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## Emerging Horizons, Part Three.

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## Kelsey's Story: Breaking Cancer's Grasp

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### Abstract

This third installment of the *Emerging Horizons* series explores Kelsey's digital storytelling (DST) experience (please see the introductory editorial, *Crafting Meaning, Cultivating Understanding*, to access the documentary film on which the series is based). In addition to providing a compelling exploration of a relatively common occurrence of Adolescent and Young Adult (AYA) cancer survivors, delayed diagnosis, Kelsey's involvement in the film illustrated the potential for DST to help participants explore, name, and represent their inner emotional experience. Her storyline illuminated how difficult it can be for AYAs to both understand their "true feelings" and share them with others in a way that moves beyond a surface level, "hashtag" description of emotion (e.g., #sad). I (Lang) conclude by discussing how the three primary modes of narrative engagement in the DST process (external, internal, and reflexive) could help AYAs cultivate a deeper understanding of their emotional cancer experiences, and in doing so, break cancer's grasp on their life, by grasping it instead.

### Keywords

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

Kelsey's second line in *Emerging Horizons* illustrates her initial nervousness around the DST workshop. She said, "I have all these "what if" questions, that I'm like, what if my story sucks? [nervous laughter] What if it is terrible? What if I don't finish it?" She even admitted to almost canceling her involvement in the project as she was driving to the first pre-workshop interview.

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In a similar way to Harmony, Kelsey was not sure if she had a story that was worth sharing.

In the first evening session of the workshop, it was quickly revealed that Kelsey had experienced a very delayed diagnosis. She described the paradoxical emotional experience of feeling validation and vulnerability at the same time by saying, “Ha! I told all you people something was wrong with me, but I’m gonna die! But yeah! [pumping fist] But I’m gonna die!” She described these conflicting emotions at the moment of her diagnosis as “a really weird feeling,” however the other participants understood her meaning as delayed diagnosis is a regular occurrence within this demographic (Herbert et al., 2018). One large cohort study of AYAs (N = 803) found that the median symptom-onset-to-diagnosis was 62 days (IQR 29 – 153) with a third of study participants having three or more consultations with a general practitioner before referral to a specialist (Herbert et al., 2018). Of the seven AYAs in the room that first evening, five had a similar experience to Kelsey, with many months of troubling symptoms before their own diagnosis was finally confirmed.

As Kelsey explored the meaningful moments of her cancer experience, it became clear that the delayed diagnosis, marked by crippling pain in her jaw, neck, and back, was more consequential than the active treatment and survivorship phase. This made her story unique among the five digital stories that were created as her diagnostic moment occurred close to the climax of her story instead of serving as the inciting incident. Despite shifting the focus of the story away from her cancer treatments and their aftermath, Kelsey’s story revealed a rarely glimpsed aspect of the AYA experience: the culturally derived “meta-narrative” pressure many patients and survivors feel to mask the physical and emotional suffering they experience (Atkinson & Rubinelli, 2012). Kelsey’s digital story offers the viewer a barefaced encounter with AYA cancer, and through her workshop experience, the potential of DST to help AYAs explore, name, and represent their inner emotional experience is manifest. Kelsey’s storyline demonstrates how DST could help AYAs break cancer’s grasp on their lives so that they can move forward.

### **#Sad: A Barefaced Encounter with AYA Cancer**

*Kelsey: I can say the logistical pieces of my story... but that doesn't really show my true feelings.*

Kelsey’s opening line in *Emerging Horizons* hints at her principal plotline which centred around revealing her “true feelings” about cancer to the world. This desire to share a more honest depiction of her cancer experience became the central theme of both the digital story she created and her overall DST experience portrayed in the film. However, the visual metaphor that she eventually chose to represent this theme in her digital story was not her idea. During the story circle, Bethany stated that she was having a “strong visual response” (meaning an idea for a visual symbol) to Kelsey’s story, a mask. Kelsey responded enthusiastically, saying “wow, that’s really good. It was only me or my mom that knew the real version. So, yeah, the mask thing is awesome. Thank you!” In that moment, the mask became a central image and metaphor in Kelsey’s story.

My initial feeling about the mask metaphor was mixed as it felt slightly cliché, and as discussed earlier in this thesis, clichés do not enhance understanding, they stifle it (McKee, 1997).

Consequently, I felt that the mask metaphor might not aid Kelsey in her aspiration to reveal her “true feelings” in and through her digital story. I wrote this observation in my field note reflections at the end of the story circle, before crossing it out, and writing next to it, “it is a meaningful metaphor to Kelsey, and this is *her* story.” Thankfully, in that moment, my awareness of DST facilitation ethics, in particular making a conscious decision around not “shaping” a person’s story (Gubrium et al., 2013), overruled my initial emotional response. In the end, the mask metaphor helped not only cultivate Kelsey’s understanding of her cancer experience but led to many honest and insightful conversations with both the participants and friends and family audiences. Interestingly, in these conversations, the mask’s primary function was to provide juxtaposition and focus the audience’s attention on what was underneath. The centre of those discussions was not the mask itself; it was Kelsey’s face.

One of the most powerful moments in Kelsey’s digital story occurred when the photo of her smiling is overlaid by a video of her crying. In that particular moment, the audience came face to face with Kelsey’s primary internal conflict, and it produced a strong emotional response (e.g., Harmony cried at this moment as well as multiple members of the friends and family audience). This moment was also one of the most difficult for Kelsey to craft. In the opening discussion of the weekend workshop, Kelsey disclosed that it was challenging to articulate the feelings that accompanied the incessant pain of her delayed diagnosis. In recounting the writing process around that particular moment in the story she said:

Cause for me it was easy to say, “and then I felt sad.” But then your [Mike] bracket comments were like, tell me how you felt sad or how you portrayed being sad. I was like, man! . . . this is what the process of story writing is, not just saying the general statements . . . “Then I felt sad” was four words, and now I have written a whole paragraph!

Despite her initial challenges, a single probing question inspired Kelsey to write an entire paragraph describing her emotional experience of sadness and pain; a description which ultimately became the voiceover for a crucial and compelling moment in her digital story. To borrow Harmony’s words, Kelsey transformed a surface level, “hashtag” description of her inner emotional experience (i.e., #sad) into a richer portrayal of the sadness and pain that was distinctive of her delayed diagnosis experience.

Determining the visual components to enhance her written representation of sadness and pain was equally as challenging for Kelsey. In particular, including the crying video was something we discussed a number of times throughout the weekend, and she was still unsure about incorporating it right up to the moment the story was shared with the other AYAs. In the discussion that followed the screening of her story Kelsey said:

I had said to Mike, I said, “I don’t want to put it in” cause it, like seemed really vulnerable. It’s kinda weird, like why was I selfie-ing myself crying? But before we had it, like, two separate things and he said, “Maybe you should just overlay it.” And in a way, that kinda made me feel better ‘cause it wasn’t just on its own, and it didn’t feel as vulnerable. And also, it kinda showed the smiling part, but then also, I guess, what we all feel inside even though we don’t show it outwardly.

In this statement, Kelsey hinted at why including the crying video was such a difficult decision for her; that short video clip was the moment she visually revealed her true feelings, her true face, to the world.

Despite the challenges Kelsey faced as she tried to present her true feelings in digital story form, she described how it was easier in the context of a story arc that had some form of resolution. As the AYA group ate lunch on the second day of the weekend workshop, Kelsey described this aspect of her experience:

Yesterday evening, like, I was feeling, like, really, really spent. Cause you are editing the first part of your video which is like going through the tough stuff part. . . and it kinda reopens the wound, or keeps picking at it. But today, you get to go to the end, where it's like "then I came through" and I'm like "Yeah!" [fist pump and laughing].

Taken together, the preceding three quotes indicate how the DST process placed Kelsey in an agentic position to reveal her true face through the words, images, and composition of her digital story. She could not change how she felt during her delayed diagnosis experience, but she could choose how to tell the story. In this way, she was able to remove her mask and be "barefaced" about her emotional experience.

The word barefaced is defined as "having the face uncovered" or "to be exposed or vulnerable" (Oxford University Press, n.d.). This definition describes Kelsey's experience as she felt vulnerable uncovering her true feelings in the words and images of her digital story. However, barefaced can also mean "shameless and undisguised" and is synonymous with "bold, unabashed, unembarrassed, or brazen" (Oxford University Press, n.d.). Perhaps this second interpretation is a more apt description of Kelsey's experience; by the end of the process, she was shameless and unembarrassed by her own emotional experience of cancer. This transformation is apparent in both her decision to include her crying video in the story and in the final lines of her voice over where she says, "I still have days where I am fearful about cancer, but I no longer ignore it. I say it *loud and proud*, and despite the fear now I can really smile."

Kelsey's acceptance of her emotional response to the delayed diagnosis was enhanced by the audience's response. She had shown her true feelings to the world and had found acceptance and caring instead of judgement and disregard. Tears were shed by both the participant and friends and family audiences because of the story content, but also because they understood what the story represented to Kelsey; she had been able to share her true feelings for the first time. Paradoxically, she could not have achieved her goal of sharing her true feelings if she had not discovered what those true feelings were through the process of writing and editing her digital story. In other words, she could not have shared her true face with the world until she understood what that was.

### **"Till We Have Faces": Narrative Self-Coherence and Digital Storytelling**

*Mike: Whenever you don't know what to do, just remember that the images are there to create a feeling.*

*Kelsey: OK.*

*Mike: So, what were you feeling in those moments?*

*Kelsey: [Slow breath out, long pause]. . . Like . . . [long pause, staring at the screen]*

The word “face” has a complex etymology, but its current form emerged from the Latin *facies* which means “appearance, form, figure” and in modern times is commonly used in a literal, physiological sense to signify the “front of the head” (Online Etymology Dictionary, n.d). However, the phrases that use the word, such as “save face,” “show your face,” “face the music,” and the previously discussed “barefaced,” all hint at its many symbolic uses. The hermeneutical excess of this word was first highlighted for me in the allegorical novel *Till We Have Faces: A Myth Retold*, by C.S. Lewis (1956/2017). The troubling lines that provided the title for the book continue to resonate deeply with me:

I saw well why the gods do not speak to us openly, nor let us answer. Till that word can be dug out of us, why should they hear the babble that we think we mean? How can they meet us face to face until we have faces? (p. 335)

Ever since reading this book and writing a report on it as an undergraduate student, I have interpreted “having a face” as being conscious of the entire self, the emotions, motivations, language, culture, history, and the resulting worldview that underlies and informs all our actions. This seed of understanding sown by Lewis’ symbolism sat dormant for many years until it was fed and watered by Gadamer’s (1960/2004) writings on “prejudice” and the historically effected consciousness. By highlighting both the importance of self-understanding and its tragic elusiveness, I believe Lewis brings his readers to the same conclusion as Gadamer: the importance of humility. As summarized eloquently by philosopher Jean Grondin (2003), “In a sense, the whole of Gadamer’s Hermeneutics wishes to remind us that we are not gods” (p. 96). Our understanding of the infinite forces acting in and upon the world is limited, and therefore our understanding of ourselves as beings shaped by these forces is limited. As humans, we may catch momentary glimpses of our “true face,” but most often it is blurry and partially obscured.

Extrapolating Lewis’ symbolism to the field of AYA cancer survivorship, the question could be asked: How can AYAs meet a cancer experience face to face until they have a face? In other words, how can AYAs begin to heal from the psychosocial traumas of cancer until they understand what those traumas were and how and why they experienced them? Cancer, as an interpretive, emotionally complex, existential event, does not “speak to us openly, nor let us answer” and therefore, the words must be “dug out of us” (Lewis, 1956/2017, p. 335). As demonstrated by Kelsey’s storyline in *Emerging Horizons*, the process of finding, telling, crafting, and sharing a digital story (Laing et al., 2017; Lang et al., 2019) could allow AYAs to look deeply into their cancer experience, unearth the emotions that are below the surface, and discover their “true face.”

Angus and Greenberg (2011), in their book *Working with Narrative in Emotion-Focused Therapy: Changing Stories, Changing Lives*, discussed the concept of narrative self-coherence which could be described as a process in which “to better understand themselves, people continually symbolize, story, and explain themselves to themselves, and in so doing, construct an ongoing, emergent self-narrative that organizes their personal stories and provides a sense of

self-coherence” (p. 46). The “narrative process model” that is the mechanism through which this process occurs contains three primary modes of narrative engagement: external, internal, and reflexive (Angus & Greenberg, 2011). The external narrative mode is driven by the question “what happened?” which encourages a detailed and specific description of a meaningful moment. The internal narrative mode is guided by the question “what did I feel?” and entails the description and elaboration of subjective feelings and emotions connected to that moment. Finally, the reflexive narrative mode asks “what does it mean?” and explores personal expectations, needs, and motivations in a way that attempts to make meaning of that moment. This narrative process model was embodied in Kelsey’s DST experience and demonstrated how DST could help cultivate narrative self-coherence in AYA cancer survivors, in other words, help them glimpse their own face so that they can share it with the world.

In Kelsey’s DST experience, the external narrative mode of “what happened?” occurred primarily in the initial evening workshop through the identification of meaningful moments, conversations with other workshop participants, and organizing these moments into a rough outline using five phase story structure (Freytag’s Pyramid, 1995). It was through this process that Kelsey realized her delayed diagnosis was the aspect of her cancer experience on which she needed to focus. The internal narrative mode of “what did I feel?” was exemplified through one particularly striking moment on day one of the weekend workshop. Kelsey called me over because she could not come up with image ideas for a piece of her story. I reminded her that images “are there to create a feeling” before asking what I have found to be one of the most productive questions in a DST experience, “what were you feeling in that moment?” Kelsey responded with a resounding silence that said nothing, and everything, at the same time. As the camera moved closer and closer into her face, the deep emotional excavation taking place was made apparent. Although Kelsey’s silence was only ten seconds in the film, in real time it was close to a full minute. I almost spoke a couple of times in that minute, but always stopped short; I intuitively understood that the “word” was being dug out of her, and I needed to hold space for that to happen. This process of naming emotions and then representing them through images could be a primary ingredient in what has been called the “sneaky” or unexpected therapeutic process of DST (Laing et al., 2017, p. 7). In the process of naming and selecting an image to represent it, AYAs could both understand and instantiate their own emotional experience of cancer.

The final reflexive narrative mode of “what does it mean?” is evident in Kelsey’s overall story arc in *Emerging Horizons*. At the beginning of the friends and family screening, I mentioned that when I first connected with Kelsey, she did not think she had a story to share. She responded sheepishly, with a nod, a smile, and by saying “yeah.” In that short exchange, it was clear that despite her nervousness to share the story, she no longer believed that it was not worth sharing. In other words, through the DST process her cancer experience had become both “meaningful and meaning filled” (Angus & Greenburg, 2011, p. 45) and had helped to break cancer’s grasp on her life.

### **Breaking Cancer’s Grasp**

*Kelsey: It’s funny. It’s a year ago, but even as I talk about this, I feel emotional. And, so, I know it has a grasp over me in some ways.*

The word “grasp” comes from the Proto-Indo-European root *\*ghrebh-* which means “to seize, reach” (Online Etymology Dictionary, n.d.). In one sense, AYAs can be “seized” and held back from forward movement in their life because of cancer (e.g., as Kelsey said in her digital story “Fall behind. Be a failure.”), but a cancer experience can also continue to “reach” a long way past the active-treatment phase and continue to influence the lives of AYA long-term (Barnett et al., 2016; Jones et al., 2020; Lang et al., 2018). Some of the AYAs in *Emerging Horizons*, like Kenzie (five years post-treatment), Derek (six years), and Bethany (10 years), and were many years removed from their cancer experience but still felt the need to engage with it on some level. In my pre-interview with Kelsey, she recognized that cancer still had a grasp on her life because of the significant emotion she experienced every time she thought about it. That portion of our conversation ended by me saying, “In my experience, decreasing cancer’s hold on you is an ongoing process,” and the result of this process is portrayed in Kelsey’s storyline.

During the story circle, Kelsey had to stop a number of times as she read her story because of the overwhelming emotion. During each pause, she apologized. After reading her story she mused about how despite reading it multiple times, something about saying it out loud made her cry. She was embarrassed by her strong emotions, and at that point in the DST process it was apparent that cancer still held her tightly. However, by the end of the weekend, and at the friends and family screening, as she watched her story and engaged in discussion about it, that same emotion was not present; there was a genuine smile instead. Validation of this internal transformation was provided by Kelsey’s best friend during the friends and family screening discussion:

Everyone would always say, “Well you look great. You look good.” And I think, I knew she was smiling, but not from the inside. And she had this front for a while and she was so strong, and now just being able to see her smile and know she is really smiling from the inside as well, it’s really nice to see.

Kelsey herself described the change that had occurred in her final interview. She stated, “I do think it [her story] changed a little bit. I refined it and was able to put my thoughts better together, and what I actually wanted to say.” Concerning the friends and family screening specifically she said, “like, they got it! Like, what I was trying to say for once, someone finally understood.” Using the central symbol of her digital story as a metaphor, it could be said that through the DST process Kelsey had been able to remove her mask and glimpse her own face, before revealing it to the world in and through her digital story. In that process, she was able to meet her cancer experience face to face for the first time, and from this agentic position, was able to break cancer’s grasp on her life, by grasping it instead.

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