

More than morning sickness: Researcher studies hyperemesis gravidarum survivor stories

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Credit: Unsplash/CC0 Public Domain

Imagine waking up one morning feeling ill, like you've come down with an unrelentingly bad stomach bug.

You throw up once, and then again. It continues for hours on end, the whole day long. You're so ill, you lay down to sleep on the bathroom floor, next to the toilet, so that you won't wake your partner when you have to vomit throughout the night.

The next day is the same—relentless illness, throwing up all day long. Twenty times. Fifty times. It just won't stop.

The next day is the exactly same. And the next. And the next.

When you go to your doctor in search of some kind of relief, they don't believe you when you tell them how awful you feel, how debilitating it is—not just physically, but also mentally—to be constantly sick. They say you need to "suck it up." Stop complaining. You're just being negative and lazy. You need to be tougher.

A nurse gives you some IV fluids and sends you home. You come back to the clinic or the emergency room over and over again for more fluids. It continues for months, but no matter what you do, the sickness never goes away.

Until you give birth.

The life-threatening pregnancy condition called [hyperemesis gravidarum](#) has gained some awareness in recent years through media attention around high-profile women who've struggled with it during their pregnancies.

But hyperemesis gravidarum remains a clinically and culturally misunderstood condition, says the UConn School of Nursing's Cheryl Beck, a Board of Trustees Distinguished Professor and certified nurse midwife.

"I have seen clinically with women how devastating hyperemesis gravidarum is," Beck says. "It's really misunderstood, and it's under-diagnosed, and many times family and friends or even clinicians will minimize it and say, "Yeah, it's morning sickness. You know, everybody gets it. It'll go away." This is so different."

'Statistics are human beings with the tears wiped off'

A prolific researcher, Beck has spent 20 years studying traumatic birth and its long-term implications. Through her work, she's uncovered some of the consequences that pregnant people face when they experience trauma during birth—it effects the breastfeeding experience and impacts mother-infant bonding, and can leave survivors panic-stricken about what they might experience in a subsequent pregnancy.

Recently, Beck has turned her research focus toward exploring the impact of specific types of traumatic birth. A qualitative and mixed methods researcher, Beck has published 200 journal articles through her work and developed the Postpartum Depression Screening Scale (PDSS) based on her qualitative studies.

When she teaches qualitative research methods to doctoral students at UConn, she often quotes the science writer Paul Brodeur, who in 1985 wrote that "statistics are human beings with the tears wiped off."

For hyperemesis gravidarum, statistically 1% to 2% of pregnancies experience the condition.

"But then, what's the tears?" asks Beck. "You've got to put the tears to that one to two percent. What are the experiences of the women? Our patients are so complex that to really understand whatever the topic is you are researching, you need both quantitative and qualitative together to really give you the complete picture."

In her qualitative work, Beck has found "rich data," she says, in examining blogs written personally by those living with diseases or conditions, which is how she approached her examination of hyperemesis gravidarum.

In [a study published in](#) the *Journal of Infusion Nursing*, Beck evaluated 33 blog posts from women in Australia published by Hyperemesis Australia, a nationwide charitable organization dedicated to supporting individuals suffering with the condition, their families, and [health care providers](#).

Debilitating not only physically, but emotionally and psychologically

In evaluating the blogs, Beck found six consistent themes expressed by survivors of the condition. The women talked about the debilitating physical and mental health problems caused by hyperemesis gravidarum. They vomited 20 to 50 times each day, beginning early in their pregnancies—the condition typically starts before 16 weeks gestation—and continuing until birth.

Their hair fell out, they lost weight, and some even lost teeth. They were constantly in hospital emergency departments seeking rehydration therapy.

They suffered from varying levels of depression, felt isolated, experienced panic attacks, and some even contemplated suicide. They also suffered [financial pressures](#), as many were unable to work, and they struggled to care for older children while in the depths of illness.

They also wrote about the agonizing choices that they faced. Some made the difficult decision to terminate their wanted pregnancies due to the

severity of their condition. Others grappled with whether they could endure subsequent pregnancies knowing that they would likely face the condition again—89% of women who experience hyperemesis gravidarum have a recurrence in their next pregnancy.

In their blogs, the women also described the guilt they felt around their unborn child. They worried not only that their illness would negatively impact the health of the child by depriving the developing fetus of adequate nutrition—studies have shown that women with hyperemesis gravidarum are more likely to experience pre-term birth and low birth weight. But they also feared that they would struggle to bond with the infant after birth, and those fears often proved true postpartum.

The women all consistently described experiencing a lack of understanding or concern from family and friends, but also from their medical providers, who would dismiss or minimize their symptoms. Conversely, women who found [support systems](#) in their [personal lives](#) and had compassionate caregivers and understanding employers reported better outcomes and expressed high levels of gratitude for that care.

They all expressed feelings of empowerment for surviving hyperemesis gravidarum and a desire to share their stories to support others living with the condition and help them feel less alone.

Attention to detail—and a human touch—are crucial

The main takeaway for clinicians from the study, says Beck, is to validate that what pregnant patients with hyperemesis gravidarum are experiencing is real and valid trauma.

"Clinicians need to be educated about the high percentage of women who go on to have postpartum depression, who view this pregnancy as traumatic and can develop PTSD," Beck says. "Women talked about

how, while they were going through it, there was no attention at all to their mental health. So, that's one of the takeaways—even if the clinicians do pay attention to their physical symptoms, there is a huge psychological aspect.

"One woman talked about the 'death zone,' the dark days of the pregnancy. Clinicians and family need to realize the depth of the struggle that these women are trying to cope with."

She also said that little things—like when infusion nurses would warm IV fluids before administering them to try to help prevent further vomiting—meant a lot to the women who wrote the blogs.

While the study focused only on women in Australia, the sample size of 33 blogs was relatively small, and further study is needed, Beck believes the findings would be applicable to individuals with hyperemesis gravidarum anywhere.

For her part, Beck plans to continue researching different types of pregnancy and birth trauma to help shine light on conditions and how they impact patients, families and clinicians, using personal online writing to uncover the experiences of those who live through them.

"There's been a lot written on blogs regarding illness and how helpful blogs are, because when somebody writes, they write about the meaning of their experience—it helps give meaning to them for their experience," she says. "There's a benefit of blogs, because you get connected, like these women with other [women](#) who have experienced hyperemesis gravidarum. You don't feel so isolated. You support each other."

Earlier this year, she published a study looking at blogs on [postpartum preeclampsia](#). In 2022, she looked at [perinatal obsessive-compulsive disorder](#), and she examined narratives of [postpartum psychosis in 2020](#).

More information: Cheryl Tatano Beck, Survivors' Experiences of Hyperemesis Gravidarum, *Journal of Infusion Nursing* (2023). [DOI: 10.1097/NAN.0000000000000520](https://doi.org/10.1097/NAN.0000000000000520)

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