



# Social Media in the Exam Room: Stories of Human Papillomavirus Disease and Prevention

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DURING AN ADOLESCENT well-child check, the exam room can be a crowded place. Although the parent, the doctor, and the young patient might be the only ones in the room, anecdotes about vaccines, mostly from social media, take up a lot of space. And these stories are not passive observers—they make themselves known. Anecdotal narratives can shape a parent's perception of human papillomavirus (HPV) vaccines and influence the doctor's approach to discussion about these cancer-preventing vaccines.

In 2014, Meredith Prohaska's story became ubiquitous across social media and had all the hallmarks of a story designed to create hesitancy in any parent considering the HPV vaccine for his or her child. Meredith was 12 years old and living outside Milwaukee when she received her first dose of the HPV vaccine. She died later that day. Rebecca Prohaska, Meredith's mother, told the local Fox affiliate, "The only thing different about that day was the shot. I wish I would've known more about it before I agreed to it."<sup>1</sup>

Meredith's story was picked up by multiple news sources and shared widely across social media. The original Fox news story was shared 10,000 times on Facebook. From there, antivaccine parents and activists spread the story of Meredith's tragic death, stating definitively that her death was tied directly to the HPV vaccine. VacTruth's post about the story was shared more than 20,000 times on Facebook,<sup>2</sup> and Health Impact News' post was shared nearly a million times.<sup>3</sup>

As it turns out, Meredith Prohaska did not die from a reaction to the HPV vaccine. Almost 3 months after her death, an autopsy showed Meredith died from diphenhydramine intoxication. The reporting on this autopsy by the local Fox affiliate was shared only 1000 times on Facebook. Thus, the real reason for Meredith Prohaska's death received only one-tenth of the social media coverage than the story linking the HPV vaccine to her death.<sup>4</sup>

Although the Prohaska story seems to confirm the observation that frightening news has more appeal than complete facts, we have room for optimism about the HPV vaccine's position in the social media landscape. One study

examining messages about the HPV vaccine across Twitter reported that positive Tweets mentioning the vaccine outnumbered negative Tweets about the vaccine, 38.99% to 25.31%.<sup>5</sup> Although this study does not suggest an overwhelmingly positive view of the vaccine on social media, it does indicate that the commonly held belief that social media is bombarded with negative chatter about the vaccine might not be true.

However, parents and providers often make assumptions that venturing into a discussion about HPV vaccines on social media is problematic, that these discussions are more contentious than online discussion about other vaccines, and that hosting HPV vaccine discussions online requires substantially more work than most other social media discussions. These assumptions might be based on experiences discussing the vaccine online, as well as experiences in the exam room. One survey found that physicians reported that exam-room discussions about the HPV vaccine were nearly twice as long as discussions about the Tdap vaccine.<sup>6</sup>

The conflict between the somewhat positive Twitter activity surrounding the HPV vaccine and the hesitance to discuss this vaccine online brings us back to stories like Meredith Prohaska's. While immunization community advocates are busy crafting tweets about studies showing that the vaccine is connected to no serious side effects, antivaccine groups like SANEvax are collecting stories about adolescents who died shortly after receiving the HPV vaccine. Although backed up by no evidence, the latter story is simply more memorable and more emotionally captivating than the scientific facts.

However, the reality of an HPV infection is not without its own emotional draw. Each year in the United States, doctors diagnose 29,100 cases of cancers related to the strains of HPV—cancers that are now vaccine-preventable.<sup>7</sup> Each of these cases contains multiple stories: stories of doctors making diagnoses and treating patients; stories of young men and women who had no predisposition to cancer; and stories of family members who stand by feeling helpless or guilty or confused. In fact, many of these stories are already available for sharing via social media through

the American Cancer Society, [ShotByShot.org](http://ShotByShot.org), and other organizations.

The stories of HPV cancer survivors and victims deserve a place in the exam room, and they need to occupy space the same way the antivaccine stories do—through social media. The social media environment is receptive to this message, as we have seen with the positive messaging about the HPV vaccine on Twitter. Although it might seem time-consuming to engage in these kinds of discussions on social media, sharing content about HPV cancer stories primes the exam room discussion about HPV vaccines in a positive manner. The exam room needs doctors, nurses, patients, and parents to create online content about their experiences with HPV cancer and the need for protection from HPV vaccines. In addition, social media is begging for more scientifically savvy users to start discussions about these stories by sharing them and wading into existing conversations. Providers and advocates can also encourage the broader community, from schools to insurers to the media, to share these stories. This would allow the immunization community to spend its time leading the discussion rather than dispelling myths, guiding it toward the area of most importance: a lesson about what these cancers we prevent look like in our lives and how the vaccines help prevent them.

## ACKNOWLEDGMENTS

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