“Stories Take Your Role Away From You”: Understanding the Impact on Health Care Professionals of Viewing Digital Stories of Pediatric and Adolescent/Young Adult Oncology Patients

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Abstract
The purpose of this philosophical hermeneutic study was to understand the effects on health care providers (HCPs) of watching digital stories made by (past and present) pediatric and adolescent/young adult (AYA) oncology patients. Twelve HCPs participated in a focus group where they watched digital stories made by pediatric/AYA oncology patients and participated in a discussion related to the impact the stories had on them personally and professionally. Findings from this research revealed that HCPs found digital stories to be powerful, therapeutic, and educational tools. Health care providers described uses for digital stories ranging from education of newly diagnosed families to training of new staff. Digital stories, we conclude, can be an efficient and effective way through which to understand the patient experience, implications from which can range from more efficient patient care delivery to decision making. Recommendations for incorporating digital storytelling into healthcare delivery are offered.

Keywords
digital stories, health care providers, qualitative research

Family-centered care, patient-centered care, and patient engagement are terms to which health care professionals (HCPs) are continually exposed, usually in the spirit of providing “better” care, improving patient outcomes, and quality improvement initiatives. The reality for many HCPs is that the sheer busyness of day-to-day care means they cannot provide care that feels more than the bare minimum. This can lead to feelings of frustration or burnout in HCPs and leave patients and families dissatisfied with their health care experiences (Boychuk Duchscher, 2008; Cho, Laschinger, & Wong, 2006; Laschinger & Leiter, 2006). One of the reasons for this may be that, traditionally, health care systems have been more focused on the economy of health care: efficiencies, expenditures, and outcomes, and less focused on the humanity of health care. Verna Yiu, current CEO of Alberta Health Services, echoed this idea, stating,

[We] have a lot of strength in our ability to relate data, statistics, and financial information, but we have never been very strong in relating the reason why we are in health care; and the only way that I think we can do that is through storytelling. (Siebold & Lang, 2016)

Individual stories of those served in health care often go unheard, and with that may follow a loss of the humanity within health care.

In our recent study,¹ we used digital storytelling with a pediatric and adolescent/young adult (AYA) oncology population. We showed the digital stories to a focus group of HCPs as a way of understanding patient experiences and to determine the usefulness of digital stories from the perspective of the HCP. In this article, we describe how watching the patients’ digital stories affected HCPs. Drawing on this experience, we further discuss the usefulness and potential of digital stories within the health care system.

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Study Objective

Our goal in this research was to understand the effect on HCPs of watching digital stories made by (past and present) pediatric and AYA oncology patients. Specifically, we sought to understand what HCPs thought about the usefulness of digital stories (eg, in what contexts and how they could be used), what they felt when watching them, and how they might influence their clinical/professional practice. Our research question for this aim of the study was the following: How might we understand the effect on HCPs of watching digital stories created by (past and present) pediatric and AYA cancer patients?

Background Information and Literature Review

The idea of collecting patients’ stories is not new, and many health care organizations have mechanisms in place to do so. Patients’ stories are an important way to understand patients’ experiences and the care that they received (KingsFund, 2016). Even with the most technically proficient care, patients’ experiences affect their memories of that care (Institute for Healthcare Improvement, 2016). It is commonplace for organizations to measure patient satisfaction but less common to seek to learn about patients’ actual experiences of care (Institute for Healthcare Improvement, 2016). Patients’ stories can be rich sources of information and serve to focus care delivery improvements in areas that matter most. What is less clear is how these stories are being used, and to what end they are collected.

Uses of Story in Health Care

In health care, stories can be used for different reasons in many different ways. Typically, patients’ stories are used for therapeutic and/or pedagogical reasons. Haigh and Hardy (2011) demonstrated that stories can be used to promote healthy behaviors in disadvantaged, vulnerable, or marginalized groups while concurrently providing insight into patients’ experiences and improving patient care. Similarly, stories have been used to facilitate learning in palliative care environments (Abma, 2003); to teach health and well-being (Stacey & Hardy, 2011), and coping and resilience (East, Jackson, O’Brien, & Peters, 2010) behaviors to children; and with high-risk youth, stories have been used to teach about violence and associated dangers (Werle, 2004). Others have argued that stories offer a culturally sensitive approach to gathering information and identifying priorities for care (Millender, 2011). Clarke, Hanson, and Ross (2003) concluded that patient stories enabled nursing home staff to “see the person behind the patient” (p. 701) and strengthen relationships between staff and patients. Similarly, Farley and Widmann (2001) suggested that the sharing of birth stories in maternity care can be beneficial to both the teller and listener, as the birth story allows the HCP to develop a deeper understanding of the mother’s needs, and to develop strategies to better assist her.

In nursing education, stories have been used as effective teaching and learning strategies. Schwartz and Abbott (2007) reported enhanced learning and development of critical thinking when student nurses collected information from patients, families, and HCPs to develop a comprehensive story about their patients. Stories can offer a fulsome understanding of human experiences and provide enhanced learning and reflective practice with patients (Moon & Fowler, 2008). Stories are remembered long after facts are forgotten (Chelf, Deshler, Hillman, & Durazo-Arvizu, 2000) and can allow for an understandable and relatable articulation of a person’s experience (Errante, 2000).

Digital Storytelling in Health Care. Digital stories are short, first-person narratives that combine recorded voice, images, and photos as a means of telling a story (Storycenter, 2016). Typically created using computer software, digital stories could be said to represent a natural evolution from traditional storytelling into a digital age. In health care, digital stories have been used predominantly for pedagogical purposes. Christiansen (2011) reported that patients’ digital stories were effective teaching tools with nursing students and increased their understanding of the patient experience. Similarly, radiography students experienced increased insight and understanding of patients’ feelings and experiences, ultimately addressing the theory-practice gap and positively affecting health care provider-patient interactions (Bleiker, Knapp, & Frampton, 2011). Stacey and Hardy (2011) argued that digital stories could also be used to effectively ease the transition from student nurse to registered nurse. Digital stories have also shown merit in quality improvement related initiatives with reported improvements in care practices and positive staff engagement and evaluations after using patients’ digital stories to address systemic change (Quaid, Thao, & Denham, 2010). Most recently, Laing, Moules, Estefan, and Lang (2017) used digital storytelling with pediatric oncology patients and determined them to be an effective psychosocial intervention with the potential to mitigate suffering.

The creation of a digital story has been said to produce a great sense of accomplishment for the creator of the story (Anderson, 2009; Davis, 2005; Davis & Weinschenker, 2012) as it allows people to create a story about an experience, event, or time that can be seen and easily understood by various audiences (Wilson, Hutson, & Wyatt, 2015). Digital storytelling is an innovative medium that still at the forefront of discovery in terms of its potential uses in health care.
Research Design

Method

This qualitative study was conducted using philosophical hermeneutics, defined as the tradition, art, and practice of interpretation (Moules, 2002). Hermeneutics is a particularly effective approach to use when understanding is sought and has been used throughout history from religion to academia to bring forth meaning. A hermeneutic approach produces rich data, allowing for a deep and generative understanding of the phenomenon in question.

Recruitment of Participants

Following ethical approval from the Conjoint Health Research Ethics Board (REB13-1197), participants were recruited via recruitment posters at the Alberta Children's Hospital, the University of Calgary, and through word of mouth. A total of 12 participants were included in this phase of the research, all of whom were HCPs from various disciplines and sites (Table 1). Purposive sampling—using participants who can best inform the topic—was used to generate richness and depth in data through the experiences of the participants (Moules, McCaffrey, Field, & Laing, 2015).

Data Collection

Once participants were recruited and had consented to participate, a focus group was held. The first phase of the study was reexplained, and the participants were oriented as to how the focus group would be conducted. Two digital stories were shown at a time, followed by thematic discussion led by the principal investigator to elicit the type of information sought (Table 2). A total of 8 digital stories were shown over the 1.5-hour focus group. The session was audio-recorded and later transcribed verbatim for data analysis, and the research assistant took notes throughout the focus group to capture details not picked up via the audio-recorder (eg, facial expressions, side conversations, etc).

Analysis and Interpretation of the Data

Hermeneutic research generates rich data from research interviews or focus groups with participants, as well as from interpretive memos written by the research team based on interview transcripts (Moules et al., 2015). In hermeneutics, data analysis is synonymous with interpretation. It is through careful reading of transcripts, attention to the particulars of experiences, looking for statements or passages of interview text that “have grab” (Moules, Estefan, McCaffrey, Tapp, & Strother, 2016) and ongoing reflections that deepens understanding of the phenomenon. Initial interpretations (beginning analyses) are developed and strengthened through conversations with the research team and rigorous communal attention to the data (Moules et al., 2015). In hermeneutic research, rigor and integrity are evident through audit trails, research memos, accounting for methodological decisions, and team consultation (Moules et al., 2015). Data analysis software is not used; hermeneutics does not search for recurring themes, codes, constructs, or theories, but rather to extend understanding of a topic or practice (Gadamer, 1960/1989; Moules, 2002; Moules et al., 2015; Moules, Jardine, McCaffrey, & Brown, 2013; Sandelowski, 2004).

Interpretive Findings

In the following section, we present the findings of the study. Woven throughout our interpretations are the voices
of participants, presented in such a way as to enhance, provide example of, or elaborate on the topic. Participant quotes stand separate from the main text, with italics used to indicate emphasis placed on a word or phrase, ellipses to indicate the omission of text due to irrelevancy, and line breaks to indicate a different participant. In hermeneutics, it is not required to attribute each quote to individual participants as it matters less who the quote came from and more about what the quote says about the topic (Moules et al., 2015). Quotes are “arranged around the interpretations rather than the persons” (Moules et al., 2015, p. 124) with the goal being not to represent the person(s) who said them, but rather to represent the knowledge that was offered regarding the phenomenon under study.

**Being Struck by Digital Stories**

Our HCP participants described the digital stories they viewed in the focus group as “powerful, therapeutic, and educational.” They offered that these stories have the potential to be used with other families as a way of helping, informing, or supporting them.

They were really powerful and they gave you a sense of the struggle that they go through. I think it might be helpful for other people to hear those stories, other families. It would be therapeutic, or it might help put things in context.

I think this can be a very therapeutic group process as well. To share these and to be able to have a dialogue around whether or not that felt, or hit home for them, and to have a different starting point for these conversations. Because these people that are shown here, they’ve been through the whole process so you know, a lot of these other parents and families are at Stage 1.

Several participants offered the idea of using digital stories instead of support groups as a way of helping families.

These could be used in lieu of support groups . . . everyone hates those anyways! This, to me, is almost offering a supportive environment in a short snippet for someone who may not feel they have either the time nor the inclination to bare their soul in a support group.

For those people who can’t go to a support group or don’t want to go to a support group, this is their support group. It’s easy to access, it’s available, it’s private, it’s you know, all those things. To me I think it’s of great value.

This is consistent with other studies (eg, Moules, Laing, McCaffrey, Tapp, & Strother, 2012; Moules, McCaffrey, Laing, Tapp, & Strother, 2012) where participants have expressed the need and desire for support, but when asked directly, if they would attend a peer support group, indicated they would not. Additionally, several other researchers have demonstrated that support groups are sometimes ineffective with respect to their intended outcome of offering support (Freeman, Barker, & Pistrang, 2008; Horgan, McCarthy, & Sweeney, 2013; Woodruff, Edwards, Conway, & Elliott, 2001).

When asked about other uses for digital stories, participants stated that a repository for these stories would be both helpful and educative for patients, families, and other HCPs.

If there was some kind of repository and you with your own time and your own inclination, personally I would sit and watch every single one if they were available and that was my situation.

I think it would be therapeutic for the public though too. And I have to think that for some families, either patients and/or siblings, just hearing that those feelings that they have about guilt and, you know, abandonment and all those things are more typical, might relieve some family members of feeling guilty or you know, not supportive.

The idea of a central location—an online repository—where both HCPs and patients/families could search for stories that matched either their learning needs or their situation was well discussed and unanimously agreed on as a desirable outcome. Participants told us that would be a way for them to come to a deeper understanding of their patients, and ultimately to provide better care.

I think sometimes we do believe we hear the stories of patients because they are our central points of interest, but this is telling us something about what that feels like.

Although the idea of digital stories, or stories in general, was not new to the focus group participants, what was apparent in the focus group was that they became instantly reflective on both the content of the stories shown and watched, but also on their effect and the possibilities of using them for educational and therapeutic benefit.

**When Roles Do Not Protect Us**

Just as participants described digital stories as powerful, therapeutic, and educative, they also told us about the profound effects digital stories had on them personally.

I wasn’t sitting there watching the stories as a healthcare worker. I think it just, it takes your role away from you. There’s something about the power of it that, that um, you can’t hide behind a role when you watch a digital story.

I immediately became a mom when I watched that.
Much discussion was generated when the participants were asked to describe what kind of effect watching the digital stories had on them. Many people, as illustrated in the above quotes, spoke about “losing their role” or “not being able to hide behind a title” (eg, registered nurse) while viewing these stories. Several individuals spoke about the protection that a role or job title offers, and how—once that was stripped away by watching the stories—they experienced an element of vulnerability. We offer that this phenomenon of “losing their role” while watching a digital story is what might contribute to the stories’ impact; without that role or “barrier” between the HCP and the patient, participants could be more open to understanding the experiences of another.

Some participants offered the idea of digital stories creating space where there previously was none, particularly after watching a digital story made by a sibling of an adolescent with cancer.

I mean, as a health professional we’re quite comfortable with the fact that the patient will have a story to tell, and our system allows space for that story to be told, but the system doesn’t leave a lot of room for the other people on the other side. Like it’s kind of interesting that we see this story [sibling] and it’s the one that’s garnered the most conversation and thought, so far. And I think it’s because it’s such an important story.

The health care system, in other words, may allow space for the patient’s story but not often for the other family members. Particularly, the HCPs whose positions involved working with children and families echoed similar sentiments, noting that siblings and other family members often suffer as much as the patient, and they too have a story that may need to be told. Digital stories, we offer, may help focus attention toward the neglected and provide insight on how to better care for the family as a whole.

Simply, Profoundly: On the Aesthetic of Digital Stories

There was consensus about the aesthetic of digital stories contributing to their impact. The combination of images, spoken voice, and music seemed to create an effect—an aesthetic—that for many was surprisingly impactful.

[That image of] those dirty dishes spoke to me. When I saw that I thought ugh, oh god. I don’t know if that was her own photo or not, but that just spoke to me about her being on her own.

The way the visuals were put together along with the way that she was talking—she started at the beginning and was kind of leading us with a forward looking story, but the images were taking us back and forth [in time], and as they went back, there was that kind of call that you feel when you hear a story being told this way.

Digital stories call on the HCP to understand the patient experience in a way that is deeper and more meaningful than what they may come to learn through daily routine care or interactions. They can help the HCP understand what the patient is experience “is like” and allow for new and deeper insight with respect to the care provided.

A Call to Compassion. Participants spoke about being “called” by these stories, and one of the ways in which they were called, we offer, was to compassion.

They’re good stories that come out of adversity, and so to me they’re more powerful. I think of being led to do better work versus pulled to do better work. . . . I’m more inclined to work harder for a wonderful story that has this person behind it than I am to be beat up by a bad story that we didn’t do a good job with.

Sinclair et al. (2016) defined compassion in health care as “a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action” (p. 195). Accordingly, a call to compassion is being driven to address the suffering of another, and we witnessed this in our participants during many of the discussions that took place following each digital story.

There’s a glimmer of hope in all of them which I think we all connect with, whether you’re a clinician, or a patient, or a family member, you can connect with that.

It’s not just about that individual person, it really does invite you into the wholeness of that person.

Being “called” to something, be it compassion or another response, necessarily implies that one is open to receive that call. Each of the 12 participants discussed this, in different ways, and one of our participants offered the language of noting how the stories “act on” individuals.

These [digital stories] then, make you ask as to how the story acts upon you. And we don’t often do that you know, where we have someone right in front of us, we don’t have the luxury of that flip in thinking. And if you take something like these stories and you start to ask as to how the story acts upon you, then you start to realize how many layers of assumptions we make about the way people live . . . and what we think we understand.

These stories do, indeed, act on the viewer. They seem to do so in such a way as to allow the viewer to be open to receive their messages, not with an obligation necessarily to respond, but rather to understand. It is in this space of
understanding that insight, compassion, and generative approaches to care may be gained.

From People to Systems

A common topic our HCP participants often circled back to was how digital stories can affect the health care system. The idea of these stories creating significant impact in a 3- to 4-minute timeframe appealed to all and was thought to be consistent with the pace and flow of the business of health care.

There’s something about these that speaks to efficiency, and I loathe efficiency as a driving force of what we do [laughter]. But you have two and a half minutes that really is saturated with potential for learning and critique to hold attention for the ways that we practice and to help people begin to think differently about what it is that we need to do to be good carers in these kinds of contexts. So you can see how digital stories have value to be able to be taken up in clinical contexts. They could be great tools.

In Canada as in many other parts of the world, health care is, and has been, in a state of unrest for several years. Political agendas, budgetary constraints, and changes in leadership all contribute to HCPs continually being asked to “do more” with fewer resources. As our health care system shifts in efforts to become more sustainable, efficiency in the workplace is paramount. As illustrated in the above quote, digital stories can be enormously useful in many ways, depending on the need. We offer that they hold potential for not only increasing efficiency but also efficacy with respect to patient education, psychosocial needs, and workplace productivity.

Some participants offered the idea that these stories can also be efficient and effective with respect to health care system leadership and executive teams.

As a clinician in [a hospital] it’s very, um, like a business model, and feeling like it’s about numbers and not about the stories and it is about efficiency, so . . . it would be a great way to educate people making policies and decisions . . . you know, by hearing people’s stories. Remind them that it’s not just numbers.

DS can go everywhere, right, so they can be brought up to the policy makers—they travel.

We offer that digital stories are a way to humanize the patient experience and could help those in positions of making decisions related to patient care. Ironically, those making decisions related to patient care are often furthest away from the front lines—from the patients and families themselves. Digital stories have the potential to bring the human experience, re-embody it, to decision makers who may have forgotten.

Knowing Better, Doing Better

Many of the ways in which our HCP participants discussed the impact from digital stories related to the increased understanding and insight that can be garnered from watching these stories. Quite simply, these stories tell the viewer about “what it feels like,” which often leaves the viewer with a greater understanding than they previously had. With that understanding may come more insight related to the patient experience resulting in more compassionate care, and services and programs targeted to specific needs identified from new understandings.

I think for healthcare workers it’s hard to be able to be empathetic and understand what everyone’s going through in their lives, their histories and everything. I think using these stories would be really helpful . . . or even allowing that time with your patient to hear their stories really helps you to just understand what they’re going through as much as you can. It’s hard, like, I haven’t gone through cancer to be able to understand a patient on an oncology unit, right? But the storytelling is one step further to be able to give better care.

It interests me how much more there is to people than the stories they tell in person. Because we look down the list and know these are the treatments for these conditions, but we don’t think about how it’s going to impact that person.

Maya Angelou wrote, “Do the best you can until you know better. Then when you know better, do better” (Goodreads, n.d.). We believe this to a poignant summation of this phenomenon. HCPs gain understand and insight they previously did not have. This understanding can lead to generative care practices, better suited to patient needs. In short, knowing better can lead to doing better. The following quote exemplifies this idea in “real time” as one participant came to came to a new realization and discussed this in the focus group.

I think sometimes we do believe we hear the stories of patients because they are our central points of interest, and then you hear someone talking this way [in the digital story] and she was saying “I don’t want to be managed.” And so her story isn’t about being managed it’s a story about the tension between being treated for something and wanting to be able to do what it is that she likes, what she loves. And yet, when you think about the language of healthcare and the way that we story the healthcare experience, sometimes management is precisely the story that gets told. Because it’s about patient management, it’s about disease management, wound management and so on. This is telling us something about what that feels like.

Part of the power of digital stories lies in their transformative effects. They are ripe with possibilities for affecting the care of patients and the lives of HCPs.
There Is More Than What Meets the Eye

HCPs in our study all agreed that digital stories were effective and powerful tools with multiple potential uses in health care. In some of our other interpretations we have discussed several reasons as to why this might be, but we asked our participants to help us further understand reasons for their effectiveness.

I think one of the reasons is how emotionally engaging they are. People are so engaged [when watching the story], that whatever they say sinks in.

The emotional engagement to which this participant spoke is, we offer, one of the key factors that differentiates digital stories from other types of stories (eg, verbal, written). Because the viewer of a digital story can remain emotionally engaged throughout the entire 3- to 4-minute story, there appears to be an almost disproportionate amount of education and/or insight that is garnered considering the short length of the video, making them powerfully effective. Another participant took this idea even further:

Do you know what I think it is, is you don’t have to respond to what they’re saying. You know how when you’re listening to someone you have make sure that you don’t look like you’re doing a grocery list in your head [laughter], you have to be very present in a way that reflects back to them, whereas with digital stories you can be totally engaged and present without the responsibility to respond.

Listening in conversation is remarkably ineffective. The average person forgets up to half of what he/she heard immediately after listening to someone speak, regardless of how carefully they thought they were listening, and within 8 hours only 25% of information is retained (Heilman, 1951; Kramar & Lewis, 1951; White & Epston, 1990).

When you’re listening to someone else speak, in the moment, when they’re right there, you’re also listening to yourself. You’re listening to “what am I going to say next”?

Digital stories not only offer a freedom from the usual “rules” of listening but might hold the potential to be a powerfully effective communication and education technique.

Discussion

Because of global emphases on patient engagement, recognition of patient voice, responsive service delivery, and better outcomes of care (Graffigna, Vegni, Barello, Olson, & Bosio, 2011; Mockford, Staniszewska, Griffiths, & Herron-Marx, 2011; National Health Service, Department of Health, 1999), new and innovative ways of connecting with patients are warranted. Patient engagement is widely recognized as a crucial component in high-quality health care delivery (Coulter, 2002; Forbat, Cayless, Knighting, Cornwell, & Kearney, 2009) and in many health care systems, patient engagement is at the forefront of policy and practice reform (Barello, Graffigna, & Vegni, 2012). We believe reflective digital storytelling powerfully assists practitioners to understand patients’ experiences. Both the creation and viewing of digital stories can lead to new insight, understanding, and more generative approaches to care. At the heart of patient engagement is the desire to understand, and while many health care systems struggle to address sustainability issues, HCPs are often asked to “do more” with fewer resources. It is a paradoxical relationship, in some ways, to seek a deeper understanding of patient experiences amidst fiscally restrained health care climates. All too often, it seems, the voices of the patients remain muted, negating the intent of patient engagement. As health care systems increasingly advocate for patient engagement as a means to improve health care delivery, digital stories are an effective and efficient tool to achieve that aim.

Digital stories, we have learned, are about understanding an experience versus simply explaining it; we believe that to be at the heart of not only patient engagement but health care delivery in general. The efficiency with which digital stories can inspire engagement and impart understanding has practical implications in health care systems that struggle to do more with fewer resources. For example, training or educational videos that incorporate digital stories could be efficient ways to teach HCPs about the patient experience and could also be integrated into orientation programs. As the body of literature related to workplace stress (often termed burnout, compassion fatigue, and/or caregiver fatigue) grows, it is becoming more apparent that this occupational hazard can have profound deleterious physical and psychological effects on HCPs (Carr, Gareis, & Barnett, 2003; Erickson, Hamilton, Jones, & Ditomassi, 2003; French, 2005; Gellis, 2002; McManus, Winder, & Gordon, 2002; Painter, Akroyd, Elliot, & Adams, 2003; Park, Wilson, & Lee, 2004; Weinberg & Creed, 2000).

Participants in this study not only spoke about the digital stories as being “impactful, heartwarming, and understandable” they were also visibly energized after watching them. One participant commented as the focus group was coming to a close, “this was exactly what I needed” and others nodded or verbally agreed. There appears to be an uplifting effect that can result from watching digital stories, even stories we did not consider to be of an uplifting nature. Digital stories may help mitigate practice burnout (Cimiotti, Aiken, Sloane, & Wu, 2012) and reintroduce compassion back to the viewer by way of opening a portal of understanding. To understand, from an etymological lens, means “to stand in the midst of” (Online Etymology
Digita stories allow the viewer “to stand in the midst” of the story he or she watches. The understanding gained from this has implications for the HCP himself or herself and also for health care delivery.

Implications and Recommendations

They could be on a Website, they could be in a therapeutic setting, they could be in a support setting, they could be in an orientation, they could be in so many things.

Each of the HCPs in our focus group discussed varying uses for digital stories, most from the context of their own place of work and/or discipline. The mental health nurses, for example, saw great potential for digital stories as teaching tools for families new to the system; those who practiced in a critical care setting discussed digital stories as being a way to “remember why we’re here” and as an antidote for burnout. One of the commonalities among the HCPs suggestions for how and when to use digital stories in health care was the idea of a receptacle within which they are housed and available for public consumption. A searchable Website where one could “pick and choose” stories to use for various purposes was unanimously deemed a next step in terms of the usability of digital stories. Future research could focus on incorporating digital stories into training and orientation programs as a means of increasing understanding of the patient experience. Universities and technical colleges that prepare students to enter a health care field could also incorporate digital stories as a way of providing a “first-hand” experience and imparting a meaningful and potentially lasting impression of how to best care for patients in their chosen profession. Research related to their effectiveness with respect to communication and education could be trialed, ultimately with the aim to improve patient care and ensure a sustainable workforce.

Limitations

We were unable to get enough pediatric oncology HCP participants for our focus group; therefore, additional HCPs from different specialty areas were recruited (eg, adult oncology, cardiology, etc). This could be considered a limitation of this research. We offer, however, that the impact of the digital stories made by the pediatric/AYA oncology population need not be exclusive to only pediatric oncology HCPs; much can be learned by having a mix of disciplines/areas of focus.

Additionally, hermeneutic research is interpretive research where understanding (vs explaining) is the aim. As such, in this study, we focused on understanding the effects of digital storytelling on HCPs. Like all qualitative studies, this study has limited generalizability; however, Lincoln and Guba (1985) proposed the term “transferability” for qualitative research (vs generalizability) as it describes the degree of similarity between two contexts. The degree of transferability depends on the similarity between contexts; therefore, the more accurately the conditions and contexts under which the research was conducted is described, the more likely the reader is to find similarity to another situation. In other words, the interpretations “fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (Sandelowski, 1986, p. 27). The degree of transferability of this study depends on how much the interpretations ring true for those who read them, and—like all hermeneutic research—a limitation of this study lies in the fact that our interpretations may not ring true for all.

Like any approach to education or communication, there is no “one size fits all” approach. Digital stories, it follows, may not “fit” with all HCPs, and therefore could be ineffective as a way of communicating, educating, or informing.

Conclusion

And I think the other thing [digital stories] do is they help to resist that practice we get into in healthcare, which is always about a deficit. That we’re inquiring into something precisely because there’s something wrong with these people . . . and I think using digital stories reveals a counter to that which is capacity, and ability, and it stops us from going down that road where we feel like we need to try and fix things.

Working in health care can be difficult; the physical and psychological demands that accompany patient care, while rewarding, can also stressful, unrelenting, and consuming. Finding ways to connect with patients, remember why we are in our chosen professions, and understand the patient experience can lead to not only improved care practices but also a more sustainable workforce.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded through a grant from the Kids Cancer Care Foundation of Alberta.

Note

1. This article reports on the secondary aim of this study. The primary aim was to determine if, and understand how,
digital stories might be effective therapeutic tools to use with children/AYAs with cancer, thus helping mitigate suffering. This has been published as a separate article, titled, “Stories That Heal: Understanding the Effects of Creating Digital Stories Pediatric and Adolescent/Young Adult Oncology Patients” (see Laing, Moules, Estefan, & Lang, 2017).

References


Author Biographies

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