning the lights on, and communicating with others.

Although support was often received within the home, few participants in this study reported receiving health management–related support within their neighborhood. One participant remarked that the traditional stay-at-home mom and neighborhood community are dying models in the rapid urbanization of the study setting, Nashville, Tennessee. 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.

Communication technologies have supported transition to a more global world, and the participants in this study are no exception. The majority of participants reported receiving support toward their health from individuals on social media, forums, and support groups form a "virtual home." While health information technology in the form of support groups, social media, and forums are readily used, our findings suggest there is room to improve the reliability of information provided while maintaining social support. Previous literature has suggested that the virtual social engagement aspects of mobile applications and websites throughout the transition to motherhood is beneficial for the self-management of health conditions and ultimate care of the child (22). Participants noted engaging with individuals with recent pregnancy experiences, as opposed to older relatives, provided more valuable or modern information. As such, patients could benefit from peer-matching applications that pair pregnant women and caregivers by gestational age, diagnoses, and location to provide support and promote the obtainment of reliable information during pregnancy (9).

Finally, although this study enrolled several individuals confronted with maternal and/or fetal diagnoses—which are

likely to be a significant source of anxiety—nearly half 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 anxiety and stress associated with pregnancy and care of a newborn. It is possible for the findings of this study to be applied to the research and development (8,23) of technological solutions—devices, virtual assistants, peer-matching programs, caregiver HIT, and mobile applications—to aid in health management activities. Although this study investigated the health management of pregnancy, such findings can be applied to a variety of health conditions.

This study has several limitations. The study population was recruited exclusively from a single medical center where the majority of pregnant participants faced high-risk pregnancies. Therefore, participants had heightened interactions with medical professionals, and thus, the findings of this study may not be generalizable to all pregnant women and their caregivers. Lastly, the study was reliant on the self-reporting of sociodemographic variables, help in the home, community, the virtual home, and biggest concerns, so it is possible that actual needs and levels of help differ from the reported results of the study.

Conclusion

The findings of this study have several implications for the design of consumer health technologies or educational resources for pregnant women, caregivers, or individuals planning to have children. The physical and informational challenges posed by pregnancy elicit room for improvement in home assistants, quality online resources, and customizable digital tools to optimize the home for the limitations of the condition. It is essential for such tools to provide targeted resources for caregivers in order to fill the gap in education. Outside the home, the community can better support pregnant women through increased expectant mother parking or enhanced online ride services. It is possible that the significant concerns related to pregnancy can be addressed through perinatal education and the ability to network or communicate with other same-term pregnant women. Ultimately, this study identified the complex needs of pregnant women and their caregivers for which technological innovations can fill the gaps. It is possible for home assistants to provide relevant medical articles, health-tracking watches to take basic vitals measurements, and cellular application to connect fellow pregnant women with others in their region. Such a frameworks might be replicated or applied to the study of health management at home for a variety of other chronic conditions.

Authors' Note

The research protocol was approved by the Vanderbilt University Institutional Review Board.

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Author Biographies

Hannah B Huth recently graduated with a bachelor's degree from Indiana University and will be continuing her education in medical school at the University of Tennessee Health Science Center this fall. Her present research aims to identify and propose solutions for gaps in both smart-infusion pump systems and clinical decision support systems in the clinical setting. Ultimately, she aims to practice as a physician-scientist, promoting patient safety and self-advocacy through medicalinformatics research.

Ryan Skeens is a neonatologist at Vanderbilt University Medical Center where she specializes in prematurity, congenital heart disease, and parent engagement. Her research in biomedical informatics frequently intersects with her medical practice as she studies the role, needs, and activation of parents in the neonatal intensive care unit (NICU).

Shilo Anders research at Vanderbilt University Medical Center applies human factors engineering and user-centered design to improve safety in healthcare. She aims to make health information technology more effective, efficient, and leverageable for the clinical setting.

Simone Herzberg is a graduate student in the MD/PhD program at Vanderbilt University Medical School in the Epidemiology department. Clinically, she is interested in pursuing a career in pediatric orthopedic surgery and is interested in researching the effects of nutrition, stress, and exercise on overall health adn the acute phase response, particularly as it relates to surgical outcomes.

Christopher Simpson is a manager and data analyst at the Department of Biomedical Informatics at Vanderbilt University Medical Center. His current research in the field focuses on consumer health informatics, health information technology, and electronic health records.

Laurie Novak is heavily involved in the sphere of social and organizational reseach in healthcare informatics. She is particularly interested in working at the cultural intersection between technology and personal life to implement AI in healthcare, develop resources for technology use in everyday contexts, and understanding the role of caregiving in the daily maitenance of health conditions.

Gretchen P Jackon's research in biomedical informatics and consumer health informatics leverages technology platforms to empower patients and caregivers to become actively involved in their health care. She continues to combine her roles as a pediatric surgeon and informatician through studying the use of MyHealthAtVanderbilt, an online patient portal utilized by patients at Vanderbilt University Medical Center.