

FIELD NOTES | FALL 2016

## A three-stranded cord is not quickly broken: a trifold narrative of a young cancer patient's journey

By Angela Cooke-Jackson, Taylor McMahon, and Dana Mendes



Though perplexed with the meaninglessness of life and the selfishness of men, Solomon finds a moment in his reflection to observe that three companions working together are more resilient than the one who stands alone. In Ecclesiastes 4:12 he says, “Though one may be overpowered, two can define themselves and a cord of three strands is not quickly broken.” The parallels of the cancer narrative and the values of making the journey with companionship can easily be transferred to this passage of scripture. Solomon’s reflections provide a beautiful connection to the narrative of three who from their unique vantage points offer a cohesive story of a journey of difficulties, triumphs and adversities. We invite you, the reader, to experience the journey of cancer through our threefold cord – field notes from three different perspectives - a teacher, a student and a young female diagnosed with cancer.

## Introduction

*Dana, it's cancer --  
Myelodysplastic syndrome.  
No college for you.*

This haiku, while structured and predictable in its 5, 7, 5 pattern muffled the mind of 18-year-old Dana, as her parents sat her down to share the news. A cancer diagnosis is devastating to anyone, but to a young field hockey player preparing for her first year of college, news of a serious disease of the blood would change her life plan – she'd feel paralyzed. Myelodysplastic syndrome (MDS) makes up 4 in 100,000 cases of precancerous blood diseases each year (Germing). Common among the elderly, MDS if untreated risks progression into acute myeloid leukemia (“Understanding Myelodysplastic Syndromes”). With little time to process, Dana began her journey -- one that would challenge her mind and body, while simultaneously transforming her outlook on life and bringing forth new friendships.



## Communication Builds [Online] Community: A Cancer Patient's Notes

Unlike most 18-year-olds, I'm not the most tech-savvy person out there. Once I knew my diagnosis however, I had a feeling in my gut that this journey was something I should document through notes and media. I knew that something big was supposed to come out of this; I prayed not knowing God's plans but trusting completely. So, I began recording: first on my iPhone. A close relative eventually introduced me to a professor - the second strain - who provided me with video camera and other equipment and happily offered assistance for my "documentary". Within days the professor introduced me to an energetic college student - the third strain. Over the next 6 months she would assist me in taping and organizing my photos, art and media. All three of us - a cord of three strains, were bound to become partners in the expression of my story – The Dana Story: Transformative Cancer. We would form an unbreakable bond.



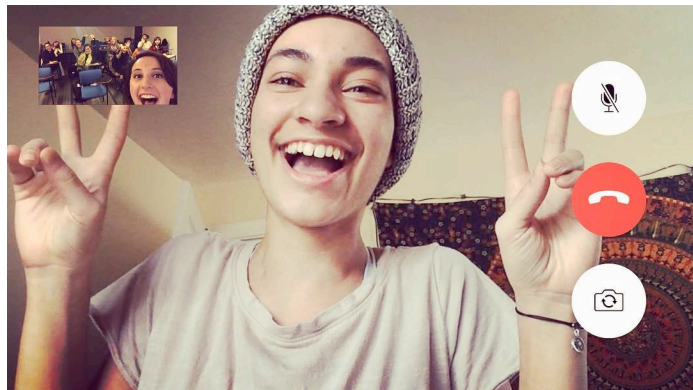
### Communication Builds [Health] Narrative: A Professor's Notes

Narrative communication has become a powerful catalyst for sharing personal health stories with larger communities. Kreuter et al., (2007) have defined narrative as “a representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed.” Videos, podcast and other social media platforms like Twitter, Instagram and Facebook are now respected mechanisms to frame and share health and illness narratives.



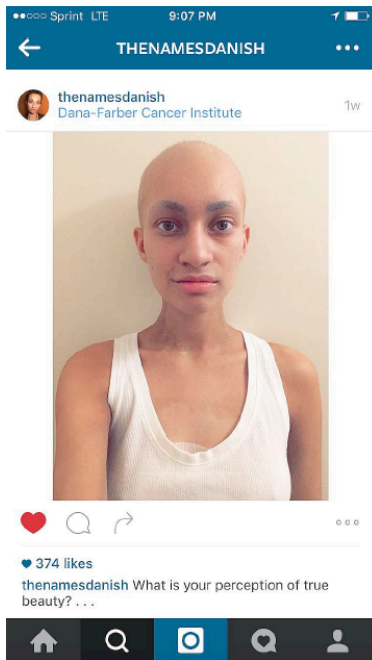
### Communication Enhances [Emerging] Identity: A Student's Notes

I was readying myself for my final year of college when Dana began her chemotherapy and bone marrow transplant with her biological sister Bianca. When my professor introduced me to Dana's Story, I knew I needed to take part. Little did I know that visits to the hospital, hours of videotaping, and countless text messages would foster a caring, honest relationship between Dana and me. Taking on the participant-observer role, I submersed myself into the lives of Dana and her family.



It was an experience that challenged my perceptions of identity, as I witnessed Dana's profound discoveries of her new normal – a young cancer patient. We are both a part of what Jeffrey Arnett terms *Emerging Adulthood* - a period of development that categorizes individuals from 18-24. Neither fully dependent nor independent from caregivers, these individuals are searching for self and understanding of the world; they are seeking autonomy. Dana's new layer of medical limbo meant she was no longer in the realm of pediatric care nor quite old enough to be the sphere of adult care. This gap in the cancer prognosis makes it difficult and rare for the adolescent cancer narrative to travel outside the hospital bed and into the public. Dana believed that conversations about cancer didn't have to be scary... that to see all sides of her illness could be instrumental in encouraging any person willing to listen.

## Communication Transforms Social Media = Artificial Beauty: A Professor's Notes



Narratives of cancer and beauty are seemingly at odds with each other. Those diagnosed talk of the beauty-related fears as one of their first reactions after being diagnosed. For instance, individuals' diagnosed with breast cancer often talk about how they will be perceived by their partners after having a partial or full mastectomy - feelings of self-consciousness and lost of femininity color and often paralyze their forward momentum. Suleika Jaouad says in her *Life Interrupted* *New York Times* column, "to share my cancer with my 1,500 Facebook "friends" felt way too public... after all cancer is not something you "like" on Facebook." So... how does Dana combat a filtered online identity while dealing with her cancer diagnosis? Her desire – do it with openness, transparency and truth. She observes:

Throughout my life, I often focused on my outward appearance. I wasn't impressed with it. It rooted from grade school; comments from people about the size of my "parrot nose", or the gap in my teeth big enough to "fit a golf ball". For someone as young as I was at the time, you can just imagine the negative effects it had on me, especially as a girl. As I matured, it began to humble me, taught me

how to treat others, and judge them based on what matters; their heart, not their beauty, or lack thereof.

Once I'd begun treatment, about ten days after my final round of chemo, the inevitable happened, chunk by chunk my hair was falling out. Weeks later, my eyebrows and eyelashes followed. I felt bare, and even jokingly referred to myself as a naked mole-rat at times. I sat back and observed the behaviors of those around me, watching which ones felt entitled to treating people a certain way all because of a pretty face, and the ones who judged those around them the right way; by who they are as a person – their words, actions, and positivity.

## Communication Propels Creativity: Transformation Mounted on Paper: Our Notes

The progression of Dana's watercolor painting emulates the journey of her cancer narrative. Her work has the power to create change in the cancer community and beyond. This portrait is but one of the many platforms of communication and expression that make up the mosaic of Dana's story. It manifests her experiences of fear, frustration, and hope. It embodies the ways in which individuals and those connected to cancer can communicate with each other. Our three narratives make up the universal story of humankind -- one to share and cherish.



*Translating Cancer by Dana Mendes (2016) watercolor and colored pencil on watercolor paper*

### **Concluding Thoughts**

The inspiration for this piece was one that grew naturally in my heart. Looking back on the timeline of my diagnosis, my core of friends realized that as the seasons transitioned so to did my health - thus the process of sickness to health paralleled paradoxically with the changing of the seasons.

*Fall (Aug-Dec)* I first discovered my diagnosis and expectations for my official admission for treatment. This period mimicked nature as it prepares for winter. My slow health “deterioration” along with my physical and mental preparation seemed inevitable.

*Winter (Dec-Jan)* The admission to clinic. My health was at its worst and essentially “dead” from a combination of full-intensive chemotherapy and a bone marrow transplant from my sister, Bianca. Like winter - known as the hardest season of all with freezing temperatures, snow, sleet, storms - my body felt dormant. I patiently hoped for Spring.

*Spring (Jan-Present)* A time of recovery with growth and regeneration of plants, animals, and life – so begin my journey toward wellness. Mentally, physically and spiritually, I saw myself maturing even flourishing beyond most people's expectations – I had been regenerated.

*Summer (The Future)* The season arrived! I am getting well becoming stronger. I have been cleared to attend college and different aspects of Dana’s Story have emerged. Art work, a short video clip and more. Opportunities and blessings bring warmth, light and beauty - my summer.

I did not have a say in this diagnosis, if I did I would have chosen a different path. Months later, I don't regret anything even amidst pain, heartbreak, betrayal, hate, doubt, and of course fear. My hope – to grow stronger physically, mentally and most importantly, spiritually. My expression “blooming where I am planted” - holding onto the promise that “I can do all things through Christ who gives me strength”.

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*This collaboration highlights the field notes from three individuals - a professor, a college student and a young female cancer survivor. The objective - share our respective insights as we seek to negotiate and understand topics of pediatric cancer in relationship to beauty, social media and art.*  
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