Journey of a Woman With Terminal Cervical Cancer

Theresa A. Kessler, PhD

When a cervical cancer diagnosis is made during a terminal stage, a woman is faced with many challenges. Although a terminal illness has many negative effects, such as physical pain, scarring, fear, and sexual dysfunction (Gotay, Farley, Kawamoto, & Mearig, 2008), women may experience a positive impact on their life, such as improved well-being (Gotay et al., 2008) and a greater appreciation of daily life (Skeath et al., 2013). The individual experience can lead to personal revelations. Sometimes, the diagnosis can even be seen as a blessing (Bahti, 2010). Understanding a personal experience in a real-life context of the terminal stages of disease is important. This story shares the day-to-day journey of a woman living with a terminal illness of cervical cancer. We will call her Tina.

Shortly after giving birth to her son, Tina was diagnosed with terminal cervical cancer. During an in-depth interview, Tina shared her experiences, insights, and hopes for those around her. Her journey included accepting the mixed blessings of her diagnosis, the hopes she had for each day, her views about the impact of disease on her body, and the legacy she hoped to leave for her family and other women.

The Journey
Acceptance of Mixed Blessings

During her illness trajectory, Tina acknowledged changes in her new role as mother and wife. These changes within a family frequently occur during the terminal stages of a disease (Zeng, Ching, & Loke, 2011).

I wanted to be woken and . . . awakened, and I wanted to feed [my son]. I wanted them to carry him down for every diaper change, and I wanted to get back to knowing my son again.

Tina also experienced the mixed blessings of learning about her diagnosis.

Apparently, I had my tumor for at least two years, so had my obstetrician discovered it earlier, I wouldn’t have been able to have children. . . . We’re really, in a sense, glad that it wasn’t diagnosed earlier.

This view that the diagnosis can even be a blessing helps to manage the diagnosis in a positive way (Bahti, 2010; Clemmens, Knafl, Lev, & McCorkle, 2008)

Tina also had to accept support from others. Being dependent on healthcare providers (HCPs) was particularly difficult.

[HCPs] made it possible for me to live as long as . . . as long as I’m blessed with living. These people . . . without them . . . I couldn’t have fought as hard . . . as I fought.

Even though dependence can undermine a sense of meaning (Khan et al., 2010), support from HCPs is essential along the journey (Reeve, Lynch, Lloyd-Williams, & Payne, 2012). Tina came to realize this dependence.

Mission of Hope for Each Day

Tina had a strong desire to control daily events, and she worked to make daily situations more manageable, whether they were insignificant actions or more consequential. “I was a bit of a control freak. . . . I thought that I would still be super-mom, super-wife, nothing was gonna change.”

Tina didn’t want HCPs, her family, or even friends to do things for her or know how she may not be able to control what was happening.

I would write everything down, and then I would come home and do everything. . . . I would purposefully go to some of my doctors’ offices and make sure that I was made up . . . so I wouldn’t become an inpatient because I was too dehydrated or whatnot.

A desire exists to tackle as much of the illness as possible to maintain daily control (Reeve et al., 2012). Tina maintained this desire to fight and control the battle as long as she could, in essence, until she had no further hope.

In her home, Tina created a “wall of love” to surround her physical living space and give her hope. This wall of love included cards sent to her from her husband, son, and family. “I started
to create . . . my wall of love, so I taped each card [to the wall]. Now it extends into the living room . . . for my wall of love.”

The wall of love gave her hope and a daily reminder of those who loved her. The physical presence of the cards was essential, and the cards served as daily reminders of hope and her desire to fight the battle.

**Badges of Honor**

A unique perspective from Tina was her thoughts surrounding the connection between the physical changes in her body and the responses she was feeling inside her body. Tina viewed her physical markers, such as surgical scars and hair loss, as honorable badges of her journey.

“My badges of honor are all the scars on my stomach and on my back, and those things just aren’t important when you’re fighting for your life. . . . You are not your hair and . . . when your hair falls out, it’s tough, but it’s another badge of honor.

These thoughts from Tina about her body’s physical changes were unique glimpses into how she viewed her battle.

**Desire for a Legacy**

In Tina’s desire to help others, she wanted to leave a message for her family, friends, and other women. Tina was worried about what life would be like after her death. She had dreams for her family and wanted to share her insights with other survivors. She expressed the following wishes. “I want them to always know in their heart that I gave everything I had for this journey . . . dedicating to do as much preparation for my son and . . . my husband as I could.”

For most patients, being worried about family is a major feature of a terminal disease (Block, 2006). Tina also wanted to reach other women and share her experiences. Tina gave her interview in hopes of helping others. Educating others about screening was essential.

“You know, when you go to the nail salon, I was on . . . my mission, [which] was to make sure women had their yearly exams, and anybody that will listen to me . . . I can weave our conversation to that.

When Tina was able, she spent time sending and receiving emails. She talked about her daily feelings and her experiences. These emails were so important to her legacy that she named them “T-mails.”

“I was honest. . . . I didn’t candy-coat anything. When I had my bad days, I wrote about that. When I had my fears, I wrote about that, and it was therapeutic. . . . I wanted to be true to . . . what the journey was.

She wanted to encourage at least one other person to fight the battle. By sharing her ideas and educating others, Tina was present for others in the future and made a positive impact on others.

**Discussion**

Although the long-term survival impact of invasive cervical cancer has been documented in the literature (Clemmens et al., 2008; Gotay et al., 2008; Zeng et al., 2011), little is known about living day to day with the terminal stages of the disease. Tina’s unique glimpses demonstrate the vibrant ways in which she viewed her journey. Her experiences were dynamic and focused on strategies to cope. Tina wanted to take charge of her illness trajectory and keep her daily life from being disrupted—a fighting spirit. Women can engage in trying to live well and prepare for the eventual end of life at the same time (Bahti, 2010; Skeath et al., 2013).

Although this was one woman’s perspective, her personal journey is valuable. Her personal experiences led to reflection and were manifested in strengthening the resolve she already had. Tina’s life reflected the interconnectedness of living with a terminal illness. She wanted to maintain control and hope each day; these desires provide meaning to her life and demonstrated the worth of everyday living (Clayton et al., 2008). Tina’s daily adversities and physical changes were badges of honor to display to all. She wanted to help her family through the journey of loss and prepare them for a time when she would no longer be there.

Personal experiences like Tina’s can be used to educate HCPs. The demands of a terminal illness are a dynamic process for not only the patient, but also for family and friends. When a prognosis is terminal, HCPs need to help patients maintain hope and assist them with treatment. HCPs must provide open, honest, and compassionate education so patients can make informed decisions across the terminal illness trajectory (Bahti, 2010). HCPs must provide strategies that help patients take charge. People need to be active participants in their care, and HCPs need to know to promote a sense of hope and support their desire for control (Clayton et al., 2008). According to Reeve et al. (2012), HCPs must consider interactions with patients in the larger cultural context of health care. Not only are the technical aspects of care important, but also the communication, empathy, and personalized care to support self-management.

**Conclusion**

The value in reading Tina’s perspective is to educate other women, their family members, and HCPs about this personal experience. Tina’s desire was to help other women who may be experiencing the same illness. She realized that this diagnosis was something that should not have happened to her. For cervical cancer, effective primary and secondary prevention strategies exist. All women should receive education on prevention and screening, and they are encouraged to follow those strategies. Until women no longer experience a terminal diagnosis of cervical cancer, HCPs must understand the unique journey of each woman and value the process as an unfolding story for each woman. Tina’s experiences should be shared with other women who have cervical cancer and their family members because, ultimately, the entire family travels along this journey.

**References**


Do You Have an Interesting Topic to Share?

Patient & Family Perspectives provides readers with a brief narrative of patients’ and their family members’ cancer experience. Length should be no more than 1,000–1,500 words, exclusive of tables, figures, insets, and references. If interested, contact Associate Editor Meghan L. Underhill, PhD, RN, AOCNS®, at meghanl_underhill@dfci.harvard.edu.