Exploring the Role of Digital Storytelling in Pediatric Oncology Patients’ Perspectives Regarding Diagnosis: A Literature Review

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Abstract
Story is a powerful tool in holistic nursing care. Narrative therapy, story circles, narrative-psychotherapy, and family therapy methodology have incorporated storytelling in a research setting. Childhood cancers isolate children from traditional childhood experiences. In recent years, survival rates for pediatric oncology patients have improved, opening up opportunities for research. The increase in life expectancy makes it necessary to investigate the psychosocial perspectives of children as they progress. This review focuses on the use of digital storytelling among pediatric cancer patients as a form of reflection. Furthermore, it addresses the possible therapeutic effects that may be realized by children who produce a digital story. Sixty-four references were identified via PubMed and CINAHL databases using the following keywords: “digital storytelling,” “narrative therapy,” “pediatric oncology,” “childhood development,” and “interactive narrative.” Future research will focus on addressing the gap in the science, particularly in evaluating pediatric oncology patients’ perspectives about the role of digital story in the context of Erikson’s developmental stages.

Keywords
digital story, storytelling, cancer, children, quality of life

Introduction
Children are a unique population, difficult to categorize coherently, and perhaps, even more challenging to assess, treat, and provide holistic care. More specifically, childhood cancers can isolate children from a traditional childhood experience, exchanging playgrounds for hospital beds and cookies after dinner for chemotherapy treatments. However, in recent years, survival rates for pediatric oncology patients have drastically improved, increasing opportunities for research regarding quality of life (de Vries et al., 2011; Enskar, 2012; Klassen, Anthony, Khan, Sung, & Klaassen, 2011; Stutzer et al., 2005; Wu, Chin, Haase, & Chen, 2009). One such area of new research comes from a directed effort to promote, implement, and facilitate storytelling by the Center for Digital Storytelling (Lambert, 2010). A digital story, as it is frequently defined, is a short film (usually 2-5 min) consisting of first-person narrative, pictures, movies and sound effects (Anderson, 2009; Jernigan, Salvatore, Styne, & Winkelby, 2012). Each story contains characters, scenes, conflicts, successes, failures, and/or reactions from the storyteller’s personal life journey (Davis & Weinshenker, 2012).

The Role of Story
Story is a powerful medium to convey meaning to others, but perhaps more importantly, to uncover previously unknown meanings to the storyteller. Stories are remembered long after facts are lost from memory (Chelf, Deshler, Hillman, & Durazo-Arvizu, 2000). Story provides space to find meaning in situations and interactions, past and present (Anderson, 2009; Enskar, 2012; Gilbert, 2002; Sinclair & Monk, 2005), and is a powerful tool in holistic nursing care (Backhaus, 1984; Banks-Wallace, 1999; Buttery, Eades, Frisch, Giguer, & Mountjoy, 1999; Chelf et al., 2000). In its most basic form, to tell one’s own story is to understand the unique memories, relationships, achievements, and failures that collectively make up one’s person, and then translate that understanding into language that can be shared (Backhaus, 1984; DeSocio, 2005). Two nurses, seeking to promote storytelling as an
avenue for holistic nursing care, developed a middle-range theory projecting that true connection to a story results when both an attentive listener and a safe environment are available (Smith & Liehr, 1999).

Story also conveys culture, combining personal experience with the commonalities of all human experiences (Backhaus, 1984; Badger, Royse, & Moore, 2011; Banks-Wallace, 1999; Larkey, Lopez, Minnal, & Gonzalez, 2009; Scaletti & Hocking, 2010). Story is not stagnant, rather, it is a process that evolves with time and provides a new lens through which reality is understood and new revelations are uncovered (Gilbert, 2002). For children, story provides an opportunity to work through anxious situations and flawed beliefs and to then redirect and rewrite their story to express their current understandings and perceptions (Anderson, 2009; Hanney & Kozlowska, 2002). For example, in illustrative family therapy, the story told begins prior to the trauma, injury, or diagnosis, allowing the child to work from a place of peace into, and back out of, anxious places (Hanney & Kozlowska, 2002). More specifically, children’s stories provide a window into their processing and understanding of culture and the resulting view of their role in it (Backhaus, 1984; Scaletti & Hocking, 2010). This culture is complex; Chelf et al. (2000) believe story to affect the cognitive (Larkey & Gonzalez, 2007), affective, interpersonal (Banks-Wallace, 1998), and personal areas of a person’s life by allowing space for problem solving, emotional release, community building (Gilbert, 2002), and new intrapersonal understanding (Smith & Liehr, 1999).

**A Brief History of Story**

From the beginning of history, specifically within indigenous populations, story has been passed from grandfather to grandson, from mother to daughter, all in an effort to preserve culture and improve one’s life from the experience of another’s (Larkey & Gonzalez, 2007). In the 1970s, the concept of a Life Book emerged in adoption literature as a way for a child and a caregiver to create a story of the child’s life together to foster relationship, personal development, and self-worth (Backhaus, 1984; Hanney & Kozlowska, 2002). By the 1980s, story, play, art, and communication were all deemed therapeutic (Scaletti & Hocking, 2010). Furthermore, throughout history, story has enabled the grieving process, as storytelling legitimizes the emotions and new perspectives grieving elicits (Gilbert, 2002). In addition, storytelling in the form of reminiscence has long been considered an effective nursing technique, providing spiritual relief, life celebration, and life review in the grieving or dying process (Backhaus, 1984; Banks-Wallace, 1999; Chelf et al., 2000).

**Child Development and Storytelling**

Children’s curiosity is an asset to storytelling therapy, allowing their inquisitive spirits to lead self-exploration and in turn, new self-discoveries (Furlonger, 1999). These self-revelations have the potential to perpetuate the healing process for future children by allowing a new avenue into understanding this unique experience. Research shows that traumatized children are often unaware of or avoid talking about areas of their life that cause emotional or behavioral problems, and therefore need assistance to explore these misunderstood areas (Gabel, 1984; Hanney & Kozlowska, 2002). According to Furlonger (1999), children commonly align their beliefs to a sense of blame for the problems and situations in their life. This in turn leads to a sense of unbreakable connection of the child to the problem (Furlonger, 1999). Current research implores therapists to define the person and the problem as two separate entities, allowing children to recognize the power and autonomy they have over, and separate from, the problem in their life (Anderson, 2009; Furlonger, 1999; Matos, Santos, Goncalves, & Martins, 2009; McCarthy & Sebaugh, 2011; Wallis, Burns, & Capdevila, 2011). Storytelling provides the autonomy needed to clarify and unravel these false beliefs, while allowing the listener to gain an understanding of the child’s internal processing and perspective.

This separation and definition is dependent upon children’s developmental stage and level of understanding as they struggle to grasp the nature of their problem, specifically as it relates to a medical diagnosis (Murray, 2000). Children aged 2 to 4 years can translate a specific event into memory as the left brain grows and develops (DeSocio, 2005; Hanney & Kozlowska, 2002). Furthermore, they are beginning to develop self-control and autonomy while fighting the fear of separation. This fear develops as they have no sense of time and lack certainty that parents or other sources of familiarity will return (Kramer, 1981; Murray, 2000). By age 3 to 5 years, children can identify and distinguish between objective characteristics, and with it determine correlation regardless of the true causal relationship (DeSocio, 2005; Murray, 2000). Furthermore, an understanding of time develops at this age, as does a sense of egocentrism, and the ability to know fault, shame, and guilt (Hanney & Kozlowska, 2002; Kramer, 1981; Murray, 2000). Children develop social comparisons by age 6 to 11 years. This allows children to see themselves as a part of, or differing from, a specific group, leading to a sense of superiority and confidence or inferiority and insecurity (DeSocio, 2005; Kramer, 1981; Murray, 2000). Early adolescent children begin developing a theory of self, a method of defining and explaining the collection of memories, life experiences, peers, and family involvement that make up their story (DeSocio, 2005; Murray, 2000). By 8 to 10 years, children can control and alter the type of personality and appearance they wish to display in social settings as well as identify when they wish to share or withhold personal insights from others (DeSocio, 2005). This sense of self-awareness and self-disclosure can empower or overwhelm individuals, and often does both simultaneously (DeSocio, 2005).
When children enter into the “teenage” years, ages 11 to 17 years, the array of successes and struggles drastically change, as does the physical body. According to Erikson’s Theory of Human Development, this age group is conflicted between identity, independence, and their role in society (Erikson, 1959). Adolescents are concerned with exploring and finding their voice, learning about social roles, personal identity, and fidelity (Erikson, 1959, 1963; Kishton, 1994). Erikson argues that at this age, adolescents can perceive true from false adoration (Erikson, 1963). As a result, true identity growth only occurs when they are allowed the opportunity to meaningfully contribute to society, which, in turn, leads to genuine recognition of their accomplishment (Erikson, 1959, 1963).

**Pediatric Oncology**

Pediatric oncology is a highly specialized field, one where substantive improvements have been made in recent years to lengthen life expectancy and survival rates (de Vries et al., 2011; Enskar, 2012; Stutzer et al., 2005). As a result, more children are living with a cancer diagnosis and the residual effects well into adulthood. The most complete picture of the child’s experience with cancer results from the study of patients’ quality of life, age, gender, ethnicity (Wu et al., 2009), phase of treatment, treatment type and intensity, times since diagnosis (Engvall, Mattsson, von Essen, & Hedstrom, 2011), and side effects from both diagnosis and treatment (Hildenbrand, Clawson, Alderfer, & Marsac, 2011; Klassen et al., 2011).

According to a study in Hong Kong, China (n = 88), age is a determining factor in how children cope with cancer (Li, Chung, Ho, Chiu, & Lopez, 2011). Younger children, aged 9 to 12 years, were more emotional-focused than concerned about the problem itself; alternately, 13- to 16-year-olds were more focused on the problem. Those children who remained focused on the emotional state exhibited avoidance, distancing, and ownership behavior; they tended to acknowledge their role in the problem and seek ways to solve it, often through focusing on positive aspects of life and the diagnosis. On the contrary, problem-focused individuals often sought social support or confronted the situation with raw emotions. No evidence suggested differences between male and female participants in their study (Li et al., 2011). This knowledge allows for tailored treatment plans for the individual, recognizing the difference that age makes (Li et al., 2011).

In another study by Ruland, Starren, and Vatne (2008), they determined that children 7 to 11 years were entertained by electronically documenting their symptoms and current status. This activity gave them a sense of accomplishment, and allowed them to contribute to something important about their health (Ruland et al., 2008). This research also showed that children often withhold troubling symptoms to protect worried parents (Ruland et al., 2008). Another study examined 7- to 12-year-olds in a convenience sample (n = 40) to determine how often pediatric oncology patients experienced chemotherapy-induced nausea and vomiting (CINV) and how they coped with it. The study found that active coping mechanisms were used twice as frequently overall than negative ones and were the most beneficial for people experiencing CINV (Rodgers et al., 2012). Although distraction and wishful thinking were the most frequently used coping strategies, using social support systems along with distraction was reportedly more effective (Rodgers et al., 2012). Other frequently used active-coping mechanisms were positive thinking, problem solving, and emotional regulation (Rogers et al., 2012). In a similar study, evaluating 15 children 6 to 12 years, investigators found that numerous coping strategies, often up to three, were employed by each child as opposed to a single strategy (Hildenbrand et al., 2011). Children most often used relaxation, social support, expressing emotions, and cognitive reconstruction as active approach coping strategies. The study reports that distraction was the one passive avoidance coping strategy used (Hildenbrand et al., 2011).

For children aged 11 to 17, the adolescent years and a cancer diagnosis lends toward numerous physical and emotional developmental challenges. Adolescents tend to miss more school days, experience difficulties with peer relationships, possess body image insecurities, have increased treatment-related side effects, and identity confusion resulting from their cancer diagnosis (Hildenbrand et al., 2011; Pini, Hugh-Jones, & Gardner, 2012). The extensive missed school days lead to social isolation and fear of rejection or mockery. Social isolation is compounded by altered physical appearance, typically weight changes and hair loss (Hildenbrand et al., 2011; Pini et al., 2012). Furthermore, this stunted developmental period can lead to future unemployment and failures in society (Pini et al., 2012).

Adolescent coping strategies have been shown to vary. A phenomenological study gathered narratives from 10 children diagnosed with cancer aged 12 to 18 years to evaluate their coping strategies (Wu et al., 2009). The results indicated a fluctuation between rebuilding hope, pursuing a normal life, and believing in their ability to overcome the diagnosis, versus losing confidence, as a result of the physical and psychological suffering.

Additional studies have supported this conclusion. A mixed-methods study examining coping mechanisms of children aged 13 to 19 years, who were recently (4-8 weeks) diagnosed with cancer, found that a wide variety of coping mechanisms were used, including acceptance and minimizing areas of distress, problem solving, positive thinking, and distraction (Engvall et al., 2011). Specifically, positive thinking as a strategy in adolescents helped to make sense of their diagnosis by redefining goals early on in diagnosis. Furthermore, this process resulted in an improved quality of life 18 months after diagnosis in comparison with the original 4- to 8-week time frame (Engvall et al., 2011).
In addition to story, a variety of other interventions providing coping methods have been tested for pediatric oncology patients to ease the difficulty of the diagnosis. One study implemented yoga as a therapeutic agent with children aged 7 to 18 years and their parents (Thygeson, Hooke, Clapsaddle, Robbins, & Moquist, 2010). Although yoga is shown to improve sleep quality, endocrine function, and physiologic responses to stress, there was no statistically significant change in children’s anxiety levels despite all participants reporting a positive overall experience (Thygeson et al., 2010). Music therapy was also examined, where 6- to 13-year-old children \( (n = 11) \) were allowed to develop their own “mix” of music that played during the patient’s radiation treatment (Barry, O’Callaghan, Wheeler, & Grocke, 2010). The mixed-methods analysis revealed that, although both the standard care group and research group began with equivalent stress levels, the standard group reported that 67% of participants exhibited social withdrawal, a negative coping strategy. In contrast, no music therapy participants demonstrated this coping strategy, and instead reported implementing distraction and cognitive restructuring (Barry et al., 2010). Furthermore, the music therapy group analysis produced themes of fun (diminishing dread toward treatments), lower distress levels, positive family experiences, assisted coping skills, and a sense of empowerment as they mastered the music development to produce a finished product (Barry et al., 2010). These positive outcomes documented establish the benefit of alternative interventions to improve coping skills and quality of life in pediatric patients.

In addition to qualitative methods and interventions to assess child cancer patients, brief quantitative assessment scales are used in a variety of studies to gather a more complete picture of the illness experience. One study defined quality of life as including the physical, psychological, and social health of a patient (Klassen et al., 2011). As such, this assessment is more complex for children as the family is a vital factor in the physical environment but also, less concretely, the psychological, emotional, and social elements of the child’s life (Hildenbrand et al., 2011; Klassen et al., 2011). The Pediatric Quality of Life Inventory™ 4.0 is used frequently to assess children’s perceptions of quality of life after being diagnosed and has been studied for its reliability and validity with positive results (Conlon, Breatnach, O’Hare, Mannion, & Lyons, 2009; Klassen et al., 2011; Parsons, Fairclough, Wang, & Hinds, 2012; Varni, Seid, & Kurtin, 2001). Furthermore, there are disease-specific variations of the scale, including a PedsQL Cancer Inventory (Klassen et al., 2011). Two studies use Kidcope, a brief measurement based on 10 basic coping mechanisms (Barry et al., 2010; Klassen et al., 2011). Another measurement, The Child Attitude Toward Illness Scale (CATIS), assesses children between the ages of 8 and 12 years asking them to self-report their attitude toward their ailments using a Likert-type scale (Wyatt & Hauenstein, 2008b). This additional step provides validation to interventions like digital storytelling, providing a more complete picture of the effects of an intervention for each participant.

The Role of Family

The role of parents and family requires extensive research as it is intertwined throughout childhood narrative therapies, storytelling interventions, and shaping a child’s final story. Parents can often act as a consultant; for example, in one study, parents were used as a filter and were asked to review a symptom list to ensure it was understandable and relevant to their children (Ruland et al., 2008; Stutzer et al., 2005). However, White (1986) notes that family influence can often go unnoticed over time, as a patient becomes immune to a mother or father’s direct effect of the problem situation and/or view of it (Furlonger, 1999). Parents act as a filter by encouraging certain memories and disregarding others, significantly influencing the collection of memories that children develop (DeSocio, 2005). Furthermore, parental and familial influence often resists change as habitual solutions are chosen over new solutions when new problems arise (White, 1986).

Narrative therapy, according to Hanney and Kozlowska (2002), should start with the child and work toward and within family context, not reversely beginning or primarily involving the family into developing the child’s story. In a family therapy setting, mapping out the influence of each family member serves to identify and explain aspects of a child’s behavior (White, 1986). As a child develops his or her story, taking newfound revelations and understanding to the family creates a sense of community and mutual bond (Hanney & Kozlowska, 2002). When the child presents his or her story to the family, no alterations to the child’s story are made, and the therapist assists the child and family to walk through the story by asking questions about the work presented (Hanney & Kozlowska, 2002). A study examining parental reactions to their child’s story with a neuroblastoma produced diverse results; however, often parental reactions were consistently more severe when the child had lasting quality of life changes (Peterson, Cousino, Donohue, Schmidt, & Gurney, 2012).

The previously mentioned investigators who examined parent coping strategies (Hildenbrand et al., 2011) found that parents frequently used between three and six coping strategies. The vast majority of parental coping mechanisms were active, approach-oriented, with the only significant avoidance coping mechanism being to promote distraction (Hildenbrand et al., 2011). Parents learn to adapt as they deal with personal loses associated with their child’s diagnosis, altering daily routines, concepts of perspective, and the fear of the future (McCarthy & Sebaugh, 2011).

Storytelling Experiments and Results

Storytelling as a therapeutic agent is studied in a variety of areas, leading to diverse experimental structures and results.
In a study by Chelf et al. (2000), 97% of patients with cancer and their family members (n = 94) found that a storytelling workshop improved their ability to cope. In a qualitative study conducted by Buttery et al. (1999), researchers asked open-ended questions to interview relatives of patients who transferred units in a hospital. Seven interviews were recorded and transcribed verbatim and then analyzed using open coding (Buttery et al., 1999). The overarching theme in the stories was family disarray as patients moved from one unit to another in a hospital, leading to strained or changing family roles.

In a personal communication by a pediatric nurse, she found that in younger children, between 8 and 9 years, story validated the child’s significance and importance to the world despite small physical stature (Freeman, 1991). In slightly older children, 9 to 12 years old, she found that the ownership of one’s story was of vital significance (Freeman, 1991). An 8-year-old girl named Emily with behavioral problems following her father’s sudden death began making a storybook with the help of a therapist (Scaletti & Hocking, 2010). As Emily was heard by and began to trust in the therapist, she and her mother worked to write a story that broke down barriers in her process and allowed progress and behavioral improvement at school and home (Scaletti & Hocking, 2010). Narrative psychotherapy methodology was tested with an 8-year-old boy and his foster mother, showing an improved sense of identity and outlook (DeSocio, 2005). In a randomized-controlled trial done with 72 oncologic patients, a combination therapy that implemented narrative therapy along with antidepressant medication produced significantly more improvement in function, quality of life (p = .007), health (p = .02), and pain scales (p = .02) than antidepressant medication and traditional care alone (Rodriguez Vega et al., 2011).

In addition to traditional storytelling, a study conducted at St. Jude Children’s Research Hospital implemented scrap-booking as a therapeutic agent to promote storytelling, personal development, coping skills, and social communities among children and their parents (McCarthy & Sebaugh, 2011). Results based on both quantitative quality scales and qualitative open-ended questioning revealed that the overall experience was positive, with the most compelling benefit being growth and increased pride in a patient’s family system (McCarthy & Sebaugh, 2011).

Research Into Digital Storytelling

Digital storytelling enables people, even those with little technological expertise, to create a story that is lasting, which can be seen and understood by various audiences, and an end result that produces a great sense of accomplishment for the storyteller (Anderson, 2009; Davis, 2004; Davis & Weinshenker, 2012). Multimedia (especially movies, television, etc.) is used as a public forum where those things deemed important and influential by society at large are displayed, setting cultural trends and norms, and sharing messages to masses. With this sentiment in mind, digital storytelling gives younger audiences, who are raised attributing an innate status to the digital medium, an attractive, powerful, and culturally congruent platform to tell their story (Davis, 2004; Sawyer & Willis, 2011). In one study, investigators piloted a program based on this assumption by using digital stories created by secondary school students to influence and improve the coping mechanisms and social behaviors of younger children (Sawyer & Willis, 2011). Another study proposed and tested digital story as a method to improve education for Latina women who needed colorectal cancer screenings (Larkey et al., 2009). Findings show that viewing digital stories led to significantly higher intent to increase the amount of vegetables eaten (p = .030) and time spent exercising (p = .018) than a risk assessment informational tool intervention (Larkey & Gonzalez, 2007). A study using a U.K.-based menopause website demonstrated that of the total respondents (n = 539) to the online survey, over two thirds of the women preferred a digital story as opposed to standard information about urogenital atrophy (Cumming, Currie, Moncur, & Lee, 2010). Furthermore, after watching the digital story, 73% of women who previously stated they were “too embarrassed to discuss their symptoms with their doctor” felt that they could do so (Cumming et al., 2010). In another study, 18 African American women were interviewed in a qualitative study that presented breast health information in a storytelling focus group. The storytelling methods resulted in improved education, support, behavioral modification incentives, and personal insight as they learned from each other and recounted their story to the group (Clarke, Hanson, & Ross, 2003; Williams-Brown, Baldwin, & Bakos, 2002).

In an innovative study, researchers analyzed the power of storytelling intervention to improve public health and welfare. Researchers combined the Tool for Health and Resilience in Vulnerable Environments (THRIVE) policy engagement tool and digital storytelling to enhance the community’s understanding of factors affecting overall health (Jernigan et al., 2012). Twelve people identified as “key stakeholders” (p. 648) from a Native American community participated in the digital storytelling process to create a story for each aspect of the THRIVE tool: opportunity for realistic change, the people involved, and the place for change (Jernigan et al., 2012). The finished product was then brought back to the community, and the THRIVE tool was shown and then discussed to move toward improved food security.

Another study looked into the psychosocial health effects gleaned by making a digital story. A study in Northwest Alaska spent 3 years collecting 566 digital stories, which resulted in 79% of the participants stating that they were satisfied or very satisfied with the story-making intervention (Wexler, Gubrium, Griffin, & Difulvio, 2013). The researchers claim that participants found the process and product of
making a digital story to be meaningful in their personal lives, reporting a sense of achievement for participants and some enjoyed sharing their stories with family and community. In a different study, digital storytelling was implemented into the reflective process for patients with early-stage dementia during a 4-day workshop (Stenhouse, Tait, Hardy, & Sumner, 2012). The study demonstrated that digital storytelling led to therapeutic benefits for patients as they learned to identify new aspects of self, their story of dementia, as well as developed beneficial, interpersonal relationships with the facilitators and other participants. In a 6-month study in one of Britain’s National Health Service hospitals, nurses found that a biological approach to storytelling improved person-centered practices and holistic nursing care by involving the patients, their family, and their cultural context (Clarke et al., 2003).

Youth in an impoverished suburb developed digital stories through the Digital Underground Storytelling for Youth “DUSTY” program (Hull & Katz, 2006). Two case studies were discussed, analyzing themes from the digital stories created, interviews, and field notes. Theme findings included the following: autonomy, improved self-concept, cultural and family values, and a sense of accomplishment upon completing the project (Hull & Katz, 2006). A similar study was performed in another after-school program in Colorado with positive results (Davis & Weinschenker, 2012). The investigators for the study stressed the added therapeutic effect of the children’s self-reflection in a safe and trusting environment, stating that “the process [digital storytelling] is essentially reflexive, folding back on itself: experience is distilled into narrative, and the narrative itself becomes a tool that shapes memory and mediates future experience” (Davis & Weinschenker, 2012, p. 53).

In another youth population, a pilot study with school-aged asthma patients created interactive narratives containing characters, conflict, and conflict resolution to improve psychosocial management strategies (Wyatt & Hauenstein, 2008a). The interactive narrative allowed the children to engage with the program, choosing between different options for addressing their asthma, each with its own results and possible consequences (Wyatt & Hauenstein, 2008a; Wyatt et al., 2013). Children displayed improved attitudes, as recorded on the CATIS, after the narrative intervention (Wyatt & Hauenstein, 2008a). This literature supports the positive outcomes of a digital storytelling intervention in a variety of populations.

**Methods of Storytelling**

Storytelling is used therapeutically and clinically in a variety of settings. However, the stories do not stand alone; rather, the person behind the story is revealed in the way his or her story unfolds. In adult populations, research documents that people are inclined to choose positive aspects of a story and neglect negative ones to display the life hoped for, revealing a false reality (DeSocio, 2005; Furlonger, 1999). However, when narrative is used positively, it can alter and realign self-understanding, creating new realities personally and relationally that, before, were unreached (Anderson, 2009; DeSocio, 2005).

Foundationally, the process of story must be respected, allowing the purest form of the participant’s story to be shared with whomever is listening (Anderson, 2009; Gilbert, 2002). Furthermore, the listener, whether therapist, counselor, or researcher, must be knowledgeable about and respect differing worldviews, opinions, and cultures (Banks-Wallace, 1999; Gilbert, 2002). Research reveals that a nurse develops trust with a patient by attentively listening, consistently guiding, and non-judgmentally documenting a patient’s journey (Smith & Liehr, 1999).

Methods to capture stories from a research perspective vary widely, as it has been used as both an intervention and a data collection method. In some situations, little researcher interaction is required, whereas in others, the research is specifically directed through questions, surveys, and scales. In one study, the participants were photographed throughout the 4-day digital storytelling workshop and then asked to reflect on the photo at the end of the process (Stenhouse et al., 2012). In narrative therapy, the therapist or researcher acts as an outside perspective in sessions, identifying strengths and areas that can be changed using those strengths (Furlonger, 1999; White, 1986). Narrative therapy seeks to separate people from problems, allowing the client to act as the expert, leading to reconceptualization and new revelation from storytelling sessions (Anderson, 2009; Matos et al., 2009; McCarthy & Sebaugh, 2011; Wallis et al., 2011). This can take the form of suggesting a new lifestyle in exchange for a negative one, breaking down the family’s response into distinct parts to better understand its influence, or promoting new, lasting ideas in the group setting (White, 1986). Retelling life stories, particularly events that involve trauma, provides space for a reclaiming of past identities, allowing the storyteller to choose to see moments of strength and success within his or her story (Anderson, 2009). Clarifying questions solidify the experience, assuring nothing is assumed by the listener that was not intended by the storyteller (Smith & Liehr, 1999). In another experiment, evaluations were mailed 3 months after the cancer patients attended a therapeutic storytelling conference. This gap allowed the participant time to process and understand the impact the storytelling had on their understanding and outlook toward their cancer diagnosis (Chelf et al., 2000).

In regard to documenting these storytelling processes as a data collection method, Smith and Liehr (1999, 2014) found that, as themes emerge through storytelling, identifying each theme led to simultaneous “anchoring and flowing” as the patterns brought a sense of safety and clarity. Data analysis of the developing themes done with coding, subcategories, and categories is often a simple way of condensing large quantities of qualitative data into a coherent picture (Barry et
al., 2010; Buttery et al., 1999; Enskar, 2012). Once data saturation occurs, that is to say no new themes arise, the most complete picture of the child’s process has been captured (Hildenbrand et al., 2011).

In contrast to this structured interaction, a study following difficult hospitalizations reports that patients often participate in self-talk, a state of talking introspectively, without regard to the listener’s presence (Buttery et al., 1999). Furthermore, allowing for tangents and deviations from a planned interview is vital providing space for true self-discovery and new insights to arise (Buttery et al., 1999; Enskar, 2012). In a qualitative study by Gilbert (2002), open-ended questions provided fluid and more complete storytelling and minimized the listener’s influence. Specifically, in a qualitative research study, a narrative-psychotherapy session revealed that when the therapist did the work of writing rather than the patient, it led to more open and free dialogue (DeSocio, 2005).

Finally, researchers found value in deconstructing the dominant story to find the underlying beliefs and influences that lead to dominant behaviors, emotions, and self-beliefs (Sinclair & Monk, 2005). In narrative-psychotherapy sessions, a case study by DeSocio (2005) documented success when therapists push past the dominant stories presented to question and explore the outlying stories that shape a patient in a distinct way, that without would leave the picture incomplete (DeSocio, 2005; Furlonger, 1999). The varying forms of storytelling in the literature, both as an intervention and as a research method, result in further understanding of human phenomenon and experiences.

Limitations in the Literature

Limitations in this field of inquiry are diverse. Storytelling, as a whole, lost ground as technology began to advance rapidly (Banks-Wallace, 1999). Ethically, storytelling as a research technique presents a dilemma of ownership as the participant retells a personal memory, and the researcher then writes it, and the audience then reads it (Gilbert, 2002). The relationship between the researcher and the participant is delicate, as the researcher takes a personal narrative and conforms it into his or her own research document (Gilbert, 2002). Furthermore, Gilbert (2002) cautions against analyzing stories with content analysis due to excessive fragmenting and coding, as it risks losing the original significance and purpose of the story.

For example, when participants offer additional detail to a story while describing events, there is inherent risk of losing the narrative and instead presenting fragmented data (Buttery et al., 1999).

Working with children also presents unique challenges, as children may have less developed communication skills, self-awareness, and coping strategies (Ruland et al., 2008). This can lead to under-diagnosed symptoms and misunderstood emotional development for children with a stressful diagnosis (Ruland et al., 2008). Ethically, young children with cancer diagnoses are often very sickly, preventing long sessions or emotionally draining participation (Ruland et al., 2008; Stutzer et al., 2005). They may also have limited time, not allowing for adequate processing and creative space for children to work on their story (Ruland et al., 2008). Furthermore, the participants in a digital storytelling study must have adequate computer skills and knowledge of technology, thereby limiting the population (Wyatt & Hauenstein, 2008a). Overall, criticism of this field of study is its exclusivity, as in its nature, digital storytelling requires advanced language development and cognitive skills that excludes younger children (Hanney & Kozlowska, 2002).

There exists very little knowledge about the use of storytelling as an intervention for children; further research is a necessary next step (Cumming et al., 2010; Wyatt & Hauenstein, 2008a). This gap in the knowledge leaves investigators to wonder about the behavioral change, improved understanding, or potentially heightened quality of life that could be gained from storytelling as an intervention for children in the health care setting (Larkey & Gonzalez, 2007). A common limitation in narrative therapy, storytelling experiments, and oncology studies is a small sample size, limited control group comparison, and low completion rates (Clarke et al., 2003; Hildenbrand et al., 2011; Peterson et al., 2012; Williams-Brown et al., 2002; Wu et al., 2009). Finally, there is limited research on parental interaction and the resulting effects on the story of a child with a cancer diagnosis (Peterson et al., 2012).

Conclusion

Digital storytelling is an innovative new avenue to analyze and perhaps improve perceptions regarding the childhood cancer experience. This method offers space for self-discovery, self-understanding, social development, and cultural congruence beyond traditional cancer treatments, particularly in the psychosocial domain. Investigators have sought to use both quantitative and qualitative methods to better understand this phenomenon. Today, storytelling can be promoted using advancing technology, providing a platform for children and adolescents to make sense of and share their cancer experience. This foundation of literature surrounding the story, childhood development, childhood oncology, experimental therapeutic interventions, family influence, and plausible methodologies all contribute to future research opportunities to fill the gap that exists in the current state of the science regarding the use of digital storytelling among pediatric cancer patients.

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