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Melissa Pigden

Bank Street College of Education

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Child Life Story Circuit: A Resource for Child Life Specialists on Therapeutic Play for
Adolescents Through Narrative

By

Melissa Pigden

Child Life

Mentor:

Jon Luongo, MS, CCLS

Submitted in partial fulfillment of the requirements of the degree of

Master of Science

Bank Street College of Education

2015

**Child Life Story Circuit: A Resource for Child Life Specialists on Therapeutic Play for
Adolescents Through Narrative**

Melissa Pigden

Bank Street College

April 15, 2015

Abstract

Adolescence, a time of extensive transition and change, can be especially challenging for those with chronic or serious illnesses that require hospitalization. At a time when patients need the support of child life specialists to navigate and process the impact of hospitalization on development, child life specialists are challenged by the lack of resources and research available that directly targets this population. The integration of bibliotherapy and narrative medicine based interventions can be beneficial in assisting adolescents in navigating these challenges. These modalities can benefit patients by providing appropriate social comparison others, a form of peer support, and support in identity formation and solidification. Additionally, the ability to tell and process one's own illness narrative can aid in a patient's coping with hospitalization and illness and empower them to influence change. The blog "Child Life Story Circuit" has been created as a resource for child life specialists providing ideas for interventions involving bibliotherapy, expression, and narrative medicine.

Table of Contents

| | |
|---|----|
| Introduction to the Project | 5 |
| • The Power of a Story | 6 |
| • Story Circuits | 6 |
| Adolescent Development | 7 |
| • Bias | 7 |
| • Typical Adolescent Development | 8 |
| ○ Socio-Emotional Development | 8 |
| ▪ Identity Development | 9 |
| ▪ Importance of Peer Support | 10 |
| ○ Cognitive Development | 11 |
| • Effects of Hospitalization on Adolescents | 12 |
| • Importance of Play | 13 |
| • Play in Adolescence | 14 |
| Social Comparison Theory | 16 |
| Bibliotherapy | 18 |
| • What is Bibliotherapy? | 18 |
| • Therapeutic Process of Bibliotherapy | 19 |
| ○ Identification and Projection | 19 |
| ○ Abreaction and Catharsis | 20 |
| ○ Insight and Integration | 20 |
| • Outcomes and Benefits | 21 |
| ○ Provide Information and Insight | 21 |
| ○ Generate Discussion | 21 |
| ○ Communicate New Values and Attitudes | 22 |
| ○ Normalize the Reader’s Experience | 23 |
| ○ General Benefits | 24 |
| • Limitations of Bibliotherapy | 25 |
| • Facilitation Process | 26 |
| • Choosing Books | 27 |
| ○ Readiness | 27 |
| ○ Literary Merit | 29 |
| ○ Cultural Considerations | 30 |
| ○ Promote Deeper Thinking | 30 |
| ○ Flexibility | 31 |
| • Follow Up | 32 |
| Narrative Medicine | 33 |
| • What is Narrative Medicine? | 33 |
| • What is an Illness Narrative? | 34 |
| • Use and Benefits of Narrative Medicine | 35 |
| ○ For the Healthcare Provider | 35 |
| ○ For the Patient | 36 |
| ▪ Narrative Therapy | 38 |
| • Narrative Medicine and Child Life | 38 |

| | |
|---|----|
| ○ Additional Benefits | 38 |
| ▪ Advocacy and Transitioning to Adult Care | 38 |
| ▪ Awareness and Empowerment | 39 |
| ▪ Family-Centered Care and Cultural Competency | 40 |
| ▪ Communication with Peers | 40 |
| ○ Connection to Therapeutic Play and Creative Arts Modalities | 42 |
| ▪ Creative Writing and Storytelling | 42 |
| ▪ Songwriting | 44 |
| Application and Reflection | 46 |
| • Bibliotherapy | 46 |
| ○ Time | 46 |
| ○ Infection Control and Sustainability | 46 |
| ○ Follow-Up Activities | 48 |
| • Narrative Medicine | 48 |
| ○ Tailoring to the Patient | 48 |
| ○ Versatility | 49 |
| ○ Resourcefulness and Sustainability | 49 |
| • Overall Reflections | 50 |

Introduction to the Project

For many child life specialists, planning and therapeutic programming with adolescents can be challenging. From my personal experience, most resources available are largely geared toward the general population of pediatrics. While helpful in the majority of child life interactions, this may leave child life specialists at a loss for working with patients older than this target population. Additionally, as a member of the Child Life Council during my time at Bank Street College I have noticed multiple postings to the council's forum wherein child life specialists across the country ask for assistance in working with adolescents. Working with teens is different from working with younger children. They have unique clinical as well as personal needs, require a different approach to rapport building, and are not as easily engaged in many of the supplies found in a typical child life playroom.

Along the same lines, the same "go-to" interventions used with pre-school and school-age patients may not be developmentally appropriate or engaging for adolescents. These interventions may also be limited in what they can provide for teens struggling with concerns regarding the future and other more abstract concepts. Without resources offering alternative ideas, child life specialists must rely on their own creativity to formulate interventions, which may prove time consuming and difficult. Without the confidence of a "go-to" activity or resource with activities that have been successful for others, the specialist's confidence in approaching the adolescent, and in turn in establishing a therapeutic relationship, may be lessened.

I created the "Child Life Story Circuit" (www.childlifestorycircuit.com) project to provide such a resource for child life specialists. The blog is specifically intended to foster therapeutic interventions using bibliotherapy, expressive arts, and narrative medicine, and

offer suggestions on implementing these interventions with patients. Child life specialists will find reviews of young adult literature and memoirs, including a summary of topics encountered and recommendations for appropriate referrals. Additionally, the blog includes step-by-step instructions for narrative medicine based expression activities, information on non-profit organizations catering to adolescents, and my own reflections on working with this population.

The Power of a Story

Child life specialists know that every patient has their own story -- a unique series of events, challenges, and triumphs leading up to their health care experience that day. Learning their stories helps specialists provide more meaningful interventions to help their patients cope and increase mastery. Going forward and sharing these stories with the medical team can, in turn, help the hospital as a whole provide more patient and family-centered compassionate care.

Patients can also learn from each other's stories and the stories of those who may have experienced similar circumstances in the past. Reading books, blogs, and stories of those who have faced similar circumstances can help patients improve their own coping and problem solving skills, advocate for themselves, expand their thinking and perspective, and gain the courage to share their own stories. Above all, by connecting with the stories of others patients may feel less isolated in the challenges they face.

Story Circuits

The process of telling and sharing stories is like a circuit -- a pathway between various points along which information and energy can be passed. When a person shares their story, they release information and energy into the world and a pathway begins. A

medical professional, another patient, or the general public, producing insight, awareness, or even a renewed sense of hope can then receive that information and energy. The story can then produce some sort of change. For example, stories can change the approach to a treatment regimen made by a medical professional, or reduce feelings of isolation for a patient. As the circuit expands, energy is passed back to the original storyteller in the form of empowerment. Though the opportunity to tell one's story can be therapeutic in its own right, the opportunity to create awareness and the possibility of producing change can hold even greater therapeutic benefit.

Child life specialists have the opportunity to help patients explore and expand these circuits. Specialists can offer bibliotherapy interventions to teen patients to provide them with a story to connect. Specialists can offer narrative medicine and expression-based outlets for patients to tell their own story. Specialists can also take these stories one step further and encourage patients to continue telling their story, whether to advocate for themselves, create awareness, or produce change.

Adolescent Development

Bias

Along with the unique challenges that the population poses, child life specialists may face problems with bias when working with teenagers. Media portrayals of adolescents tend to be negative and emphasize problems faced by and involving teens in both fictional plots and non-fictional headlines (American Psychological Association, 2002). With all of these negative portrayals, stories of the accomplishments and triumphs of adolescents seem to be overshadowed. The Public Agenda (as cited in American Psychological Association, 2002) found that for 71% of the general public polled "... negative terms, such as 'rude,' 'wild,'

and ‘irresponsible’ first came to mind when they were asked what they thought about American teenagers” (p.3). In spite of their training, child life specialists may be just as susceptible as the general public to this media induced bias.

In healthcare, we not only are faced with the above stereotypical bias but also those based on reason for admission, diagnosis, and pain control needs. Adolescents brought into the emergency room following a car accident may automatically be considered reckless. Teens with gun shot wounds may be immediately labeled delinquents. Those coming in for sickle cell crises may be viewed as drug seeking. Beyond that, there is also the simple assumption of being a “big boy/girl” who does not need anything from child life and can cope on their own.

Child life specialists must be confident in their knowledge of adolescent development in order to advocate for the needs of these patients, attempt to overcome this bias with other healthcare staff and facilitate meaningful therapeutic interventions. By establishing rapport with these patients and encouraging them to tell their stories, healthcare professionals may be more likely to change their views on these adolescents and provide more compassionate care.

Typical Adolescent Development

Socio-emotional development. Adolescence is a time of many changes and an associated roller coaster of emotional highs and lows. According to Hall’s theory of “storm and stress” (as cited in Lightfoot, Cole, & Cole, 2013) “adolescence is a time of heightened emotionality and oppositions: stratospheric highs and deep depressions, boundless self-confidence and nagging insecurity, astounding generosity and equally astounding selfishness” (p. 510). Despite this heightened emotional reactivity, it is also at this time that

executive functioning -- the ability to control and regulate one's own thoughts, feelings, and behaviors -- develops at a rapid rate due to the increased functionality of the prefrontal cortex (Lightfoot et al., 2013). Though adolescents face a confusing time of identity clarification resulting in increased emotions and reactivity, their brains are more equipped to help them cope with and problem solve these changes and emotions.

Identity development. According to Erikson (as cited in Lightfoot et al., 2013), adolescents are undergoing the developmental task of identity versus role confusion during which they must successfully determine their place in the social realm or may face confusion on who they are. Marcia (1980) described identity as “an internal, self-constructed, dynamic organization of drives, abilities, beliefs and individual history” (p. 109). He further explains that the more developed a person's identity is, the more self aware a person will be of their similarities, differences, strengths, and weaknesses compared to others. The less developed it is the more they will have to rely on external sources for this information. Marcia (1980) also emphasizes the dynamic nature of identity and the continuous process of adding and removing over time.

On this topic, Lightfoot, Cole, and Cole (2013) differentiate between the I-self portion of identity and the me-self. The me-self is the object self, inclusive of all identifiers (i.e. student, patient, female, etc.), and the I-self is the subject self which constantly reflects on, guides, and directs the me-self. Included in the I-self are a person's self awareness, self agency, self continuity, and self coherence (Lightfoot et al., 2013). The American Psychological Association (2002) instead differentiates the concepts of identity between self-concept (the beliefs one has about oneself and one's attributes) and self-esteem (one's own evaluation of self-concept). With this distinction in mind, Harter (as cited in American

Psychological Association, 2002) describes low self-esteem as a “gap between one’s self-concept and what one believes one ‘should’ be like” (p. 16).

Though identity development has been historically thought to be a task solely of adolescence, identity formation is now thought of as a lifetime process. “Adolescence is the first time, however, when individuals have the cognitive capacity to consciously sort through who they are and what makes them unique” (American Psychological Association, 2002, p. 15). Now capable of increased cognitive functioning, self-reflection, and executive functioning, adolescents are more capable of taking on this developmental task than their younger selves.

Importance of peer support. Another key aspect of adolescent development is the importance of and reliance on peer support. During adolescence, not only does the amount of time spent with peers increase but the ability to do so independently from parents, size and diversity of peer groups, and intensity of relationships also increase (Lightfoot et al., 2013). This shift happens partially as a separation process from dependence on parents, but also as a reference point for identity development (American Psychological Association, 2012). Identity formation is a socially constructed process, as the adolescent seeks out examples of what may be called a “social comparison other.”

As defined by Lightfoot, Cole, and Cole (2013), social comparison is the “process of defining oneself in relation to one’s peers” (p.467). Beginning in primary school, we use social comparisons to measure our own successes (Lightfoot et al., 2013) based on our classmates, friends, family members, and eventually coworkers. We turn to social comparison information when unsure of our abilities, opinions, and emotional reactions (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990). In addition to self-evaluation, social

comparison information is also used for self-enhancement (boosting self-esteem by comparing to someone who is worse off) and self-improvement (by striving to be like someone who seems better off) (Buunk et al., 1990).

There are many important developmental milestones during adolescence that can be influenced by comparison information obtained from peers. Teens spend almost twice as much time with friends as they do with their parents (Lightfoot et al., 2013) and depend on their feedback in regards to both physical and emotional functioning (Meltzer & Rourke, 2005). As teens seek to solidify their identity and independence (TenHuisen & Standish, 2004), this information helps them determine their success.

Cognitive development. Peer support can also be attributed to cognitive development. From a Vygotskyian perspective, social interactions are critical to the learning process (Lightfoot et al., 2013). “Growing evidence that social influences are ever present in cognitive skills widely accepted as universal and that social engagement is a powerful force in transforming children’s thinking has played a major role in convincing child development specialists that cognition is socially situated” (Berk & Winsler, 1995). As teens are presented with different perspectives from their peers, a cognitive imbalance occurs. The resolution of this allows the adolescent to develop a “higher, more inclusive level of understanding” (Lightfoot et al., 2013, p. 533) by assimilating new information into existing schema.

In terms of Piaget, adolescents have entered the Formal Operations phase in which they are capable of processing problems systematically and logically along with abstract thought. Adolescents are also typically interested in abstract ideas and the process of thinking itself (Lightfoot et al., 2013). Because of this, they are introspective and constantly reflect

upon themselves, leading back again to identity formation, self-concept and self-esteem (American Psychological Association, 2002).

Effects of Hospitalization on Adolescents

Hospitalization and/or chronic illness can often cause disruptions in development. At a time when most teens are becoming independent from their parents, chronically ill or hospitalized teens are more dependent on their parents and have less control of day-to-day lives. They may also face concerns of identity loss, body image, sexuality, bodily injury and pain, and separation from peers and family (Pearson, 2005).

Lois Pearson (2005) describes the ages of 14 to 18 as the “most difficult time for an adolescent to be hospitalized” (p. 14). This is the time when most adolescents gain the independence and freedom to spend the majority of their time with their peers without adult supervision. Adolescents with chronic illnesses, however, may face a number of different peer related issues including general difficulty with peers, impaired social functioning, anxiety, depression, body or self-image concerns, and withdrawal (Hicks & Davitt, 2009). Teens with chronic illnesses may encounter taboos or stigmas associated with their illness and face bullying because of it (Webb, 2009). Isolation due to absences from school or infection control policies within the hospital environment can further strain existing peer relationships. Even when peer relationships remain intact throughout the teen’s illness, the teen may feel too different from friends to rely on feedback from these relationships (Haluska, Jessee & Nagy, 2002; Meltzer & Rourke, 2005).

Child life specialists have the opportunity to combat these disruptions through interventions focused on peer support (Pearson, 2005). Adolescent units that adapt policies to allow more liberal peer visitations and provide access to developmentally appropriate

activities in an exclusively adolescent setting have been shown to improve coping and cooperation (Pearson, 2005). Additionally, Hicks and Davitt (2009) stress the importance of assisting chronically ill teens with forming a second peer support group through contact with other teens with chronic illnesses. By encouraging involvement in teen programming, support groups, and camps, child life specialists are encouraging developmentally appropriate play, which, as described by Jessee and Gaynard (2009), “becomes the training ground for a more adequate adult life” (p. 141).

However, there are times when opportunities for peer support within the hospital setting are not available due to census, unable to be carried out due to infection control, or are not adequately fulfilling the needs of the patient. In these cases, child life specialists need to seek out alternative interventions that will help their patient process their experiences, relate to an appropriate social comparison other, and express themselves.

Importance of Play

Child life specialists understand the importance of play for patients regardless of developmental stage. Play is the process by which children learn about their world, increase social and developmental skills, and prepare for future roles as adults (Jessee & Gaynard, 2009). For children with limited verbal expression, play can serve as a mode of communication (Koller, 2008). In addition to these developmental benefits, play also helps children cope with and process stressful circumstances and experiences (Jessee & Gaynard, 2009; American Academy of Pediatrics, 2014). Thus, though play is important for all children, the opportunity to play is especially important for hospitalized children.

Being in an unfamiliar environment, experiencing novel threatening situations, and loss of control and autonomy are some of the things hospitalized children may express and

process through play. According to Landreth “Play is children’s way of working out balance and control in their lives, for, as children play, they are in control of the happenings of the play, although it may not be possible to actually be in control of the life experience represented in the play” (2012, Chapter 2, Play in the Therapeutic Process). Child life specialists can use therapeutic play to help children understand upcoming procedures, make the environment less threatening, or help their patients express emotions at their own pace (Gaynard, Wolfer, Goldberger, Thompson, & Laidley, 1990).

Therapeutic play is defined as “specialized activities that are developmentally supportive and facilitate the emotional well-being of a pediatric patient” (Koller, 2008, p. 3) or “play that is used to prevent psychologic injury” (Matthews as cited in Bolig, 2005, p. 91). Studies have shown that therapeutic play can reduce children’s emotional distress (Gaynard et. al., 1990) and increase both coping with the hospital environment and compliance with medical care (Koller, 2008). In addition, studies have shown therapeutic play to reduce physiological symptoms of stress including palm sweating, excessive movement, escalated pulse rate, and high blood pressure (Koller, 2008).

Play in Adolescence

“Play,” however, is not necessarily a term commonly used in an adolescent’s vocabulary. As teens attempt to separate from their parents and childhood in general, they may see the term “play” as immature or childish. Despite this, adolescents constantly play, though in different ways than their younger selves. Bergen (as cited in Jessee & Gaynard, 2009) describes this shift in play as becoming “miniaturized, socialized, and abstracted” (p.141). Teens may play through doodling, art, organized sports, symbolic board games, video games, daydreaming, music, etc. in attempts to acquire skills and talents reflecting

their need for identity formation and clarification (Jessee & Gaynard, 2009). The American Academy of Pediatrics (2014) suggests these types of activities also fulfill the adolescents' needs for mastery and achievement while allowing them to build and maintain peer relationships.

Taking this shift in play into consideration, child life specialists can plan and facilitate more developmentally appropriate therapeutic play interventions. Frey (as cited in Webb, 2009) suggests that adolescents might be more likely to engage in creative arts interventions like writing, bibliotherapy, and video therapy rather than the more typical play based interventions child life specialists use with younger children. Child life specialists must also take into consideration Koller's (2008) three categories of therapeutic play: activities that encourage emotional expression, those that educate patients about medical experiences, and those that enhance physiological functioning. Though creative arts activities most obviously fall into the first of Koller's (2008) categories, encouragement of emotional expression, these modalities can fall into any of the three with careful planning. The "Child Life Story Circuit" project provides guidance in therapeutic play interventions for adolescents with these characteristics in mind.

The "Child Life Story Circuit" projects seeks to combine developmentally enhancing elements and activity preferences of adolescent play along with the characteristics of therapeutic play to provide specialists with ideas for meaningful interventions for their teenage patients. The interventions provided will take into account needs for peer support and social comparison information, identity formation and clarification, emotional expression, and mastery. To further support this project the following research and literature behind

social comparison theory, bibliotherapy, narrative medicine, and expressive arts interventions has been compiled.

Social Comparison Theory

Social comparison can take a variety of forms, especially with chronically ill adolescents. One form of social comparison specific to patients with chronic illnesses includes determining whether they are better or worse off in terms of medical situation or coping in relation to others. There are many factors that determine whether this information will have a positive or negative effect on the patient. These include whether the comparison is upward or downward, whether the comparison is assimilating or contrasting, the person's degree of social comparison sensitivity (SCS) and the person's perception of their own health status (Brakel, Dijkstra, Buunk, & Siero, 2012). Studies have shown that both upward and downward comparisons can have both positive and negative effects depending on these other factors (Buunk et. al, 1990).

Social comparison sensitivity (SCS) can influence whether a person sees their comparison other as similar to them (and, therefore, assimilates with them) or different from them (and, therefore, contrasts with them) (Brakel et al., 2012). For those who have a high SCS, information tends to have a greater impact on their self-evaluations and they tend to have a higher reactivity to the information they obtain. A study involving how social comparison information affects cancer patients' quality of life has shown that those with high SCS tend to distance themselves by finding ways to contrast themselves from their comparison other for their own protection (Brakel et al., 2012). For these individuals, contrasting downward and assimilating upward lead to positive consequences while

contrasting upward and assimilating downward lead to negative consequences (Brakel et al., 2012).

A study examining the affective consequences of social comparison information on patients determined that the patient's sense of control of the situation may affect their perception of social comparison information. Those patients who felt that they had control of their prognosis, symptoms, or course of treatment felt less threatened by it (Buunk et al., 1990). The study also found that hopeful patients were positively affected by upward comparisons. They considered these comparisons "as progressing toward the target's superior state" (Buunk et al., 1990, p. 1240). In the same study, Buunk and his colleagues found patients most frequently engaged in downward self-enhancing comparisons but that almost as frequently made self-enhancing upward comparisons. Many people felt comforted and inspired by those who had recovered from their illness, regrew their hair, or coped well with their experience (Buunk et al., 1990).

Along with these positive results, both studies also cite negative effects of social comparison information. Specifically, Buunk and his colleagues (1990) found that individuals who felt less in control of their illness felt threatened by exposure to similarly diagnosed patients who were doing poorly because "it forced on them the realization that things could be worse" (p. 1239). Brakel and her colleagues (2012) cautioned against blindly exposing patients to social comparison information because mismatching types of information to the person's current state of being can have serious negative effects.

When facilitating therapeutic play for adolescents, child life specialists need to be cognizant of the role of social comparison. In order to truly support the development and well being of adolescents (Koller, 2008), we should keep in mind what comparison information

they may be obtaining from other patients in the group. There may be times where the teen needs help navigating that information or needs to be emotionally supported as they process that information. Child life specialists can help by offering expressive activities such as art, journaling, music, or specifically targeted games. Child life specialists should also be mindful of patients (particularly with new diagnoses) who are not connected to appropriate comparison others.

Bibliotherapy

Depending on census, availability of support groups in the area, and other factors, there may not always be an opportunity for a child life specialist to connect patients with appropriate social comparison others. In these instances, bibliotherapy may provide a suitable alternative.

What is Bibliotherapy?

Bibliotherapy is the use of books and literature to promote personal growth (Rozalski, Stewart, & Miller, 2010), self-understanding (Allen et al., 2012; Gavigan & Kurtts, 2010), healing (Allen et al., 2012), and/or coping with challenging situations or developmental needs (Gavigan & Kurtts, 2010). There are two main fields of bibliotherapy: developmental and therapeutic. Developmental bibliotherapy is often used in educational settings to help students through transitions, everyday issues or developmental tasks (Rozalski, Stewart, & Miller, 2010). Therapeutic bibliotherapy is a guided process used by mental health professionals with a specific therapeutic goal in mind (Katz and Watt as cited in Jones, 2006; Rozalski, Stewart, & Miller, 2010).

Although the two primary methods used in bibliotherapy are self help books and literature (Briggs & Pehrsson, 2008), the “Child Life Story Circuit” project focuses on

literature and memoir based interventions. In literature-based bibliotherapy the facilitator uses specifically selected poems, short stories, and novels to provide the reader with new insight and emotional catharsis (Briggs & Pehrsson, 2008). This method takes advantage of our natural tendency as human beings to get pulled into a story and identify with a character or problem they face, even from an early age. “We experience stories. Such experiences shape us in ways that abstractions cannot, for they appeal to all of what we are as human beings -- feeling and meaning-making beings with bodies, not just reasoning” (Allen et al., 2012, pp. 44-45). Though this phenomenon is not limited to the therapeutic basis of bibliotherapy, it is especially pertinent in the patient’s ability to connect with a character and view them as a social comparison other. Though a majority of the literature on bibliotherapy refers to teachers and students or therapists and clients, for the purpose of this paper I will use facilitator and reader.

Therapeutic Process of Bibliotherapy

Identification and projection. The therapeutic process involved in bibliotherapy occurs in three stages: identification and projection, abreaction and catharsis, and insight and integration (Pardeck & Pardeck as cited in Detrixhe, 2010; Jones, 2006; Rozalski, Stewart, & Miller, 2010). The first stage, identification and projection, involves the reader finding themselves in the main character or in problems they have in common (Pardeck & Pardeck as cited in Detrixhe, 2010; Shrodes as cited in Jones, 2006). However, identifying with a character does not necessarily mean identifying with their personal or physical characteristics. Rather, it can involve identifying with them in relation to the situations they find themselves in (Hoffman, 2010). In a study involving children’s reviews of Roald Dahl’s *BFG* Hoffman (2010) found that “the assumption that children look for themselves in a book

may reflect a posteriori connections rather than actual reading experiences” (p. 243). Instead, it is more important to be able to see themselves in the character’s shoes and connect with their emotional reactions, thoughts and actions taken as a result of their challenging situation. Though careful book selection is crucial to the process, matching the patient to the character in terms of physical and personal traits is not particularly important.

Abreaction and catharsis. The second stage, abreaction and catharsis, occurs when the character resolves the situation or conflict that the reader identified with (Jones, 2006). In turn, the reader experiences some sort of emotional release, relief, or passionate response (Pardeck and Pardeck as cited in Detrixhe, 2010). Although this is a formal stage in the therapeutic process of bibliotherapy, it is a common experience shared by those reading for pleasure. Regardless of the problem the character faces, it is only human to feel some sort of emotional connection to a character during the climax of a well-written novel and to feel some sort of release when the conflict is resolved. When the conflict is more personally connected to the reader, this can produce an even greater effect. Rudman, Gange, and Bernstein (as cited in Detrixhe, 2010) describe it as expressing feelings regarding the situation that the reader may have previously bottled up.

Insight and integration. The final stage, insight and integration, involves the reader’s greater realization of the problem in their own life (Pardeck and Pardeck as cited in Detrixhe, 2010), reflection upon their personal situation, and internalization of the character’s solution (Jones, 2006). This may involve many different realizations, reflections, or outcomes based on the reader and their own personal situations.

Outcomes and Benefits

Provide information and insight. Bibliotherapy can have many different goals, outcomes, and/or benefits depending on the reader's background and the facilitator's guidance. One possible outcome is that the intervention will provide the reader with information about and insight into the problem (Pardeck, 2014; Briggs & Pehrsson, 2008; Abdullah, 2002). By internalizing the way a character solves a similar problem or copes with a shared issue, readers generate solutions applicable to their own situation (Pardeck, 2014; Briggs & Pehrsson, 2008; Abdullah, 2002; Detrixhe, 2010).

It may be obvious that readers obtain information from non-fiction sources or self-help books, but readers also obtain information or "facts" about their situation from literature and works of fiction (Detrixhe, 2010). Coleman and Ganong (as cited in Detrixhe, 2010) observe, "In reading about a character who is facing a situation similar to their own, readers may identify with the character and in so doing gain some awareness and understanding of their own motivations, thoughts, and feelings" (p. 60). In relation to illness narratives, fictional stories with accurate portrayals may also provide the patient with expectations for treatment, side effects, and overall experience of the illness.

Generate discussion. Additionally, bibliotherapy can be a means of generating discussion about a topic, issue, or problem either on an individual or group basis (Pardeck, 2014; Briggs & Pehrsson, 2008; Abdullah, 2002). Just as child life specialists use play to convey information and allow for expression, bibliotherapy can be used alternatively to generate these important discussions through a non-threatening modality. Bibliotherapy can enable readers to "communicate openly with others about what they have read and make connections to their life experiences" (Rozalski, Stewart, & Miller, 2010, p. 34). Using

bibliotherapy, readers are able to speak about the character rather than themselves, which minimizes their own vulnerability and allows them to speak more freely.

Communicate new values and attitudes. Another possible outcome of bibliotherapy is the ability to communicate new values and attitudes (Pardeck, 2014; Briggs & Pehrsson, 2008; Abdullah, 2002; Detrixhe, 2010). Through books, readers can gain new interests, a greater sense of cultural identity, and expanded worldviews (Briggs & Pehrsson, 2008). Bibliotherapy has also been used in empathy building. In a classroom setting, especially for school re-entry processes, bibliotherapy can help other students understand what their classmate has experienced. They can then ask questions of their teacher to understand more fully and collectively brainstorm ways to ensure their classmate feels welcomed back.

Coleman and Ganong (as cited in Detrixhe, 2010) used bibliotherapy with their graduate students to help sensitize them to the issues their clients face. This same concept could be applied in the hospital setting for child life interns and students, volunteers, and even nursing or medical students. In my own experience, engaging in bibliotherapy as part of my child life education opened my eyes to the needs of populations with whom I had not yet worked. It also made me rethink interactions and adjust my approach with patients to be more culturally sensitive and inclusive.

In thinking about students as a target audience, one book that comes to mind is After Ever After by Jordan Sonnenblick (2010). This book focuses not on the diagnosis or treatment of cancer but its after effects. By reading this book, healthcare providers can better recognize cancer as a lifelong, chronic illness. Though a patient may be in remission, finished with treatment, or even considered “cured” they may never be freed of the challenges cancer can leave behind.

Normalize the reader's experience. By connecting with a character experiencing a similar hardship, readers feel less alone and isolated in their struggle (Pardeck, 2014; Briggs & Pehrsson, 2008; Abdullah, 2002; Detrixhe, 2010). Bibliotherapy can create awareness that other people have endured similar adverse situations and normalize that experience. Kirk and McManus (as cited in Briggs and Pehrsson, 2008) found bibliotherapy to help depathologize and normalize the grief process for people who have entered into counseling following a loss. When those experiencing a loss feel less alone in their struggle, they are more likely to allow themselves to be vulnerable in a group setting and share their experiences.

Death and dying can be particularly isolating for children and adolescents. Many children and even adolescents are sheltered from death by their parents and families and may be discouraged from talking about it. Because of this, children and teens may have unanswered questions about death, particularly after being diagnosed with a life threatening or terminal illness. Ways to Live Forever by Sally Nicholls (2008), one of the novels reviewed on "Child Life Story Circuit," is one book that may help normalize the confusion and mystery surrounding death. In this novel Sam McQueen, an eleven year old boy dying of acute lymphoblastic leukemia, uses scientific inquiry to gain answers to questions he is too afraid to ask his parents. Sam puts together his questions and findings in a book that not only helps him process his feelings of grief but eventually also helps his parents process theirs. By reading this book, the confusion and unanswered questions children and teens may have about death are normalized. The reader may then be more apt to ask the questions they want answered or use a similar process as Sam did to obtain the information they need to cope with their current situation.

Though normalization is helpful at any age, teenagers specifically may find a great sense of relief in knowing they are not the only one to go through what they are facing (Abdullah, 2002). Gavigan (2012) suggests the use of graphic novels with teens because they deal with common issues for teens. Gavigan (2012) explains, “reading about comparable experiences through the lives of fictional contemporaries can help to alleviate teenagers’ angst and let them know they are not alone” (p. 80). Seeing their situation being struggled through and overcome by another can produce great validation for their own feelings, thoughts, and actions (Allen et al., 2012). Tying back to the importance of peer support during adolescence and the need for a social comparison other, finding someone else to relate to about their situation is important in identity formation and mastery over their current situation. By relating to a character in a novel facing a similar illness or situation, teens may find a more appropriate social comparison other than can be found in their healthy peers.

General benefits. Beyond these recognized goals and outcomes initially discussed by Pardeck and Pardeck, Allen et al. (2012) describe many additional benefits of being involved in stories. For some, the opportunity to read in a library can in and of itself create a place of safety and offer an opportunity to actively cope with a problem rather than being a passive victim (Allen et al., 2012). Stories can reinforce assumptions (i.e. that there is good in the world), address common misconceptions, help the child put together a sequence of the events they experienced, and scaffold the co-construction of meaning and context for children (Allen et al., 2012). Stories promote an understanding of internal motivation and prevent expectations for future helplessness or lack of safety (Allen et al., 2012).

For teens, reading can also aid in coping with adverse situations through escape and distraction. Though some young adult novels or television programs like the “*Red Band*

Society” may include elements of fantasy and even romance that may not accurately portray an illness, it does not mean that they cannot be beneficial to the reader. As long as these novels do not give the reader a sense of false hope, they are not harmful. It is, however, important to assess whether the reader will understand these elements as fantasy or whether they will internalize them as false hope.

The Probability of Miracles by Wendy Wunder (2011) falls into this category. In this book Cam, a teenager dying of neuroblastoma, and her family move from Florida to a town in Maine known for its “miracles” as Cam’s mother’s last ditch effort to cure Cam’s cancer homeopathically. For a while, Cam actually feels better and physical signs of her cancer decrease and some pretty miraculous things do seem to happen. A flock of flamingos settle in town, their bird that they lost along their journey in New Jersey returns, and they even stumble upon free housing in a mansion. Though Cam does not believe in miracles the way her mother and sister do, she can’t deny she has never felt more alive than she does now living in Promise, Maine. In the end, reality does eventually sink in as Cam declines and eventually dies a very peaceful death surrounded by loved ones. Though there are many fantastical elements to the book, they do not take away from the message the book leaves with the reader of dying on one’s own terms and doing what you can to lead the life you do have in the way you choose.

Limitations of Bibliotherapy

Though bibliotherapy can be helpful for people in a variety of situations and of different ages and backgrounds, there are factors that can limit its effectiveness. First of all, not all children or teens are good candidates for bibliotherapy. Those with severe emotional, adjustment, or developmental problems tend to benefit less from bibliotherapy than those

with mild to moderate mental health issues (Detrixhe, 2010; Jones, 2006). Children and teens who struggle with reading may get frustrated, compromising their ability to focus on therapeutic goals. Thus, careful book selection based on reading level is important (Rozalski, Stewart, & Miller, 2010) and the client must be willing and interested in reading and participating (Abdullah, 2002). The effectiveness may also be limited by the availability of appropriate literature on a topic (Abdullah, 2002) as well as facilitation by a mental health professional, educator, or specialist. Both the reader and facilitator must be willing to go beyond surface issues for bibliotherapy to be successful (Abdullah, 2002).

Facilitation Process

In order for bibliotherapy to be most effective it requires facilitation before, during, and after the reading process. The facilitator must be able to foster discussion with the reader and/or provide follow-up activities to assist them in processing and internalizing what they've read. Gavigan and Kurtts (2010) suggest a framework of pre-reading, guided reading, post reading discussions and follow up activities. During the pre-reading the facilitator gathers information about the reader's existing knowledge of the subject through predictions. Throughout the reading, the facilitator encourages readers to make connections between the challenges faced in the book and their own lives. During post reading discussions, readers should be encouraged to brainstorm alternative solutions to the challenges. Finally, students should participate in activities such as role-playing, art, or interactive games that facilitate a similar problem solving process (Gavigan and Kurtts, 2010).

From a facilitator's perspective, Rozalski, Stewart, and Miller (2010) recommend a five-step process to providing bibliotherapy for a reader. First, the facilitator must identify

the problem the reader is facing. Then, potential books with characters that struggle with similar issues should be identified. Once a list has been generated, the facilitator must read the books to ensure they are appropriate. From the chosen book or books, the facilitator must develop lessons for during and after the reading. The final step is to begin teaching the curriculum (Rozalski, Stewart, & Miller, 2010). This process is important because the facilitation of bibliotherapy can be the determining factor in what a reader takes away from the intervention. Lessons must have enough freedom for the child to process on their own but enough structure to promote thought, and books must be carefully chosen to fit the purpose.

Choosing Books

Choosing an appropriate book is crucial to the success of a bibliotherapy intervention and takes considerable skill and insight (Pardeck, 1994). The book must captivate and keep the reader's attention, align with their situation and beliefs, and promote deeper thinking and discussion. In order to select an appropriate book, it is important for the facilitator not only to be familiar with the book but also to have read it (Briggs & Pehrsson, 2008). As this process can take considerable time, one purpose of the "Child Life Story Circuit" project is to provide facilitators with reviews from a child life perspective that include salient points from which the facilitator can narrow their field of selection. Without proper book selection, the patient may not be able to make connections or gain insight from the intervention. According to Hynes & Hynes-Berry (as cited in Briggs & Pehrsson, 2008), they may also "project unhealthy motives and beliefs onto story characters and, thus, reinforce negative patterns" (pp. 36-37). In choosing a book, there are many factors a facilitator must consider.

Readiness. The reader must be academically, developmentally, and emotionally ready for the chosen book. The facilitator must have background knowledge of human development (Briggs & Pehrsson, 2008) and must accurately assess the reader's developmental level, reading level, and academic ability (Briggs & Pehrsson, 2008; Rozalski, Stewart, & Miller, 2010; Pardeck, 1994). To do so, the facilitator should reflect upon whether the reader will be able to understand the context and vocabulary, if they will be interested in it, and if the book is appropriate for the reader's grade and developmental level (Rozalski, Stewart, & Miller, 2010). Patients with reading disorders or a history of academic problems may experience more anxiety than benefit from bibliotherapy (Briggs & Pehrsson, 2008), therefore assessment is critical prior to introducing the idea.

Alongside academic readiness, patients must also be emotionally ready for the content of the literature and to share their reflections on their own situation. Pardeck (1994) states that inappropriate timing could hinder the process and therefore suggests that three conditions be met prior to initiating bibliotherapy: "(1) rapport, trust, and confidence have been established by the therapist, (2) the client and the therapist have agreed upon the presenting problems, and (3) some preliminary exploration of the problem has occurred" (p. 3). In order to initiate bibliotherapy with patients, a child life specialist must first build considerable rapport and a therapeutic relationship.

Readiness is a particularly important consideration for books that include death and dying. This topic should not be approached with bibliotherapy until the patient or family member is ready for it. Some families may not be ready for this type of literature until well after the patient has passed. Before recommending books like Somebody Up There Hates You by Hollis Seamon, This Star Won't Go Out by Esther Earl, Lori Earl, and Wayne Earl,

or The Probability of Miracles by Wendy Wunder, it is important to not only assess the patient's understanding of their current situation but also their current emotions toward the subject and current level of coping to determine readiness. Though bibliotherapy can aid in coping, patients who are in denial or coping poorly may not be ready for or actively engage in this type of intervention. The main characters in the three aforementioned books approach and cope their own mortality in completely different ways that may or may not align well with certain patient's current state of readiness.

Literary merit. Facilitators should also take into consideration the literary merit of the work (Detrixhe, 2010). This does not mean the book needs to have won awards, been a best selling novel, or have been written by a critically acclaimed writer; however, it must be written well enough to captivate the reader's attention and pull them into the character's life. Most importantly, the story and characters must be realistic and believable (Rozalski, Stewart, & Miller, 2010; Pardeck, 1994). Facilitators should look for characters that grow and change over the course of the story and are presented without being stereotypical (Rozalski, Stewart, & Miller, 2010). Realistic characters will aid the process of building connections and utilizing bibliotherapy for social comparison information.

Stephen Alpert, the main character in Drums, Girls, and Dangerous Pie by Jordan Sonneblick (2005), is one example of the type of character to look for. Stephen Alpert is an eighth grader whose annoyingly cute younger brother gets diagnosed with leukemia. Though Stephen's life completely changes with his brother's diagnosis, it is important to note that his life does not stop. Stephen still has to navigate going to school and doing homework despite his challenging home life. He has to find a way to cope with his emotions and the additional challenges he encounters on his own while his mother is not physically present while with his

brother at the hospital and his father is emotionally unavailable as he struggles through his own grief. Over the course of the novel, Stephen experiences a plethora of emotions from confusion to grief, sadness to anger, and at times feels as though his life is spinning out of control. Over the course of the novel, however, Stephen also learns coping mechanisms and ways to be involved in his brother's care and there are moments of humor, happiness and hope throughout the book to encourage the reader to continue on.

Cultural considerations. When choosing books, facilitators should be mindful of cultural and world-view considerations (Briggs & Pehrsson, 2008; Detrixhe, 2010). Though this should be standard in child life practice, there are particular concerns with bibliotherapy. Knowing the reader's cultural and religious beliefs is especially crucial for books dealing with death and dying. When choosing a book on this topic, specialists should be mindful of patient and family perspectives on death and grief as well as any accompanying religious considerations (Briggs & Pehrsson, 2008). In my own reading of illness narratives, religious views have been a major consideration. Most of the books I have come across on the topic of death and dying portray Christian, Agnostic, or Atheistic beliefs. Some have been overt while others are subtler. As a professional, this must be a major consideration in recommending a book at such a delicate time. In many cases, differences between the character and reader in terms of culture may not affect the reader's ability to connect. After all, it is normal for our readers to interact with people of varying cultures on a daily basis. However, the facilitator still must be mindful of situations where a child or family may find a book offensive to their culture or belief system.

Promote deeper thinking. For effective bibliotherapy, it is important that the book align closely with the reader's situation (Detrixhe, 2010; Briggs & Pehrsson, 2008; Rozalski,

Stewart, & Miller, 2010). The reader must be able to see connections between the character's struggle and their own. The book must present accurate information about the problem or illness displayed (Pardeck, 1994) and the resolution of the struggle should present the reader with clear, specific solutions (Detrixhe, 2010) and offer realistic hope (Pardeck, 1994). Though the problem need not necessarily be fully solved by the character, specific strategies must be presented for improving the situation or coping with the hardship or loss. Studies show that the presentation of realistic strategies is much more effective than providing simple, unrealistic, solutions to a problem (Rozalski, Stewart, & Miller, 2010). Along with the process of resolution, the book should promote deeper thinking (Briggs & Pehrsson, 2008) about the problem, possible solutions, and coping with the process.

In considering this aspect of bibliotherapy, facilitators should keep social comparison theory in mind. The reader's degree of social comparison sensitivity could influence whether they are able to see similarities with the character or if they will focus on their differences (Brakel et al., 2012). In a medical setting, facilitators should determine how much control the reader feels they have over their prognosis, symptoms, and treatment. Readers who feel more in control of their condition may benefit from a wider variation of books (that include either upward or downward comparisons) because they are generally less threatened by social comparison information (Buunk et al., 1990). Those patients that may be very sensitive to social comparison information or who are at a point where they feel they have lost control or hope may not be good candidates for bibliotherapy.

Flexibility. Though it is important to choose books wisely, facilitators should not get so caught up in specifics that their interventions become rigid. Keeping with the idea of adolescent play and the joy that can come with reading, specialists must be cautious not to

transform their intervention from a “soulful” experience to a didactic exercise (Detrixhe, 2010, p. 65). Detrixhe (2010) also suggests that the process of identifying with a character itself is one of the most important aspects of bibliotherapy. Therefore, if the character is too similar to the reader, it may take away from their experience. The reader should have to work through the character’s situation in order to apply it to his or her own. It is important that they come to their own awakening through reading rather than having it simplistically handed to them (Detrixhe, 2010).

Resolution of the problem should not be overly simplistic. It also does not necessarily have to culminate in a happy ending. Since adults and adolescents may not feel that their problems can be “adequately captured by a fictional story, a facile resolution may confirm their fears” (Detrixhe, 2010, pp. 65-66). Without a realistic solution or ending, the reader may have a difficult time internalizing the story and taking something away from it. An oversimplified solution may also give false hope or minimize the range of discussion (Detrixhe, 2010). Processing the cognitive dissonance between the reader’s perspective of the problem and the character’s perspective will help the reader learn from the character’s struggle by assimilating new information into their existing knowledge.

Follow Up

During follow up, facilitators should plan activities that bring focus to the main theme (Rozalski, Stewart, & Miller, 2010) or the therapeutic goal. A variety of different activities can fill this purpose including structured discussions, retellings of the story from the patient’s point of view, visual art projects, creative writing, song writing, character mapping, letter writing, and theatrical arts (Briggs & Pehrsson, 2008; Pardeck 1994). Returning back to [the](#)

metaphor of a story circuit, these activities not only help the patient process what they've read and apply it to their own lives, they also further expand the story circuit.

The more the story circuit is expanded to include the experiences of others the more the experience becomes normalized for the teen and the more connected rather than isolated they feel with their condition. The Child Life Story Circuit project seeks to provide ideas for projects that can be used as follow up to bibliotherapy or as stand alone interventions. These activities will include creative arts and narrative medicine based interventions and can be used in either individual sessions or group settings to further expand the circuit.

Narrative Medicine

What is Narrative Medicine?

As cited in Vannatta and Vannatta (2013) the term "Narrative Medicine" was first used by Rita Charon, professor of literature and medicine at Columbia University, to describe "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (p. 34). Personally, I find this definition to be intentionally broad and up for interpretation because I feel that narrative medicine can be utilized in many different ways both in the healthcare environment and with the general public. Kalitzkus and Matthiessen (2009) ask the rhetorical question, "What is NBM [Narrative Based Medicine]? Is it a specific therapeutic tool, a special form of physician-patient communication, a qualitative research tool, or does it simply signify a particular attitude towards patients and doctoring?" (p. 80). They conclude that it can be all of the above. Reaching beyond the confines of the physician-patient relationship to include child life and other members of the interdisciplinary healthcare team, narrative medicine can prove to take on even more roles than Kalitzkus and Matthiessen have enumerated.

To explore this topic in relation to child life and the interdisciplinary healthcare team, we must first start with the basics. What do we mean by narrative? How has narrative medicine been used thus far? What benefits can narrative medicine have for the health care team or the patient?

What is an Illness Narrative?

In the most basic sense, a narrative is simply a story. Illness narratives tell the story of a patient or medical professional's encounter with illness or trauma. However, illness narratives do not stay at the surface telling solely a timeline of events during diagnosis and treatment. In the words of Kalitzkus and Matthiessen (2009) illness narratives dig deeper into the "intensive, ultimate, and most authentic reality of life or death of a person" (p. 81). Illness narratives seek to convey the depth of emotional and physical pain and suffering that the trauma of illness or hospitalization can evoke. They can also, however, convey feelings of hope for a future, for a cure, or simple for the acceptance of a new normal.

When most people think of illness narratives, they think of patient stories. These stories provide the patient's perspective of illness, how it may feel from the inside, how they experience their illness from a social context, and how they cope with the various facets of having an illness (Kalitzkus & Matthiessen, 2009). However, illness narratives can take other forms including physician's stories where physicians document the human experience of delivering medical care or their own experience with illness. They also include patient-physician encounters that document how the patient's narrative changes as they interact with the medical team and proceed with treatment, as well as grand stories that document sociocultural understandings of the body and illness (Kalitzkus & Matthiessen, 2009). From the perspective of a child life student, I would also include caregiver stories, as there are

many aspects of illness unique to the caregiver perspective that necessitate consideration in the big picture of medical care.

Uses and Benefits of Narrative Medicine

For the healthcare provider. Though science has come such a long way in diagnosing and treating the physical aspects of medical conditions, it cannot provide a full picture of a person's experience with illness. Patient narratives provide the information scientific tests cannot, including the meaning and context of illness for a patient from a personal, emotional, and cultural perspective (Kalitzkus & Matthiessen, 2009; Vannatta & Vannatta, 2013). Without this information it may be difficult for the physician to develop a mutual understanding and partnership with the patient because they may have very different ideas of what the illness means and how it should be treated. As stated by Greenhalgh and Hurwitz (cited in Vannatta & Vannatta, 2013) "The study of narrative offers the possibility of developing an understanding that cannot be arrived at by any other means" (p. 37). Along with context of illness, a greater understanding of suffering, grief, pain, and hope can be obtained through the patient narrative that could not be revealed through any scientific medical testing (Vannatta & Vannatta, 2013; Charon 2001).

Along with understanding the context of illness, narratives can help with the diagnostic process itself. Before modern medicine brought the capability of diagnosis through testing alone, physicians relied on symptoms described by patients centuries before many of the tests we have today existed. At the start of the diagnostic process, physicians must also determine what to test for. Listening to a patient's narrative about their lifestyle, when they started to feel symptoms, and what they think made them sick can help physicians narrow the field of what may be causing the symptoms (Vannatta & Vannatta, 2013).

Listening to patients, and reading their narratives, can also help physicians empathize with patients and be moved to act on their behalf (Charon, 2001). When physicians are able to empathize with, and are moved to act on the behalf of, their patients they are more likely to provide compassionate bedside care. Through narrative medicine and literature based classes in medical school, physicians can learn to connect to a story and reflect on the emotions the story elicits and what it might feel like being in the patient's shoes (Charon, 2001; Kalitzkus & Matthiessen, 2009).

As physicians are better able to empathize with patients and self-reflect on the impact of their stories, they are more able to see the mutual connection in the doctor-patient relationship (Charon, 2001). A mutual sense of trust, respect, and engagement in the process not only helps with communication between the physician and their patient but also can increase compliance with treatment and patient satisfaction.

For the patient. Along with the trickled down benefits of a more empathetic and efficient healthcare team, the opportunity to tell one's story can be therapeutic for a patient and of itself. Expressing emotion through narrative can have a cathartic effect for the patient (Kalitzkus & Matthiessen, 2009), especially with a completely engaged and active listener who approaches the narrative without judgment or an agenda other than to hear the person's story (Vajda, 2007). In interviewing Holocaust survivors, Vajda (2007) found by providing a listening but uncommenting and unquestioning audience, interviewees quickly became comfortable opening up and telling their stories in depth. During this process, Vajda (2007) found that even in cases of tragic experiences, being able to tell one's story gives relief. In her words, "Telling the story makes the unbearable possible to live with" (Vajda, 2007, p. 100).

In a study that used narrative interviews to understand children's experience of chronic pain, Meldrum, Tsao, and Zeltzer (2009) found that much like adults children want to be able to share their story with someone they feel would respect them and react to their story in a helpful way. Many of the children interviewed expressed that not having the validation from a physician regarding their pain story increased their frustration with their condition along with their sense of isolation and difference from their peers. Without this validation, they felt that their physicians were implying that their pain was not real (Meldrum, Tsao, & Zeltzer, 2009). By taking the time to listen to their stories, physicians can validate patients' concerns and help them feel less alone in their struggle.

The opportunity to write one's story can also provide therapeutic benefits. In an interview with Rian and Hammer (2013) a patient who has documented her journey with cancer through blogging stated, "Most of us can't absorb all the science of diagnosis. I have a science background, and I still have to find a way to think about it that helps me make sense of it. Writing helps me understand and gives me a foundation to move forward with. I can write my way out of anxiety" (p. 673). For this patient, writing helped process and make sense of her experience, while allowing control over coping with her anxiety and treatment. According to King (2013), "Narrative is simply how human brains like to think, arranging apparently random and thus disturbingly meaningless events into patterns which reveal a purpose or move towards a resolution" (p. 686). By taking stressful situations and confusing circumstances and putting them into a more logical format for the brain to process, patients may be more able to cope with their experience.

Studies have shown that reflective writing can also improve physical symptoms. Improved immune functioning, lower blood pressure, lower heart rate, decreased anxiety,

decreased depressive symptoms, have all been found in patients who use certain types of reflective writing for therapeutic benefits (Pennebaker as cited in Rian & Hammer, 2013). Hatem and Rider (as cited in Kalitzkus & Matthiessen, 2009) found that writing about stressful experiences helped improve lung functioning in patients with asthma and decreased disease activity in patients with rheumatic arthritis.

Narrative Therapy. Though the opportunity to tell one's story can be beneficial in a variety of circumstances, some patients need to take additional steps in order to process aspects of their personal story that may be hindering them from moving forward (Rian & Hammer, 2013). Giving patients the opportunity to rewrite their story using a positive light, and/or more effective coping strategies, can help them overcome this hurdle. White and Michael (as cited in Rian & Hammer, 2013) describe narrative therapy as assisting "clients in building a scaffold for re-authored histories, alternative storylines consisting of 'thickened' or more in-depth memories of lived experience" (p. 675). Narrative therapy takes into account that personal narratives can shape how the person views the world and themselves, but that sometimes they aren't always seeing the complete truth (Parker-Pope, 2015). Being given the chance to edit their own stories can help the patient determine obstacles in the way of better health and happiness and lead to positive changes in behavior (Parker-Pope, 2015).

Narrative Medicine and Child Life

Additional benefits. Referring back to Rita Charon's definition of narrative medicine as cited in Vannatta and Vannatta (2013), "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (p. 34), there are many ways in which narrative medicine connects with child life goals and practice.

Advocacy and Transitioning to Adult Care. Narrative medicine can be used to encourage patients and families to self-advocate. Specifically, it can be used to encourage teenagers to advocate for themselves and take responsibility for their care as they transition from pediatrics to adult care. If patients become comfortable sharing their story first with people they trust and eventually with new healthcare professionals they encounter, they may also become more comfortable in advocating for themselves. Adolescents can then participate in care discussions more regularly and be involved in decision-making processes. Participation in such discussions has been shown to improve social skills, academic performance, and self esteem along with increasing compliance and adaptation to a new normal (Koller, 2003). The ability to self-advocate, as well as participate in, and take responsibility for, care is crucial for adolescents as they transfer to adult care.

Awareness and Empowerment. Through narrative medicine based interventions and the sharing of final products, patients can raise awareness for their medical conditions and the overall experience of a hospitalized teen. Though the general public, and even healthcare professionals, can learn about a medical condition through books or on the internet, they will never truly understand the impact of the condition without a firsthand account. There are also many rare diseases that most people would never think to look up. By telling their stories, patients with these illnesses can bring their condition to light.

A friend of mine, Lisa (pseudonym), started her own blog to raise awareness for her own condition, Fibrodysplasia Ossificans Progressiva (FOP). Until I met Lisa, I had never heard of FOP. When I first met her, I looked up the disease to get a basic understanding of the rare bone disorder that causes bone to form in place of muscles, tendons, and ligaments on a progressive basis. I never, however, understood the debilitating and painful nature of the

illness until I listened to Lisa's story and began following her blog. When projects like Lisa's blog are shared, little by little people become aware of the specific condition or experience and are inspired to help, either by paying the awareness forward, donating to the cause, or volunteering their time. When this happens, the patient feels empowered that they were able to catalyze that change, make an impact on the world, and establish their legacy. It is important, however, to manage expectations when it comes to the impact a project will cause when facilitating a narrative medicine project.

Family-Centered Care and Cultural Competency. Narrative medicine interventions can assist healthcare professionals in providing patient- and family-centered, culturally competent care. When a patient or caregiver shares their healthcare experiences with the child life specialist or another member of the healthcare team, what they include and how they phrase things can give clues on their cultural background and care preferences. In order to practice true patient- and family-centered care a collaborative approach to care and decision-making is necessary (Hollon & Palm, 2007). Upon learning of the patient or family's beliefs and preferences during a narrative medicine based intervention, child life specialists can advocate for their needs and preferences with the rest of the care team (Bell, Johnson, Desai & McLeod, 2009). Studies have shown that by providing patient and family centered care, healthcare institutions can increase patient satisfaction and improve patient outcomes (Johnson, 2000 as cited in Hollon & Palm, 2007).

Communication with Peers. Tying back to adolescent development, peer support is important in identity formation and gaining independence from caregivers. Hospitalization and chronic illness can put a strain on a patient's relationship with their peers due to both physical and emotional separation. Patients may be prevented from seeing their peers

because of distance from home to the hospital or infection control policies. However, they may also feel emotional distance from peers who do not understand what they are going through. Peers who do not understand may shy away from the patient because they are unsure of how to act around them or what to say. If patients are comfortable doing so, encouraging patients to share their story or narrative medicine based project may help bridge the gap in understanding. By initiating the conversation through a non-threatening modality like a video, blog, or art project, patients and their peers may be more comfortable discussing the patient's situation and providing support during their experiences. Through blogs, video blogs, or social media patients can also keep their friends updated on their situation and keep the conversation going.

Through these modalities, it is also possible for a patient to connect with a new peer group going through similar circumstances. When narrative medicine is used either as stand alone interventions or in conjunction with bibliotherapy in a group setting, patients can connect to others' stories expressed in these projects. As stories are shared between the members of the group, the circuit expands **by** adding in the experiences and information shared by each member. Through these shared stories, members become social comparison others for one another. As group cohesion increases and intimate experiences are shared, members may feel less isolated within this new peer support system.

In the absence of a group setting, stories shared on the web through blogs and social media can similarly expand the circuit and create additional support for the patient. In the process of creating the Child Life Story Circuit blog and connecting it to social media, I have found many individuals and communities who share their experiences of illness to foster community, awareness, and support. Even teens with rare conditions can find people going

through similar circumstances willing to share their story and offer advice in dealing with the challenges the illness may bring. Though specialists should caution patients on the accuracy of medical information and advice found on the internet, advice on social elements of illness like telling friends about their condition, returning to school, and becoming more comfortable with a new normal can be especially helpful for adolescents to learn from someone who has truly lived that experience.

Connection to therapeutic play and creative arts modalities. Though Narrative Medicine has typically been facilitated through interviews or writing a personal narrative, it does not have to be limited to these modalities. For children and teens, outright writing or telling their story may not be the most conducive therapeutic intervention. Many pediatric patients may decline these modalities because they seem too much like schoolwork. Child life specialists can get creative with narrative medicine to include more playful interventions to help their patients share the same story through creative arts modalities. Besides the typical patient narratives and interviews patients can share their stories through blogging, visual arts, songwriting, creative writing, spoken word, videography, letter writing, comic books, graphic novels, animation, and other modalities that align with the patient's interests.

Like traditional narrative medicine interventions, creative arts activities give patients the opportunity to express their emotions, become more self aware, and foster personal growth (Rollins, 2005; Gaynard, Wolfer, Goldberger, Thompson, & Laidley, 1990; Webb, 2009). By catering to a patient's interests, and using elements of adolescent play, child life specialists can help patients tell their story and express their emotions in a less daunting and threatening way. The more a child life specialist can normalize the experience and

environment and be a nonjudgmental and uncommenting supportive presence, the more likely an adolescent will open up and share their story in greater depth.

Creative writing and storytelling. Creative writing and storytelling, though similar to an illness narrative, may be a less threatening modality for patients to tell their story. Through storytelling patients can deal with unfaceable fears and realities in a more indirect way while releasing feelings of despair, anger, and anxiety through characters in the story (Rollins, 2005). The structure and definitive timeline associated with storytelling can also provide a sense of predictability for the patient during such time of uncertainty (Rollins, 2005). By telling their own story in the form of a fiction, patients can retain a sense of anonymity while still allowing their voice to be heard.

Similarly, creative writing, including poetry, can be another way patients can give voice to their situations and feelings. Since poetry can be written metaphorically, some patients may respond more favorably than when asked to tell their story outright (Rollins, 2005). Despite the metaphoric nature of creative writing and storytelling, information can still be obtained from these modes of expression. Emotions associated with the patient's medical experiences will come across in the tone of the writing, actions of the characters, and word selection in the poem. The main character's experiences and focus of the poem may also directly connect to the patient's situation. Though it may take some work to decipher the work, much can be communicated through poetry and fictionalized stories.

Kelly. Though I have not had much experience facilitating poetry writing with patients, I did have conversations with a teenager named Kelly (pseudonym), who talked about writing her own young adult novel. Kelly has Crohn's disease and although she enjoyed and was able to connect with "The Fault in Our Stars," she was disappointed that she

was not able to find a similar book based on a teenager with her own illness. She wanted to write a fictionalized novel loosely based on her own story to create awareness about her condition and give other teens with Crohn's a character to connect to.

Songwriting. Along the same lines, songwriting can provide a less threatening platform for patients to tell their story. Many adolescents interact with music on a daily basis and are used to listening to music in the car, on their way to school, while doing homework, or while spending time with friends. In the hospital environment, music can be used for relaxation, stress relief, normalization, and to add a little fun into the patient's day. Because music is such a familiar modality, particularly for adolescents, songwriting can hold a particular appeal (Rollins, 2005). Research by North, Hargreaves, and O'Neill (as cited in Rollins, 2005) found that music is especially important to adolescents because "it allows them to (a) portray an 'image' to the outside world and (b) satisfy their emotional needs" (p. 147).

Through songwriting, teens can express emotions regarding hospitalization or illness, reframe their experiences, and tell their story either metaphorically or directly depending on their preference. Songwriting also can be used as a distraction from negative stimuli, offer a sense of accomplishment and mastery, and promote positive self-esteem (Tatro, 2002). By listening to the tone and lyrics of a song written by a patient, child life specialists can also obtain a great deal of assessment information (Tatro, 2002). By scaffolding the topic of the song, child life specialists can gain specific information based on the mood of the song or the words chosen in the song.

Natalie. During my internship, I was able to work with a 17-year-old relatively newly diagnosed oncology patient, Natalie (pseudonym), and her older brother, Josh (pseudonym)

on a song. Since none of us were particularly musically inclined, we decided to take an existing song and change the lyrics. I left the topic open for the intervention as I knew this patient and her family had undergone many hardships in the past year that she might need to process. Ultimately she decided to write the song about the untimely passings of her stepfather and cousin, which unfortunately occurred within one month of each other. Though this was the first time I had met either Natalie or Josh, they were both very open with me and I was able to establish rapport and trust quickly with them.

At the start of the intervention, instead of diving into the song we focused on brainstorming. I asked Natalie and Josh to tell me about their stepfather and cousin. During this conversation I not only learned about Natalie's relationship with her late relatives but also the bond she shares with her brother and the support she receives from other immediate family members. I learned that music has been a common thread within their family, and that her various family members have used music in different ways to release stress, relax, and cope with the hardships they have experienced. I learned that her family has always been very open with each other and remained strong for each other despite their hardships.

Though we never for a moment talked about Natalie's cancer or treatment, I learned a great deal from this first interaction with Natalie and Josh. I was able to assess Natalie's social support system, her ability to cope with life stressors thus far, her resilience, and her overall positive outlook on life. I was able to assess her socioeconomic and family dynamic stressors and her history of loss. I also helped discover a mode of expression and coping that worked for her. This session with Natalie and Josh was a jumping off point for a later session with Natalie. This time we focused solely on her diagnosis story as I helped her write a speech for a "Relay for Life" fundraiser for the American Cancer Society.

The rapport I developed with her through our unstructured songwriting session helped me to bring out some of the feelings and details she wanted to share with her classmates, who have thus far been making assumptions as to why she was missing so much school. She wanted them to know the truth so that everyone had the same story, wanted them to understand what it was like to go through the diagnosis process, and wanted to inspire them to keep up their morale through the night. What resulted was a beautifully honest progression from embarrassment to worry, shock to shame, misdiagnosis to closure. This speech was not only for her classmates, but also for her own processing of the events leading up to her final diagnosis.

Application and Reflection

Bibliotherapy

Time. During my internship I was unable to try out any bibliotherapy interventions simply because of the time schedule. In order for bibliotherapy to be successful, the specialist must either be able to follow a patient long-term through outpatient treatment or during a long-term inpatient admission. Patients must have enough time to read (or listen) to the book and there must be opportunity for follow up processing sessions. It is also helpful to have the opportunity to touch base with the patient as they read and process along the way. If the patient has semi-regular or regular appointments in a clinic, or has a longer inpatient admission, there would be more opportunity for such sessions.

Infection control and sustainability. For patients who do not have the opportunity to use a library or purchase their own copy of a book, child life specialists will need to provide the book for them. Per infection control policies in many facilities, paper books cannot be passed from one patient to another. Instead, it may be more sustainable to lend

patients electronic reading devices or audio books. When these devices are all connected to a common account, books can be shared or opened on any device within the department (with the proper application installed), including e-readers, laptops, desktop computers, and tablets.

Some of these services also allow a person to “lend” a book to another account, making it possible to also share to outpatient patients. Many libraries also have online libraries where patrons can borrow e-book or audio book versions for free for a designated period of time. For larger programs that plan to use bibliotherapy (or books in general) with patients on a consistent basis, a service like “Kindle Unlimited” may be worth looking into. This service allows unlimited reading, as well as listening to audiobooks, for a subscription fee. Terms of service for this option may limit the number of titles being accessed by one account at any one time. And although the application can be registered on any and all devices within the department, lending capabilities are not possible without purchasing the book.

For patients who may not have the energy or concentration to be able to read the book themselves, there are a few options. Using paper books or e-readers, various people who happen to be sitting with the patient can take turns reading to them as a community activity. This could involve volunteer support or family and friends, but could also be part of the time a child life specialist sets aside with the patient, depending on the specialist’s workload. Audiobooks are also an option, but without borrowing from a library or through a subscription service, this may get expensive. Many e-reader applications and tablets have an accessibility option called “Text to Speech” that could enable the patient to have the e-book read aloud. The only downside to text to speech is that the voice is very computerized. For programs with large numbers of volunteers, or connections with organizations, high schools,

or universities, asking people to donate time recording themselves reading may also be an option. The audio files can then be loaded onto department devices or lent out on CDs or department mp3 players.

Follow-up activities. Follow up activities to bibliotherapy can range from direct to metaphorical, simple to in-depth. Specialists can use general narrative medicine activities where the story line is brought into the discussion for those patients who are ready to delve into their personal situation. Comparative activities that encourage the patient to compare and contrast their situation to the character's, or role-playing activities in which the patient attempts to place themselves in the character's shoes, can also be used with a self-reflective patient. For those patients who may not be as ready to open up about their own situations, general activities based on the book can be used, including creative art projects, reenactments, or book club-like discussion. These activities may allow the patient to speak about themselves through the character without the vulnerability that may come with speaking directly about their own situation. Specialists should gauge the patient's reaction to the story, their current emotional state and health status, and their sensitivity to social comparison information when deciding on appropriate follow up activities. Specialists can also start off with more metaphorical activities and advance to more direct activities as the patient's comfort level increases.

Narrative Medicine

Tailoring to the patient. Tailoring activities to the patient's developmental age, interests, and abilities is crucial to engage the patient and encourage them to be as open as possible during the intervention. More direct narrative medicine interventions work best when the patient has developed a trusting relationship with the specialist. When working with

a new patient, offering them choices and finding a modality that is comfortable and enjoyable for them can start the therapeutic relationship on the right foot. When including narrative medicine while establishing rapport, projects should be as patient-directed as possible. Allowing them to share what they feel comfortable sharing without pushing, and to choose the topics they feel comfortable talking about, may lead to deeper discussions as the relationship continues. As interventions continue, though it is always important to offer choices in projects, patients may feel more comfortable with the specialist scaffolding topics of discussion.

Versatility. Narrative medicine interventions encompass such a broad range of activities that with some creativity an appropriate activity can be found for almost any situation. Narrative medicine interventions can double as anger play, legacy building, memory making, post-procedural play, intern and student education, and group socialization when planned appropriately. Individual activities can also be tailored to a variety of situations.

Top ten lists. “Top 10 Lists,” is one activity I include on the Child Life Story Circuit blog. In this activity, the child life specialist offers a topic and asks the patients to provide their top ten responses to that topic. For rapport building this could be as simple as “Ten Facts About Me.” For patients frustrated with the hospital environment, specialists could try “Ten Things I Wish My Medical Team Understood.” For patients who are receiving end of life care, specialists could use something like “Ten Things I Want My Family to Know.” The possibilities with this activity are virtually endless. Since most narrative medicine interventions are flexible, they can be tailored and tweaked to the patients needs without taking away from the intervention.

Resourcefulness and Sustainability. One of the best things about narrative medicine is that these interventions can be done with minimal supplies on minimal budgets. While some interventions may require use of technology or specific art supplies that the department may need to purchase, for the most part these interventions can be done with basic office and art supplies. Paper, pens or pencils, and coloring materials can go a long way with these interventions as the facilitation is much more important than the availability of top of the line supplies. The low cost nature of these intervention ideas make narrative medicine accessible to almost any child life department.

Overall Reflections

When choosing an integrative master's project, I knew I wanted to work on something that would benefit adolescents and assist specialists in becoming more comfortable working with them. The Child Life Story Circuit project offers projects that can help child life specialists establish rapport, encourage expression, empower patients to self advocate and raise awareness for their condition, and assist with identity formation and social comparison navigation. While I originally started the blog for the purpose of fulfilling my master's project, my passion has grown to want to continue the blog as a resource. While writing the blog I have developed my written communication, social networking, and marketing skills on top of fostering my own creativity. Trying my ideas out with patients has helped me continuously to assess and determine adaptations to tailor projects to patient situations. Along the way, I have developed deeper rapport and learned a great deal from the stories my patients have shared with me. Going forward, I hope to continually add innovative ideas to the site to improve the accessibility of narrative medicine and bibliotherapy with adolescents.

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