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## Emerging Horizons, Part Four.

### Derek's Story: More Than Words

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**Michael J Lang & Catherine M Laing**

#### **Abstract**

This fourth installment of the *Emerging Horizons* series explores Derek'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 contrast to other workshop participants, Derek's primary goal for his digital story was to convey a specific, pre-determined meaningful moment from his cancer experience in a more compelling manner. Building from the image system Derek utilized in his digital story, and further contextualizing the events he describes, this interpretive article depicts the unique cancer survivorship experiences of Adolescent and Young Adult (AYA) cancer survivors and demonstrates the possibilities of DST to help AYAs release "bottled up" emotions before they become rancid (i.e., release suppressed or repressed emotions before they transform into diagnosed psychosocial comorbidity). Finally, Derek's experience demonstrates how the multi-modal nature of DST can enable AYAs to incite an emotional response from their audience that can in turn confirm and affirm the life lessons embedded in their cancer experience.

#### **Keywords**

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

For some AYAs, like Amanda, Harmony, and Kelsey, the finding and telling phases of the DST process can present a significant challenge (Laing et al., 2017). Derek, however, provided an example of a cancer story that was fully formed, just waiting to be crafted and shared in a digital story format. During the informal check-in conversation at the beginning of the weekend

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**Corresponding Author:**  
Michael J Lang, PhD  
Email: [mike@mikelangstories.com](mailto:mike@mikelangstories.com)

workshop Derek shared, “mine came together pretty quick,” and stated that after the evening Introduction to DST session he was “thinking about it the next day, all day. And then, I just put it down on paper.” In actuality, he had been thinking about his story for a much longer period of time as he shared both the climax moment and controlling idea of his story with me during the study intake phone call.

However, this detail was not included in *Emerging Horizons*, and through the first half of the film, Derek’s ease of identifying his meaningful moments and determining the controlling idea for his story was a mystery. It was apparent during his description of the moment where he “released” his emotions that he had already spent a significant amount of time reflecting on his cancer experience, but it was not until watching his digital story in the film that the particular provocation of this experience was revealed. The DST workshop was not the first time Derek and I spent time reflecting on his cancer story together; we had history.

For 10 years (2009-2019), I facilitated week-long adventure expeditions for AYA cancer survivors and supporters with the charity I founded called *Survive & Thrive Cancer Programs*. Derek was an alumnus of the 2013 Owyhee River kayaking expedition, and that experience was central to his digital story. By recounting the trip in vivid detail, he revealed how he underwent much of the reflection that occurs in the finding and telling phases of the DST process through the journaling, morning quiet times, and group discussions that occurred during those eight days on the river. In contrast to participants like Harmony, Kelsey, and Amanda who approached the DST workshop as an opportunity to begin storying their cancer experience, Derek had already spent considerable time exploring the meaningful moments of his cancer story.

Consequently, Derek’s primary goal for his digital story was to convey a specific meaningful moment from his cancer experience in a more compelling manner. He stated in his opening line of the film, “I have told people that story, but I don’t know if people realize how profound it was for me, I guess.” Expressed differently, for Derek, crafting and sharing (Laing et al, 2017; Lang et al., 2019) his cancer story using words alone was not sufficient to convey the significance and meaning of that particular story to his audience. Through the reflective lens of Derek’s kayaking expedition, his experience in *Emerging Horizons* revealed how DST could help AYAs release the “bottled up” emotions that can follow them through the wilderness of cancer survivorship, and then convey the transformational nature of that expedition in a more meaningful way upon their return home.

### **Bottled Up: Experiencing the Wilderness of Cancer Survivorship**

*Derek: My emotions kind of just built up, and then, there was a moment where it all just released. And I didn’t really know that I was bottling it up but, it was a big moment.*

The most commonly used definition of cancer survivorship in an academic setting is “from the moment of diagnosis and for the balance of life” (Rowland, 2007, p. 29) regardless of the ultimate cause of death. However, in colloquial usage and where treatments are undertaken with curative intent, the term cancer survivorship is commonly used to refer to the period of time following acute treatments. Using either definition, Derek was a “cancer survivor” when he attended the kayaking expedition, despite his three-month scan results being inconclusive, and

like other AYAs, his transition from acute treatment to survivorship had triggered strong and conflicting emotions (Jones et al., 2020). He described this in his digital story by saying, “I could tell that something still didn’t feel right. I was supposed to be a survivor and feel better about being done treatments. Why was I apprehensive? Why wasn’t I happy? I had cheated death.”

The post-treatment cancer survivorship phase for AYAs can paradoxically feel both turbulent and still at the same time. This can occur as survivors continue to struggle with the late or long-term effects of cancer treatments (i.e., neuropathy, fatigue, anxiety, depression, financial toxicity, body image, etc.; Jones et al., 2020) while lacking the regular interaction with cancer care professionals that defined the past months, or years, of their lives. In this way, the kayaking trip depicted in Derek’s digital story could provide a salient metaphor for the cancer survivorship experience: the river is loud and turbulent, the surrounding landscape quiet and isolated. Cancer survivorship can be challenging because it is an expedition that encompasses both the turbulence of a white-water river and the loneliness of the wilderness. In particular, feelings of isolation and loneliness may be severe for AYA cancer survivors as the lack of interaction with healthcare providers is compounded further by the challenge of relating to, and engaging with, their pre-diagnosis peer group (e.g., due to missed or delayed life milestones and/or loss of ability or desire to pursue certain activities; Kent et al., 2012; Zebrack & Isaacson, 2012). This phenomenon is why many AYAs experience a profound sense of relief that comes from connecting with cancer survivor peers who understand (Kent et al., 2013; Treadgold & Kuperberg, 2010; Zebrack et al., 2006; Zebrack & Isaacson, 2012) and could also be why I never had to recruit participants for our *Survive & Thrive* expeditions. AYAs like Derek always found us; they were searching for connection in the wilderness.

With this context, Derek’s description of the feeling he was hoping to create through the music selection for his digital story holds substantial meaning. When searching for his song I asked him, “What is the feeling you are trying to create?” He responded, “Well, it’s kinda like, loneliness, I guess.” I immediately picked up on the connection between loneliness and the wilderness imagery he was using in his story, and using “wilderness” as a keyword, we found a unique song that distinctly cultivated this feeling. Indeed, in the AYA screening Kelsey immediately responded to Derek’s story by saying, “I loved the music, it really fit your theme.” The agreement from the group following her comment confirmed that we all resonated with Derek’s aural representation of the loneliness of cancer survivorship.

However, for Derek, the survivorship challenge he specifically wanted to address in his digital story was the “bottling up” of his emotions (i.e., emotional suppression or repression; Weinberger, 1979). He used this phrase to describe his experience multiple times throughout the DST process as well as embedding it directly in his story. Remarkably, as I watched Derek’s digital story and saw myself in some of the photos, I realized his emotions were not the only bottled thing that made an appearance on that particular kayaking expedition.

On day two of the trip, I found a Pabst Blue Ribbon (PBR) beer floating in an eddy at the side of the river. It was not surprising to find the can, as river rafting culture includes drinking copious amounts of cheap beer, but it was surprising to find it fully intact. The can was faded and dented but the seal was unbroken, and its discovery was extraordinary enough that it bobbed to the surface of my memory six years later while watching Derek’s story. The PBR became a mascot,

of sorts, for the rest of Derek's trip. I would carry it in the front of my open kayak until it was washed out in a rapid, rediscovered in the calm water downstream and returned to my boat. Its durability was inspiring, and to honor the many miles it travelled downstream with us, we decided to open it when we arrived at the take-out.<sup>1</sup> After the first sip led to a bout of dry heaving, we poured the rest of it out as an "offering" to the river for our safe passage. Despite our attachment to the PBR, once it was opened, we were eager to leave it behind.

Derek's "bottled up" emotions portrayed in *Emerging Horizons* have a unique kinship with the PBR encountered on his kayaking expedition on multiple levels. First, both demonstrate that unless opened and emptied, bottled things may stay bottled indefinitely. The PBR was bleached and dented but still intact after floating in the river for weeks or months, and in Derek's digital story it is apparent that the strong emotions tied to his cancer experience also persisted as he resumed regular activities post-treatment. Similarly, the frustration that Derek felt because of his inability to convey to others the significance of his emotional "release" during the 24-hour solo (i.e., "people didn't really seem [to think], like, it was that good of a story") persisted, despite the kayaking expedition occurring six years prior to the DST workshop.<sup>2</sup>

Second, bottled things can temporarily disappear in the turbulence of life's rapids. I was shocked every time the PBR bobbed to the surface in the calm pool below a rapid in the same way Derek described it as "a complete shock" when he began crying while reading the letters from home and realized that he had been repressing his emotions since the first day of diagnosis.<sup>3</sup> Furthermore, just as Derek was surprised by his emotional release on the 24-hour solo, he was also surprised by the intensity of the emotions he experienced throughout the DST workshop. He told me this during a lunchtime conversation on the final day:

Mike: Do you feel tired at all?

Derek: Uhhh, I don't know. I was definitely getting emotional . . .

Mike: As you were watching it?

Derek: . . . yeah.

Mike: Like, every time you watch it?

Derek: No, not every time, but certain parts.

Derek was not alone in his astonishment at the intensity of the emotions that surfaced throughout the DST process as all participants indicated the same sentiment in their final interviews. Throughout the film it was apparent that the DST process surfaced emotions that had been submerged by the persistent current of daily life.

Finally, the turbulence of the river, the scorching sun of the desert, and the constant battering of rocks can conspire to make both beer and bottled-up emotions more rancid over time. After listening to thousands of hours of AYA cancer stories on week-long expeditions like Derek's, I have learned that a cancer experience alone often does not create the strong, fetid emotions that bob to the surface long after acute treatment; it is almost always "Cancer, and . . . and . . . and . . ." It is the relentless battering of life's rocks and rapids in the sun-scorched wilderness of cancer survivorship that can transform common cancer-related emotions into psychosocial morbidity months or years after treatment completion. In Derek's case, it was his own cancer diagnosis and treatments, *and* his friend committing suicide, *and* his mentor dying of cancer, *and* the

uncertainty of his inconclusive follow-up scan, all compounding the usual pressures of young adulthood. Indeed, AYA cancer survivors could report a higher prevalence of psychosocial morbidity than both younger (<15) and older age groups (40+) because:

- the AYA phase of life naturally produces more turbulent rapids (i.e., career, family, finances, identity, etc; Docherty et al., 2015);
- the wilderness of survivorship is more severe (i.e., profound feelings of isolation; Zebrack & Isaacson, 2012);
- the opportunities to release bottled up emotions before they become rancid are more limited due to significant barriers to accessing psychosocial support (Holland et al., 2020).

It was clear that a deep desire of the AYA participants in *Emerging Horizons*, including Derek, was to break the seal of their suppressed, or in some cases repressed, emotional experience of cancer through the creation of their digital story.

Emotional suppression is defined as a deliberate withholding of emotional expression while repression indicates a lack of cognitive awareness of distressing emotion despite evidence to the contrary (Giese-Davis et al., 2008). In other words, repressed individuals believe they are not upset whereas suppressed individuals are aware of their negative emotions but choose not to express them (Weinberger, 1979). Both Amanda (“I hid a lot of that emotional stuff to make it easier for everyone else”) and Kelsey (“smiling harder” to mask her true feelings) spoke of knowingly suppressing their emotional experience. In contrast, Derek’s digital story provided an example of emotional repression as he did not recognize that emotional pressure had been building until the seal was broken during his 24-hour solo time.

Interestingly, Derek’s storyline in *Emerging Horizons* also illustrated emotional suppression. While other AYAs purposely chose to suppress aspects of their emotional experience by not sharing it with others, Derek had tried to share about his moment of emotional “release” in the wilderness but was unable to convey it in a satisfactory way, so he stopped trying. He pushed that important cancer story back below the surface of the river, only to have it reappear periodically and remind him that one of the most important moments of his cancer experience was still not understood by the very friends and family who helped make that moment happen by writing him letters. Derek intuitively recognized that if he was going to be understood - pull that can out of the water, crack the seal, and empty it - he needed to use more than words. He needed to *show it*.

### **More Than Words: The Meaning of River Rocks**

*Derek: It always seemed like, people didn't really seem like it was that good of a story, but to me it was, like, so profound... I would tell it to people, but it's hard to explain it in words.*

After Derek’s transformative 24-hour solo time next to the Owyhee River he was instructed to bring back two rocks. In the group discussion later that evening, each person put their name on one rock and placed it in a hat, while the other rock was labeled with one thing that they wanted

to leave behind in the wilderness; something that they did not need anymore, or was holding them back, or weighing them down. Everyone was then encouraged to throw that rock into the river when they were ready, and they all found their own moment to let it go. It is hard to explain in words what it felt like to hear a rock splash into the river as you lay on the warm sand under a vast curtain of stars. It is hard to explain in words the satisfaction of watching someone pause in the middle of a rapid to drop a rock into the roiling foam. It is hard to explain in words the look on someone's face as they slowly turn around having confidently walked to the river's edge during dinner, let out an animalistic roar, and sent their rock flying a hundred feet downstream. As I reflect on these moments, I feel closer to understanding Derek's frustration and feelings of inadequacy with sharing his own transformative experience from that expedition. Sometimes, words are simply not enough.

Throughout the DST workshop, Derek was relatively quiet during group discussions and had a difficult time formulating responses during his interviews. He was self-conscious enough about his speech and word usage that I had to ask him to stop apologizing for "not saying things right" or "being good at answering" my questions in the pre-workshop interview. This uncomfortableness with words was also apparent before reading his story for the first time to the other AYAs. Even though his story came together quickly, and he was confident that it was a good story, he said, "I can go. . . ummm . . . pretty nervous, but ahhh . . ." Derek's struggle with words in the film directly mirrored the challenges he faced in conveying to his friends and family the significance of that moment during his 24-hour solo where he released the repressed emotions of his cancer experience.

Fortunately, hermeneutic philosophers through the ages (beginning with Schleiermacher in modern times) have expanded our understanding of what constitutes language (Gadamer, 1966/2007). They have demonstrated that silent images or artworks can "speak," and because of this, images and artistic composition are able to play an active role in discourse and understanding (Davey, 2013). After all, if an artist could express what they had to say in words, there would be no need for them to create the artistic form of their ideas (Gadamer, 1977/1986).

The creative possibilities inherent in the amalgamation of word, image, and composition could provide a keener representation of the author's inner emotional experience and, at the same time, open up that experience to a multiplicity of interpretations that cultivate deeper understanding. Indeed, the possibilities of the hermeneutic excess nurtured in digital stories highlights their potential as both compelling entry points into ongoing conversations and stimulants to keep conversation going (Lang, Laing et al., 2020). Consequently, for someone like Derek who continually deprecated his linguistic abilities, DST provided a significant opportunity to tell the story of his 24-hour solo in a way that everyone, himself included, could come to a deeper understanding of that experience. Clearly, Derek recognized this potential and plainly stated it during the AYA screening after Kelsey's story:

All our stories, you know, there were physical aspects and that is what we talk about when we go to the doctor, but you know it is the emotional stuff that we don't really talk about [nodding heads and sounds of affirmation from the group]. And this is a good way to talk about it *and show it*.

The affirmation from the group spoke to the value of being able to “show” the emotional experience of cancer survivorship. Derek was not alone in his struggle to convey his cancer story using words alone. A central developmental task of young adulthood is learning to understand and articulate inner emotional experiences (Arnett, 2000), and therefore, an opportunity to *show* a cancer experience to others through a digital story in a safe, facilitated environment could support AYAs to both express and regulate their cancer-related emotions (Laing et al., 2017; Zebrack et al., 2015).

By using images and compositional elements to show his story, Derek was able to help his three friends who attended the final screening understand the deep significance of that wilderness experience. By overlaying the images of friends and family with the image of the canyon, he visually demonstrated his realization that he was *not alone* in the wilderness (“Oh my god, I am not in this alone. I am not doing this by myself”). This conveyed his appreciation for those supporters in a way that never seemed to be as meaningful when he thanked them verbally. More importantly, Derek’s friends were able to understand how much cancer had emotionally affected him (i.e., “I was just as scared as anyone who had cancer”), even though he had not talked about it with them.

This deeper understanding of Derek’s internalized fear and anxiety was evident in the discussion between Derek, his best friend Glean, and Kelsey’s mother after watching Derek’s story. The opening part of the discussion was not included in the film, but it began with Glean saying that they had done so many activities together (e.g., fishing, hiking, camping) since Derek’s cancer experience, but this was something that they had never talked about:

Glean: This is something [fear and anxiety] I never thought, ummm, existed.

Derek: Yeah!

Kelsey’s Mother: Why don’t we talk about it?! We’re all like that. None of us. It’s like we don’t talk about it, the elephant in the room.

Derek: Well, especially men. . .

Kelsey’s Mother: Especially men, yeah!

Derek: . . . Cause it is emotional.

Although this exchange portrayed the stereotypical characterization of men avoiding conversation about emotions, it also demonstrated that both Glean and Derek desired to understand and be understood. The digital story became a clear entry point into a conversation that they both desired. In the same way that I was able to ask Derek on the final day of the kayaking expedition what the “Letting Go” rock represented to him, he and Glean were able to start a conversation about the emotional side of Derek’s cancer experience. The rock and the digital story came first, and the words followed.

### **Returning to Life: The Importance of the “Other Rock”**

*Derek: I had a huge wave of endorphins flow through my body, and I never felt better in my life. I felt free like nothing was holding me back anymore. I had always tried to be strong, but really, I was just as scared as anyone with cancer.*

On the last morning of Derek's kayaking expedition, the group blindly selected from the hat that contained the other rocks brought back from the 24-hour solo. Each participant had put their name on a rock, and everyone was instructed to choose one word that represented the person whose rock they selected, then think of a story from the trip that illustrated their choice. That night, during the final evening discussion of the trip, we shared the word and the story before placing the rock in our person's hand. I began the process with this prompt:

We appreciate what a person does, but we affirm who a person is. Appreciation comes and goes because it is usually related to something someone accomplishes. Affirmation goes deeper. It is directed to the person himself or herself. By far the rarer of the two is affirmation (Swindoll, 2005, p. 194). We have been able to see deep into each other's lives on this trip because together we have struggled and suffered, cried and laughed, and most importantly, listened deeply to each other's stories. Now that we have seen each other for who we are, we need to make sure that we *tell each other what we have seen*. Tonight, we speak truth into each other's lives.

Often, AYAs are appreciated for *what* they have accomplished (i.e., staying positive, being strong, beating cancer, starting a cancer charity, etc.) when being affirmed for *who* they are could be more important during the difficult transition from cancer treatments back to everyday life. In this way, a digital story could play the same role as a river rock, helping to affirm AYAs for who they are not just what they have accomplished. Specifically, in the DST process, screening and discussing digital stories provides an opportunity for affirmation through audience engagement (Lang et al., 2019) while re-watching a digital story in the months and years following the workshop can reaffirm the lessons embedded in it.

The word "affirmation" comes from the Latin root *firmare* which means "strengthen, make firm" (Online Etymology Dictionary, n.d.). The significant hardship of the wilderness can strengthen AYAs' physical, mental, and emotional resilience (Zebrack et al., 2015), and this needs to be acknowledged and celebrated, but just as importantly, the valuable lessons learned in the wilderness need to be understood and made firm in the heart and mind so that they can pay dividends throughout the rest of life (i.e., post-traumatic growth; Koutrouli et al., 2012). For these same reasons, the DST process also ends with affirmation through audience discussion (i.e., "tell each other what we have seen") that goes deeper than the surface level appreciation that storytellers receive through the "mandatory standing ovation."

In the animated discussion during both screenings, it is apparent that the words, images, and composition of Derek's story went beyond *telling* the audience what happened, it helped them *feel* what happened. In other words, the multi-modality of DST helped Derek incite the emotional response from the audience that he was looking for (Bethany: "It was really powerful." Kelsey: "That was so good!" Mike: "Yeah, Derek!"); a response that had been missing as he spoke the story to others. The enhanced emotional engagement from the AYAs and his friends affirmed the importance of that 24-hour solo as a transformative moment in his life story. For Derek, affirmation that the emotions he had experienced were real, normal, and could be understood by others was profoundly important, and together, the expedition and DST experience provided the opportunity to be affirmed. Furthermore, in all the discussions that occurred during the screenings, the conversation about cancer naturally shifted from appreciation

(e.g., you were so strong, you beat cancer) to affirmation (e.g., you learned important lessons through your cancer experience, and now I am learning from you). The life lesson of “releasing bottled up emotions” that Derek learned in the wilderness was both confirmed and entrenched through audience discussion in this way. Consequently, in his final interview Derek described the DST screening as “a great experience,” and revealed that he felt he had accomplished his goal of conveying the significance and meaning of that story.

The unique paradox of Derek’s cancer survivorship experience is that, although he experienced a profound release of his bottled up emotions during the 24-hour solo, his emotions were again bottled up when he returned home and was unable to tell the story of that experience in a way that would help others understand what it meant to him. Many *Survive & Thrive* alumni have indicated that the return to everyday life after an expedition was the most challenging part of the entire experience, in the same way that the survivorship phase of a cancer experience can often be more challenging than acute treatments (Institute of Medicine, 2006). In particular, I have heard many AYAs describe the intense feelings of loneliness that can occur when they return to home, be it from acute cancer treatments or a wilderness expedition, and discover that they are not be able to fully convey the significance of that experience to their friends and family. Despite their desire to be understood (Laing et al., 2017), many AYAs like Derek stop trying to tell the story, when ultimately the depth of understanding they desire might not be possible with words alone. Showing their cancer story to their friends and family in digital story form could provide a valuable opportunity to be understood, and by consequence, decrease feelings of loneliness and isolation in their ongoing cancer survivorship expedition.

Many *Survive & Thrive* alumni, including me, also indicate returning to their rock in the weeks, months, and even years following their expedition. Some take their rock with them into surgery or chemotherapy treatments, others place it on their nightstand or on the dashboard of their car. I have my 23 rocks in a basket next to my desk and periodically look through them to be reminded of who I am amidst the challenges, triumphs, and more often the monotony of everyday life. Similarly, AYAs indicate returning to their digital story often to be reminded of who they are (Laing et al., 2017), and in this way, both river rocks and digital stories can act as touchstones to help endure and navigate the rapids of life. They are much more than simple river rocks or a composition of words and images; they are a word and a story, a reminder and an affirmation. Derek’s DST experience in *Emerging Horizons* demonstrates that it is possible for AYAs to embrace transformation in and through the wilderness of cancer survivorship by releasing their emotions, telling the story, and then taking it with them as they move forward in their lives. If this can be accomplished it is possible to feel, as Derek said, “free, like nothing was holding me back” after cancer.

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<sup>1</sup> Survive & Thrive Expeditions were strictly “dry” trips with zero tolerance towards consumption of recreational drugs or alcohol. The PBR incident was the single deviation from this rule and seemed appropriate given the context and amount of alcohol in question.

<sup>2</sup> The “24-hour solo” was described in Derek’s digital story and involved participants spending 24-hours alone in a secluded section of beach along the river. Participants were encouraged to reflect and write in their journal with provided prompts, and towards the end of the solo time they were given letters of affirmation and encouragement written by their friends and family at home.

<sup>3</sup> Interestingly, the majority of participants on *Survive & Thrive* expeditions were 2-3 years removed from their acute treatments. It was only after the initial turbulence of returning to life post-treatment had calmed that adverse emotional sequelae and feelings of loneliness surfaced, and people decided to register for an expedition.