

# Digital Storytelling as a Psychosocial Tool for Adult Cancer Survivors

Catherine M. Laing, RN, PhD, Nancy J. Moules, RN, BN, MN, PhD, Shane Sinclair, PhD,  
and Andrew Estefan, RPN, DipNSc, BN, MN, PhD

**PURPOSE:** To understand the meaning and impact for adult patients with cancer (past or present) of creating a digital story related to their cancer experience.

**PARTICIPANTS & SETTING:** Ten participants made digital stories with the help of a research assistant trained in digital storytelling. This research took place in a large, urban center in Calgary, Alberta, Canada.

**METHODOLOGIC APPROACH:** This research was done in the tradition of philosophical hermeneutics. Ten one-on-one interviews were conducted, and data were analyzed using an interpretive qualitative methodology.

**FINDINGS:** Findings revealed that digital stories were cathartic; reconnected individuals with family, friends, and parts of their lives that had been interrupted from cancer therapy; helped participants reflect in a way that was often described as therapeutic; and bridged communication with others about their cancer experiences.

**IMPLICATIONS FOR NURSING:** Digital stories can be used to highlight the immense psychosocial impact of cancer and point healthcare professionals and other researchers toward creative and nontraditional ways to address this issue.

**KEYWORDS** qualitative research; quality of life; coping; digital storytelling

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Survival rates have increased, and the mid- to long-term psychosocial effects of cancer are still being discovered (Siegel, Miller, & Jemal, 2015). Understanding how to better address these issues can help healthcare providers tailor services, improving the quality of care. Digital storytelling may be one way to help individuals cope with the experience of cancer and may serve as a medium for healthcare professionals to better understand their patients' experiences. Although this medium has shown great promise with the pediatric oncology community, the effect of digital storytelling on adult patients with cancer has not been investigated (Laing, Moules, Estefan, & Lang, 2017a).

A digital story is a first-person perspective of an individual's experience told in a two-to-three-minute video. They combine moving and still images, music selected by the storyteller, and a voiceover narration told by the storyteller (Lal, Donnelly, & Shin, 2015; Storycenter, n.d.). Digital stories are a powerful medium to convey understanding as different forms of aesthetic combine to create enhanced meaning for the viewer (Lal et al., 2015).

The use of digital stories in health care is a recent phenomenon (Lal et al., 2015). Traditionally, they have been used as pedagogical tools with nursing and other health disciplines, with increased understanding, compassion, resilience, and empathy often noted as outcomes (Christiansen, 2011; Stacey & Hardy, 2011). Research related to digital storytelling has expanded to include patient perspectives and intervention strategies (Akard et al., 2016; Lal et al., 2015). When used as a legacy-making intervention in children with cancer, digital stories were noted to improve the quality of life of children with cancer and their families (Akard et al., 2016). Digital storytelling has also been successfully used as a way of understanding pediatric oncology survivors' experiences with psychosocial late effects of treatment (Laing, Moules, Estefan, & Lang, 2017a, 2017b). Although the goal of traditional digital storytelling is

not to replace therapy, several studies have demonstrated their therapeutic usage (Laing et al., 2017a; Lal et al., 2015; Wexler, Gubrium, Griffin, & DiFulvio, 2013), often leaving participants with a sense of pride, empowerment, and catharsis (Wexler et al., 2013).

Predominantly used in qualitative research, digital storytelling can be a deeply reflective process for participants, allowing researchers to delve deeply into participants' personal experiences (Lal et al., 2015). Creating digital stories can result in a sense of empowerment, pride, and catharsis on the part of the participant (Lal et al., 2015; Wexler et al., 2013). The digital medium can serve as a powerful way to understand and connect to human experiences. The current authors aimed to discover how the creation of a digital story affects adult patients with cancer (past or present) and how the meaning (therapeutic or otherwise) of creating a digital story related to the cancer experience might be understood.

## Methods

### Participants and Setting

After ethical approval was obtained from the Health Research Ethics Board of Alberta–Cancer Committee

(HREBA.CC.16-0754), 18 participants were recruited via posters hung in multiple places at a large, urban outpatient cancer treatment center in Calgary, Alberta, Canada, and consent was obtained. Participants were aged 18 years or older and diagnosed with cancer as an adult. All were either in active treatment or follow-up; one participant was receiving palliative care (see Table 1). During the course of the study, eight participants were lost because of attrition, some withdrawing between agreeing to participate and commencing the digital story, and some individuals who began the digital story but did not complete the full protocol. Reasons for withdrawal included living out of town and being unable to make the sessions with the digital storytelling facilitator (two participants), participants' health deteriorated (two participants), cancer treatment regimen too intense to continue (one participant), and unknown (three participants). Overall, 10 individuals completed the entire protocol, which included making a digital story and participating in a follow-up interview. Purposive sampling (participants who can best inform a topic) was used because the intent was to elicit rich data through participant experiences (Moules, McCaffrey, Field, & Laing, 2015).

TABLE 1. Participant Characteristics (N = 10)					
Participant	Gender	Age at Diagnosis (years)	Age at Interview (years)	Original Diagnosis	Treatment Status
Brenda	Female	55	56	Breast cancer	Finishing treatment at time of interview
Candice	Female	41	44	CNS lymphoma	Off treatment for 6 months
Dan	Male	35	51	Ewing's sarcoma	Off treatment for 16 years
Hope	Female	70	70	Breast cancer	In active treatment
Jeffrey	Male	59	59	Lung cancer	In active treatment
Marsha	Female	35	36	Breast cancer	Off treatment for 15 months
Melinda	Female	61	63	Colon cancer	Off treatment for 8 months
Regina	Female	43	44	Metastatic pancreatic cancer	Palliative care
Thomas	Male	48	59	Hairy cell leukemia	Finishing treatment at time of interview
Yvette	Female	55	57	Breast cancer	Off treatment for 1 month
CNS—central nervous system					
Note. Participants were given pseudonyms.					

### Digital Storytelling Protocol

This research was conducted using philosophical hermeneutics, a qualitative, interpretive methodology. Hermeneutics is defined as the tradition and practice of interpretation (Gadamer, 1989), and the aim of this approach is a deep and generative understanding (versus objective explanation) of the phenomenon in question.

The digital storytelling protocol involved three two-hour sessions with the aid of a research assistant trained in digital storytelling facilitation. The goal of the first session was for the participant to write his or her story in 250–300 words describing a defining and meaningful event or a part of the experience with cancer. The research assistant aided in tone and formatting of the digital story. In the second session, the research assistant worked with the participant to create the story in a digital medium (i.e., Apple iMovie) using the participant's recorded voice, participant-selected images, and video. In the final session, music and effects (e.g., panning, zooming, fades) were added. During these three stages of digital storytelling, the research assistant recorded field notes to aid in the data analysis. After the completion of the digital story, the participant was interviewed by a member of the research team (see Figure 1). The semistructured interviews lasted from 45–90 minutes and occurred within one week of completion of the digital story. Although most interviews were conducted in person at a mutually agreeable location, two were conducted via telephone because of location or difficulty coordinating schedules. All interviews were audio recorded and transcribed for data analysis.

### Data Analysis

In hermeneutic research data, analysis is synonymous with data interpretation (Moules, Laing, McCaffrey, Tapp, & Strother, 2012) and is the practice of bringing together knowledge, information, conversation, experience, and data (Moules et al., 2015). Beginning analyses (called "initial interpretations" in hermeneutics) are developed and consolidated through team conversations and rigorous attention to the data from the research team (Moules et al., 2015). In contrast to other qualitative methodologies, results are not presented by way of themes, codes, constructs, or theories, but rather in ways that deepen understanding of the topic so that it can be seen and understood differently (Gadamer, 1989; Moules, Jardine, McCaffrey, & Brown, 2013; Moules et al., 2015; Sandelowski, 2004). Member checking is not a part of the tradition of hermeneutics. Understanding is generated and

### FIGURE 1. Sample Interview Questions

- What was it like for you to go through the process of making a digital story?
- How did you find your story?
- What made you want to do this?
- How did you decide which direction to take the story?
- What kinds of changes have you noticed in yourself since making the digital story?
  - What do you attribute these to?
  - Can you give me some examples?
- What kinds of things did you find yourself thinking about when you went through this process (good and bad)?
- Was there anything about making this digital story that you did not enjoy? Please explain.
- Did making the digital story affect you and/or your family in any way?
  - Did it bring up conversations you might not have had?
  - Did anyone react in a way they might not have otherwise?
- What would you tell another patient with cancer who was considering going through this process?
- What stood out most for you during this process?
- What stands out most for you now, after the story has been made?
- What did you learn about yourself that you did not already know?
- Do you think anyone could benefit from this? Why or why not?
- How do you think these stories could be used?
- Was there anything you would change about the process of making a digital story?
- How do you think your digital story was different than if you had just written a story?
- What do you think you might have learned from making your digital story that you could not have learned elsewhere?

articulated through detailed and repeated reading of interview transcripts and field notes, interpretive memos (beginning analyses) written after each interview, team discussions related to emerging findings, and a recursive back-and-forth between the data in parts and wholes. Rigor and integrity are established through audit trails, research memos, recorded methodologic decisions, and team consultation.

### Findings

In congruence with philosophical hermeneutics, the authors' interpretation of the data is coalesced and

woven with the voices of participants in the form of embedded quotes (Moules et al., 2015). The weaving of researcher interpretation and participant quotes is a hallmark of philosophical hermeneutics, where interpretation is used not only in data analysis, but also in writing in a literary, engaging, and eloquent manner to remain true to the rich details and tones of participants' stories.

### **Untold Stories: The Catharsis of Digital Storytelling**

All of the participants, who were given pseudonyms, spoke about the process of making a digital story as being cathartic. One participant named Dan described his catharsis by way of letting go of something he felt had a hold on him for many years since his cancer treatment.

I think sometimes, when you think back about what you were thinking or what you were feeling at a time that was so horrible [referring to cancer treatment], it kind of lets loose some of the stress that has a hold on you, I guess. And I think that just kind of verbalizing it, and making this digital story, and knowing that somebody may see this, and it may impact them in a way that they would understand is cathartic. It kind of allows you to let go of some of the stuff that you may be holding, you know?

For him, catharsis was coupled with a need for others to understand his current emotional state based on his previous experience with cancer. He described feeling unable to adequately communicate to those closest to him why fear of relapse and worry about the future sometimes crippled him, even 16 years post-treatment.

Other participants described their own catharsis as "closure," "a way of working through all this complexity," and "a huge release." One participant, Candice, spoke of digital stories providing a way to "do something" with her emotions:

Like, your choice really is to let [the emotions] crush you or not. And when your choice is to not, then you have no choice but to stand up and make sure you are in the best frame of mind, which means you have to do something with those emotions.

Candice elaborated on this idea by offering how the process of reviewing her experiences of cancer with a trained facilitator, writing her story, finding pictures and music to represent her ideas, and viewing the completed product felt "empowering and transformative."

This is consistent with the tenets of narrative therapy (to which digital storytelling is intimately linked), an approach to counseling that recognizes that people are experts of their own lives and views problems as being separate from individuals (White & Epston, 1990). This therapeutic approach involves re-authoring or re-storying critical life events with the intent for them to be understood differently (White & Epston, 1990). The process of making a digital story offers participants the opportunity to release and then re-story their experience with cancer, which may allow them to make sense or meaning of their experiences (Laing et al., 2017a; White & Epston, 1990).

### **Life Interrupted: Reconnecting to What Matters Through Story**

For most participants, making their digital story related to the idea of reconnection. For some, it was about reconnecting with their children, spouse, or partner; for others, it was a more general sense of reconnecting with their life.

So, when I was writing the story, I knew it was going to be around connection—or maybe loss of connection—but I didn't want it to focus on loss. I wanted it to focus on reconnection, because we all go through things in life that interrupt—it doesn't matter who the person is. It could be a divorce; it could be various life events that cause a disconnect. It's coming out on the other side that's important. (Candice)

The idea of cancer as an interruption in one's life was echoed by others. Hope described cancer as follows:

[A] pregnant pause in my life . . . that makes me feel like the old me is a million miles away, and I can kind of remember her sometimes, but I don't know if I'll ever get back to who I was, who I used to be. But I really want to.

A cancer diagnosis is a significant event that can be thought of as an interruption in one's life. Although participants spoke about the discomfort, untimeliness, and sometimes terror of this interruption, they described an intense longing to feel reconnected to that which they were missing. The process of making a digital story appeared to serve as a conduit or medium, bridging this existential chasm. Candice's digital story, for example, related to reconnecting with her children, both of whom she felt she had

alienated as a result of the intensity of her treatment. In Thomas's story, he reached out to his wife in an attempt to regain the intimacy they had lost during his treatment. For Melinda, the story related to re-engaging with her community, friends, and other groups she used to belong to, despite a poor prognosis. Regardless of the type of connection, most of the participants described the importance of moving on in their lives, getting back to their old selves, and reconnecting with others. Although this is a highly personal and unique process for everyone who has experienced cancer, digital stories appear to be one way to reestablish lost connections and reclaim or reintegrate their story in the future.

### Looking Back and Looking On: The Reflective Action of Digital Storytelling

Making a digital story is an inherently reflective process, albeit in an oblique way (Laing et al., 2017a). Its project-based feel might be why some described it as "therapeutic" or "helpful in ways I didn't expect." Every participant described one of the most valuable parts of this process as the opportunity for reflection. Even individuals not prone to reflection or expressing emotions spoke about the value of this activity.

And I think it was maybe after I watched the video, I realized how beneficial it was to me. You know, that it really made, well, even during the process too, it made me think about a lot of things, and I hadn't really expressed a lot to very many people. (Brenda)

It sort of forces you to reflect on things that maybe you don't sit down and do every day, right? It's not like you go, "Today I'm going to think about this." This is kind of an opportunity that forces you into something like that. It made me think about things that maybe I didn't want to, or hadn't very much, you know? (Jeffrey)

Although the medium of digital storytelling itself was described as therapeutic, having this process guided by a trained facilitator seemed to optimize its therapeutic effect. Individuals are not left on their own, but rather are guided by the facilitator to tell, create, and show their stories. This guidance through the digital story process is coupled with a guided reflection based on each step. Just as the participants described an intense longing to reconnect with their lives and others, they also spoke about the need to reflect on their cancer experiences.

What I loved about this exercise is that it brought the most important thing out very quickly. And that now gives me more of a framework, so when people ask questions, I can talk about it within that framework. (Thomas)

Reflection also happened by comparing the present to the past and enabling them to literally see progress that may have otherwise gone unnoticed. Candice offered an explanation of how she felt the reflective process worked and how the outcome of this led to reframing her interactions with her children.

So, I think what's really hard in all of this, is there's just so much to tell. And then, when we finished writing the story, I went through this whole, like, emotional business for a couple of days, you know? I sent the story to my sister to read and got my mom to read it, and a couple of good friends had read it, and it was just, like, I felt myself going back and reading it and was almost surprised that this was me. And then it just showed that there was so much there that was still being processed or still being thought about. And as we went through the photos . . . it brought so much clarity to me. Like, when I look at my kids now, because I'm still on prednisone, which is a struggle every day, I can now look at them and go, OK, stand back, what's the priority here? If this comes out of your mouth right now, or if you have this attitude, are you leaving it with them? With feeling strong, resilient, knowing that they can take risks? Or are you damaging that? And that's become such a powerful thing. (Candice)

Reflection about the cancer experience appears to be an important part of the digital storytelling process. Regardless of where individuals were in their treatment or survivorship, the need to reflect upon or make sense of their experiences was profound. Reflection is known to be an important mechanism behind learning. Di Stefano, Gino, Pisano, and Staats (2016) argued that learning from direct experience is most effective when coupled with reflection, defined as the intentional attempt to synthesize, abstract, and articulate the key lessons from an experience. Digital storytelling and the inherent intentional reflectiveness that comes from this process necessarily has participants synthesizing, abstracting, and articulating parts of their experiences. The process may serve as a bridge between the past and the present and be the line that connects the proverbial dots.



### Conversations Waiting to Happen

Digital storytelling had an immediate effect in reconnecting to themselves and their significant others, but several participants used their digital story as a way of communicating with others, providing a means to tell their stories that often could not be conveyed through words. One participant, Thomas, said the following:

I know that I was looking for a way to say all this. Because I couldn't talk in those terms, the way I talked in making the digital story, to my own grown-up children . . . because cancer is something that we did not discuss in an open forum.

Thomas described using his digital story as a bridge to the conversation that he needed to have with his two children, now grown, about his cancer diagnosis. He knew they did not want to engage in this conversation, likely because of their own fears related to the idea of their father's mortality. For Thomas, however, it was important to find a way to discuss this topic. His story provided a means to broach a sensitive topic in a non-threatening way.

The idea of digital stories as a "bridge" or "portal" for communication was expressed by others. Sometimes the intent was to give or receive support. After showing his digital story to a room of his peers, Jeffrey described an encounter with someone who had just viewed his story. He stated, "And she said in a very soft tone—she was an elderly lady—she said, 'Jeffrey, you've been through a lot. And you don't even know how much you make a difference in other people's lives.'"

Having others watch the created stories, usually in front of the participant, was described as "scary and vulnerable" but also "validating and legitimizing." More so than the need to be understood, the participants wanted their experiences to be acknowledged and validated.

I think it kind of legitimized the fear I had. I think it validated it. So, finances were the biggest worry for me, and making the digital story kind of helped to validate and legitimize that worry. It made it real, what I experienced was real. (Brenda)

Often, the act of sharing their digital stories facilitated emotional expression by others, extending the digital storytelling therapeutic effect from the storyteller to those who interacted with the story on a relational level. In her interview, Melinda offered that sharing her digital story also allowed others to share

important aspects of their stories. When she shared that others opened up about their lives after she did, the interviewer asked her to clarify whether sharing the story encouraged others to be more open about having cancer. Melinda responded as follows:

Yeah, before this [digital story] came, I wasn't sharing that I had cancer or the processes that I was going through; I hadn't explained it. So, yeah, people came forward and said, "Oh, you know, I'm seven years in remission," or "five years in remission," or that "I'm stage IV cancer too." It was a really nice way to connect with others, I guess.

Another way in which communication occurred via digital stories was related to the message of the story itself. Many of the participants focused the message of their story outwardly (toward and for others) versus inwardly (a story largely focused on themselves). This is in stark contrast to the authors' previous study with adolescents and young adults with cancer, most of whom created stories exclusively related to themselves, with limited incidences involving other characters (Laing et al., 2017a). Common messages within the digital stories of the participants included that the experience of cancer never leaves you, messages of hope for other individuals with cancer, and specific ways of coping with parts of the cancer experience. Some of the digital stories felt similar to a public service announcement, wherein the participant was adamant that no one should have to endure what he or she did, and the story was used as a way to help others mitigate the pitfalls they experienced. Regardless of the message within the story, most stories were used to communicate with others in a way that was previously inaccessible.

### Discussion

As advancements in cancer care continue to lead to greater life expectancy, it is important to have greater consideration of and appreciation for the psychosocial effects from this experience. A better balance between physical and psychosocial care is needed. By virtue of their diagnosis and the largely biomedical focus of their oncology health care, participants felt their physical care should remain their main priority, but not at the expense of neglecting psychosocial care. They want both and see the priorities as inseparable. As more research in psychosocial care, particularly in cancer survivorship, occurs (Artherholt & Fann, 2012; Stanton, 2012), the authors suggest that healthcare teams incorporate digital storytelling into their toolbox

of approaches to psychosocial care. Digital stories are a powerful medium for individuals with cancer and survivors to share their story on their own terms. In many ways, it allows them to tell the story that is rarely told.

It is also important to recognize that, for many people, traditional approaches to psychosocial care (e.g., individual or group therapy, peer support groups) may not fit. Zaza, Sellick, and Hillier (2005) supported this finding, noting that individual counseling and group therapy were endorsed by only 10%–15% of individuals with respect to coping strategies used during cancer care. For example, in the current study, Hope said, “I never wanted to go to see a counselor or, you know, any of the services. I thought, ‘No, no I don’t need those,’ you know? And I still don’t think I did, but I did need something.”

However, like Hope said, an unwillingness to engage in traditional therapy should not be mistaken for a lack of need for psychosocial care. The authors have learned from the participants in the current study about the need for a psychosocial outlet, a way to manage the effects of cancer. It is incumbent upon those who care for patients with cancer and survivors of cancer to incorporate different approaches to psychosocial health; digital storytelling is an example of a non-traditional approach that may be considered.

Compared to the previous study using digital storytelling with pediatric and adolescent and young adult participants with cancer and survivors using identical protocols (Laing et al., 2017a), the authors of the current study noticed that the adult participants tended to have different motivations for telling their stories and, therefore, very different stories. In the adult group, there was usually an underlying message, either for their family, friends, other individuals with cancer, or healthcare professionals. As such, the stories tended to be less internally focused (as with the pediatric and adolescent and young adult group) and more externally focused. This may be because adults are in a less developmentally formative stage of life than adolescents and young adults (Erikson, 1959). Regardless, this opportunity for reflection was important for the participants in the current study. Reflecting, they said, was often hard to do in the moment. Determining how and when this is best achieved is challenging; however, digital storytelling is one way to start this process of reflection.

### Limitations

This study, like all qualitative studies, has limited generalizability. Lincoln and Guba (1985) proposed that “transferability” is a more appropriate term to

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### KNOWLEDGE TRANSLATION

- To have a therapeutic effect, digital stories should be made with the help of a trained facilitator to guide the patient and participant through the process.
  - Creating an online repository where digital stories are housed and categorized based on characteristics (e.g., age, diagnosis) can improve the accessibility and effectiveness of this medium.
  - Training inpatient and outpatient staff how to facilitate the digital storytelling process would allow for more patients to be able to access this medium.
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consider in qualitative studies because it describes the degree of similarity between two contexts. The degree of transferability of this study depends on how much the interpretations ring true for those who read them; therefore, a limitation of this study lies in the fact that the interpretations may not ring true for all. In addition, digital storytelling is not an approach that may fit with everyone and may, therefore, be ineffective as an approach to psychosocial care with individuals not finding fit with this medium.

### Conclusion

Cancer affects not only the physical body, but also—and sometimes to a greater degree—the psychological health of individuals. Innovative, unique, and non-traditional ways of approaching psychosocial health are warranted, and digital storytelling may be an effective therapeutic tool to incorporate into the psychosocial care of individuals with cancer and survivors. More research is needed with respect to the scalability of this approach and to further understand and evaluate how and in what ways participants find this approach helpful. In addition, understanding for which individuals and at what phases of treatment digital storytelling is most helpful can help make this approach most effective. Addressing the psychosocial aspects of cancer care is important during treatment and into survivorship and palliative care.

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**Catherine M. Laing, RN, PhD**, is an associate professor, **Nancy J. Moules, RN, BN, MN, PhD**, is a professor, and **Shane Sinclair, PhD**, and **Andrew Estefan, RPN, DipNSc, BN, MN, PhD**, are associate professors, all in the Faculty of Nursing at the University of Calgary in Alberta, Canada. Laing can be reached at [laingc@ucalgary.ca](mailto:laingc@ucalgary.ca), with copy to [ONFEditor@ons.org](mailto:ONFEditor@ons.org). (Submitted March 2018. Accepted August 20, 2018.)

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Laing, Moules, and Sinclair contributed to the conceptualization and design. Laing completed the data collection. All authors provided the analysis and contributed to the manuscript preparation.

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