Journal of Applied Hermeneutics
ISSN: 1927-4416
March 1, 2022
©The Author(s) 2022
DOI: 10.11575/jah.v2022i2022.74855

Invited Editorial

Crafting Meaning, Cultivating Understanding: A Prologue to the "Emerging Horizons" Series

Michael J Lang

Facts bring us to knowledge, but stories lead to wisdom. (Remen, 2006, p. 40)

First, a Story about the Importance of Stories

I clearly remember the moment I began to realize that the healthcare system as a whole, the people that work in it, as well as the patients and their families, needed more stories. In April 2010, I did a showing of my first documentary film, *Wrong Way to Hope: A Story of Young Adults and Cancer*, to a packed theatre of 250 oncology professionals and support staff at the Saskatoon Cancer Centre. I was told it was the first time anyone had proposed showing a film at Grand Rounds[1], and people were intrigued. After the presentation had concluded and the crowd had cleared, a lone doctor in a white lab coat stood up from his seat at the back of the auditorium and began walking down the aisle toward me. He seemed deep in thought, walking slowly with his head bowed. I stopped packing up my computer and stood waiting for him. When he was a few feet away, he slowly looked up and said:

You know, I have been an oncologist for over 20 years and I thought I understood my patients... But until watching your film, I never realized what is truly at stake for them; it is not just their health, it is their entire identity.

We continued to talk for a few minutes about some of the other major themes highlighted in the

Corresponding Author:
Michael Lang, PhD
Email: mike@mikelangstories.com

film and audience discussion that followed, but it was the four words from his opening line, "*until watching your film*," that lingered in my mind as I drove to the next stop on the cross-Canada tour. I had met only eight young adult cancer survivors in my entire life and knew almost nothing about cancer apart from my own experience of it over the previous two years. How could a 20-year oncology veteran who had treated thousands of patients glean practice-changing insight from my film?

Over the next 30 days, that same scenario repeated itself many times as cancer care professionals continued to discuss with me the lessons they had learned from the film. When I screened the film for patients and families at community-based cancer support organizations the response was the same. I witnessed rich discussion and flashes of insight at every single screening, no matter the audience. On that tour, I learned that many healthcare professionals, patients, and their families had never been given the opportunity to stop and reflect on the experience of cancer through a patient-created film, despite films and video being a dominant form of communication in our culture. It became clear that cancer care systems had not yet explored the possibilities of video-based storytelling on a broad scale. In this setting, simply sharing young adult cancer experiences in a candid, compelling, and aesthetic way on screen, had offered healthcare professionals, and the patients they cared for, access to a deeper level of understanding of the cancer experience, and sometimes, life in general.

Twelve years, five feature length documentaries, three web series, and over 800 digital stories later, I am thrilled to continue exploring video-based storytelling in healthcare settings through the serialization of the interpretive chapters of my PhD thesis in the Journal of Applied Hermeneutics (JAH). The "Emerging Horizons" series and the editorials that accompany it, are all based on a film of the same name which acted as the primary data source for my thesis. The film explores the Digital Storytelling (DST) workshop experiences of a group of six Adolescent and Young Adult (AYA) cancer survivors[2]. It is a 53-minute film crafted from almost 30 hours of footage, and in the same way that numerous salient moments from the workshop were necessarily left on the "cutting room floor," many possible interpretations were culled from the interpretive papers of this series. Indeed, *aletheia* reminds us that covering, and uncovering are always concurrent events (Caputo, 1987) and together, the film and the interpretations offered provide only one possible path to understanding what could occur as people create digital stories about their healthcare experiences. The primary goal of the film was to maintain the incommensurability between what an artwork says and what it is capable of saying so that the viewer can have the experience of something emerging (Davey, 2013); the interpretive writing serialized in JAH is meant to keep that conversation going. The remainder of this introductory editorial will set the stage for the series by briefly reviewing the topics of AYA oncology and DST, exploring the fit of applied hermeneutic research with documentary filmmaking, and finally, "dimming the lights" to promote an intellectual shift in engagement with both the film and the interpretive writing that follows.

Adolescent and Young Adult Cancer and Digital Storytelling: A Developmentally Appropriate Psychosocial Tool

Over the past 50 years, in parallel with increased survival, there has been mounting evidence of the late effects and long-term impact of cancer treatment on psychosocial outcomes in addition to

physical sequelae of treatments (Adler & Page, 2008; Institute of Medicine, 2006). Routine integration of psychosocial supports with biomedical treatments, from diagnosis through survivorship, is now a standard of care in oncology (Balogh et al., 2011, Holland & Weiss, 2008). One sub-population that has begun to be delineated, better understood, and increasingly highlighted for specific biomedical and psychosocial intervention are adolescents and young adults (AYA, 15-39yrs; National Cancer Institute, 2006).[3]

Over the past 15 years there has been increasing recognition of the differential psychosocial impact of cancer by age, with the AYA age-range experiencing elevated levels of clinical distress, depression, and anxiety relative to all other age groups of cancer survivors (Lang et al., 2015; Lang et al., 2018). Beyond the basic psychosocial outcomes of distress, depression, and anxiety, being an AYA at the time of diagnosis and treatment is a significant risk factor for poor health-related quality of life (Husson & Zebrack, 2017) and post-traumatic stress (Abbey et al., 2015) in cancer survivorship. Many other commonly studied cancer-related psychosocial sequelae, such as self-efficacy (Jones et al., 2010), financial toxicity (Gordon et al., 2017), education and employment regression (Ketterl et al., 2019; Kosola et al., 2017), fear of recurrence (Lim & Humphris, 2020; Simard et al., 2013), infertility (Logan et al., 2018), and body image (Fingeret et al., 2014) all indicated "younger age" (i.e., AYA age-range) as a primary risk factor for negative outcomes. As a whole, the literature provides compelling evidence for the long-term differential impact of a cancer diagnosis and treatment on AYAs' overall psychosocial health (Bibby et al., 2016; De et al., 2021), and there is increasing recognition of the many unmet physical, psychosocial, and practical concerns in this population (Jones et al., 2020).

The elevated adverse impact of a cancer experience on AYAs' psychosocial health is primarily attributed to the unique characteristics of the AYA developmental life-stage (Arnett, 2000; Docherty et al., 2015). Transitioning to adulthood consists of important developmental tasks including developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating, and making decisions about careers, higher education, and/or family; all important tasks related to identity formation (D'Agostino et al., 2011; Zebrack, 2011). Consequently, cancer-related issues such as changes in physical appearance, increased dependence on parents, premature confrontation with mortality, loss of fertility, treatment or recovery related disruptions in social life and school/employment, and health-related concerns about the future can be highly distressing for AYAs (Bibby et al., 2017; Canadian Partnership Against Cancer, 2017). As long-term survivorship is possible in the AYA demographic (i.e., 50+ years), physical, emotional, and social quality of life needs to be protected so that AYAs can be productive members of society over the long-term (Baird et al., 2019). Therefore, age-appropriate psychosocial care (i.e., psychosocial care which supports key developmental life tasks) is essential to ensure that AYAs are able to not only survive cancer but thrive throughout rest of their years as productive members of society (D'Agostino et al., 2011). Despite this awareness very few psychosocial interventions for AYAs have been developed and "AYA-focused interventions delivered on platforms that are acceptable and accessible to AYAs are urgently needed" (Jones et al., 2020, p. 1454). One such intervention could be Digital Storytelling (DST).

The terms “digital” and “storytelling” have become commonplace in the internet age and are often used to broadly refer to “telling stories with digital technologies” (Alexander, 2017, p. xiv). Numerous frameworks and variations of this broad concept of “digital storytelling” have been developed, with many fields of study (e.g., business, social justice, arts and humanities, education, healthcare) incorporating their own theoretical, logistical, and ethical perspectives (Dunford & Jenkins, 2017). However, the first articulation of what has become known as “classical” DST today was by Dana Atchley and Joe Lambert of the StoryCenter in Berkley, California (Hardy & Sumner, 2018). Their first DST workshop was held in 1993 around the beginning of the personal computer revolution that allowed lay-people access to the tools necessary to create “mini-movies” about their lives (Lambert, 2013). Currently, the StoryCenter’s three-day workshop process that they pioneered, and the style of digital story that they produce (i.e., simple three-to-four-minute narrated stories using still photos and minimal video effects and transitions), is termed “classical” DST (Hardy & Sumner, 2018), and is considered the foundation from which new approaches and modifications arise (de Jager et al., 2017; Hartley & McWilliam, 2009; Lambert, 2017).

At its most basic level, the DST process comprises the creation of short digital media products with “the assistance of *skilled facilitators*, in a *safe, technology-enabled* environment [emphasis added]” (Flicker & Hill, 2014, p. 3). In other words, it is an intentional, co-creative process involving some level of facilitation or interaction with others in the production or screening of the story. However, within this generic understanding there is significant variation in the temporal, technological, and procedural aspects of DST (de Jager et al., 2017) with the DST workshop of *Emerging Horizons* demonstrating a single facilitator, two-and-a-half-day group workshop model with iMovie as the video editing software.

The product of the DST process is a digital story. Generally, digital stories are two-to-five-minute visual narratives “that synthesize images, video, audio recordings of voice and music, and text to create compelling accounts of experience” (Gubrium, 2009, p. 186). It has been proposed that a digital story should: include compelling narration of a story; provide a meaningful context for understanding the story being told; use images to capture and/or expand upon emotions found in the narrative; employ music and other sound effects to reinforce ideas; and invite thoughtful reflection from their audiences (Alexander, 2017).

In reviewing the literature concerning AYA psychosocial oncology and DST, the congruence between the developmental needs and preferences of AYA cancer survivors and the theory, form, and functions of DST is apparent. DST occurs in an informal group setting which offers many opportunities for conversation and relationship building. Many participants report a strong connection formed with other program participants which persists long after the workshop is finished (Paterno et al., 2018). DST is also inherently participatory with the content of the stories and group discussions entirely driven by participants (Gubrium et al., 2015). This aligns well with the AYA developmental task of developing personal autonomy and could be one of the reasons that a DST experience is empowering for AYAs (Laing et al., 2017). The non-pathologizing approach of narrative-based interventions (White & Epston, 1990) is exemplified in the DST process and creates a compelling opportunity for AYAs to reframe and incorporate their cancer experience into their life story (Laing et al., 2017). Finally, DST is an emotion-focused process with participants exploring their inner emotional experiences of specific events

in their life through the finding, telling, crafting, and sharing of their stories (Fiddian-Green et al., 2019; Lang et al., 2019). As AYAs have difficulty processing the many difficult and conflicting emotions that accompany their cancer experience (Jones et al., 2011), DST could provide them with an appropriate opportunity to feel, name, process, and convey these emotions as a form of "sneaky-therapy" (Laing et al., 2017, p. 6).

In short, AYAs have a preference for non-traditional, technology-based psychosocial interventions, value meaningful connections with their peers, have difficulty naming and processing the difficult emotions associated with a cancer experience, and are in the midst of the important developmental task of identity formation. An appropriately designed and facilitated DST experience (i.e., a theory based, professionally facilitated experience with clear project goals and outcomes) could provide a group-based, emotion-focused, peer-driven, technology-mediated intervention that supports AYAs to cultivate understanding of, and craft meaning from their cancer experiences while integrating it into their life narrative. *Emerging Horizons* and the associated interpretive writing, offer both a visual example of DST facilitation and a deeper understanding of the AYA DST experience so that healthcare professionals and researchers can better theorize and apply DST in their own contexts.

Cinema Verité Documentaries and Hermeneutic Research: Parallels in Philosophy and Praxis

The camera . . . has to be open to the moments that reveal the thing that you cannot otherwise see.
– Wolf Koenig, in *Cinema Verité* (Wintonick, 1999)

For all parties involved in this study, using a documentary film as a primary data source was a unique undertaking. However, seeking understanding through *what was seen,* and not only through *what was said,* aligned closely with the ethos of DST and fulfilled the appeal of hermeneutic research to allow the phenomenon being studied to influence how understanding of that phenomenon was pursued (Moules et al., 2015). Cinema Verité, which is translated as "truthful cinema," is a style of documentary filmmaking that is observational in nature and relies on the use of a camera to reveal the "truth" (Aufderheide, 2007). Despite its common usage, a formal definition does not seem to exist, with many early progenitors of the form having different opinions on its principles and origins (Aufderheide, 2007; Parkinson, 2012; Wintonick, 1999). However, Cinema Verité is closely related to the documentary genres of Direct or Observational Cinema, in that the camera is often positioned as a "fly-on-the-wall" and records life as it happens with a reliance on the editing process to give shape, structure, and meaning to the material recorded (Watson & Hill, 2015). It has been proposed that a distinctive feature of Cinema Verité which separates it from pure Direct and Observational Cinema is that the filmmaker participates in front of the camera and creates situations within the structure of film that are designed to provoke and reveal (Kroon, 2014; Parkinson, 2012). The film *Emerging Horizons* aligns best with the Cinema Verité documentary genre as I participated on screen as the DST facilitator, a film crew captured the entire DST workshop in a "fly-on-the-wall" style, and the storylines in the film emerged afterwards in the editing suite, being cut together in a way to reveal the process of DST with AYA cancer survivors. Throughout the creation of *Emerging Horizons* and the encompassing hermeneutic research project, striking similarities were

recognized between Cinema Verité filmmaking and hermeneutic research in both philosophy and practice.

Parallels in Philosophy

The very first, and perhaps most noticeable, similarity between Cinema Verité filmmaking and hermeneutic research is the pursuit of revelation and understanding. In the same way that a hermeneutic research project centres the concept of *aletheia*, or "the event of concealment or unconcealment" (Caputo, 1987, p. 115), Cinema Verité films are meant to look past the surface level characterizations of experience to reveal, or unveil, the deeper "truths" that may be embedded in the moments observed by the camera (Kroon, 2014). Relying on the aesthetic attentiveness of the camera lens, Cinema Verité filmmakers are looking for moments of truth that emerge in the spontaneous events of life (Wintonick, 1999) in the same way that hermeneutic researchers follow leads and look for the particular word, phrase, or idea that enlivens understanding of the topic when conducting a research interview (Moules et al., 2015). This complementary philosophical approach enables Cinema Verité filmmaking to be an effective hermeneutic research approach when the lens is turned towards a particular phenomenon of interest, in this case DST with AYAs.

It is important to note that the term *Verité*, and the discussions of "truth" that many pioneers of the Cinema Verité form engage in, do not refer to presenting events exactly as they happened. In the words of Canadian Cinema Verité pioneer Wolf Koenig:

> All documentary is theatre. It's all manufactured. Every cut is a lie. It isn't really like that. Those two shots were never next to each other in time that way. But you are telling a lie in order to tell the truth. (Wintonick, 1999)

In other words, Cinema Verité is not an exact representation of events as they unfolded in time and space, but an attempt to identify and film the truth in a way that the audience and the characters in the film deem trustworthy (Aufderheide, 2007). Another Cinema Verité pioneer, Albert Maysles, described it in this way:

> If you are worried about subjectivity and objectivity, you are afraid to film! So . . . you are going to be fair and end up with something that is truthful in that it would *demand the respect of the person you are filming* [emphasis added]. (Wintonick, 1999)

The spirit of Maysles' comment aligns well with the assertion that rigorous hermeneutic research has both a deep resonance with the experiences of the stakeholders *and* a strangeness or newness (Koch, 1996). Similarly, Cinema Verité filmmakers are attempting to create an artwork that is both recognizable *and* revelatory for the audience and the participants in the film. The goal is to relate the events and emotions of filmed participants in a way that cultivates both in them, and the viewer, a deeper understanding of those very events and emotions.

Another philosophical similarity is a shared ontology and epistemology. Ontologically, both Cinema Verité filmmakers and hermeneutic researchers are anchored in realism and believe that

the life of a phenomenon exists beyond our interpretations of it (Aufderheide, 2007; Lang et al., 2020). However, both assert that it is impossible to remove, or "bracket," the researcher or filmmaker to present an objective representation of a phenomenon (Aufderheide, 2007; Lang et al., 2020). Cinema Verité filmmakers recognize that the very process of capturing and editing footage removes objectivity and therefore do not attempt to disguise their involvement in the film (Parkinson, 2012). Similarly, PH researchers accept that the very act of formulating and asking questions about a phenomenon of interest influences the qualitative data collected (Lang et al., 2020), and embrace the role that their preunderstandings play in the data analysis (interpretation) process (Moules et al., 2015). In this way, both Cinema Verité filmmakers and hermeneutic researchers accept that a phenomenon exists beyond their experience of it (realist ontology) and reject the idea that they can access it objectively (subjectivist epistemology).

There are other philosophical parallels that could be explored, but a cogent summary statement that encompasses the philosophical ethos of both Cinema Verité filmmaking and hermeneutic research is, "rather than finding or claiming truth, we attempt to stay true *to* something (the topic) and to interpret in such a way that is true *of* something (within the topic)" (Moules et al., 2015, p. 175). Or, in the words of the Canadian documentary film pioneer Michel Brault, "you can't claim to write the truth with a camera. What you can do is reveal something to your viewers" (Wintonick, 1999). In both Cinema Verité filmmaking and hermeneutic research, truth is an event in which we actively participate to cultivate a deeper understanding of ourselves, others, and the world(s) we inhabit.

Parallels in Praxis

Beyond the philosophical parallels of Cinema Verité filmmaking and hermeneutic research, the filming/editing and data generation/analysis practices are also similar. To begin with, both follow an inductive, reflexive, and active approach to filming/data generation. In hermeneutic research, this occurs in the unstructured interview format that encourages researchers to listen deeply and follow leads as they engage in the back-and-forth of conversation with a participant (Moules et al., 2015). In Cinema Verité, the filmmaker often participates on screen and follows leads in real time, engaging with participants and asking questions that could help to reveal the subject matter on camera (i.e., "interviewing" participants about their experiences while still being engaged in the activity). Both hermeneutic researchers and Cinema Verité filmmakers are not dispassionate observers but active participants in pursuit of understanding and meaning through reflective engagement with both the participants and the topic being explored. This requires a practice of "listening right behind your eyes . . . [meaning a] watchfulness, openness, and searching to find the truth in what the other is saying [or experiencing]" (Moules et al., 2015, p. 94). The disciplined openness required to have the "experience of something emerging" (Gadamer, 1993/2007, p. 207) and then following that lead, which is essential to both Cinema Verité filmmaking and hermeneutic research, is remarkably similar in praxis.

The editing process of Cinema Verité films is also similar to the interpretive analysis and writing of hermeneutic research. A "transformation into structure" is an entirely apt description of both processes (Moules et al. 2015, p. 126) with the story and interpretations slowly emerging from the video footage and interview transcripts through thoughtful, in-depth, intellectual, and emotional engagement. The editing process of Cinema Verité films is multi-staged and circular,

constantly moving between individual storylines and that of the film as a whole, a process which mirrors the hermeneutic circle of interpretive writing in hermeneutic research. Furthermore, the editing process and the writing process is organized around particular moments that enliven understanding, not the frequency of an event, word, or phrase (Moules et al., 2015; Wintonick, 1999). Indeed, in filmmaking, repetition is called cliché, and clichés do not enhance understanding of phenomena, they stifle it (McKee, 1997).

Interestingly, many early Cinema Verité filmmakers were influenced by the phrase *Camera-stylo (*Wintonick, 1999), translated as Camera-as-Pen, originally coined by French film critic Alexandre Astruc (1948/2009). This is a productive metaphor to summarize these parallels in praxis. In the same way that hermeneutic researchers cultivate interpretations of a phenomenon through (re)reading, (re)writing, and conversations with the research team, Cinema Verité filmmakers (re)watch and (re)edit as a team, utilizing the camera to pen their interpretations of the phenomenon. Using their own unique yet related means of communication, the hermeneutic researcher interprets experience using the creative tools available in spoken and written language (i.e., etymology, metaphor, plurivocity, etc.) while the Cinema Verité filmmaker interprets experience by utilizing the aesthetic and creative tools available in filming and editing (i.e., framing, temporality, juxtaposition) to focus the audience's gaze on moments that "speak." In each case, Cinema Verité films and hermeneutic research do not simply "capture" phenomena on film or in writing, but set them free within it (Moules et al., 2015).

There are many more philosophical and practical parallels between Cinema Verité filmmaking and PH research that could be explored. The goal of this short exploration was to highlight that a congruency exists, and that using Cinema Verité filmmaking as a data generation tool in hermeneutic research may be an interesting and fruitful relationship to continue to explore. Practitioners of both value the "experience of something emerging" (Gadamer, 1993/2007, p. 207), and what emerged in the experience of both editing and writing about the film *Emerging Horizons*, is what will be explored in this series.

Dimming the Lights

To borrow a metaphor from the cinema experience, this editorial, up until this point, has been the intellectual equivalent of driving to the theatre, purchasing tickets and snacks, and watching the previews; it is now time for the main feature. Dimming the lights is the universal signal used in cinemas around the world to quiet the audience. But the "quieting" that it signals goes beyond a simple reduction in auditory stimuli; it encourages a quieting of the mind, by putting aside other concerns and conversations, so that a story can be fully experienced. In other words, dimming the lights signals to the audience that it is time to alter their default mode of intellectual engagement with the world around them so that they can inhabit the lives of the characters on the screen and see the world afresh through their experiences. In the same way, an intellectual shift is required here by the reader as we transition to the interpretive articles that explore the AYAs' DST experiences in the film *Emerging Horizons*. At this juncture there will be a change in the style, tone, language, and structure of the writing. It is my hope that through these interpretive chapters the reader will be transported deeper into the lives and DST experiences of the AYAs in the film.

To promote this shift in intellectual engagement, I suggest watching the film before reading further (a direct link is provided in footnote 2). At the beginning of the film, you will meet Amanda, Bethany, Harmony, Kelsey, Derek, and Kenzie. At the time of filming, Amanda was a 35-year-old police officer and mother who was one-year post-diagnosis from Non-Hodgkin's Lymphoma. She wanted to share her story of having a cancer-induced abortion as a way to help other women who may be facing that same reality. Bethany, also 35, was the furthest of the group from her initial cancer diagnosis of Synovial Sarcoma, which occurred 12 years prior. She felt like creating a digital story could be a marker in her cancer experience but was worried that no one else would understand or appreciate her story. Harmony, a 32-year-old elementary school teacher, was back at work three years after her initial thyroid cancer diagnosis. She felt like there were aspects of her cancer experience that she had not explored or shared with anyone and thought a digital story could help her do just that. Kelsey was diagnosed with Acinic Cell Carcinoma (salivary gland cancer) and finished treatment a year prior to her participation in the film at the age of 27. She did not feel like she had a meaningful story to share and admittedly almost did not come to the first session because she was so nervous. Derek, 36, is an environmental engineer and was the oldest participant. He was diagnosed with stage four Hodgkin's Lymphoma six years prior to the DST workshop and was looking for a better way to share one particularly meaningful story from his cancer experience in a way that people could understand. Finally, McKenzie ("Kenzie") is a paramedic who was diagnosed with Acute Myeloid Leukemia six years prior to the DST workshop at 15 years old. She had created a digital story with me while she was still in treatment and wanted to see if, or how, her cancer story had changed five years later. Of these six participants, two had never met another AYA cancer survivor before (Harmony and Amanda), and none of them knew each other. Through the process of creating their digital story they were able to craft meaning out of their challenging cancer experience and cultivate a deeper understanding of the lessons embedded in their own stories.

Last, A Story about the Importance of Stories

I had a unique experience of déjà vu after a recent online screening of *Emerging Horizons*. One participant stayed on the Zoom call for a long moment after the session concluded before she turned on her camera, and after brief hesitation and prompting from me, said,

> I have read a lot of research papers about digital storytelling and have even used digital stories in my work, but *until watching your film* I don't think I really understood the emotional energy it takes for people to make a story like this. They are sharing their soul with us! I don't think I will ever watch a digital story the same again.

I feel honored to be invited daily into the most meaningful moments of people's lives as DST facilitator, and I have benefited immensely from their candor and trust. In the dedication section of my thesis I wrote, "to all the AYA cancer survivors and supporters I have met: if I have any wisdom to offer the world, it has come from the stories and experiences you have shared with me." It is my hope that by watching the film and reading the interpretations that emerged from it, wisdom is gleaned, and horizons changed. If this occurs even to a fractional amount of my own learning throughout my PhD studies, it will be well worth the effort.

Acknowledgements

This series would not be possible without the steadfast support, supervision, encouragement, and skills of many wonderful people. As my supervisor, Dr. Catherine Laing guided the entire process of my PhD from beginning to end, reviewing research proposals, early versions of the film, and many chapter drafts, continually offering invaluable feedback that kept this project on course and moving forward. Dr. Nancy Moules and Dr. Deborah McLeod lent their wisdom and expertise to the conceptualization of this project and were vital members of my interpretive community that enhanced the rigour and salience of both the film and the written thesis. All six participants in this study, Amanda, Harmony, Kelsey, Derek, Kenzie, and Bethany, were incredibly open and honest with their thoughts, experiences, and personal cancer stories, which ultimately enabled the in-depth exploration of the DST process in this thesis. There was also the amazing film crew, Joel, Evan, Phil, Alex, Jill, Justan, Les, and Louw, who captured the DST workshop with such tact and aesthetic awareness. To everyone listed here, this project is as much your accomplishment as it is mine. Thank you.

Funding

Michael Lang's PhD studies and research were funded by the Canadian Institutes of Health Research Fredrick Banting and Charles Best Doctoral Award and the Eyes High Doctoral Recruitment Award from the University of Calgary.

Conflict of Interest Statement

Michael Lang is the owner/operator of two private business related to DST. In his involvement with Mike Lang Stories (mikelangstories.com) he works directly with researchers, healthcare systems, charities, and other health-focused organizations around the world to create digital stories with their stakeholders. With Common Language Digital Storytelling (commonlangugagedst.org), he is a Level Three Facilitator and is responsible for coordinating, developing, and leading DST Facilitation trainings.

References

Abbey, G., Thompson, S. B., Hickish, T., & Heathcote, D. (2015). A meta-analysis of prevalence rates and moderating factors for cancer-related post-traumatic stress disorder. *Psychooncology, 24*(4), 371-381. https//:doi.org/10.1002/pon.3654

Adler, N.E., & Page, A. (Eds.). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. National Academies (US). https//:doi.org/10.17226/11993

Alexander, B. (2017). *The new digital storytelling: Creating narratives with new media* (2nd ed.). Prager.

Arnett, J.J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *The American Psychologist, 55*(5), 469–480.

https://doi.org/10.1037//0003-066X.55.5.469

Astruc, A. (2009). Du stylo à la caméra et de la caméra au stylo. In G. Vincendeau & P. Graham (Ed. & Trans.), *The French new wave: Critical landmarks* (pp. 45-58). Palgrave Macmillan. (Original work published 1948)

Aufderheide, P. (2007). *Documentary film: A very short introduction.* Oxford University.

Baird, H., Patterson, P., Medlow, S., & Allison, K.R. (2019). Understanding and improving survivorship care for adolescents and young adults with cancer. *Journal of Adolescent and Young Adult Oncology, 8*(5), 581-586. https://doi.org/10.1089/jayao.2019.0031

Balogh, E.P., Ganz, P.A., Murphy, S.B., Nass, S.J., Ferrell, B.R., & Stovall, E. (2011). Patient-centered cancer treatment planning: Improving the quality of oncology care. *The Oncologist, 16*(12), 1800-1805. https://doi.org/10.1634/theoncologist.2011-0252

Bibby, H., White, V., Thompson, K., & Anazodo, A. (2016). What are the unmet needs and care experiences of adolescents and young adults with cancer? A systematic review. *Journal of Adolescent and Young Adult Oncology, 6*(1), 6-30. https://doi.org/10.1089/jayao.2016.0012

Canadian Partnership Against Cancer. (2017). *Adolescents & young adults with cancer: A system performance report.* https://s22457.pcdn.co/wpcontent/uploads/2019/01/Adolescents-and-young-adults-with-cancer-EN.pdf

Caputo, J. (1987). *Radical hermenutics: Repetition, deconstruction, and the hermeneutic project.* Indiana University.

D'Agostino, N.M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer, 117*(S10), 2329-2334. https://doi.org/10.1002/cncr.26043

Davey, N. (2013). *Unfinished worlds: Hermeneutics, aesthetics, and Gadamer.* Edinburgh University.

De, R., Sutradhar, R., Kurdyak, P., Aktar, S., Pole, J.D., Baxter, N., Nathan, P.C., & Gupta, S. (2021). Incidence and predictors of mental health outcomes among survivors of adolescent and young adult cancer: A population-based study using the IMPACT cohort. *Journal of Clinical Oncology*, *39*(9), 1010-1019. https://doi.org/10.1200/JCO.20.02019

de Jager, A., Fogarty, A., Tewson, A., Lenette, C., & Boydell, K.M. (2017). Digital storytelling in research: A systematic review. *The Qualitative Report, 22*(10), 2548-2582. https://nsuworks.nova.edu/tqr/vol22/iss10/3

Docherty, S.L., Kayle, M., Maslow, G.R., & Santacroce, S.J. (2015). The adolescent and young adult with cancer: A developmental life course perspective. *Seminars in Oncology Nursing, 31*(3), 186-196. https://doi.org/10.1016/j.soncn.2015.05.006

Dunford, M., & Jenkins, T. (2017). *Digital storytelling: Form and content.* Palgrave Macmillan.

Fiddian-Green, A., Kim, S., Gubrium, A.C., Larkey, L. K., & Peterson, J.C. (2019). Restor(y)ing health: A conceptual model of the effects of digital storytelling. *Health Promotion Practice, 20*(4), 502–512. https://doi.org/10.1177/1524839918825130

Fingeret, M.C., Teo, I., & Epner, D.E. (2014). Managing body image difficulties of adult cancer patients: Lessons from available research. *Cancer, 120*(5), 633-641. https://doi.org/10.1002/cncr.28469

Flicker, S., & Hill, A. (2014). Digital storytelling. In D. Coghlan & M., Brydon-Miller (Eds.), *The SAGE encyclopedia of action research* (pp. 267-270). Sage. https://doi.org/10.4135/9781446294406

Gadamer, H.-G. (2007). The artwork in word and image: "So true, so full of being!" In R.E. Palmer (Ed. & Trans.), *The Gadamer reader: A bouquet of the later writings* (pp. 195-224). Northwestern University. (Original work published 1993)

Gordon, L.G., Merollini, K., Lowe, A., & Chan, R.J. (2017). A systematic review of financial toxicity among cancer survivors: We can't pay the co-pay. *Patient-Centered Outcomes Research, 10*(3), 295-309. https://doi.org/10.1007/s40271-016-0204-x

Gubrium, A. (2009). Digital storytelling: An emergent method for health promotion research and practice. *Health Promotion Practice, 10*(2), 186-191. https://doi.org/10.1177/1524839909332600

Gubrium, A.C., Harper, K., & Otanez, M. (2015). *Participatory visual and digital research in action.* Routledge.

Hardy, V., & Sumner, T. (2018). *Cultivating compassion: How digital storytelling is transforming healthcare* (2nd ed.). Palgrave Macmillan.

Hartley, J. (2013). A trojan horse in the citadel of stories? Storytelling and the creation of the polity – from Göbekli Tepe to Gallipoli. *Journal of Cultural Science, 6*(1), 71-105. https://espace.curtin.edu.au/bitstream/handle/20.500.11937/9092/196532_107675_A_Trojan_Horse_in_the_Citadel_of_Stories__J_Hartley_2013.pdf?sequence=2&isAllowed=y

Holland, J., & Weiss, T. (2008). The new standard of quality cancer care: Integrating the psychosocial aspects in routine cancer from diagnosis through survivorship. *Cancer Journal, 14*(6), 425-428. https://doi.org/10.1097/PPO.0b013e31818d8934

Husson, O., & Zebrack, B.J. (2017). Perceived impact of cancer among adolescents and young adults: Relationship with health-related quality of life and distress. *Psychooncology, 26*(9), 1307-1315. https://doi.org/10.1002/pon.4300

Institute of Medicine. (2011). *Patients charting the course: Citizen engagement in the learning*

health system. National Academies.

Jones, J.M., Cheng, T., Jackman, M., Rodin, G., Walton, T., & Catton, P. (2010). Self-efficacy, perceived preparedness, and psychological distress in women completing primary treatment for breast cancer. *Journal of Psychosocial Oncology, 28*(3), 269-290. https://doi.org/10.1080/07347331003678352

Jones, J.M., Fitch, M., Bongard, J., Maganti, M., Gupta, A., D'Agostino, N., & Korenblum, C. (2020). The needs and experiences of post-treatment adolescent and young adult cancer survivors. *Journal of Clinical Medicine, 9*(5), 1444-1459. https://doi.org/10.3390/jcm9051444

Jones, B.L., Parker-Raley, J., & Barczyk, A. (2011). Adolescent cancer survivors: Identity paradox and the need to belong. *Qualitative Health Research, 21*(8), 1033-1040. https://doi.org/10.1177/1049732311404029

Ketterl, T.G., Syrjala, K.L., Casillas, J., Jacobs, L.A., Palmer, S.C., McCabe, M.S., Ganz, P.A., Overholser, L., Partridge, A., Rajotte, E.J., Rosenberg, A.R., Risendal, B., Rosenstien, D., & Baker, K.S. (2019). Lasting effects of cancer and its treatment on employment and finances in adolescent and young adult cancer survivors. *Cancer, 125*(11), 1908-1917. https://doi.org/10.1002/cncr.31985

Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: Philosophy, rigour, and representation. *Phenomenological Research, 24*(1), 174-184. https://doi.org/10.1046/j.1365-2648.1996.17224.x

Kosola, S., McCarthy, M.C., McNeil, R., Orme, L.M., Drew, S., & Sawyer, S.M. (2017). Early education and employment outcomes after cancer in adolescents and young adults. *Journal of Adolescent and Young Adult Oncology, 7*(2), 238-244. https://doi.org/10.1089/jayao.2017.0045

Kroon, R.W. (2014). *A/V a to z: An encyclopedic dictionary of media, entertainment and other audiovisual terms.* McFarland.

Laing, C.M., Moules, N.J., Estefan, A., & Lang, M.J. (2017). Stories that heal: Understanding the effcts of creating digital stories with pediatric and adolescent/young adult oncology patients. *Journal of Pediatric Oncology Nursing, 34*(4), 272-282. https://doi.org/10.1177/1043454216688639

Lambert, J. (2013). *Digital storytelling: Capturing lives, creating community* (4th ed.). Routledge.

Lambert, J. (2017). The central role of practice in digital storytelling. In M. Dunford & T. Jenkins (Eds.), *Digital storytelling: Form and content* (pp. 21-26). Palgrave Macmillan.

Lang, M.J., David, V., & Giese-Davis, J. (2015). The age conundrum: A scoping review

of younger age or adolescent and young adult as a risk factor for clinical distress, depression, or anxiety in cancer. *Journal of Adolescent and Young Adult Oncology*, 4(4), 157-173. https://doi.org/10.1089/jayao.2015.0005

Lang, M.J., Giese-Davis, J., Patton, S.B., & Campbell, D.J.T. (2018). Does age matter? Comparing post-treatment psychosocial outcomes in young adult and older adult cancer survivors with their cancer-free peers. *Psycho-Oncology, 27*(5), 1404-1411. https://doi.org/10.1002/pon.4490

Lang, M., Laing, C., Ewashen, C., & Moules, N. (2020). Digital stories as data: An etymological and philosophical exploration of cocreated data in philosophical hermeneutic health research. *International Journal of Qualitative Methods*, *19*(1), 1-9. https://doi.org/10.1177/1609406920913673

Lang, M., Laing, C., Moules, N., & Estefan, A. (2019). Words, camera, music, action: A methodology of digital storytelling in a health care setting. *International Journal of Qualitative Methods*, 18, 1-10. https://doi.org/10.1177/1609406919863241

Lim, E., & Humphris, G. (2020). The relationship between fears of cancer recurrence and patient age: A systematic review and meta-analysis. *Cancer Reports*, *3*(3), 1-14. https://doi.org/10.1002/cnr2.1235

Logan, S., Perz, J., Ussher, J.M., Peate, M., & Anazodo, A. (2018). A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. *Psycho-Oncology, 27*(2), 401-409. https://doi.org/10.1002/pon.4502

McKee, R. (1997). *Story: Substance, structure, style and the principles of screenwriting.* HarperCollins.

Moules, N.J., McCaffrey, G., Field, J.C., & Laing, C.M. (2015). *Conducting hermeneutic research: From philosophy to practice.* Peter Lang.

National Cancer Institute. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer.* www.cancer.gov/types/aya/research/ayao-august-2006.pdf

Paterno, M., Fiddian-Green, A., & Gubrium, A. (2018). Moms supporting moms: Digital storytelling with peer mentors in recovery from substance abuse. *Health Promotion Practice, 19*, 823-832. https://doi.org/10.1177/1524839917750816

Parkinson, D. (2012). *100 Ideas that changed film.* Laurence King.

Remen, R.N. (2006). *Kitchen Table Wisdom: Stories That Heal.* Penguin.

Sawyers, C. (2004). Targeted cancer therapy. *Nature, 432*(7015), 294-297. https://doi.org/10.1038/nature03095

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., & Ozakinci, G. (2013). Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *Journal of Cancer Survivorship, 7*(3), 300-322. https://doi.org/10.1007/s11764-013-0272-z

Watson, J., & Hill A. (2015). *Dictionary of media and communication studies* (9th ed.). Bloomsbury.

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. W. W. Norton.

Wintonick, P. (Director). (1999). *Cinema Verité: Defining the moment* [Film]. Canadian National Film Board. https://www.nfb.ca/film/cinema_verite_defining_the_moment/

Zebrack, B. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer, 117*(S10), 2289-2294. https://doi.org/10.1002/cncr.26056

[1] "Grand Rounds" are a form of continuing medical education used in most hospitals and larger clinics. It is a regularly scheduled (i.e., weekly or monthly) invited presentation on topics of interest that often cross disciplinary boundaries. Most cancer treatment centres have weekly Grand Rounds to which all staff are invited.

[2] The film and associated digital stories can be viewed in their entirety here: https://youtube.com/playlist?list=PLrt4Tm_IHjJTy5n0jdlHAKK1qSsGBh6NL

[3] This definition of the AYA age range endorsed by the National Institute of Cancer has also been recognized by the Canadian Partnership Against Cancer (CPAC) AYA Task Force.