


# Stories That Heal: Understanding the Effects of Creating Digital Stories With Pediatric and Adolescent/Young Adult Oncology Patients

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## Abstract

The purpose of this philosophical hermeneutic study was to determine if, and understand how, digital stories might be effective therapeutic tools to use with children and adolescents/young adults (AYA) with cancer, thus helping mitigate suffering. Sixteen participants made digital stories with the help of a research assistant trained in digital storytelling and were interviewed following the completion of their stories. Findings from this research revealed that digital stories were a way to have others understand their experiences of cancer, allowed for further healing from their sometimes traumatic experiences, had unexpected therapeutic effects, and were a way to reconcile past experiences with current life. Digital stories, we conclude, show great promise with the pediatric and AYA oncology community and we believe are a way in which the psychosocial effects of cancer treatment may be addressed. Recommendations for incorporating digital stories into clinical practice and follow-up programs are offered.

## Keywords

digital storytelling, adolescents and young adults (AYA), coping, qualitative research

Human beings lead storied lives: stories shape who we are, and we are compelled to tell and listen to stories. Stories have been used for centuries to share wisdom and pass knowledge from one generation to the next, but they have not been thoroughly explored as a health care intervention, specifically as a way of delivering care to the child or adolescent/young adult (AYA/AYAs) affected by cancer. The act of telling one's story is powerful, often transformative, and fundamentally helpful as we attempt to understand our experiences. Digital storytelling has been called both a method and a movement and is intended to give individuals a voice through the use of computer tools. Many of the created stories are deeply personal, and through the use of images and sounds, individuals can creatively enhance the stories they are telling by adding emphasis and meaning.

There exists very little research related to digital stories. To the best of our knowledge there has never been a study investigating the therapeutic benefits on the creator of a digital story, particularly in the pediatric and AYA oncology population.

## Study Objective

Our goal in this research was to determine if, and understand how, digital stories might be effective therapeutic

tools to use with children/AYAs, thus helping to mitigate suffering. We sought to understand the meaning, therapeutic or otherwise, for the child/AYA with cancer of creating a digital story related to their cancer experience.<sup>1</sup> The research question was the following: How might we understand the meaning of, value for, and effect on the child/AYA with cancer (past or present), in the creation of a digital story about their cancer experience?

## Background Information and Literature Review

Treatment for childhood cancers has improved significantly since the 1960s with 5-year survival rates now reported at more than 80% (combined) in high-income countries (Canadian Cancer Society, 2015; National Cancer Institute, 2016). While aggressive, multimodal therapies and high enrolment in clinical trials (more than 80%; Canadian Cancer Society, 2015) are primarily responsible for the

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improved survival rates, both physical and psychosocial short- and long-term side effects are often the price that is paid for survival. Childhood cancer typically encompasses 0 to 14 years of age (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005), adolescence is 15 to 19 years of age (Barr, 2007), and young adulthood begins at 20 years of age. The upper age limit for young adulthood has been the subject of debate over the past few years (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016) and currently tends to range from 29 to 39 years of age (Lang, David, Giese-Davis, 2015). For purposes of this study, we are defining adolescents and young adults from age 15 to 39 years of age, which is in accordance with the suggested guidelines of the Adolescent and Young Adult Progress Review Group (National Cancer Institute, 2006), a partnership between the National Cancer Institute and the LiveStrong Foundation.

### Storytelling

Storytelling has been used for centuries as a fundamental means of communication (Koch, 1998). Stories were a way through which individuals, communities, and societies conveyed important messages and experiences to others (Bowles, 1995). In today's modern world, while other means exist through which to pass along knowledge, stories and storytelling continue to shape our lives and culture (Parkinson, 2001). Stories can assist with reaffirming lives and experiences (Atkinson, 2002), and with respect to illness, they can help make sense and give meaning to dramatic and confusing times of life (Abma, 2005; Bosticco & Thompson, 2005). For young people, stories offer a way to make sense of situations and work through feelings (Anderson, 2009; Hanney & Kozłowska, 2002); they serve to increase understanding of personal experiences (Carlick & Biley, 2004) by promoting awareness of, and reflection on, life circumstances (Bosticco & Thompson 2005).

Stories, along with play and art, have been considered to have therapeutic use since the 1980s (Scaletti & Hocking, 2010), and storytelling has been used therapeutically in a variety of settings. Only recently, however, have researchers examined story in different contexts and with different populations. Used primarily for pedagogical purposes, the use of story varies widely (Wilson, Hutson, & Wyatt, 2015). Stories and storytelling have been used to facilitate learning in a palliative care context (Abma, 2003); teach high-risk youth about violence and associated dangers (Werle, 2004); promote health and well-being in children (Stacey & Hardy, 2011); and teach coping and resilience (East, Jackson, O'Brien, & Peters, 2010), but far less is documented on this technique as an intervention. Particularly with children and AYAs, very little is known about using storytelling as an intervention, with some investigators calling for this as a necessary

next step (Cumming, Currie, Moncur, & Lee, 2010; Wyatt & Hauenstein, 2008). This gap in knowledge leaves question as to the potentially heightened quality of life that could be gained from storytelling as an intervention for children and AYAs in the health care setting (Larkey & Gonzalez, 2007).

### Digital Storytelling

A digital story is a short, first person video narrative created by combining recorded voice, still and moving images, and music or other sounds (Storycenter, 2016). Distinct from digital blogging or photovoice, a digital story today is typically created using computer software and other multimedia tools, resulting in a story conveyed through images, music, narration, text, and video clips (Christiansen, 2011; Gazarian, 2010).

While digital stories are used in business, education, and health care, only in the last decade or so have researchers turned their attention to their efficacy. In business, for example, Oxygen Media noted a 14% increase in website traffic after the posting of a digital story (Stepanek, 2000). In education, digital stories have been shown to improve coping mechanisms and social behaviors of children (Sawyer & Willis, 2011), and tap into students' underlying altruism, contributing to the lives of others and the well-being of the environment (Fletcher & Cambre, 2009). In health care, several researchers have described using digital stories as pedagogical tools with nurses and other health care professionals, noting empathy, resilience, compassion, understanding, and reflection as common outcomes (Christiansen, 2011; Hardy, 2007; Stacey & Hardy, 2011; Sumner, 2009). Digital stories have also been used with patients or consumers of health care. Larkey, Lopez, Minnal, and Gonzalez (2009), for example, demonstrated the efficacy of digital stories compared with a risk assessment informational tool intervention as a method to improve education for Latina women who needed colorectal cancer screenings. In the health care arena, digital stories have also shown to be effective as teaching tools (Clarke, Hanson, & Ross, 2003; Cumming, Currie, Moncur, & Lee, 2010; Williams-Brown, Baldwin, & Bakos, 2002). Most recently, Akard et al. (2016) tested the use of digital stories as a legacy making intervention in children with cancer, noting its promise to improve quality of life for both children with cancer and their families.

Digital stories are an excellent medium to use with children and AYAs, as they are easily engaged in stories, technology, and interactive information (Wyatt & Hauenstein, 2008), and have shown a preference for technology-based interventions (Keegan et al., 2012). Digital storytelling is also linked with narrative therapy, a non-pathologizing approach to therapy which recognizes that people are the experts about their own lives (White &

Epston, 1990), the tenets of which are beyond the scope of this article.

## Research Design

### Method

This research was conducted in the tradition of philosophical hermeneutics, a qualitative, interpretive methodology. Hermeneutics is defined as the tradition and practice of interpretation (Gadamer, 1960/1989) and dates to 17th century biblical and theological textual interpretation. Throughout history, from religion to academia, hermeneutics has been used to interpret text and bring forth meaning. At the heart of hermeneutics is a deep and generative understanding of the phenomenon in question, and the richness and depth of data generated allows for this understanding to happen.

### Recruitment of Participants

After ethical approval was received from the Conjoint Health Research Ethics Board (REB13-1197), participants were recruited via recruitment posters placed at the Alberta Children's Hospital and also posted on the Kids Cancer Care Foundation of Alberta's website. Study participants for this research project included children/AYAs (5-39 years), who were currently being treated for pediatric/AYA malignancy, or were survivors of pediatric/AYA cancer. Members of families were also included and invited to participate, originally under the guise of "helping" their child create the digital story or to participate in the interview, however an early request from a sibling to make her own digital story about her experience as a sibling bone marrow donor resulted in an ethics amendment (REB13-1197\_MOD2) to allow for the inclusion of any family member who requested to make their own story throughout this process.<sup>2</sup> A total of 16 participants were included in this research project (Table 1), with all interviews occurring within 1 week of completion of the digital story. Similar to other qualitative research methods, in hermeneutic research, measures of "power" and random sampling are not used (Koch, 1996; Morse & Field, 1995; Moules, 2002). Purposive sampling—participants that can best inform understanding of the topic—was employed, as it was the researcher's aim to elicit a richness of data through the experiences of the participants (Moules, McCaffrey, Field, & Laing, 2015).

### Data Collection

Once participants were recruited, they met with the principal investigator for the consenting process. There were 2 levels of consent from which they could choose: the

first level of consent included the making of a digital story and participation in an interview afterwards; the second level included the addition of allowing the principal investigator to show his/her digital story in educational or research forums (eg, conferences). All but 2 participants chose both levels of consent. After consent was obtained, the first step in the process was to make the digital story with the help of a research assistant trained in digital storytelling. The experienced and skillful research assistant would work with the participant to "find" the story, then create the story in a digital medium (iMovie), using their recorded voice, selected images and video, and music. On average, digital stories were created over three, 2-hour sessions with the research assistant, with participants doing the work of finding pictures and music in between sessions.<sup>3</sup> The research assistant also recorded notes during the process of the digital story creation, capturing contextual details to assist with the data analysis. Once the digital story was complete, the participant met with a member of our research team (first author) for an interview. Interviews were semi-structured and occurred within 1 week of the completion of the digital story at a mutually agreeable location. While most interviews were conducted in person, some were done over the phone or via Skype due to geographical location or difficulty coordinating schedules. Interviews lasted between 40 and 90 minutes, and all were audio-recorded and transcribed for data analysis.

### Analysis and Interpretation of the Data

Hermeneutic research generates richness and depth in data, and *analysis* is synonymous with *interpretation* (Moules, Laing, McCaffrey, Tapp, & Strother, 2012). It is through careful reading and rereading of interview transcripts and research notes, along with writing around significant interpretations arising in the data, that understanding is generated and articulated. Analysis, or interpretations in a hermeneutic study, is a rigorous practice of bringing together knowledge, information, conversation, experience, and data (Moules et al., 2015). The aim in hermeneutics is to come to a deeper understanding of the phenomenon—in this case, the impact of making digital stories on children or AYAs with cancer (past or present). Rigor and integrity in hermeneutic research is evident through audit trails, research memos, methodological decisions, and through team consultation. Unlike other qualitative methods, hermeneutics does not present findings in terms of themes, codes, constructs, or theories, but rather seeks to deepen understanding of a topic, or practice, so that it can be seen and understood differently through its rich interpretations (Gadamer, 1960/1989; Moules, 2002; Moules, Jardine, McCaffrey, & Brown, 2013; Moules et al., 2015; Sandelowski, 2004).

**Table 1.** Participant Characteristics.

Participant	Gender	Age at Diagnosis (Years)	Age at Interview (Years)	Original Diagnosis	Comments
Anna	Female	16	24	Osteosarcoma	Relapsed as young adult
Ben	Male	4	18	Acute lymphoblastic leukemia	Relapsed at 13 years
Cate	Female	<1 year	32	Rhabdomyosarcoma	Has had significant physical and psychosocial issues to live with since surgery as an infant
Dana	Female	N/A	25	N/A	Sibling bone marrow donor at age 11 years
Elliot	Male	6	8	Burkitt's lymphoma	
Franca	Female	N/A	32	N/A	Mother to Participant 5
Georgia	Female	14	24	Hodgkin's lymphoma	
Hilary	Female	14	27	Acute myeloid leukemia	Significant long-term effects since bone marrow transplant (eg, heart disease, secondary cancers, chronic graft-versus-host disease, depression, etc)
Hank	Male	N/A	56	N/A	Father to Participant 8
Ian	Male	16	24	Central nervous system tumor	
Jenna	Female	15	16	Hodgkin's lymphoma	Interview incomplete
Kyle	Male	5	5	Non-Hodgkin's lymphoma	
Lydia	Female	N/A	35	N/A	Mother to Participant 12
Mark	Male	24	32	Hodgkin's lymphoma	
Nadia	Female	13	26	Acute lymphoblastic leukemia	
Olivia	Female	14	17	Burkitt's lymphoma	

## Interpretive Findings

### *Understanding: A Profound Need for Others to Know What it Was Like*

Interviewer: Why do you think it matters that people understand what you've gone through?

Hilary: (10 second pause . . . thinking) Because then they can *understand*. It's pretty simple, really.

Most of the participants in this study told us that making their digital story was a way for others to understand their experience of cancer. From friends and family to health care workers, they described an overwhelming need to have others understand what they had been through. For some, their digital story represented the first time they had ever told their story. Dana, for example, had not spoken about being her sister's bone marrow donor in 11 years.

I think it [my experience] just had to be known. I tend to write letters to my dad to get my emotions out. I think this was another way of telling him what happened.

She expressed a deep desire to have her father understand what it was like for her to be the sibling of someone with cancer and also her sister's bone marrow donor at age 11.

This desire to have others understand "what it was like" was repeated over and over in the interviews.

Participants described not only wanting others to understand on an intellectual level, but using their digital story as a way to help others *feel* their experience.

My goal was to make the person feel uneasy with it, with the whole thing. Each image I put in there was in there for a specific reason. Every picture I had was representative of what I was saying in my story. (Ben)

We learned through this research that one of the most impactful and appreciated questions we asked of participants—one which many said had never been asked of them before—was, "Tell me what it was like for you."

I think I was really excited that uh . . . someone just approached me to hear my story. (Anna)

The act of asking someone to tell you their story can have a profound effect. The question "tell me what it was like for you" seemed to invite participants into a conversation and a way of speaking and thinking about their cancer experience that most had not previously had the opportunity in which to engage.

Digital stories also contribute to understanding because it can be used in circumstances when a person is unable to or is constrained in telling their story verbally. Digital stories thus contribute to the sharing of experience, helping people to speak differently and to hear more inclusively. Specifically, their multidimensional elements (language, imagery, music) appear to have additive effects insofar as contributing to the ability to explain their experiences. Children, adolescents, and even young adults often lack the language to explain what it was like for them; digital stories seemed to help overcome this challenge and allow them to access different ways in which to communicate. Mark, for example, described the difference between telling his story via a digital medium versus telling his story verbally.

I think with digital stories you're just way more thoughtful . . . the images and the music allow for more of the emotion to come across . . . they allow you to feel things. Cause it's difficult to express how you felt in a moment just off the top of your head. You need to spend some time with it, you need to sit with it and you need to write your story and formulate your sentences and craft your words, you know?

Just as it was important for participants to have others understand their experience of cancer, they too appeared to experience understanding as well. Many described a new or different understanding of their own experience of cancer after making their digital story. Anna, for example, shared what it was like for her watching her completed digital story and how it helped change her perception of herself.

Like in the last 3 days, every time I watch it, it . . . it's like you don't give yourself enough credit for going through that much and just watching that . . . oh wow, that's actually amazing (laughs). I never thought of it like that, but when you put it all together, that's . . . that's really awesome.

Digital stories, we have learned, are about understanding an experience versus simply explaining it. They can put the maker of the story in a place of understanding their experience of cancer differently, and the viewer of the story in a place of better understanding the experience of the person with cancer. Much like Gadamer's (1960/1989) concept of *sensus communus*, there is a privacy and almost inarticulateness to the experience of having cancer; one that cannot be understood unless one experiences it personally (Laing & Moules, 2014a). Hilary echoed this idea as she told us about disliking when her friends or health care professionals say (glibly, in her opinion) "I understand." *How can anyone really understand? Up until now, I've never really told them!* Digital stories, we believe, allow for as close an understanding of someone's experience as one can get. Until we understand, we

cannot help, and perhaps understanding all by itself is all the help that is sometimes required.

### A Brick in the Pathway to Healing

I was feeling so lost . . . and then now I just kind of feel filled with so much purpose. Just being able to share your story with someone who wants to listen is . . . well . . . I, I think we often don't realize that something simple and little like that can be so helpful. (Anna)

Many participants spoke about experiencing a degree of healing related to their cancer experience as a result of making their digital stories. For some, it came by way of working through a psychosocial issue that had been with them, in some cases, for a decade or longer. For others, it came by way of letting go of "secrets," or opening up a very private part of themselves. Healing, or the therapeutic value of making a digital story, was experienced differently by every participant, but each one of them spoke to this. There appears to be significant therapeutic value to making a digital story, and while we were not able to predict the form in which it took, those who participated in this study found the process of making a digital story to be helpful.

Telling my story and kinda expressing it in this way, helped me heal a little bit more, than um . . . than I have in the past. I didn't worry about what other people may think of it . . . what pictures my mom would or wouldn't want me using. It was more about finding truth in some of this things. (Cate)

Cate also described her experience as *a brick in my pathway to healing*. This description reflects what we learned about other participants' experiences with making a digital story as well; making a digital story is not the "cure" to psychosocial recovery from cancer, but it can be step forward, or a brick along the pathway, that helps people move forward in their lives.

The younger children who were still on treatment spoke about the distraction making a digital story provided them, and how they appreciated the fact that it gave them something to do while in the hospital. Digital stories may offer a way of coping during the mundane and often difficult phases of treatment for childhood cancer. Kyle (6 years) told us,

It gives you something to do . . . a little more than doing nothing. It gives you something else to think about instead of just lying in your bed or whatever.

Kyle's mother echoed that sentiment, saying,

It gives these little kids something to think about other than lying in bed. It's all in the process of healing and getting

better, and just making your mind think of other things. (Lydia)

The therapeutic value that comes from making a digital story may be linked to the motivation to do the digital story in the first place. For some, it might be a distraction or something to do while in the hospital, and for others it can be a way to work through complex and troublesome psychosocial issues. Regardless of the motivation to do a digital story, the process participants underwent—from conception of an idea through to the final interview—seemed to offer a degree of therapeutic value.

Dana: I feel a lot different [after making her digital story]. Cause I'd kept it up inside for so long that to finally let it go was a weight off my shoulders. Like, it was really a relief.

Interviewer: It was? Did it make you want to tell it [your story] again?

Dana: No. I've let it go.

Interviewer: Really? Why, what do you think that is about?

Dana: I don't know. I really don't know. (thinking) All of those hard feelings . . . the hard feelings and the loneliness I went through. That stuff is all off my shoulders now.

We were surprised to find how several participants used their digital stories as a way of letting go of what they deemed as “secrets.”

It's a side of me that a lot of people didn't know about or didn't see, even among my close friends I think there are those that don't know about this. People have their secrets. And um . . . it's been kind of cool opening up this part of my life to them because they see a different side of me . . . and just kinda like . . . the story of who I am. I mean, I almost started putting less emphasis on it as a problem in my life [after making a digital story] because it was a secret and it shouldn't be problem anymore because the secret is not a big deal. (Ian)

Ian was discussing how he had kept his body image issues a secret, feeling ashamed both of his body (the outward physical effects as a result of cancer therapy) but also of his issues toward it. His digital story allowed him the opportunity to work through this issue, and as a result come to view it differently, in this case—in a more helpful and healthy way. Having the opportunity to “tell one's secret” or reveal something once held as private often renders the secret inert, no long capable of exerting power, at least to the same degree, over one's life.

The more you tell your story the easier it gets . . . the easier it gets and the less scared you are talking about it. (Mark)

## When It Is Least Expected

There is something unexpected about digital stories: they often start one way, then change; they seem simple, yet are complex; the audience changes, the maker of the story changes, and the viewer of the story changes—and all of it is unexpected by the participants and viewers of the stories. The most unexpected part however, was the therapeutic value that participants experienced as a result of making a digital story about their cancer experience.

I didn't think it [making a digital story] was going to mean anything profound because I just thought “Oh yeah, I have shared my story, I can help share it for whoever you might show it to at the hospital,” but I didn't realize how healing it was going to be for me. (Cate)

All participants told us they volunteered (or volunteered their child) for this research for altruistic reasons; “I want to help others” was a common phrase we heard. While we have experienced this phenomenon of altruism in other studies with the pediatric/AYA cancer population (Laing, 2013; Moules, Laing et al., 2012; Moules, McCaffrey, Laing, Tapp, & Strother, 2012; Moules, Estefan, McCaffrey, Tapp, & Strother, in press-a; Moules et al., in press-b; Moules et al., in press-c), it was interesting to note how almost all participants echoed Cate's statement above, not realizing the therapeutic benefit that was to come from making a digital story. For many, this represented the first therapeutic endeavor they had ever done or would ever consider doing.

Like, they tried to get me to a psychologist but I'm very much like my grandfather—I have my problems, they have theirs, they don't need to know mine. And so I never spoke about it. Ever. I think about the weight off my shoulders as being the best thing about making a digital story. As well, this is my type of format to express myself too . . . something that's not face to face! That's what's so cool, like I could sit in front of a psychologist now and still mouth shut, zippered, locked, key out the window. . . . I just don't talk about this kind of stuff. So this was a type of therapy for sure . . . it just helped me! (Dana)

Dana described her experience of making a digital story as “sneaky therapy”—not in a sly, manipulative way, but rather in an unexpected way. Several other participants offered similar sentiments describing the process of making their story as “therapeutic, not therapy” (Nadia), “like therapy, only not” (Ben), and “healing in a way I didn't expect” (Anna). Perhaps due to the nonthreatening nature of digital stories, coupled with the fact that many people are drawn to the technology and the idea of playing with this medium, participants seemed to enter into the process with an open mind and willingness to share a part of themselves.

Digital stories “fit” well with the participants in our study, most of whom are part of the millennial generation. Millennials, born between 1982 and 2003, are digital natives; the first generation in history to be immersed in information communication technology their entire lives (Considine, Horton, & Moorman, 2009). In addition to being interested and savvy with technology, Millennials prefer brief, meaningful communication, respond well to stories and anecdotes, and prefer non-face-to-face communication (Myers, 2010). Digital stories provided a way of processing issues that were sometimes very complex without the traditional approach of psychotherapy or other common therapeutic interventions. Digital stories, we suggest, offer an “oblique approach” (Laing & Moules, 2014b) when considered under the guise of a therapeutic intervention.

I remember when I was in the hospital and they'd have this psychologist come in and talk to me and I just didn't want to, I didn't want to talk to her or anything. I was just like, no, I'm fine, I'm good, I don't need anything, this is not a big deal. But, now that I made the video, I know that I had so much anger and stuff inside of me that I just had to let it out. (Georgia)

It is precisely this oblique, or nondirect approach that we believe contributes to the therapeutic effectiveness of digital storytelling. Making a digital story does not “feel” like therapy, yet undoubtedly the results can be therapeutic.

### *Truth and Reconciliation*

Truth and reconciliation is currently a predominant topic in Canada, as the country as a whole attempts to atone for its “cultural genocide” (p. 1) toward Aboriginal peoples (Truth and Reconciliation Commission of Canada, 2015). Six years and 6,000 interviews resulted in a report that attempts to unveil the “truth” of how this culture was treated,<sup>4</sup> and reconcile its relationship with the Aboriginal community. It strikes us that this idea of “truth and reconciliation” is not dissimilar to what we learned from our participants about the process and outcomes of making a digital story related to their cancer experience. For many, it was about finding, facing, or confronting a “truth” from their experience with cancer; this “truth” is what often became their story. Once the truth was found, faced, or confronted, it could to be reconciled. Reconciliation is defined as “the process of finding a way to make two different ideas, facts, etc, exist or be true at the same time” (Merriam Webster, n.d.), and for our participants this came by way of making sense of, or meaning from, their experiences with cancer.

So it wasn't easy, to share my story, but I guess it's being able to step back from those immediate moments, and look at them a little more objectively. It really helps to make sense

of things, make meaning, and see how your story is connected to other pieces of your life. (Mark)

The process of making a digital story allowed individuals to take a step back from the immediate moment, and understand where their story fit within the scope of their life. It helped them make sense of their experiences and sometimes to understand them differently.

I needed to make sense of it [the experience of having cancer]. And I think just because—I think in particular the millennial generation—we're looking for meaning, and I just wanted to find some meaning in what I'd been going through. (Mark)

I think it was making the video and putting the pictures in, it was kinda like . . . I got through it [cancer]. I don't think it's that bad anymore, to look at those pictures. I think I've just gotten used to it now. I hadn't looked at those pictures since—like before I did the video, I hadn't seen those pictures, so it was just a bit of a shock to see. When you're healthy and you look at those pictures and you're super pale and bald and sick (laughs). But I'm none of those things anymore. I got through it. (Georgia)

The idea of making sense or meaning from the experience of cancer was pervasive and articulated throughout almost all our interviews. There was a need for many to reconcile, come to terms with, and have their experiences (or parts of their experiences) be less threatening or negatively effective in their present-day lives. We learned that the full psychological effect of having cancer is not unlike the physical late effects; it sometimes takes years for the impact to show. Several participants described thinking they were “ok” for years, until an event—some perturbation—incited something within them that let them know they were, in fact, not “ok.” Olivia told us that it was coming across the recruitment poster for this research that triggered her, gave her insight that perhaps this was something that might benefit her. She talked of discovering a deep-seeded anger within her, of which she was not consciously aware, and the process of making a digital story not only alerted her to the impact it was having on her life, but also helped her manage it.

The making of the video was out of anger, like you know, I just wanted to get it out so bad. And yeah, it's a little hard to explain. . . . Like I just let it all spill out on the video, kind of thing . . . I was really angry when I was looking at those pictures. (Olivia)

Everyone's motivation to do a digital story was different, yet there was a common thread woven among them—particularly for those who were at least several years from finishing treatment—that there was something “unfinished” from their cancer experience, something that had

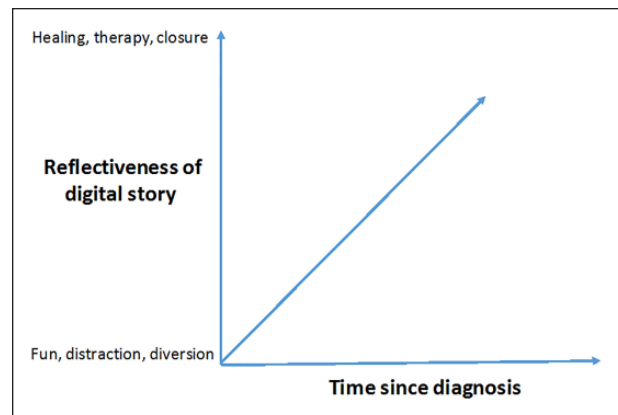
not yet been attended to or dealt with from a psychosocial perspective. Digital stories seemed to help individuals “deal with” whatever it was that served as motivation to engage in this research. Be it making meaning of, sense from, or confronting an issue, until it is unearthed, examined, re-storied (White & Epston, 1990), or let go—it is not dealt with.

I didn’t—couldn’t—make sense of it while I was in the thick of it [treatment for cancer]. It wasn’t until later that I realized I had so much shit I had to deal with—psychological shit, you know. I guess until it’s dealt with, it’s not dealt with. (Ben)

## Discussion

The more sophisticated the science of treating cancer becomes, the more obvious it is that curing the disease is only half of the equation. A great deal of attention has been given to cure, however more attention is needed in areas of care. While survival rates for many cancers have greatly improved over the last decades, the cancer community is still discovering the long-term effects of treatment, and the immense psychosocial impact this disease can have; there are often as many psychosocial effects of therapy as there are physical effects (Siegel, Miller, & Jemal, 2016). Understanding how to better address these issues, and ultimately how to mitigate suffering, can help health care professionals and cancer programs refine and improve on the services offered to this population, thereby improving on the quality of care they receive. Digital storytelling, we believe, is a way in which to help children and AYAs cope with the experience of cancer. We suggest that digital storytelling can be used to highlight the immense psychosocial impact of cancer, and point health care professionals and other researchers toward unique and creative ways to address this issue.

As one of our participants stated, making a digital story is “therapeutic—not therapy” and we wish to highlight that important distinction. We make no assertion that digital stories should replace traditional approaches to therapy; however, what became clear through this research is that for many, traditional therapeutic approaches are not a “fit.” Most of our participants had never engaged in any type of psychosocial or therapeutic work, yet through the process of making a digital story, they became clear that working through the process of making a digital story was not only beneficial, but more often something they described as “needed.” Because the life expectancy of children and AYAs with cancer has greatly increased, it is important that we start to appreciate the psychosocial effects of cancer treatment and be creative in the ways we use to address this need. Digital storytelling, we assert, is one way in which to help those affected by childhood/AYA cancers.



**Figure 1.** Relationship of time since diagnosis with reflectiveness of digital story.

Just as there is no “one size fits all” approach to addressing psychosocial needs, we learned there is no “one reason” someone should do a digital story. Digital stories, in other words, seemed to serve the purpose of whatever the participant needed it to. The stories can be about messages for others, healing from past psychosocial trauma, understanding, education, or simply a distraction or diversion from therapy; they can serve whatever function is asked of them.

One of the most salient things to come from this research is the relationship between timing of making a digital story, and distance from diagnosis (Figure 1). It appears that the further away one is from diagnosis, the more reflective their story. By reflective we mean the more likely it is to be about healing, acceptance, or closure, than about a distraction or diversion. It takes time to process the experience of cancer, and unsurprisingly, timing appears to be an important consideration with digital storytelling. Stories are not always ready to be told, and we learned that sometimes it takes years to even figure out what the story *is*. Participants seemed to need distance (time) from the experience of having cancer to fully appreciate the impact, and that, we believe, is why digital stories can serve different purposes, depending on the proximity to the experience.

## Implications and Recommendations

The medium of digital storytelling has great promise with the pediatric and AYA oncology community, and we believe it is a way in which the psychosocial effects of cancer treatment may be addressed. Specifically, we offer the following recommendations to better meet the psychosocial needs of young people with cancer:

- Health care professionals must acknowledge and address the psychosocial needs of children and AYAs during, and after cancer therapy.



- Innovative and creative ways must be used to address psychosocial needs, recognizing that traditional structures for therapy delivery may not fit with everyone, particularly the millennial generation. It is important to broaden our ideas about what is therapeutic and appropriate for use with this population, recognizing that digital storytelling can reveal needs that are otherwise hidden, unconventional, ordinary, and thus ignored.
- Digital storytelling could also be incorporated into clinical practice guidelines for late effects, as it often takes years for psychological scars of cancer therapy to emerge.
- Further research should be undertaken with different populations, but also using different research methods. For example, a quantitative study (specifically a pretest/posttest approach) could build on the understanding that has been generated from this study. Additionally, other modes of storytelling could be researched (eg, verbal/recorded, group vs individual) and compared with digital storytelling to determine the impact and efficacy of each method.

## Conclusion

The experience of cancer affects not only the physical body, but the psychosocial health of an individual as well; several of our participants told us that it was the psychological scars from their cancer therapy that were far more damaging than their physical scars. Digital storytelling can be used as a therapeutic tool to help those suffering the psychosocial effects of treatment for childhood/AYA cancer. It is important to understand, recognize, and address the mental health aspect of childhood/AYA cancer not only during treatment but long after its completion as well.

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## Notes

1. The secondary aim of this research was to understand the effect on health care professionals of viewing the digital stories of these children/AYAs. This will be discussed in a separate article titled, “‘Stories Take Your Role Away From You’: Understanding the Impact on Healthcare

Professionals of Viewing Digital Stories of Pediatric and Adolescent/Young Adult Oncology Patients.”

2. The research team felt it unethical to deny her request as she shared that she had never spoken of her experience in 11 years and felt compelled to talk about it after watching her sister undergo the process of making a digital story. No other family member requested to make a personal digital story.
3. The methodology of making a digital story is complex and warrants a separate paper of its own to explain the intricacies and details involved. This, along with more details related to the actual content that came from the digital stories themselves, will be discussed in a separate article titled, “Words, Camera, Music, Action: The Methodology of Digital Storytelling in a Healthcare Setting.”
4. Predominantly related to the Indian Residential School Program, wherein approximately 150,000 children were taken from their homes to live in residential schools designed to remove from them the influence of their families and culture, and assimilate them into the dominant Canadian culture (Truth and Reconciliation Commission of Canada, 2015).

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