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Understanding the Impact on Healthcare Professionals of Viewing Digital Stories of Adults with Cancer: A Hermeneutic Study

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Abstract

The purpose of this study was to understand the effects on oncology healthcare providers (HCPs), both personally and professionally, of watching digital stories made by adults with cancer (past and present), and what HCPs envisioned for the uses of digital stories. Seven healthcare professionals from various disciplines volunteered for this study. This research took place in a large urban center in Western Canada and was done in the tradition of philosophical hermeneutics. A 90-minute focus group was used for data collection, where participants watched eight digital stories (batched in four groups of two stories) that had been created by individuals with cancer (past or present). Data were analyzed using the interpretive method of hermeneutics. Findings revealed that watching digital stories made by adults with cancer was emotionally compelling, provided context, incited deep introspection, and may offer a protective effect with respect to HCP burnout.

Keywords

hermeneutic research, digital storytelling, healthcare providers, adult oncology, cancer

Our purpose in this study was to understand the effects on oncology healthcare providers (HCPs) of watching digital stories made by oncology patients (past and present). Digital stories are short, first person narratives that combine the participant's voice, photos, video, and music to tell a story (Storycenter, 2016). Specifically, we sought to understand in what ways HCPs were affected by watching the stories; how digital stories might influence their clinical/professional

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practice; and in what contexts HCPs thought digital stories could be used. In this paper, we report on the secondary objective of our recent study aimed at understanding the meaning and impact of creating a digital story with adult cancer patients.

Digital stories have been used in a wide variety of industries with varying functions from marketing to education. Recently, digital stories have gained increased attention in healthcare, with four predominant uses (Lang, Laing, Moules, & Estefan, 2019): (a) education and quality improvement (Alberta Health Services [AHS], 2019; Christiansen, 2011; De Vecchi, Kenny, Dickson-Swift, & Kidd, 2016); (b) advocacy and public health (Briant, Marchello, Escareno, & Thompson, 2016; Haigh & Hardy, 2011); (c) research (Laing, Moules, Estefan, & Lang, 2017a, 2017b; Laing, Moules, Sinclair, & Estefan, 2019); and (d) as a therapeutic intervention (Akard et al., 2015).

While much attention has been paid to the effects of the digital story on its creator (often a patient), little is known about the effects on the viewer, in this case, HCPs. A recent systematic review (Moreau, Eady, Sikora, & Horsley, 2018) related to digital stories in health professional education determined that patients' digital stories alone had minimal impact on HCPs' learning. In a previous study, HCPs who viewed the digital stories of pediatric, adolescent, and young adult cancer survivors found them to be powerful, therapeutic, and educational tools with the potential to change their practice (Laing et al., 2017b). Digital stories may be an efficient and effective way through which to understand the patient experience, thus affecting patient care delivery.

At the heart of a digital story is a *story*, and storytelling has existed since the development of language (Eder, Cajete, & Natural Child Project, 2010). Stories and storytelling were the way of teaching, learning, and passing wisdom through generations (Koch, 1998). They remain an important form of communication today, and while we are no longer reliant on them for survival, stories can assist with reaffirming and making sense of experiences (Frank, 1995; Whiddershoven, 1993), fostering resiliency (East, Jackson, & Peters, 2010), linking our past to our and allowing for reflection (Frank, 2000). The telling of stories may increase resiliency (East et al., 2010), insight (Stone, Machtynger, & Machtynger, 2015), and hardiness (Haigh & Hardy, 2011).

Participants and Setting

Following ethical approval (HREBA.CC.16-0754), participants were recruited via posters at a large urban outpatient cancer centre in Western Canada, and through word of mouth. Seven healthcare professionals from various disciplines volunteered for this study (Table 1). Eligibility criteria included being a member of any health discipline with a focus in adult oncology (either inpatient or outpatient). Purposive sampling, where participants who can best inform the topic, was used to elicit rich data through participant experiences (Moules, McCaffrey, Field, & Laing, 2015). With this sampling method, the careful selection of participants helps ensure that each will provide valuable information to the study (Suen, Huang, & Lee, 2014).

Methodologic Approach

This study used the research method of hermeneutics, as informed by the philosophical hermeneutics of Hans-Georg Gadamer (Gadamer, 1960/1989; Moules et al., 2015). Hermeneutics is an effective research approach to use when understanding of a phenomenon or concept, versus explanation, is the desired outcome (Moules et al., 2015). Data were collected via one 90-minute focus group where participants watched eight digital stories (batched in four groups of two stories) that had been created by individuals with cancer (past or present) as part of the first aim of this study. After each batch of two stories, semi-structured interview questions were asked related to the function, effect, and utility of the stories (Figure 1). The entire 90-minute focus group was audio recorded and subsequently transcribed for data analysis. Field notes were taken during and after the focus group to capture body language, non-verbal communication, and other relevant factors to aid with the data analysis.

In hermeneutic research, data analysis is known as data *interpretation* (Moules, Laing, McCaffrey, Tapp, & Strother, 2012), where the focus in not on coding or thematizing, but on "interpreting" the data such that the topic in question can be deeply, or sometimes differently, understood (Gadamer, 1960/1989; Moules, Jardine, McCaffrey, & Brown, 2013; Moules et al., 2015; Sandelowski, 2004). Interpretations are presented as results, and are developed via repeated readings of the transcripts and field notes both in detail and as a whole, interpretive memos (initial interpretative conjectures), team discussions related to initial interpretations, and a synthesis of knowledge, information, conversation, experience, and data (Moules et al., 2015). Unlike some qualitative traditions, member-checking is not done in hermeneutics as it is the topic that is of central importance versus representation of the individual participants (Moules et al., 2015). Rigor and trustworthiness are established through the robustness, facility, and resonance of the interpretations (Moules et al., 2015).

Findings

As is tradition in hermeneutics, findings are presented as interpretations, and woven throughout are the participant voices meant to illustrate and enliven the understanding. Participant quotes are verbatim, however the presence of ellipses (…) indicates some text removed due to irrelevancy, square brackets ([ ]) indicate word change needed for clarity, and bolding is used to indicate words where participants placed emphasis.

Enriching the Content and Enhancing the Context

The content of the digital stories – what the stories were about – was of considerable interest to participants, despite gentle reminders and "urgings" of the interviewers to focus on the topics/questions asked after each pairing of digital stories. While frustrating at first, we came to see that discussion around the content – while an unanticipated focus – was serving a very important function for the participants; it was giving them context. Most of the HCPs who participated knew most of the digital story authors, especially if their treatment was ongoing or recently completed. In one story, Renee (pseudonym) centered her digital story around her decision to discontinue her treatment and chose to focus on quality of life versus extending her life. Unbeknownst to us, this decision had been highly controversial and upsetting to many HCPs who

cared for her. Watching her video, and how her story related to her reasons for doing so, was fodder for much discussion from our participants:

> *P1: Yeah, that one is really interesting because here's someone who turned down chemotherapy. It's the patient who turned down conventional therapy.*
> *P2: She stopped chemotherapy. She did take some.*
> *P1: Sorry, she discontinued therapy and continues to turn it down. So…I can make sense of this decision a little bit more now, knowing this. And she starts to tell you about her life and where's she's been and these moments of realization that she has had, and all of a sudden it starts to make sense to you.*

In her digital story, Renee discussed her childhood and adult life to date, along with many salient events, turning points, and decisions she had made along the way. When she discussed her decision to stop chemotherapy (early, against medical advice), participants understood that decision much more so than they had previously. It seemed to provide a degree of relief for them, as if it had been something with which they had struggled or been distressed by.

> *P3: You know, it makes more sense now, after seeing this story. It really bothered me when I heard about it [Renee's decision] and I thought "why would you do that? We are nowhere near being out of options for you!" But it's very clear that she's at peace and she's happy and, like, she's committed to life. Which I think is helpful for people to see that this wasn't a crazy sort of decision. We have to accept that people are living their lives.*

As our participants discussed Renee's story, often circling back to it, it became clear that watching it helped them not only understand her decision but to also understand her as a person. It struck us that digital stories can help "fill in the blanks," and add to HCPs' understanding of the individuals in their care from all aspects versus as someone with cancer. The context that these stories offered was welcomed and desired, with participants often expressing that they "wished they knew this before" (P2) and "it's so great to know more about their lives before cancer but also to see how they are now" (P7). The digital stories seemed to create a more fulsome picture of their patients, and a more complete understanding of them as individuals.

The Effects of Digital Stories on HCPs

Just as participants discussed the content of the stories, so too did they discuss the effects that the stories had on them personally. *P4: "some of those [digital stories] almost brought me to tears because at the end of the day we're all human, and we all have thoughts and feelings. And to hear somebody's experience…it's powerful. It's gets right to the heart.*" Healthcare providers described the digital stories they watched as "powerful," "focused," and "meaningful." One participant elaborated:

> *There is something about watching this story and interacting with it this way. It's like, you're looking at their life story, part of it at least, but it feels like you're doing it together, with them. I don't know…there's something about that interaction that is generative, you know? It allows you to look at their life differently.* (P5)

Participants felt that watching digital stories were particularly meaningful when they knew the person in the story. When asked the question "what do you think the differences would be watching a digital story of someone you know, versus someone you don't know" they unanimously stated that while they thought digital stories could have utility in either case, they were "immeasurably more powerful" (P6) when watching the stories of someone you know (e.g., current/former person in their care). P6 clarified: "*When you know them, there is sort of this immediacy of being drawn into the story…as you're watching the story, you're connecting to all these other events, other interactions you've had with them*." All of our participants agreed that watching stories of individuals with whom they were familiar was more emotional, powerful, and meaningful than for individuals with whom they were not familiar. It helped them more fully understand the person in the story.

When the Other is No Longer the Other

Participants in this study described "getting to know the person better" and "seeing another side of the person" resulting from watching the digital stories. However, this ran deeper than simply getting better acquainted with an individual; watching the digital stories appeared to "de-other" (Levinas, 1969/1980) the person in the story. "*There's this whole person, and I really need to actually take time to go further to understand them*" (P5). The "other" is defined by Levinas (1969/1980) as different, not one of us, and part of how we understand ourselves depends on how we define the other. Participants described a sense of obligation to "*do better*," (P1) "*not judge*," (P4) and "*take more time*" (P7) in their own practice to get to know the individuals in their care more fulsomely after watching the stories. Understanding their stories, as in the example above with the patient who refused chemotherapy, seemed to "de-other" the author of the story. Reflecting on the patient who refused treatment, P2 offered:

> *It was interesting, the turning point for her* [the patient] *was when her mom threw open the curtains, because there were a lot of pictures of spiritual light or bright light and her looking up at it somewhere in the mountains or wherever that was. And she talked about a transformation, really with that realization that there were people who loved her and that she loved… Kind of that you're bigger than the sum of your parts.*

The idea of pulling back a curtain has metaphorical meaning in this instance as well, as it evokes the idea of exposing or revealing something or someone. Pulling back the curtain necessarily brings the other person closer to us and separates the differences between us. Levinas (1969/1980) offered, recognizing the other starts with the opening of oneself in an encounter, exposing oneself while truly seeing the other. It is unclear from this study whether or not that is what the participants felt specifically, however there was an undeniable "call" they described, that invoked a desire to understand individuals in their care as whole people, "*bigger than the sum of [their] parts*" (P2).

Re-humanizing Healthcare

De-othering the authors of the digital stories also seemed to incite a deep introspection in our participants. While they discussed having a greater understanding for the other, so too did this

lead to an inward gaze on themselves, particularly about their practice and contentment, or lack thereof, in their professions. HCPs in this study unanimously described entering their chosen profession with a desire to help others. Heavy workloads, bureaucracy, and the regular demands of personal lives, over time, seemed to result in many losing site of their original reason for entering a healthcare profession, even experiencing burnout or compassion fatigue in some cases. They described a result of watching these stories as having them remember, or rediscover, why they entered their chosen field in the first place.

> *I loved watching these stories because it made me feel something again…I think I've been kinda, I don't know, routine about my job, I guess. I don't really* ***feel*** *things at work anymore. And I guess I didn't even realize that until I watched [the stories] and had tears in my eyes during every one of them*! (P6)

They also offered the idea of bringing this medium to their colleagues, many of whom they recognized as feeling similarly to them:

> *I mean, I have only been a nurse for 5 years and I think this would be a fantastic way for others to see the other side of somebody's diagnosis. I just know [staff] are so overwhelmed with like, "I have to give this med and this med," but like, can I just bring you back to the fact that this is a person?!* (P1)

Another participant added to P1's idea, offering "*maybe these [digital stories] are an antidote to burnout!*" (P6).

A Salve to Burnout

Digital stories allowed access to another side of the individuals in their care and seemed to "personalize" them for the participants. P7 offered:

> *I mean, I know that one [patient] really touched me, and although I never directly cared for her, I always think, you know, there is a patient in this bed, they aren't just a number or a disease, they are people. And it doesn't matter how hard I try I can never get that story out of them. And that [digital story] was only three minutes! So that's, I don't know, I feel that was very powerful to just bear witness to a very vulnerable story*.

Participants described their appreciation – almost relief – at learning more about their patients and being reminded about why they are in their chosen profession.

> *But I think for staff that may have become a little bit complacent it would just bring them back to that "Oh dear, I need to do better" idea. I think [watching these stories] could be really valuable for care providers who don't have the opportunity to get to know their patients in a personal way*. (P5)

There is a busyness to most healthcare professions that cannot be ignored, and a stark reality that there is often too much work for too few hands. P6 offered that "*this stuff [the psychosocial side of patient care] often gets left out, when in reality it can be the most rewarding part of the job*."

P7 then elaborated, saying "*They're [digital stories] like an antidote to burnout!*" The vigor with which the participants took to this idea, of digital stories as an antidote to burnout, speaks to the potential protective effect these stories may have with respect to compassion fatigue, or burnout, so often seen in caring professions. Interestingly, they all agreed that watching these stories is best done in a facilitated manner, as the discussion elicited by the story increases the understanding, effect, and poignancy for the viewer.

Discussion

Digital stories can be a powerful medium for understanding the human condition—both for creators and viewers. For oncology healthcare providers, they can illuminate a more fulsome picture of individuals in their care, and particularly when it comes to unconventional choices (e.g., early cessation of treatment), may provide the human context and help open minds. They add to the individual's story and diminish the "otherness" of those receiving our care. Levinas (1969/1980) first described the idea of "otherness," and offered that recognizing the suffering of another leads to an opening of the self so as to put oneself into a place of vulnerability. This vulnerability is the starting point for the responsibility, or ethic, we feel toward another human being (Levinas, 1969/1980). Kearney (2003) argued that, by recognizing ourselves in the other, we begin to understand how our most basic fears and desires manifest themselves in the world; this increased understanding oneself can lead to a more mindful, holistic approach in one's practice.

Much like the shift in North America to personalized medicine with respect to the physical care, so too did the participants in this study advocate for a "personalized" approach to the psychosocial care of individuals with cancer.

> *P3: It gives more of a sense of… I don't know, narrative. Or completeness, or something.*
> *Interviewer: Like you understand them a little more, or --?*
> *P3: It feels like you get a sense of trajectory of a life… I mean, a whole person instead of a repository for drugs. We need to treat the whole person. We know their illness, but we need to know the person, not just their cancer.*

Digital stories may also allow for a different way of caring for a person. They may provide a more fulsome picture of an individual's life and provide context from where HCPs can provide holistic care. Including their digital stories as part of care plans, for example, could provide HCPs a deeper understanding of individuals in their care prior to stepping foot in the room. A more personalized approach to psychosocial care of adults with cancer could benefit not only those receiving treatment for cancer, but also allow the HCP to deliver more fulsome and efficient care.

> *You know, [digital stories] kind of circumnavigate our developed way of interacting with patients. So if I'm asking a patient questions [directly] I'll keep it fairly… on a common path, whereas the digital story allows you to go into a totally different place and allows you to have a different conversation with a patient because you're starting from a different place.* (P7)

Digital stories may also offer insight into healthcare practices: "*I thought it was interesting to hear how they perceived some of the care providers and what they found helpful. It kind of leaves you to wonder what can I do better as a health care provider*?" (P2). They may offer efficiencies around the care of individuals with cancer by reminding HCPs of the human dimension of the individual versus just the cancer. While most healthcare systems are facing increasing demands coupled with fiscal limitations, ways in which to provide efficient care are urgently needed. Digital stories, typically 3-4 minutes, are robust with information that is easily accessed, quick to watch, and full of information about individuals in our care that could otherwise take weeks to months (if ever) to know.

Limitations

Hermeneutic research is an interpretive, qualitative approach where understanding (versus explaining) is the objective. Accordingly, the aim of our study was to *understand* the effects of digital storytelling on HCPs. While generalizability of any qualitative research is limited, Lincoln and Guba (1985) advocated for the idea of "transferability" (versus generalizability) in qualitative research as it describes the degree of similarity between two contexts; the more similar the contexts, the higher the degree of transferability. A limitation of this study lies in the fact that our interpretations may not resonate – or be transferable - with all who read them. Similarly, while statistical power and large sample sizes are not indicators of rigour in hermeneutics, the views of our seven participants, who were self-motivated and volunteered to participate in this study, may not be congruent with other HCPs, particularly those who are critical toward the topic. Finally, further research, comparing digital storytelling to other interventions intended to expand HCPs understanding and ability to see the whole person, is needed to determine the impact that digital storytelling versus other mediums.

Conclusion

> *Maybe [digital stories] are a way that staff would be influenced ... seeing a larger snapshot of a person's experience in three minutes instead of just how they present in the room when they don't want to say the wrong thing, they don't want to over share*. (P4)

Participants in this study told us that digital stories compelled them to look, and consider, the whole person versus just the disease for which they were being treated. Further, they expressed what might be considered a sort of "relief" with this, suggesting that this is what they have wanted all along (e.g., P2: "*I always want to know more about them, but how can I?*"). It is perhaps the type of individual drawn to an oncology setting in the first place, one where individuals often stay weeks to months at a time, which offers insight as to why these HCPs would want to more fulsomely understand their patients and ultimately deliver truly person-centred care. Connecting with those in our care, and understanding their experiences, can generate new ways of practicing, leading to improved care practices and even, perhaps, a happier workforce.

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Table 1. Participants and Discipline

Participant	**Area of Practice**
1	Registered Nurse
2	Clinical Psychology
3	Registered Nurse
4	Clinical Psychology
5	Social Work
6	Registered Nurse
7	Patient Advisory Group

Figure 1. Focus group sample questions

1. What was it like for you to watch these digital stories?
2. What did you learn about these individuals that you didn't already know?
3. What was most/least impactful?
4. Do you think these digital stories might affect your practice or the way you think about/relate the individuals in your own area? How?
5. Do you think digital stories could it work in your area?
6. What do you think digital stories might be beneficial in your workplace? For you as an individual? What about them might not be beneficial?
7. How would you describe these digital stories to someone who hasn't seen them? How would you describe the impact they had on you?
8. What kind of use do you think these digital stories could have? Can they be used in other areas?