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Emerging Horizons, Part One.

Amanda's Story: Wound Care

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Abstract

This first installment of the *Emerging Horizons* series explores Amanda's digital storytelling (DST) experience (please see the introductory editorial to the series, *Crafting Meaning, Cultivating Understanding,* to access the film). Although attenuated, Amanda's involvement in the film provides valuable insight into important safeguards that should be in place when using DST in healthcare settings. Using the metaphor of broken bones and open wounds, this interpretive article highlights the importance of recognizing chaos narratives and unstoried emotions in the early stages of the DST process. It concludes with three practical "wound care" measures that can help safeguard participant wellbeing as they find, tell, craft, and share their digital story.

Keywords

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

As a five-year-old in the late 1980s, I (first author, Lang) smashed my leg into a large wooden post that supported a dangerously tall playground swing. My father, who was pushing me on the swing, picked me up and comforted me while I cried, and when it was apparent that I was not going to stop crying, he put me on my feet and said, "It's just a Charlie Horse Michael, you need to walk it off." I still remember feeling the three distinct pieces of my femur (that should have been one bone) grating together as I attempted to walk home before laying down on the pavement in the middle of a crosswalk. I also clearly remember my mother yelling, "It is not a Charlie Horse, Maurice! Call the ambulance now!" I spent the next two months in a body cast

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that went all the way from my armpits to my toes.

Thirty-two years later that story is routinely told during family holidays and accompanied by laughter and teasing, much to the chagrin of my father. The temporal distance from that traumatic and painful experience and knowing that my leg eventually healed and still works well (despite being three centimeters longer than my other leg), makes the telling of that story possible. In the midst of that terrible spring, however, there was nothing that could be said without overwhelming sadness and tears; the story was not ready to be told.

In *Emerging Horizons*, Amanda was experiencing her own terrible spring, and her presence in the film, though attenuated, provides a striking storyline. In many ways, she "steals the show" in the opening act, and then abruptly leaves the show. Her early departure looms over the film like a giant question mark, the audience wondering about the aftermath of her involvement in the Digital Storytelling (DST) workshop and her psychosocial wellbeing as she struggled with the loss of her unborn child. It is not until the final seconds of the ending credits that Amanda's storyline has any closure, a miracle pregnancy confirmed only a few weeks after discontinuing her involvement in the workshop, and a beautiful newborn girl in her arms.

Losing a pregnancy because of a cancer diagnosis is a uniquely female adolescent and young adult (AYA) sequela. Amanda's few short moments on screen conveys both the emotional distress that accompanies a potential loss of fertility due to cancer treatments (Lawson et al., 2015), and how this distress can be compounded by the forced choice between one's own life and the life of a wanted unborn child (Reardon, 2018). Amanda had decided prior to her intake interview to make this aspect of her cancer experience the focus of her digital story and expressed a strong desire to share her story to help other AYA women who may be facing the same devastating choice. However, during the initial evening session of the DST workshop it became clear that this particular story was not ready to be told, and through her experience, Amanda highlighted a specific challenge of DST with AYA cancer survivors: recognizing and caring for the emotional broken bones and open wounds that accompany every cancer experience.

Broken Bones: In the Midst of the Trauma

> *Amanda: You know, you lost the second child that you wanted to have... and then you don't know if you can have children... and then, the doctor is telling you to wait because the cancer could come back and there's all these decisions and you are trying to balance what you want and then all your fears and the different outcomes.*

Broken bones, apart from complex open fractures, are under the surface (Baudour et al., 2018). They are recognizable by swelling and bruising, deformation, loss of function, and pain that increases during palpation (Baudour et al., 2018). Similarly, emotional "broken bones" exist under the surface and become apparent in particular storytelling symptoms (Angus & Greenberg, 2011). Symptoms such as the inability to tell the story (loss of function), chaotic or "broken" story structure (deformation), or uncontrollable emotional pain during reflection (pain on palpation) all could indicate the grating ends of unknit bones below (Angus & Greenberg, 2011). Exposing and palpating emotional broken bones during a DST experience is not as straight

forward as a broken femur, however, narrative theory can help provide a general sense of where to start.

In his book *The Wounded Storyteller*, medical sociologist Arthur Frank (2013) described three archetypal illness narrative structures: restitution, quest, and chaos. Restitution narratives describe an illness being treated and resolved, quest narratives chronicle the illness experience as a series of obstacles to overcome, and chaos narratives are those in which the illness experience has no resolution (Frank, 2013). Although cancer stories are often complex and resist compartmentalization, Frank's typologies are a helpful starting point to recognize and understand an AYA participant's illness narrative in the early stages of a DST process (Lang et al., 2019). In particular, understanding the characteristics of a chaos narrative can help determine if an AYA is in the midst of the trauma that they desire to turn into a digital story (Lang et al., 2019). In *Emerging Horizons*, Amanda provided an example of a chaos narrative, while her experience during the first evening session revealed the difficulties of storying a concurrent traumatic experience.

One hallmark of a chaos story is the "and then and then and then" syntactic structure (Frank, 2013, p. 98). The quote that opens this interpretation utilizes this structure, and Amanda's voice, tone, and pacing as she shared these words in the film conveys a feeling of being overwhelmed by the conflicting desires and fears of motherhood after a cancer diagnosis. This inner turmoil was compounded by having previously experienced the joy of having had one successful pregnancy, and by her choice to have an abortion despite the practice conflicting with her Evangelical Christian belief system which was highlighted in her pre-workshop interview.

Chaos stories also lack coherent sequence or discernable causality (Frank, 2013). Telling a story about our life requires us to order and casually link events in and across time (Ricœur, 1990), essentially, creating order out of chaos. In the process of creating the outline for her digital story, Amanda struggled to determine where each moment belonged in the storyline (i.e., inciting incident, rising action, climax, falling action, etc.) and could not articulate the relationship between the meaningful moments she selected. Her story was too fractured, and the pain too immediate, to knit together those moments into a cohesive whole. During the process of constructing a story outline about her abortion experience Amanda was brought face-to-face with the broken, chaotic, unresolved nature of that experience.

Frank (2013) provided some insight into Amanda's struggle to craft her story outline:

> Those who are truly *living* the chaos cannot tell it in words. To turn the chaos into a verbal story is to have reflective grasp of it. The chaos that can be told in story is already taking place at a distance and is being reflected on retrospectively. For a person to gain such a reflective grasp of her own life, distance is a prerequisite . . . Lived chaos makes reflection, and consequently storytelling, impossible. (p. 98)

Laing et al. (2017a) provided additional support for this idea of reflective distance by suggesting a linear relationship between length of time since diagnosis and the "reflectiveness" of a digital story (p. 279). It was noted that AYAs closer to, or in the middle of, their cancer experience, primarily used DST as a distraction tool, while those who were further from diagnosis were more likely to use it as an opportunity to process and share their cancer experience with others (Laing

et al., 2017a). Together with Amanda's experience, these observations suggest that the exploration of lived chaos narratives with AYAs should be done differently, in an individual psychotherapy setting for example, or at the very least, not in a group DST setting that is being filmed and turned into a publicly available documentary film. Indeed, Angus and Greenberg (2011) identified two subtypes of chaos stories (i.e., "broken stories," p. 73), narrative incoherence (fragmented plot structure), and emotional incoherence (conflicting emotional plotlines), which are amenable to individual psychotherapy.

Ultimately, Amanda was not able to story her experience of having a cancer-induced abortion potentially because she did not have the necessary reflective distance from that experience; she was still lying in the crosswalk with her femur in three pieces, still living amid the trauma of losing her unborn child. It was not yet an experience that could be storied in three short minutes despite the supportive environment and the creative possibilities that the DST workshop provided her.

Open Wounds: Recognizing Unstoried Emotions

> *Amanda: I don't know about you, but I hid a lot of that emotional stuff to make it easier for everyone else.*

Open wounds are often more obvious than broken bones. In the acute stages, there can be copious amounts of blood followed by pus, discoloration, and sometimes malodour while the wound heals (Baudour et al., 2018). It is hard to miss an open wound, and despite some nuances, the same could be said for emotional expression. Generally, humans recognize the emotions of others, even if they do not understand the underlying causes (Ekman, 2007). This occurs intuitively and almost instantaneously without the need to identify all the exact facial expressions, body postures, or voice tone that indicate surprise, anger, or sadness, for example (Ekman, 2007). This intuitive emotional understanding, and corresponding reactions, was documented repeatedly in the filmed pre/post-interviews, DST workshop, and digital story screenings that was the source material for *Emerging Horizons.*

One unmistakeable moment of emotional expression and reaction occurred in the initial evening session as Kelsey recognized Amanda's expression of sadness and instinctively responded by placing a hand on her shoulder in a gesture of support. This short clip was included to represent all the moments of emotional support Amanda received that evening. Throughout the session, the lived chaos of Amanda's chosen story topic was painfully apparent through her raw emotional expression. No one was surprised when I explained her decision to discontinue participation at the beginning of the weekend workshop; the emotional wound of losing her unborn child was still open and bleeding. However, this is not to say that all forms of emotional expression in a DST workshop indicate open wounds.

In the DST process, as with most group-based psychosocial interventions, specific forms of emotional expression are not only encouraged, but they are also seen as essential to crafting a meaningful digital story and/or processing an emotionally laden cancer experience (Angus & Greenberg, 2011; Classen & Spiegel, 2011; Giese-Davis et al., 2002). Primary negative affect (i.e., sadness, direct fear, and anger) is common and encouraged when AYAs share their cancer

story in a supportive group setting (Giese-Davis et al., 2005; Giese-Davis et al., 2002). From a DST facilitation perspective, if the meaningful moments an AYA selects for their digital story do not elicit strong emotions, it is worth asking, *is this the story that needs to be told*? Whenever meaningful moments are being shared, emotion is a reliable, and necessary, by-product. However, emotion that appears to be unmanageable in its intensity and duration, and occurs out of context, could be important to recognize and address throughout a DST experience (Grecucci et al., 2015).

Again, Amanda's experience is informative. During the "meaningful moments" exercise at the beginning of the evening session, Amanda expressed low sadness (i.e., drawing down of the corners of the mouth, upper eyelids drooping, eyes and forehead down; Giese-Davis et al., 2005) as she reflected on the meaningful moments associated with her abortion. This slowly progressed from low sadness to high sadness (i.e., tears; Giese-Davis et al., 2005) throughout the evening, culminating with the sudden appearance of tears during the final didactic teaching portion of the evening that provoked Kelsey's empathetic gesture. Although expressions of sadness could be expected as Amanda shared moments from her difficult cancer experience with others, the slow escalation and expression of high sadness outside of a narrative context (i.e., tears during didactic teaching, not when telling her story) indicated that she was struggling to manage both the intensity and duration of her emotion. In Amanda's own description of her experience she said, "I think about this [on] a certain day, and it just always comes out." Specifically, she was describing her experience of "unstoried emotions" (Angus & Greenberg, 2011, p. 69).

Unstoried emotions are identified as "undifferentiated, maladaptive emotional states not embedded in a narrative context" (Angus & Greenberg, 2011, p. 69). In *Emerging Horizons*, as with most DST workshops, the story circle aroused strong emotions (e.g., Kelsey: "I have read that story like eight times, but then you say it out loud and you start to cry"), but these emotions are often short in duration and embedded in a "narrative context" (i.e., reading the story aloud) despite their intensity. In other words, the difference between Kelsey's tears during the story circle and Amanda's tears during the didactic portion of the evening workshop was their context, intensity, and duration. Angus and Greenberg (2011) provided a salient description of the difference between Amanda and Kelsey's experience of high sadness:

> It is as if the emotion is in charge rather than that they are experiencing a situated discrete emotion. It is only when these unexplained emotional states are embedded within a specific narrative context . . . that a client can achieve a nuanced understanding of what the feeling specifically means and says about him or her. (p. 70)

Amanda believed that she was ready to share her cancer-induced abortion story to help other young women facing the same tragic circumstances, but her emotions were still "in charge," the wound was still open and bleeding. Together, we decided that this particular wound needed more acute care to staunch the bleeding before it could be turned into a digital story.

Wound Care: Safeguarding Participant Wellbeing

> *Mike: Just let us know if you'd like to chat with someone, and yeah, I can connect you with that person if you want.*

Amanda: No, I'm good, but thank you.

There is a lot of exposing and palpating that occurs during a DST experience. Kelsey highlighted this during lunch on the second day of the weekend workshop as she described her experience so far, "You know, you keep relistening and relistening to it [cancer story]. Like, it kind of reopens the wound, or like, keeps picking at it." With this description, it could be suggested that the DST process may not be the best form of psychosocial support for certain AYA cancer survivors. In particular, if a chaos narrative and unstoried emotion are apparent, a decision needs to be made that safeguards storyteller wellbeing.

The word "safeguard" comes from the old French *salve* or *sauve* (safe) and *garde* (a keeping; Online Etymology Dictionary, n.d.). The term *salve* in English also signifies a healing ointment applied to a wound (Online Etymology Dictionary, n.d.) and consequently, one interpretation of the word safeguard could be "wound keeping." If we are all wounded storytellers (Frank, 2013), it could be said that our wounds need to be kept safe until and during their storying. Specifically, a wounded digital storyteller may not need to be fully healed, but perhaps the bone needs to be set and immobilized, the wound salved and bandaged, and the acute emotional pain subsided before a DST process can be a meaningful "brick in the pathway to healing" (Laing et al., 2017a, p. 276). A chaos narrative with unstoried emotion is a raw, complex open fracture of the psyche, and the salve of time, or in some cases professional psychotherapy, may be necessary to cultivate the reflective distance and emotional understanding necessary to craft it into a digital story. If a chaos narrative is still being lived and the emotions remain unstoried, it follows that the response to an open complex fracture being exposed and "picked at" through the DST process is intense and uncontrollable emotional pain.

Amanda's DST experience demonstrates that the complexity and severity of the psychosocial wounds of a cancer experience may not be apparent until the DST process is underway. As she said in her opening line from the film, "Is it going to, you know, be exhausting? Is it going to be too much to handle? You just never know." If it is apparent in the early phases of a DST experience that an AYA is attempting to story a broken bone or open wound, the ethical imperative is to have safeguards in place. One of these safeguards is providing ongoing opportunities for AYAs to disengage from the DST process during routine check-ins and the established continual consent process. In designing the DST workshop for *Emerging Horizons* and in my enrollment communication with participants, I indicated that the Introduction to DST evening session was a no-commitment opportunity to see if this DST project was a good fit. Not only did this allow me a face-to-face opportunity to assess participant readiness, but it was also a developmentally appropriate approach that empowered the AYAs to make their own decisions (i.e., in contrast to the paternalism of intervention suitability being determined entirely by the facilitator/researcher in advance).

Another safeguard was to provide opportunities to pursue a different storyline than what arose from the "meaningful moments" exercise. In one of my two follow-up phone calls with Amanda, I proposed that she could share another story from her cancer experience. In particular, I suggested that she could share about how being a police officer who was used to helping others made it difficult to ask for help during her cancer experience. In contrast to Amanda's broken and chaotic abortion story, this particular story from her cancer experience had already been

transformed into a quest narrative, with Amanda overcoming the obstacles of cancer treatments by learning to ask for help. This storyline could have been more amenable to the DST process and conveyed an important lesson from her cancer experience. However, Amanda felt like that was not as meaningful a storyline for her to pursue at that time.

The final safeguard was shown in the film through the hallway conversation between Amanda and me, where I asked her if she wanted to talk with the psychosocial oncology specialist who was part of my supervisory committee (Moules). In that moment, she declined the additional support, but this initial conversation continued over the next eight days via email and phone before we came to the decision that "this was not the right time or place for her to tell that story." She decided to continue visiting the psychosocial oncology professional that she had previously connected with at the local cancer centre. However, despite dropping out of the study, Amanda still had a strong desire for her footage and storyline to be included in the film. This is an indication that storyteller wellbeing was maintained; Amanda felt invested in the project even after her decision to discontinue participation. Furthermore, 11 months later in the online small group screening of *Emerging Horizons* for the AYA participants, she acknowledged that her experience was indeed a good "inciting incident" in processing her abortion experience, as I had hopefully suggested in the film.

Ultimately, for Amanda, completing a digital story was not what she needed from the process; it was an awareness that she had been living with an open fracture that had not yet been set, salved, or casted. Amanda's experience suggests that, although it may not be possible to determine in advance if it is the right time and place for an AYA to share a particular story, it is possible to support them to make that determination for themselves and safeguard their wellbeing throughout the process. If this is done well, it could be possible for AYA cancer survivors to move forward with a deeper understanding of profound wisdom embedded their scars and the enhanced strength and resilience of their broken bones.

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