CHAPTER 3

Caring for Children With Cystic Fibrosis in a Hospital Setting in Australia

The Space Where Play and Pain Meet

Judi Parson

If I never had CF, I’d be a little taller, my lungs a little fuller, my skin a tad less salty. If I never had CF, I’d take my sweet time, take it all for granted, be terrified of doctors and hate the smell of hospitals.

—Lauren Bombardier (2010)

To explore the lifeworld of a child with cystic fibrosis (CF), Jaime, an 11-year-old boy, will be introduced, along with a range of health care professionals who care for him, within the context of an Australian hospital setting. Drawing on doctoral studies, professional knowledge, and clinical experience, this chapter explores the complex relationships found in medical environments through the lens of discourse theory. This is because discourse theory offers a way to understand the lifeworld of the child within the hospital setting from different positions. For example, the discourse of play is often marginalized in favor of the dominant biomedical discourse (Parson, 2008). However, the techniques and skills found in humanistic play therapy may be integrated into health care practice either before, during, or after medical procedures or when a child is suffering chronic or acute pain and as such provides a voice for the child.

The roles of the medical play therapist and/or child life specialist are particularly important to communicate to the child in and through play and to model and interpret therapeutic play interventions to others. Therapists are able to translate play-based assessments and behaviors to health care professionals such as medical doctors, nurses, and other allied health care providers, which in turn helps to expand the psychotherapeutic space needed for hospitalized children. The quality of the relationship establishes the foundation on which therapeutic play with child patients is based. And
using a holistic humanistic approach to child-centered and family-focused health care practice is core to ‘being with’ the sick child. Thus, humanistic play therapy will be explored and linked to medical play therapy in this chapter to bridge discourse theory with clinical practice in the context of the hospital setting.

The lifeworld concept is based upon one’s life experiences, events, or incidences and how these are perceived at a given point in time. Children admitted to hospital come into the medical world with their own health history and experiences. Sometimes children have experienced multiple admissions and have a sophisticated understanding of the hospital system and medical terminology. Children may speak in ways that make them sound older than their chronological age. When this happens, health care professionals could lose sight of the child’s developmental need for play. Therefore, evaluating the child’s development holistically is important when considering play-based therapeutic interventions. The inclusion of assessments, such as Mooli Lahad’s (1992) six-part story method, may be useful to therapists to facilitate psychotherapy that focuses on the child’s strengths and coping capacity. This chapter includes one of Jaime’s stories to introduce this method. First, an overview of discourse theory sets the theoretical scene.

THEORETICAL ORIENTATION

The concepts that guide this chapter focus on the social construction of ‘reality’ through discourse. Specifically, discourse constructs relate to both the child with CF and the health care professionals’ perception of ‘reality’ or ‘truth’, which are experienced within the context of an acute pediatric ward within a hospital in Australia. The sociological context considers relationships found in the medical environment. Tension is created at the site of multiple discourses that construct the child’s reality within the hospital ward. The informal relationships of the community, family, and lifeworld of the sick child intersects with the formal relationships found in an acute pediatric ward, professional, and hospital culture, and the world of biomedicine (Parson, 2008).

Emerging from postmodernism, discourse theory typically aims to provide a lens to observe symbolic aspects of human and social life from a sociological viewpoint (Wodak, Maingueneau, & Angermuller, 2014), and as such is useful to examine the positions found in hospital environments as a social construct. Discourse is all about the way language is used within a specific field, and as a way of speaking that in turn gives meaning to experiences from a particular perspective (Danaher, Schirato, & Webb, 2000). Discourse represents what people do, think, and act, and at the same time portrays the relationship of power and subjectivity (Wodak et al., 2014). Thus, the relationship between people and experiences, the place in which they dwell, encompasses a specific ‘field’, be it the field of science, sport, or pediatric care in a hospital.

The Complexity of Discourse

Meaning is constructed from experiencing ourselves in the world, and meaning is communicated as representations (Larkin, 2004), such as perceptions and language, maps and traffic signs, artwork and play. While this appears simple, it becomes complicated
by multiple and sometimes opposing discourses. Foucault's idea that power and knowledge are interrelated is a complex conceptual construct. Discourse is a medium for and an effect of power, privileging a point of view and silencing opposing points of view (Foucault, 1981). This is particularly important in relation to play, which is a marginalized discourse in relation to the hegemonic discourse of biomedicine (Parson, 2008).

**Biomedicine: The Hegemonic Discourse**

It is extensively documented that the dominant biomedical model influences Western health care practice (Haralambos, van Krieken, Smith, & Holborn, 1996; Jenkins, 2014; Turner, 1987). Biomedicine bases its knowledge on the scientific method of research to understand and cure illness. To do this, an objective, mechanistic, positivistic, biologic, scientific approach is used (Grbich, 2004). While medicine has indeed made some remarkable advances in the last few decades, “these scientific and technological advances have contributed to the shift away from models of person-centred medical care to models which may depersonalize the patient” (Clifton-Soderstrom, 2003, p. 447). Thus, as Jenkins (2014) states, biomedical hegemony continues to be an ethical problem. If, in the acute pediatric ward environment, the focus is fixed on the biological aspects of illness, then other aspects may not be seen, such as the importance of play in the lifeworld of the child. Discourse theory provides a way to consider the hegemonic discourse together with other socially constructed discourses.

Descriptions of phenomena may be drawn from several available discourses. Examples of other competing discourses in hospital environment include hospital and organizational discourse, multidisciplinary team discourse, nursing discourse, family discourse, play discourse, and procedural play discourse (Parson, 2008). Play is represented in the literature as the child’s way of communicating what he or she knows about the world and is an essential aspect of the child’s physical, emotional, cognitive, and social world. Procedural play may be integrated into the child’s hospitalization experience and becomes a medium to help assess, plan, implement, evaluate, and reflect upon the child’s thoughts and feelings about their medical treatment and pediatric care. However, Parson (2008) found that procedural play was a silenced discourse in hospital settings due to lack of knowledge, understanding, and skills to integrate or action procedural play. In the context of an acute pediatric ward environment, discourses could also include child-centered or family-centered care (Ahmann, 1998), evidence-based practice (Foster, 2004), together with organizational, economic, or political discourses to articulate, or position, discussion regarding the facilitation or inhibition of integrating a specific clinical practice including play therapy. Drawing on discourse theory to construct the meaning of caring for a child with CF may be considered according to subject positioning.

Discourse theory asserts that language positions people, and therefore discourse creates subject positions (Wetherell, 2001). Subject positioning is the flexibility to move within and between available discourses, and the factors that facilitate or inhibit flexibility depend on power relationships and the context where interactions occur (Hardin, 2001; Sundin-Huard, 2001). The transitory nature of subject positioning provides the richness to view context and culture through discourse. The clinician
can then consider and analyze a variety of subject positions as a point of entry into the discourse. This is the important point that showcases the role of the therapist in being able to move between subject positions to translate and communicate play as a language and to promote the voice of the child. One such subject position is the therapeutic language and stance that therapists use to engage the child through play.

**Therapeutic Positioning**

Play therapists are mindful of the lifeworld of the whole child. This means that they are cognizant of the child’s past and present, and how the medical condition has impacted on all domains of the child’s life, including physiological, psychological, emotional, social, and spiritual health and well-being. Consideration is given to whether or not the medical condition is a source of concern for mental health or if psychopathology impacts on the medical condition. This is an important point of difference, as some health care professionals may prioritize the physical body, attend to activities of daily living, such as feeding, toileting, and providing medical care, and have limited time to prioritize and ‘be present’ to the child’s psychosocial health care and need to play. However, all hospital personnel could develop and model relational skills by adopting a humanistic stance. Play therapists develop and integrate a therapeutic approach by communicating through their skills in providing the core conditions: unconditional positive regard, empathy, and congruence as described by Rogers (1961). Axline (1947) provided an extension of Rogers’s work by developing the Eight Basic Principles, which include that the therapist:

1. Develops a warm, friendly relationship with the child
2. Accepts the child exactly as they are
3. Establishes a feeling of permissiveness within the relationship so the child can fully express their thoughts and feelings
4. Attunes to the child’s feelings and reflects these back to help the child gain insight into their behavior
5. Respects the child’s ability to solve their own problems, leaving responsibility to make choices
6. Tries not to direct the child’s behavior or conversation, but rather the therapist follows the child’s lead
7. Tries not to attempt to rush therapy and recognizes that therapy may be a gradual therapeutic process
8. Sets only limits that anchor the child to reality or make the child aware of responsibilities in the relations.

While it is not always possible to employ all eight principles in short-term hospital admissions, it is possible to generate the attitudinal approach that facilitates the humanistic stance. Medical play therapists must quickly establish a therapeutic relationship and be mindful of the lifeworld of the child and the support systems around the child in the hospital setting. Nursing and medical play therapist literature seem to align to support the child using a humanistic approach.
MEDICAL PLAY THERAPY

Medical play therapy is similar to the humanistic approach to play therapy, with the added dimension of an acute or chronic medical ailment/diagnosis. In medical play therapy, the focus is always on the child first and how the diagnosis may impact on the child's physical condition and in relation to the child's mental health and well-being. The physical condition may either exacerbate the child’s emotional responses or may be the source of distress. Therefore, therapists need to understand the child's interpretation of what this means to them and how they will respond to medical treatment.

To do this, the same play therapy skills and techniques are used to develop a secure and trusting relationship. The child cannot play if he or she is scared. Play is the child’s voice! This is particularly important in the care of the child patient with CF, because the relationship is established from the very first admission to hospital and built upon with every subsequent hospitalization encounter over the years. As Parson (2008) identified, nurses who integrate procedural play into their clinical practice may quickly observe the short-term benefits to the child patient and may even witness the long-term benefits. It needs to be acknowledged that every moment creates the context in which the next moment will take place. And the immediate context is crucial in determining the direction and final form of what will happen. In other words, each present moment influences the destiny of where things will go next. And the next moment will serve as the context for the moment that follows, and so on.

(Stern, 2004, p. 367)

The nursing and family discourses become visible at the site of interpersonal interaction before, during, and after medical treatment. Within the social milieu of the play relationship, Parson (2008) listed a number of facilitating factors that influenced successful integration of procedural play. These findings centered on positive relationship values of trust, honesty, understanding, acceptance, and friendship. Nurses understood the importance of gaining the child’s trust and the negative impact caused by losing the child’s trust in their relationship with the child and the child’s family.

Crole and Smith (2002) identified four phases of nursing care of the hospitalized child, namely, the introductory phase, the building trusting relationship phase, the decision-making phase, and the comfort and reassurance phase. While play and trust are featured in all phases, in the second phase of building a trusting relationship, play is strongly encouraged, for both the child and the nurse.

Building trusting relationships with children is achieved through a nurse’s use of appropriate language, games and play, adequate preparation of a child for procedures, and providing explanations and encouragement . . . A child will be more trusting of nurses who are willing to get down on their level and play on their terms. Play has many benefits for both children and nurses. Play can be a normalising experience for children in hospital. It may enhance development and prevent regression resulting from stressful experiences.

(Crole & Smith, 2002, p. 30)
Crole and Smith (2002) state that if trust is not established or is impeded, it becomes more difficult to obtain the child’s cooperation. The potential for losing trust occurs when the child’s sense of autonomy is damaged, for example by being physically or chemically restrained for treatment (McGrath, Irving, & Rawson-Huff, 2000). This issue is also raised in another Australian study. Bricher (1999) identifies a dilemma in the child–nurse trust relationship, whereby trust is seen as particularly important by nurses, but breaking trust was seen as essential for completing clinical procedures. She goes on to state that little is known about the types of strategies used to develop trust or how they repair damaged relationships (Bricher, 1999). Parson (2008) identified that nurses were aware that play strategies facilitated the establishment of trust and that nurses were aware of the link between general play and procedural play for establishing and repairing trust in the child–nurse relationship. Preventing the loss of trust is the ideal, but if trust is lost, then post-procedural play may also help to re-create and preserve the relationship. More research into the complexity of these play interactions is warranted to understand the short-term and long-term development of the establishment and maintenance of the child–nurse or child–therapist trust relationship.

All health care professionals should, therefore, be aware that for every clinical decision made and acted upon, consequences will follow. If the child is offered procedural play within a trusting relationship, subsequent procedural experiences will be anticipated according to the child’s prior experiences. During an invasive procedure, decision making occurs rapidly and highlights the importance of developing the trusting relationship through procedural play. If at any stage trust is lost during a procedure, it is important to allow time to re-establish the trust relationship (Crole & Smith, 2002).

A person [parent] cannot be committed to a child unless other people [nurses] are committed to that person’s commitment to children.

(Bronfenbrenner cited in Grille, 2005, p. 361)

This statement acknowledges and positions the lifeworld of the child as dependent not only on the child’s family, but also on the people supporting the family in caring for the child. In terms of procedural play, parents depend on their own abilities and previous experiences to support their child through the current procedural experience. The health care professionals should act as the support people to work with the child through this family-focused framework.

Family-centred care can be literally defined as placing the needs of the child, in the context of their family and community, at the centre of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs.

(MacKean, Thurston, & Scott, 2005, p. 75)

Modern parents are more participatory in the care of their children when compared with previous generations. The literature indicates that parental participation and involvement is central to their child’s hospitalization experience. Early work stemming from the Platt Report of 1959 into the Welfare of Children in Hospital (United Kingdom) indicates that parental presence is vital for children to cope with hospitalization (Darbyshire,
1994; Harvey, 1980; Livesley, 2005; Shields, 2000). Since expanding visiting hours to include parental living-in, further demands have been placed on parents to become more involved in the care of their children. This transition has increased from parental access, to participation in the usual parent–child tasks such as bathing and feeding, to more technical nursing roles such as assisting with invasive procedures in hospitals (Melnyk, 1994; Piira, Sugiura, Champion, Donnelly, & Cole, 2005), to operating complex machinery in the home (Jamieson & Wilson, 1997). Parents now share the tasks of preparing and treating their children with the nursing staff and hospital-based play therapists. Parents know their children intimately and are the most appropriate human resource to help staff assess and plan for their child’s needs.

Recommendations have previously been documented to include the concept of the child–parent dyad as a singular patient unit during any interaction with a health care service (Shields & Nixon, 2004). However, not all parents are able to be physically and/or emotionally present for their children in hospital (Livesley, 2005). It is important to acknowledge that sharing of roles within the care triad has added additional burdens to both parents, as co-workers, and nurses, in providing parental support and education to parents as co-clients (Callery, 1997). Health care professionals should not expect that parents have the skills to independently prepare their children. In an Australian study, Goodenough, Thomas, Champion, Perrott, Taplin, von Baeyer, and Ziegler (1999) identified that in one-quarter of children requiring venipuncture, the child had not been told by their parent that they were about to have a blood test. During the assessment phase of preparing a child for an invasive procedure, nurses ought to identify and build on the information, if any, which has already been imparted to the child. Parents also require sound education regarding their role in assisting with their child’s procedures. The literature also states that some parents are not always able to assist their child in coping because of their heightened anxiety, which can be transmitted to the child (Barrera, 2000). Hence, part of the pre-procedural planning must incorporate assessing the parents’ abilities and desire to assist in providing procedural care.

To further enhance the effectiveness of procedural preparation, it has been suggested that making the child and parent more active participants in the learning process might lead to more clinically significant outcomes (Peterson & Shigetomi, 1981). Leblanc and Ritchie (2001) demonstrate that parental participation and involvement in play therapy do indeed provide a significantly higher predictor of a positive outcome. However, this participation has taken longer to be integrated into acute health care encounters. One concern that health care professionals expressed was that parental presence would reduce procedural efficiency and increase parental distress. However, Bauchner, Vinci, Bac, Pearson, and Corwin (1996) conducted a randomized controlled trial to determine the effect of a parent-focused intervention on pain and performance of an invasive procedure, anxiety of parents and clinicians, and parental satisfaction with care. While this study did not reveal a reduction in pain during procedures, it did indicate that parental presence did not negatively affect performance of the procedure or increase clinician anxiety. In fact, this study demonstrated that parents who were present were less anxious than parents who were absent. This is further supported in a systematic review of the literature, when Piira et al. (2005) found that there are
potential advantages for parents, that is, less parental distress and parents more satisfied due to being present during medical procedures, however the benefits to the child remain unclear.

Parson (2008) found that nurses’ awareness of the child’s developmental attributes and an ability to assess the child’s individual attributes positively influenced the integration of procedural play within the care triad. This may be because children cope better with adult guidance. A significant increase in both parent and child coping was demonstrated when parents were supplied with information about the child’s procedure (Melnyk, 1994). However, the majority of children undergoing painful, invasive procedures do not engage in effective coping strategies unless prompted to do so by an adult (Barrera, 2000; Broome, 2000). Children require an understanding of what is happening to them and an ability to be distracted so that pain perception is reduced (Broome, 2000). One study examined the efficacy of training children to cope with immunization pain with or without the assistance of a breathing technique and positive self-statements (Cohen, Bernard, Greco, & McClellan, 2002). In this study children demonstrated an understanding of the techniques, but they did not use the coping skills during the procedure. The authors offered several reasons for this outcome, but supported the understanding that children need the guidance of adults to cope with procedural experiences. This indicates that nurses and parents are in a position to plan developmentally appropriate pre-procedural educational play, as well as individualized strategies from the child’s perspective to cope with the procedure.

While family-centered care is a valued, collaborative and respectful model of care in pediatrics conceptually, interpretation and implementation of family-centered care differs among individuals and institutions (Regan, Curtin, & Vorderer, 2006). The literature identifies that the practice of family-centered care is not routinely safeguarded by policy and procedures within the National Health Service in Britain (Walker, 1999) or in the United States (Regan et al., 2006). Peden-McAlpine, Tomlinson, Forneris, Genck, and Meiers (2005) found one way to integrate family-centered care philosophy into pediatric wards was to use a family-focused, reflective practice intervention. The researchers found that nurses who participated in the intervention:

- Acknowledged and re-framed preconceived ideas about families
- Recognized the meaning of family stress
- Began to incorporate the family into nursing care.

This led to change in the nurses’ attitudes about family, enhanced their communication skills and their ability to build trusting relationships with families, and brought about a new appreciation of the uniqueness of family stress (Peden-McAlpine et al., 2005).

Acknowledging that parents are co-workers within a care triad has demonstrated a shift in the power relationship of caring for hospitalized children. Parents are an important human resource that health care professionals ought to utilize for assessing and preparing children for medical procedures. Parents should also have the choice to be involved (or not) in preparing and assisting with procedural play with the aim of providing family-centered care. This has highlighted the great importance of developing a
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trusting relationship with the child patient and his or her family, and one way this can
be achieved is through a successful procedural play interaction.

It is important to understand the discourse of play in relation to other discourses
found within the hospital environment. The powerful biomedical discourse needs to
acknowledge general play and procedural play. Parson (2008) states that play is a fragile,
unspoken discourse in hospital settings. It is explicitly understood that play is difficult to
define due to the many complex and varied definitions available, and may be one reason
why procedural play is silenced. However, the benefits of play have been well-established
in educational literature (Honig, 2006). It forms the basis of learning, creative thinking,
problem solving, the ability to cope with tensions and anxieties, acquiring new under-
standings, the ability to use tools, and the development of language (Christie & Johnsen,
1983; Piaget, 1972; Rothlein & Brett, 1987). Play offers children the opportunity to
express, both verbally and non-verbally, their thoughts and feelings (Wittenborn, Faber,
Harvey, & Thomas, 2006). However, and most importantly, the value of play in hospital
has been clearly recognized over the past century (Murphy, 1910).

Children with CF are vulnerable to emotional distress, pain, anxiety, fear, and pro-
cedural trauma, and therefore these factors highlight the need for therapeutic play inter-
ventions through procedural play. It is from this position that the potential positive
integration of play and specific procedural play may be built. As stated earlier, the clini-
cian may consider and analyze a variety of subject positions as a point of entry into the
discourse. In practice, this means the entry point is based on the lifeworld of the child
and how the child is presenting in real time. To do this, the following case describes one
assessment to help facilitate an entry point to commence therapeutic engagement.

JAIME: A CASE DISCUSSION

The pediatric ward manager notifies me that Jaime, an 11-year-old boy, is about to be
admitted. Jaime is well-known to staff, with his charismatic personality and incredibly
brave persona due to his routine visits to the CF clinic since his birth and recurring
admissions to the pediatric ward in the general hospital in regional Australia. He is
familiar with the ward environment and is able to navigate his way through admission
to an awaiting bed. He knows he is being hospitalized for elective surgery “to have a
port put in.” An implanted port, or port-a-cath, is a device that is inserted to allow for
frequent and long-term access to the bloodstream (Cystic Fibrosis Foundation, 2016).
Because Jaime has to have an upcoming extensive medication treatment, the port will
allow for repeated antibiotics, IV nutrition, and other IV fluids. When he gets his port
placed, he will not need repeated peripheral IV catheters put in; instead the port is
accessed. Thus, while it may be initially more painful than a regular IV catheter, it is
anticipated that the pain will be reduced for a year or two.

CF affects 1 in every 2,500 births and is one of the most serious genetic diseases
in Australian children today (Lai, Cheng & Farrell, 2005). It is an autosomal recessive
genetic disease that affects the exocrine glands of the body, and is characterized by abnor-
mal airway secretions, chronic endobronchial infection, and progressive airway obstruc-
tion (Mogayzel et al., 2013). This means that people with CF produce thick mucus, which
eventually clogs the lungs and may lead to a variety of lung infections. It also affects the
exocrine glands in the pancreas, which deactivates the digestive enzymes to break down and absorb food. However, the most common reason children are admitted into hospital is for the administration of intravenous antibiotics and intensive physiotherapy to treat respiratory exacerbations of CF, commonly referred to as a ‘tune-up’ (Parson, 2014). For more information about CF, visit https://cysticfibrosisnewstoday.com.

Jaime’s first admission to the ward was when he was 2 years old, and since then he averaged one or two admissions per year. He lives with his mother, Margaret, and father, Robert, and two younger sisters, Beth (7 years) and Sarah (5 years). Neither of his sisters has CF, but each has a 50% chance of being a carrier of the CF gene. Jaime’s parents must manage their time very carefully to meet the needs of all family members. However, Margaret assumes most of the parenting responsibilities and is the primary carer for Jamie and his sisters. Robert works full-time as a lawyer and often stays at work late into the evening. Developmentally, like most children, Jaime was advanced in some areas and lagged behind in others. Academically, his teacher reported that Jaime was a fairly bright student, he was more of a visual learner and preferred electronic media compared to reading or writing. He likes to create, draw, and paint, and engage in a range of art activities, but he said that “I don’t think I am very good at it.” Physically, he is thinner and shorter than his peers. He does not enjoy sport, because as soon as he starts to play he would often cough, and cough, and cough, and he didn’t like it when other children looked at him. Recently, he discovered that he liked surfing, which had the added bonus of helping him to breathe in the fresh, salty air. Margaret said that she was so pleased that he liked it, and it was a sport that would help him in the long term.

According to the Cystic Fibrosis Foundation, it seems that surfing can extend the life of people suffering from CF. Australian doctors observed that young surfers with cystic fibrosis had significantly healthier lungs. He had been introduced to surfing through a school friend, Frank, who had another friend with CF. Frank had been upset to hear that Jaime had CF because his other friend had died. According to Margaret, Jaime seemed preoccupied with death since he had heard about the other boy with CF who had died because of a bad respiratory infection.

While the admission focus was on inserting the port, an assessment was required to ascertain the most appropriate educational procedural play plan. So in order to understand Jaime’s coping strengths, it was suggested to draw a six-part story, based on Mooli Lahad’s (1992) BASIC Ph method. I asked him to draw a story that had six pictures; this prompted him to divide the page into six boxes, and he was guided to draw as follows (see Figure 3.1):

1. A main character hero or heroine
2. Identify a task or mission
3. Who or what helps the main character
4. Who or what are obstacles to prevent the task or mission being accomplished
5. How does the main character deal with the obstacle
6. Then what happens next.

Jaime then drew from top left to right in relation to the numbers 1, 2, and 3 and bottom left to right as numbers 4, 5, and 6.
Once he completed the drawings without interruption, Jaime then described each drawing based on the six aspects in the list and stated:

Once upon a time there was a boy named Frisk and he has blonde hair and a vibrant red scarf and a blue tattoo on his face. The tattoo was given to him at birth. He lived for over 100 years in the form of a 14 year old. Frisk feels like a caged bird, he appears happy enough but on the inside, he is truly emotionless. His mission is to protect and do jobs for the village. The village is called Tatakai.

Frisk’s companion is a brightly colored red bird with a black collar and she has the same tattoo on her wing that Frisk has on his cheek. The bird is called Chiara, pronounced Cara. Chiara is part of Frisk and contains Frisk’s emotions and is like his soul. She is not able to fly. Because of the tattoo, Frisk cannot leave the village at night. To stop this from happening he carved off the skin that had the tattoo on it. The tattoo, whilst it keeps him inside the village at night, it also prevented him from dying. He wanted to experience what night-time was like and he had lived a very long time and he thought it was time to do so. When this happened Chiara could fly. But after he carved off the tattoo he knew that in three years’ time, Frisk would finally die.

Additional clarifying information was provided by Jaime after the story was narrated.

Frisk’s mother gave him the scarf which she sewed herself and soon afterward she had given it to him she died in a war. The village was always at war. Frisk’s father was a warrior too and he died in the same war. The village chief, Puro, raised Frisk to be a protector of the village.
The BASIC Ph is an acronym that emerged from the various aspects that the six-part story method assessment measures, which represent the following: Belief, Affect, Social, Imagination, Cognition, and Physical (see Table 3.1). Each domain has particular strengths and is useful to inform the therapist how the child’s coping strategies may be enhanced. The story is scored based on the contents of the story. For Jaime’s story, a lot of information (cognition) is given in the details about the main character Frisk and his companion Chirara. In this case, it can be hypothesized that his coping strength focused on cognition and social, then to a lesser degree drawing on beliefs and physical elements, and finally with

<table>
<thead>
<tr>
<th>Domain</th>
<th>Theorist</th>
<th>Domain</th>
<th>Skills &amp; Subskills</th>
</tr>
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<tbody>
<tr>
<td>Belief (B)</td>
<td>Frankl (1963)</td>
<td>Self, ideology</td>
<td>Attitudes, Beliefs, Life span, Value clarification, Meaning</td>
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<td></td>
<td>Maslow (1962)</td>
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<td>Affect (A)</td>
<td>Freud (1933)</td>
<td>Emotions</td>
<td>Listening skills, Emotions, Ventilation, Acceptance, Expression of feelings (verbal and non-verbal)</td>
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<td>Rogers (1951)</td>
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<td>Social (S)</td>
<td>Adler (1956)</td>
<td>Roles, others, organizations</td>
<td>Social role systems, Social skills, Assertiveness, Groups role-play, Simulations</td>
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<td>Erikson (1963)</td>
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<tr>
<td>Imagination (I)</td>
<td>De Bono (1992)</td>
<td>Intuition, humor</td>
<td>Creativity, Play, Psychodrama, ‘As if’ symbols, Guided imagery/fantasy</td>
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<td>Jung (1977)</td>
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<td>Cognition (C)</td>
<td>Ellis (1994)</td>
<td>Reality, knowledge</td>
<td>Information, Order of preference, Problem solving, Self-navigation, Self-talk</td>
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<td>Physical (Ph)</td>
<td>Pavlov (1927)</td>
<td>Action, practical</td>
<td>Activities, Games, Exercise, Relaxation, Eating, Work</td>
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<td></td>
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Source: Adapted from Lahad and Leykin (2013)
limited or silenced affect. This final aspect is interesting as it is also reflected in the story as well. This first phase of the assessment process is useful to provide an understanding of the child’s coping style. For more information about scoring and the full and subsequent assessment steps, read Ayalon, Lahad, and Shacham (2013).

Therefore, in order to engage Jaime in play-based interventions, a cognitive approach would be the most aligned. Psychoeducational information giving and open discussion would be of benefit to explore the concepts of death and dying. Using a humanistic approach to acknowledge Jamie’s concern and worries about death and dying, he subsequently led to an open discussion. He revealed that he didn’t want to talk to his Mum or Dad because he didn’t want to upset them, and wanted to protect his parents because they would think it was their fault. He said he felt all alone. This discussion led to providing some of the facts about the life expectancy of people living with CF. The life expectancy of individuals with CF has increased in the last few decades, and since 2014 for the first time in Australia there are more adults with CF than children (CF Foundation, 2016). Acknowledging that no one really knows when they will die, I could provide some hope, and informed Jaime about other children and young people living with CF, including a man I personally knew who at the time was 65 years old, and that although he had to have a lung transplant, he was happily living in a regional part of Australia. This conversation then led to a discussion about Jaime’s newfound love of surfing and how doctors were looking into how surfing has been noted to help people with CF have healthier lungs. Finally, procedural play in the form of psychoeducation was provided to prepare Jaime for his port insertion.

**Personal Reflections**

I believe that children have a right to health care treatment that is genuinely child- and family-centered. Children have the right to be informed in a developmentally sensitive and age-appropriate manner about any procedures that may be performed on them while in hospital. As a registered nurse, I had to find ways to help children cope with their experiences. To do this, I often asked the child or their family how I could best help him or her. While the child did not always have the words to be able to tell me, and sometimes the parent could not either, I closely observed their body language, appearance, expressions, and non-verbal communications. I intuitively knew that if the child could eat, drink, and breathe, they always strived to play. Play became my ally, my go-to point of entry to engage the child. Jaime was able to draw a story, then find words to project onto the drawing, real-time thoughts and feelings about Frisk and Chiara. He was working in the metaphor, and what a creative and heart-wrenching metaphor was communicated. I hypothesized that Jaime too felt alone in his thoughts and feelings about death and dying. However, by being present to the needs of Jaime’s emotional pain, in the context of his lifeworld, provided an entry point through the BASIC Ph assessment. I understood it was more important at that time to facilitate the discussion of death and dying, otherwise the procedural education would not be heard. Jaime had developed many relationships with hospital staff, including myself, and found a safe space through the creative expression of play to explore his thoughts and feelings about death and dying.
SUMMARY

Discourse theory provides a lens to review and reflect on the dominant biomedical model at the site of the marginalized and silenced discourse of play and procedural play in the hospital setting. The inclusion of assessments, such as Mooli Lahad’s (1992) six-part story method, may be useful for therapists to facilitate psychoeducational and therapeutic play because it focuses on the child’s strengths and coping capacity. This chapter included one of Jaime’s stories to introduce the first phase of this method. Even though Jaime had already experienced multiple admissions to the regional hospital and had an understanding of the system, use of the six-part story method (BASIC Ph) provided an entry point into the lifeworld of Jaime. He was able to explore death through the metaphor, which had been worrying him. Once this was acknowledged, he was able to hear the preparatory information being given to him about his port insertion. This demonstrates that holistically evaluating the child’s development is important when considering implementation of play-based therapeutic interventions.

REFERENCES


