
Emerging Horizons, Part Two.

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Harmony's Story: Answering the Big Question

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Abstract

This second installment of the *Emerging Horizons* series explores Harmony's digital storytelling (DST) experience (please see the introductory editorial to the series, *Crafting Meaning, Cultivating Understanding*, to access the film). In this article I lean on the philosophy of Paul Ricœur to suggest that 1) the metaphorical possibilities of DST could enable Adolescent and Young Adult (AYA) cancer survivors to come to a deeper understanding of their own cancer experiences and 2) the process of "emplotment" in the creation of a digital story has the power to transform the random and coincidental, pre-narrative experience of cancer into a meaningful whole. I conclude by discussing how attaching meaning to, and learning from, an otherwise meaningless cancer experience through the DST process, can help AYA cancer survivors construct their own answer to the "big question" of cancer in young adulthood.

Keywords

Hermeneutics, digital storytelling, adolescents and young adults, psychosocial oncology, narrative interventions, arts-based methodology, documentary filmmaking

Harmony's bubbly personality was apparent from the moment she appeared on the screen. She was energetic, expressive, and engaged -- a perfect fit for her job as an elementary school teacher. However, underlying her extroverted character were deep existential questions; something about her thyroid cancer diagnosis and treatments still lingered.

Like most adolescent and young adult (AYA) thyroid cancer patients, she was told that she had

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the “good cancer” (Randle et al., 2017) with a 98% 5-year net survival rate (Canadian Cancer Statistics Advisory Committee, 2019). Her major neck surgery took weeks to recover from leaving a significant scar, and the radioactive iodine required physical isolation from her family for 10 days, but for the most part, her treatments were straightforward. Even when she had a reoccurrence a year later, with the cancer having spread to lymph nodes in her neck, a second round of the same treatments seemed routine. So, why was she still thinking about cancer eight months later, she wondered? That whole chapter of her life seemed like a random and meaningless detour in her life story. In her own words, “It was not a story that was worth telling,” so why did she feel compelled to sign up for the study?

Together, Harmony and I (first author, Lang) mused about these questions in her pre-workshop interview and were unable to answer any of them, yet she intuitively understood that it was important for her to be involved in the project. Ultimately, it was Harmony herself who discovered the answers to her questions, with the DST process providing both the impetus and framework to do that important work. Her story arc in *Emerging Horizons* illustrates the value of DST as an opportunity to use metaphor to deepen understanding and make the coincidences of life meaningful and, in this process, help AYAs find their own answer to the “big question” that can confront them when they are diagnosed with cancer.

stop, Stop, STOP!

Harmony: I'm kinda going off this stop sign.

Mike: Love it! You are starting to develop a central metaphor.

Harmony: Ha! OK!

Mike: So, what about going past it was meaningful?

A central element of digital storytelling (DST), that will be explored in more detail in a future publication, is the use of metaphor and imagery to enhance hermeneutic excess (Davey, 2013; Ricœur, 1976) and access the deeper emotional level of lived experiences (Van Laer et al., 2014). Historically, metaphor is a central element of hermeneutic research due to the ability of a judiciously used metaphor to carry or convey interpretations (Moules et al., 2015). Ricœur (2003), in particular, devoted significant attention to the exploration of how metaphors can create and recreate meaning. Harmony's experience in *Emerging Horizons* is a practical example of how DST can leverage the “positive and productive use of ambiguity” (Ricœur, 1976, p. 74) available through metaphor.

In the first session, Harmony quickly identified the stop sign as a central image of her experience when she shared her “meaningful moment” with the group (i.e., finding the story phase of DST; Laing et al., 2017a; Lang et al., 2019). She vividly remembered the stop sign in the middle of the hospital hallway as she was preparing for her radioactive iodine treatments. It was strange and out of place with caution tape draped around it, and this strangeness produced one of the most memorable moments in her cancer experience. The sign literally stopped her. She turned around and walked back to the nursing station to ask if she could go past the stop sign. The nurse responded “Yes you can. Those signs are for everyone else.”

Reflecting back, Harmony intuitively knew that moment was one of the most meaningful of her entire cancer experience, but she had not yet stopped to think about why. In the early stages of the DST process, she had difficulty articulating why the stop sign moment was meaningful and what it represented to her. All she understood was that it mattered, and it was in the conversations with other workshop participants, and through the reflection required for creative writing (i.e., telling the story phase of DST; Laing et al., 2017a; Lang et al., 2019), that she discovered *why* it mattered.

After recognizing the importance of the stop sign, she began developing her digital story around it, and was surprised and excited when I pointed out that she had intuitively begun developing a central metaphor for her story. In subsequent writing, she used the stop sign metaphor literally when describing her trips to and from the hospital and hitting “every red light” along the way. She also used it metaphorically in the way that cancer had stopped her from living the life she wanted or had expected (“Stop traveling. Stop being a present mother. Stop plans to grow your family. Stop dreaming. Stop looking forward. . . Stop, STOP!”). Eventually, in a story circle conversation with Bethany, she recognized the visual potential of the metaphor as well. Bethany suggested using images of driving in the city versus an open country road to visually leverage our cultural understanding of the “open road” as a symbol of freedom (i.e., freedom from personal expectations, freedom from the routine and mundane, freedom from cultural constraints). In this way, as Harmony continued the video editing process (i.e., crafting the story; Laing et al., 2017a; Lang et al., 2019) and conversing with the other AYAs, the stop sign morphed into a robust metaphor that helped everyone, including Harmony, understand at a deeper level her inner emotional experience of cancer.

Harmony’s experience also demonstrated the ability of a digital story to leverage the interpretive potential of metaphors beyond what is possible in the creation process alone (i.e., beyond the finding, telling, and crafting phases of DST). Through the screening and discussion of her digital story (i.e., showing the story; Laing et al., 2017a; Lang et al., 2019), the understanding of her own experience that had been cultivated through the creation of the digital story was further deepened as her stop sign metaphor was reinterpreted in conversations with others. In other words, the emerging horizon of her cancer experience was continually reformed as it merged with the horizons of other audience members. Below is a short list of the interpretations that were offered by the AYAs and their friends and family following the viewing of her digital story:

1. At diagnosis, it feels like cancer has stopped you from living the life you had expected (i.e., achieving independence from parents, start a family and careers, travel, etc.);
2. Cancer, like all stop signs, only creates a momentary pause in your life, and eventually you need to keep going. Cancer only stops you from living if you allow it to (“I moved beyond that sign”);
3. After being diagnosed with cancer as an AYA, the culturally determined road signs and mile markers of life (e.g., education, family, career, etc.) do not seem to matter as much (“Those signs are for everyone else . . .”);
4. AYAs are free to choose their own road after cancer because they have been forced to stop and determine what matters to them early in their life. (“It has also given me the opportunity to open my heart, my thoughts, and my perceptions of what matters”).

Many of the interpretations offered by the AYAs and their friends and family went beyond Harmony's original intentions for her stop sign metaphor, providing a clear demonstration of how the hermeneutical excess available in a digital story can help cultivate understanding in both the storyteller and the audience. Through conversation with others, Harmony's understanding of her own metaphor, and consequently her cancer experience, was deepened.

One particular moment represented the resonance of Harmony's stop sign metaphor with the other AYAs. In the small group screening at the end of the DST weekend workshop, Kelsey responded with widened eyes and an audible gasp when the music in Harmony's story suddenly stopped exactly as she heard the word "cancer" from her doctor. For Kelsey, and the other AYAs in the group, the music stopping at that moment reverberated through their own experience; when hearing the word cancer for the first time it can feel like the whole world stops, just like the music in Harmony's story.¹ In the discussion that followed the screening of Harmony's story, Bethany highlighted the power of that particular story element, and Harmony explained that it was actually an editing "mistake." The group was shocked, and out of this moment emerges another interpretation of Harmony's DST experience.

When Coincidence Creates Harmony

Bethany: Really loved the way you just stopped the music. Very dramatic.

Harmony: Again, a mistake!

Bethany: What?! Really?!

Harmony: That's what I was hitting Mike about when he was working with Derek... it just stopped, and I don't know if I would've thought . . . to do that.

Ricœur (1990), in his three volumes of *Time and Narrative*, explored the hermeneutic circle that exists between the human experience of time and narrative. He argued that human experience has a "pre-narrative" coincidental quality that needs to be meaningfully and coherently organized into a narrative by means of developing a plot, which he termed "emplotment" (Ricœur, 1990). As the basic feature of narrative, a plot allows humans to pick out, order, and assign significance to the otherwise random and temporally disconnected events of our lives, turning them into an intelligible whole (Ricœur, 1990). Essentially, Ricœur argued that narrative allows humans to make sense of our confused and unformed experience of time itself. When crafting a narrative, we can place specific experiences together *in time* to re-present causality (i.e., moments selected and included in a digital story are connected to each other because they occur within three minutes of time) and create connections between events that occurred *across time* (i.e., moments selected and included in a digital story could have occurred days, months, or years, apart, but are connected to each other through their emplotment). In Harmony's DST experience, the power of narrative to transform the coincidental, pre-narrative experience of cancer into a meaningful event is on full display and offers a practical example of the theory suggested by Ricœur (1990) in two different, but parallel, ways.

First, in Harmony's digital story itself, the relatively mundane experience of driving in the city and the basic traffic signs and symbols (e.g., stop signs, traffic lights, congested roads) become meaningful when temporally ordered in her story plot. Specifically, the significance of "hitting

every red light” on the drive to the hospital on both the morning of her cancer diagnosis and the morning radioactive iodine treatment becomes significant in their emplotment; their temporal location in the plot (i.e., *in time*) foreshadowed both Harmony’s cancer diagnosis and her stop sign encounter in the hospital hallway. Furthermore, connecting both driving experiences with the other events of her cancer experience, which occurred over the space of many months (i.e., *across time*), these mundane or “meaningless” driving moments became meaningful; they became a symbol of cancer stymying Harmony’s desires and plans for her life. By providing Harmony the opportunity to construct a plot that assigned significance to these seemingly coincidental events surrounding her cancer diagnosis and treatment in her digital story, all of these events became more meaningful.

A second illustration of how emplotment can help assign meaning to coincidental events occurred in real-time on screen through the events surrounding the creation of Harmony’s digital story. During the discussion of her story at the end of the weekend workshop, it was revealed that, in two different places, a “mistake,” or coincidence, led to meaningful and compelling story elements. The first was the accidental recording of a truck passing on the highway outside of the workshop space during her voiceover recording. When Harmony and I were completing the final edits to her story she said, “Did you purposely let there be a sound at the end of a transport truck? . . . You hear it! Would we be able to bring it up a little . . . drove past it!” We intentionally boosted the audio level of the truck and the resulting effect contributed a compelling auditory complement to Harmony’s closing image of the open road. Bethany immediately noticed this auditory element saying, “love that sound at the end!” and Harmony responded with an enthusiastic “ha!” as I explained its origins.

The second “mistake” of the music stopping when Harmony heard the word cancer from her doctor was also revealed in the group discussion. The visceral response of Harmony during the editing process (i.e., hitting my arm), Kelsey’s wide eyes and gasp during the viewing of the story, and Bethany’s additional comment and surprise all demonstrated that this coincidence also contributed a meaningful aesthetic element to the story. Crucially, when Harmony recognized how the representation of her cancer experience was enhanced by those two coincidences in the video editing process, she chose to highlight them instead of fixing them. In other words, those coincidences were only meaningful because she actively chose to make them meaningful; she chose to craft meaning out of coincidence to create greater harmony in her story.

These two examples from Harmony’s DST creation experience of hitting red lights and embracing video editing mistakes demonstrate how highlighting, or interpreting (i.e., “all interpretation is highlighting,” Gadamer, 1960/2004, p. 401), coincidental life events within an artwork can make those events more meaningful. In the first case, providing AYAs the opportunity to narrate, visualize, and compose their cancer experiences into a digital story (i.e., casually connect life events *in* and *across* time), promotes the identification of life lessons that may be embedded in a “pre-narrative” cancer experience. This could be an important outcome for AYAs as learning is antithetical to meaninglessness; nothing is wasted if you learn from it. Secondly, Harmony’s experience of incorporating “mistakes” into her story displays how making meaning out of coincidental life experiences can be an internally driven activity, potentially enhanced through DST (i.e., emplotment). Together, these two realizations could be

transformative for AYAs, and could ultimately help lead to a partial and momentary answer to the “big question” that confronts many of them.

Answering the “Big Question”

Over the past 12 years I have facilitated film screenings and discussions with thousands of AYA cancer survivors and continue to do so. As part of these screenings, I often share moments from my own cancer story. One moment I share happened three months into my treatments when I was lying face down on the floor of my parent’s basement at 4 am, punching the carpet until my knuckles were bloody. That moment, for me, represents the extreme limit of the existential distress that accompanied my cancer experience. I explain to the audience that in that moment, I was struggling with “the big question,” and I ask if anyone has an idea of what I am referring to with that phrase? Without fail, in a matter of seconds someone calls out, “*Why me?!?*”

This question is particularly troublesome for AYAs as it is unlikely for people in their 20s and 30s to have had sufficient exposure to the known behavioural or environmental causes of cancer that could explain their diagnosis (e.g., smoking, alcohol, poor diet, obesity, air pollution, sun exposure, carcinogens, etc; National Comprehensive Cancer Network, 2020). For this demographic in particular, cancer is most often a random occurrence of gene mutation that can only be explained by factors completely outside of our awareness or control (American Cancer Society, 2020). Consequently, the “big question” can be a constant, nagging companion, a companion that could be quieted by attaching meaning to the experience of cancer in an AYA’s life.

One tool AYAs can use to give their cancer experience meaning, as demonstrated by Harmony’s experience, is to connect the coincidental experiences surrounding it together into comprehensible relationships using story (Ricoeur, 1990). Through the lens of emplotment, it could be said that Harmony is who she is because of the associations she has created among coincidental life experiences in the stories she has knowingly, or unknowingly, crafted about her life. In other words, the meaning-making process of emplotment is always already occurring, so the more appropriate question to ask may be if, or how, AYAs are participating in the process. If AYAs are passive participants, carried along in the uninterrupted “pre-narrative” experience of time, other influences – be it individuals or cultural forces – may shape and dictate their stories. Being able to stop and take a step back from the pre-narrative experience of cancer could allow them to more actively participate in the meaning-making process of their cancer experience.

Crucially, Harmony’s intuitive awareness that she needed to *stop* and reflect on her cancer experience, to *Stop* and story her experience, to *STOP!* and engage in a conversation about cancer, was enough impetus for her to enroll in this research project. She expresses her need to stop when she said in the film:

I think, as you move through your experience it is like, get to the other side, get to the other side, next thing, next thing. At least for me it was, and so this was a time where I actually, like, thought it all the way through and, like, lived back in it . . .

Cancer can be a powerful stopping force in an AYA's life. Bookending this stopping moment with a DST workshop could allow them to craft meaning from coincidence and draw out the lessons embedded in their experience so they can rebuild their lives in a way that is meaningful for them. Harmony exemplified this in her final post-workshop interview when she said, "this entire process of digital storytelling is a great way to engage with *yourself*." AYAs may need more opportunities to engage with themselves as they attempt to understand their complex emotional experience of cancer.

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¹ Amanda highlighted this common experience during a discussion with Kelsey in the Introduction to DST session when she said, “So, one of the things that. . . ummm. . . I think we [AYAs] all probably have, is like, when you are told you have cancer, it is kind of like Full Stop!”