


# Supporting Caregivers in Pregnancy: A Qualitative Study of Their Activities and Roles

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## Abstract

**Background:** The significant role of lay caregivers has been explored in chronic and acute illnesses. In pregnancy, caregivers' (eg, the baby's father, friends, and family) roles in promoting the health of the mother and baby are not well understood. **Objective:** We characterize the activities and roles of pregnancy caregivers and offer opportunities for engaging this important group. **Method:** We conducted interviews with 29 pregnancy caregivers. Interview transcripts were analyzed inductively, resulting in a coding scheme of actions and roles that pregnancy caregivers perform. **Results:** The most common actions and roles included searching for information (97%), accompanying patients to medical appointments (69%), and being a source of emotional support (76%). Identified actions and roles fit a patient work framework, including work types identified by Corbin and Strauss: illness, everyday life, biographical, articulation, and invisible. **Conclusion:** The patient work framework can be employed to describe the activities and roles of pregnancy caregivers. We have contributed new insights into the experiences of pregnancy caregivers and recommendations for educational and technological interventions.

## Keywords

caregiving, challenges, patient engagement, women's health

## Introduction

Prenatal care is one of the most common and important forms of preventive health care; it lowers the risk of low birthweight infants and birthweight-specific deaths and reduces maternal and infant mortality (1). Advances in prenatal care enabled earlier detection of anomalies, resulting in opportunities for fetal intervention and the reduced risk of fetal death (1,2). While prenatal care typically refers to services provided by health-care professionals and directed at the pregnant patient, it is also recognized that layperson caregivers, such as the father of the baby, other family members, or friends, may play significant roles in promoting and maintaining the health of the mother and baby. The unique actions, roles, and needs of caregivers in pregnancy have not been explored, and as such, few resources and tools are available to pregnancy caregivers, either in traditional prenatal care settings or in electronic or online formats. This article describes the activities and roles of a group that has not been extensively studied: pregnancy caregivers. This

study aims to advance the science and knowledge about caregivers by (1) applying a patient work framework (3) previously proposed for understanding the activities of chronically ill patients in caregivers of pregnant women and (2) contributing new insights into the experiences and challenges of pregnancy caregivers.

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## Caregiving

Caregiving is defined here as supporting or acting on behalf of a patient. In pregnancy, the participants of caregiving are both the expectant mother and her fetus. The roles and activities of caregivers are diverse, complex, and ill-defined, and they likely depend on many factors associated with the patient, the caregiver, and the environment. Multiple studies have found that patients and caregivers mutually benefit from the caregiving experience (4–6). In addition to traditional medical tasks, caregiving has been shown to include activities such as sharing food, babysitting, errands, connecting patients to supportive social networks, and inspiring patients to return to certain activities (7). Despite the significant contributions of caregiving, these activities are often not recognized by society, health-care institutions, and insurance companies.

Caregivers are often at risk for increased depression and health problems (8). A study of pregnant couples demonstrated that the stress of pregnancy was experienced differently by mothers and fathers, and the types of support provided to each group may not match their unique needs (9). It is important to note that pregnancy caregivers not only assist mothers with a self-limited medical condition but also act as a caregiver of the baby and mother immediately after birth.

While both prenatal care and caregiving for chronic illnesses have been studied (2,10), their intersection—pregnancy caregiving—has not been rigorously examined. The most well-studied caregiving role in pregnancy is that of the father of the baby, and a father's participation during pregnancy has been demonstrated to have important social, emotional, and clinical effects (11). For example, a father's involvement in the pregnancy has been shown to increase the likelihood of the mother receiving prenatal care by 1.5 times and reduce tobacco usage by mothers who were smokers at conception (12). Similarly, another study found that the type of involvement by the father correlated with clinical outcomes (eg, birth weight) and maternal behaviors (eg, alcohol use and prenatal visit attendance), thus suggesting that the nature of the caregiving role mattered (13). Pregnant women who perceived themselves to have more social support from their partners had lower anxiety during pregnancy (11). Although caregiving during pregnancy is a common and important set of activities that has the potential to improve the pregnant person's mental and emotional health by alleviating anxiety and giving the mother a greater sense of support, few studies have examined pregnancy caregiving activities.

## Patient Work

Patient work, as conceptualized by Valdez et al (3), is an interdisciplinary framework for describing the (typically

unpaid) efforts of patients and caregivers. Informed by theory and practice in the social sciences and human factors engineering, the key benefit of the patient work approach is that it connects activities to their context, allowing for a broader conceptualization of the actions of patients and caregivers. 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” (14). Three major types of work are involved: (1) *illness work* includes tasks directly related to the illness (eg, taking medications, monitoring blood pressure); (2) *everyday life work* includes all of the other activities that must go on, regardless of the illness (eg, meal preparation and child care); and (3) *biographical work* includes more strategic activities to reposition oneself or the family in the face of illness (eg, training for a new type of career or planning a budget for hiring a professional caregiver) (14). Other relevant concepts from Strauss include *articulation work*, coordination across actors, tasks, artifacts, and spaces (eg, arranging for time off from work to attend a medical appointment), and *invisible work*, the activities that are often overlooked, yet essential (eg, being available to talk to a patient after she gets test results) (15).

The research aim of this study was to describe the activities and roles of caregivers of pregnant women. To address that aim, we applied the patient work framework (3) to pregnancy caregivers with the goal of contributing new insights that will assist in the development of new education and supportive interventions that address the experiences and challenges of pregnancy caregiving. Describing elements of the “system” of activity and the types of activities can produce specific guidance for educational interventions.

## Ethical Clearance

This study was approved by the institutional review board of Vanderbilt University. Each participant provided written informed consent, and all study participants received a \$25 gift card and travel reimbursement.

## Methods

### Participants

This analysis comes from a prospective, cross-sectional, mixed-methods study that aimed to identify the characteristics of health-care consumers, their information needs, and their information-seeking behaviors. Pregnant women and their caregivers, speaking English or Spanish, were recruited from the Junior League Fetal Center (FCV) at Vanderbilt University Medical Center (VUMC) or the Vanderbilt Expect With Me (EWM) group prenatal care program. The FCV sees mothers who are experiencing a pregnancy with a risk for or an identified congenital anomaly or complication

and administers care through a multidisciplinary team of skilled medical specialists at a single location. The EWM is an innovative group prenatal care program that involves traditional prenatal care with health education and support delivered in a group setting. Pregnant women recruited from both sites were allowed to invite up to 3 caregiver participants. Caregivers were defined as anyone who would be involved with the care of the mother or child in a significant way. Eligibility criteria included a pregnancy less than 36 weeks' gestational age at enrollment and a home address within 100 miles of VUMC.

This study enrolled a total of 100 participants, with study size estimated to be sufficient to achieve theme saturation for the topics being explored and maximum determined by the budgetary limitations of the funding source. Eligible individuals were approached by research personnel not involved in the clinical care of the pregnant woman or her child, and informed consent obtained from pregnant women and caregivers at the time of their research activities. Enrollment continued until 100 individuals completed the study.

### Procedure

The participants in this study completed 1 research visit involving a sociodemographic questionnaire and a semi-structured interview. The interviews were audio-recorded, transcribed, translated to English, and deidentified prior to analysis. Topics of the interviews included issues related to the pregnancy, concerns of the caregivers, information needs, and an assessment of the utility of various technologies. Spanish-speaking participants completed a Spanish language questionnaire, and a Spanish interpreter was present for the research visit.

### Analysis

The goal of the analysis was 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. The transcripts were subjected to a general thematic analysis (ie, open coding) and subsequently analyzed using Corbin and Strauss's patient work framework (14,15). Two interview transcripts were coded by 5 team members to develop and refine the coding scheme. The coding scheme included 21 codes that described activities and roles assumed by caregivers, as summarized in Table 1. Two of the team members then applied the coding scheme to the other 27 transcripts. Two different team members reviewed the coding for accuracy and consistency. The coding scheme described activities that were analyzed to examine the *patient work types* as outlined by Corbin and Strauss (14,15).

### Results

Twenty-nine caregivers were enrolled in the study. Of these, 21 participants 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. Participants' demographic information is shown in Table 2.

Caregiver actions and roles identified in the analysis of interviews are summarized and classified in Table 1. Although not explicitly articulated as roles, the categories of activities reported define additional pregnancy caregiver roles, namely, being available to serve as a source of administrative support, physical support, information, and assisting with caregiving of others. Thus, activities defined the caregiver's role, for example, the act of driving the patient to an appointment comprises the role of driver. However, some roles involved little activity related to the pregnancy, for example, being the source of insurance through one's workplace does not entail specific, pregnancy-related activity yet is an important caregiver role.

The most common actions were searching for information, accompanying the patient to medical appointments, planning for the baby, asking questions, and listening and/or providing emotional and physical 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 place as the mediator between the patient and a variety of entities (eg, 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 2 people and is easily overlooked in an assessment of "tasks." Yet, providing emotional support is an essential activity that can be supported through health services and technology. Finally, the caregiver's intimate role in the pregnant woman's life (eg, spouse, mother, housemate) led to documentation of a substantial number of actions that constituted everyday life work. There were many examples of household tasks (eg, care of an elderly parent or meal preparation) that the caregiver performed and may have performed even if the woman were not pregnant. However, caregivers did report taking on tasks that the pregnant woman would have otherwise normally performed.

**Table 1.** Actions and Roles of Caregivers.

Work Type	Activity or Role	Percent Reporting	Description
Articulation work	Administrative: Driving the patient (various destinations)	34	Driving the patient to appointments or other locations
	Administrative: Making appointments	10	Arranging pregnant participant's prenatal appointments
	Administrative: Making phone calls	21	Talking to doctor on behalf of patient on the phone
	Information seeking: Asking questions	66	Active way of searching for information, if the caregiver voices specific questions or concerns they have, asking health-care provider or friends or family
	Information seeking: Searching for information	97	Attempting to obtain answers to information needs by asking questions, looking online, reading written materials, watching videos, etc
	Miscellaneous: Making care-related decisions	24	Being involved in the decision about which health-care provider to use for prenatal care, which hospital to go to for delivery, or other details concerning the birth plan
	Payment: Source of insurance	17	Appointments and prescriptions are covered by caregiver's health insurance
Biographical work	Planning: Planning for baby	66	Engaging in activity that aids the transition when baby is born (ie, supplying baby clothes, crib car seat, room, and/or other emotional or mental preparation)
	Planning: Planning for future	14	Discussing lifestyle changes that are not directly related to care of the baby but are brought about by the anticipated arrival of the child
Everyday life work	Assisting: Assisting other people	69	Act of caregiving to anyone besides the pregnant woman, prior to or during pregnancy
	Assisting: Caring for other children	38	Tending to pregnant participant's other children during pregnancy
	Emotional and cognitive support: Participating in social activities with patient	34	Attending a class with pregnant woman or other social activity that is new during the span of pregnancy
	Emotional and cognitive support: Source of experience with children	45	Provide answers, reassurance, or explanations for pregnant patient's concerns or question about pregnancy or raising a child
	Physical support: Exercising with the patient	17	Doing physical activity with the pregnant woman
Illness work	Administrative: Handling prescriptions and other medications	14	Picking up prenatal medications and/or remind patient to take them
	Emotional and cognitive support: Source of experience with disease	10	Being available to provide answers, reassurance, or explanations for pregnant patient's concerns or questions about the congenital anomaly
	Interaction with medical provider: Accompanying patient to medical appointments	69	Going with patient to prenatal appointments, more active than driving patient
	Medical task: Monitoring physiological status	17	Checking patient's vital signs (ie, blood sugar, blood pressure, fetal heartbeat)
	Physical support: Nonspecific support and care	59	Physical care support such as massage, reminders to eat, rest, and elevate feet
	Payment: Paying for care-related expenses	24	Monetary source for items related to prenatal care, newborn items
Invisible work	Emotional and cognitive support: Listening/providing emotional support	76	Talking with participant about pregnancy, voicing desire to support mother of baby, listening to mother talk about pregnancy
	Emotional and cognitive support: Make sense of illness	31	Contribute to mother's understanding of pregnancy and/or other prenatal diagnosis, the action of giving information that one possesses by virtue of having experience with illness/pregnancy

## Discussion and Conclusion

### *Discussion: Using the Lens of Health-Related Human Work to Improve the Experience of Caregivers*

Caregiving involves much more than basic illness (or in this case, pregnancy) care (7). 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. They served or were available to fill significant roles, including being the source of health insurance, emotional support, administrative support, physical support, information, and assistance with the caregiving of others.

**Table 2.** Participant Demographics.

Demographic Category	Percentage (n)
Race <sup>a</sup>	
Caucasian	72.4 (21)
African American	20.7 (6)
Hispanic or Latino	10.7 (3)
Caregiver type	
Spouse or significant other	62.1 (18)
Parent	24.1 (7)
Sibling	6.9 (2)
Adult children	3.4 (1)
Living situation	
With pregnant women	79.3 (23)
Live elsewhere	20.7 (6)
Where receiving pregnancy care	
FCV	89.7 (26)
EWM	10.3 (3)

Abbreviations: EWM, Expect With Me; FCV, Junior League Fetal Center.

<sup>a</sup>Not mutually exclusive.

Our findings indicate that some of the caregiver actions involve specific, sometimes sequential steps (eg, making phone calls or searching for information on the Internet). Other actions are less specified (eg, providing emotional support or caring for children). Still others are difficult to classify as actions because they represent the caregiver holding a “role” rather than actively performing a task. Examples of such roles include being the source of health insurance and having experience with a disease or with infant care in general. Many of the activities we identified can be supported by consumer health informatics technologies and innovative educational interventions. In this regard, it is instructive to consider the types of work performed, how they involve specific elements of the work system, and how they could be supported by new or existing interventions including health information technologies.

In general, compared with other health conditions (eg, diabetes or heart conditions), pregnancy demands fewer traditional forms of *illness work* such as medications and monitoring. Even in cases that involved a fetal diagnosis, the pregnant patients in our study rarely required medications or other therapy. 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 afford 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 are 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. In our study, information needs included prognosis for children with specific diagnoses, experiences of other families, general information about financial and career planning, and counseling for other significant life changes such as drug or alcohol rehabilitation.

*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 (eg, 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.

## Conclusion

This study suggests that caregivers perform a rich set of activities and serve in important roles that support pregnant women to benefit the health and well-being of both mother and child. These activities and roles 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 contexts and the work required to navigate them helps us empathize with and more fully understand the experiences of patients and caregivers, and we believe such understanding can be translated into better-designed education and technology interventions for support.

In addition to the sociological classification of work described here, future work with the patient work framework would extend to modeling tasks, actors, and environments (3). Using a human factors engineering perspective, concrete contextual factors could be described that would contribute to identifying and developing supportive education and technology-based solutions. Caregivers certainly play a role, and better support for them can have ripple effects to improve the experience of the mother and baby. For this reason, this research should be extended to include caregiver activities throughout the pregnancy and into the postpartum phase. Research among dementia caregivers has demonstrated that caregiver needs change over time (16). This article reports on a study that included only 1 interview with each caregiver. In a second longitudinal study, our preliminary results suggest that caregiver needs may change over the trajectory of the pregnancy and birth.

Finally, more research is needed to extend our understanding of pregnancy caregivers' activities by examining specific, at-risk populations such as undocumented immigrants and pregnant women suffering from addiction, where caregivers may have an intensified role in the care of the mother or baby.

## Practice Implications

### *Patient and Caregiver Education*

The participants in our study described activities and roles that aimed to manage stress and uncertainty and provide emotional and cognitive support to the pregnant woman. These goals suggest an opportunity to supplement the “boot camp” educational interventions with content that helps participants:

- develop coping and stress management strategies,
- help the pregnant woman develop coping and stress management strategies,
- make difficult lifestyle changes to accommodate a baby in the household, and
- plan for incorporating the new baby into family life, and for the future.

Our findings align with those of 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.

## Health Services Delivery

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. This would include not only administrative aspects such as appointment-making but also 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 who are unable or unwilling to use them, but they are infrequently utilized for caregivers in pregnancy (17). 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, health-care providers could be sure to encourage adoption, not only by pregnant women but also by the caregivers who accompany them to appointments or are mentioned in interactions.

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