

Living with Chronic Renal Failure During Adolescence:
An Exploration of Issues Through Art Therapy

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ABSTRACT

Living with Chronic Renal Failure During Adolescence: An Exploration of Issues
Through Art Therapy

Heather R. Hawkins

Chronic renal failure is a pervasive illness that drastically affects the lives of adolescent patients. The complexities of how living with chronic renal failure affects the psychosocial adjustment for patients during adolescence can be better understood by taking into account the developmental tasks that face this age group. This research presents a qualitative case study that investigates how art therapy can be used to explore the psychosocial issues experienced by a 15-year-old female diagnosed with chronic renal failure. Over a seven-month period, data was gathered during art therapy sessions conducted while the participant was receiving hemodialysis treatments at a pediatric hospital. Prevalent issues that emerged from the data were the participant's perceived lack of control, difficulty integrating her illness into her self-concept, and challenges in adhering to treatment. Violet was able to express, acknowledge and work through these issues through art therapy. The findings suggest that art therapy is an appropriate intervention while working with this population. Further study is needed to evaluate the effectiveness of art therapy in addressing specific issues, such as treatment adherence.

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LIVING WITH CHRONIC RENAL FAILURE DURING ADOLESCENCE: AN EXPLORATION OF ISSUES THROUGH ART THERAPY

Overview

The kidneys are vital organs responsible for a number of essential bodily functions. Chronic renal failure is a pervasive illness, affecting every aspect of a person's life. When the kidneys fail to function at a level that maintains life, invasive medical interventions are required. Patients often experience painful procedures and spend a large portion of their time at the hospital receiving treatments. The physical symptoms and treatment regimens are emotionally and physically taxing for the patient, especially during adolescence. The complexities of how living with chronic renal failure affects the psychosocial adjustment for patients during adolescence cannot be understood without taking into account the developmental tasks that face this age group. The developmental theories of Erikson (1950/1963, 1968) and Piaget (1967) provide relevant perspectives through which to explore and understand the psychosocial effects of renal disease. Adolescent patients diagnosed with chronic renal failure tend to show poor psychological adjustment, low self-concept (Devins, Beanlands, Mandin, & Paul, 1997; Eiser, 1985; Fielding & Brownbridge, 1999; Garralda, Jameson, Reynolds, & Postlethwaite, 1988), poor body image (Reynolds, Garralda, Jameson, & Postlethwaite, 1986; Travis, 1975), lack of control (Rosenkranz et al., 1992), and poor treatment adherence (Brownbridge & Fielding, 1994; Maikranz, Steele, Dreyer, Stratman, & Bovaird, 2006; Rianthavorn & Ettenger, 2005). This paper presents the case study of one adolescent female with the

purpose of exploring the use of art therapy as a means of addressing the psychosocial effects of chronic renal failure.

Renal Disease

Sequelae

Renal disease is not a single illness but a category of diseases affecting the kidneys, the causes of which range from diabetes to congenital malformations. The kidneys are vital organs that are part of the cardiovascular-renal system. Kidneys are described as two bean-shaped, fist-sized organs that lie below the back of the rib cage. Their function is to maintain the chemical balance in the body by cleansing the blood of metabolic wastes and various ingested substances (Travis, 1975). The kidneys regulate the volume and concentration of urine produced. They also regulate blood pressure and the production of red blood cells. When damage is caused to the kidneys to the point of failure, uremia occurs. This means that waste products, normally removed, remain in the blood stream and eventually lead to death. Symptoms of renal failure include loss of appetite, stunted growth, weakness and lethargy, high blood pressure, and impaired cognitive functioning. End stage renal disease (ESDR), or chronic renal failure, occurs when “the kidneys are permanently impaired and can no longer function normally to maintain life” (Canadian Institute for Health Information, 2001). It wasn’t until the 1940s, when Wilhelm Kolph invented the artificial kidney machine (hemodialysis) that renal failure didn’t mean certain death (Weldt, 2003). The Canadian Institute for Health Information reported that between 1990 and 1999, there were 677 new pediatric patients (18 years and under) diagnosed with ESRD. Over half of these patients were between the ages of 10 and 18 years (Canadian Institute for Health Information). Prior to kidney

transplant, children and adolescents diagnosed with renal failure are treated both through diet and hemodialysis.

Treatment

Diet

Individuals diagnosed with renal failure are put on restricted diets to slow the progression of kidney deterioration, which in some cases can put off the need for dialysis for over a year (Brownbridge & Fielding, 1994). Diet is usually changed in four main ways: the amount of protein, sodium, potassium, and phosphorus, which are limited in the patient's diet. Protein consumption is limited to reduce the amount of waste present in the blood, which slows the progression of kidney failure. Foods that are high in protein include meat and dairy products. Due to a low-protein diet, patients are often severely anemic and have an iron deficiency, requiring iron supplements (Travis, 1975). To help control health problems prevalent for patients diagnosed with renal failure, such as high blood pressure and fluid retention, sodium consumption is limited. Table salt and salty snack foods are restricted.

Due to renal failure, the body is no longer able to remove excess phosphorus from the blood. A buildup of phosphorus causes the patient's bones to lose calcium, often resulting in bone disease (Travis, 1975). Phosphorus intake is limited and calcium supplements are taken to prevent bone deterioration. Foods high in phosphorus include dairy products, beans, nuts, cocoa, and some cola drinks.

Another mineral that can build up in the bloodstream due to renal failure is potassium. Potassium, found in most fruits and vegetables, plays a role in maintaining muscles and a regular heartbeat. High levels of potassium in the blood can result in

irregular heartbeats and heart attack. Levels of these nutrients are monitored through frequent blood tests, which then determine how much of each can be allowed in the patient's diet. The restricted diets allowed are relatively unpalatable contributing to the loss of appetite that patient with renal failure experience (Travis). In addition to these diet restrictions patients are usually restricted to a certain amount of fluid per day to prevent excess fluid from being retained in the patient's body tissue, which can result in high blood pressure. Fluid restrictions are determined by regularly measuring the patient's fluid weight.

Hemodialysis

Hemodialysis is one of two forms of dialysis treatments meant to replace the functions of the human kidney. On average children spend four hours a day, three days a week on hemodialysis (Brownbridge & Fielding, 1994). It is not an end in-and-of-itself; rather, it is the means by which patients are kept alive while awaiting a kidney transplant. Waste products and fluid from the patient's blood are removed through the use of a hemodialysis machine (see Figure 1).

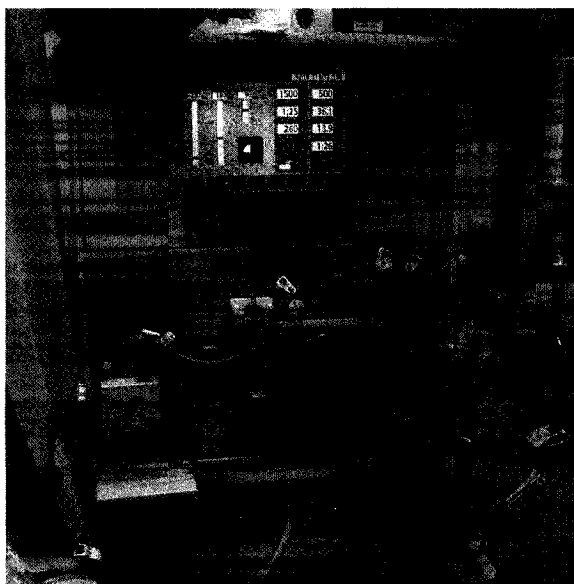


Figure 1 Hemodialysis machine

The patient's blood is accessed through a number of methods. One of which is through a central venous catheter (CVC) inserted into a large vein near the patient's neck. A circuit is created through which the patient's blood is withdrawn and filtered through the dialysis machine, then replaced back into the patient's circulatory system. The patient's blood is filtered through a dialyzer, which functions as a semipermeable membrane, diffusing waste products from the blood into the dialysis solution (Brownbridge & Fielding, 1994).

There have been vast improvements in the use of hemodialysis with children, but it is by no means a perfect replication of the functions performed by the human kidney. The medical complications and cost of hemodialysis make it a less than ideal form of treatment (Travis, 1975). The symptoms of hemodialysis are caused by the rapid removal of fluid from the body. During a typical three to four hour hemodialysis treatment, over two liters of fluid and waste products are removed from the patient's blood. Symptoms include headaches, vomiting, muscle cramps, and fatigue (Travis). These tend to be increasingly present as more fluid is removed, making the end of treatment sessions particularly uncomfortable (Brownbridge & Fielding, 1994). Additionally, the sight of blood running through tubes and the alarms that sound on the equipment can be very anxiety provoking for the new hemodialysis patient (Travis).

Transplantation

Over the past few decades the success rates of renal transplants for pediatric patients have improved due to medical advances (Fischbach, Edefonti, Schroder, & Watson, 2005; Goldstein et al., 2006; Rianthavorn & Ettenger, 2005). Depending on the cause of renal failure, a new kidney serves to prolong the child's life, but is not always a

cure for the underlying cause of damage to the kidneys. Transplant kidneys come from either living or cadaveric donors. In Canada, the list of patients waiting for kidney transplants is long. Recent statistics show that the waiting recipients far outnumber the kidneys available to be donated (Canadian Institute for Health Information, 2005).

Kidney failure patients comprise 78% of all patients waiting for organ transplants. In 2000 alone, 3,085 patients were waiting for new kidneys, of which 3% were under the age of 15 (Canadian Institute for Health Information). In the same year there were 54 kidney transplants performed in patients under the age of 15. This number has seen a steady increase over the past decade (Canadian Institute for Health Information).

Receiving a transplant is generally considered the best treatment option for renal failure, but it is not without risks. There remains a high risk that the recipient's body may reject the new kidney. For adolescents, this occurs in approximately 23% of kidney transplants after five years (The Scientific Registry for Transplant Recipients, 2005). There is a long recovery period after receiving a transplant, which includes multiple visits to the hospital for monitoring. Individuals who receive kidney transplants must take immunosuppressant drugs their entire lives, which put them at risk for infection. With medical advances, such as hemodialysis and kidney transplantation, the lives of those with chronic renal failure can be extended and maintained, but concerns have been raised in regards to the psychosocial effects living with renal failure has on these individuals (Garralda et al., 1988; Rianthavorn & Ettenger, 2005; Wallace et al., 2004).

Adolescence

The age and developmental stage of the patient are important indicators of how his or her life is affected by renal failure and treatment (Garrison & McQuiston, 1989;

Goldstein et al., 2006; Hergenroeder & Brewer, 2001; Polinsky, Kaiser, Stover, Frankenfield, & Baluarte, 1987; Travis, 1976). Developmental issues can be viewed through two lenses: The first emphasizes the impact that chronic illness has on how children and adolescents develop; the second focuses on how the developmental stage of the child or adolescent influences their conceptualization of their illness (Garrison & McQuiston). As Council (1993) so aptly points out, children and adolescents who are living with a chronic illness go through the same developmental stages that any other child would. What would be considered a normal developmental task is made exponentially more difficult by the physical, mental, and environmental factors related to living with renal failure (Garrison & McQuiston). Adolescence is a time fraught with social tensions and stress (Erikson, 1968). The already rocky terrain of adolescence is made even more difficult by the symptoms and restrictions of a chronic illness.

Erikson

Erikson's (1968) stages of psychosocial development are helpful in understanding how age and development influence the psychosocial issues manifested in children with chronic illnesses (Eiser, 1985; Garrison & McQuiston, 1989; Travis, 1976). According to Erikson's (1968) developmental tasks, adolescence is defined by the search for identity. Individuals either resolve this crisis through identity synthesis, which is a "reworking of childhood and contemporaneous identifications into a larger, self-determined set of self-identified ideals;" or identity confusion, which is "an inability to develop a workable set of ideals on which to base an adult identity" (Schwartz, 2001, p. 9). These two states represent polar ends of a continuum. Erikson (1950/1963) believed that it was best to be near the middle of the continuum, but closer to the identity synthesis pole.

Identity synthesis is normally achieved through identification with peers and separation from parental figures to demonstrate independence (Garrison & McQuiston, 1989). The demands that renal failure places on an adolescent's time restrict the amount of social contact that he or she has. Physical limitations due to renal failure also limit adolescents' involvement in social activities. This makes it very difficult to identify with an appropriate peer group.

Using Erikson's theories, Marcia (1993) developed two dimensions of identity formation: exploration and commitment. Exploration is defined as "problem solving behaviour aimed at eliciting information about oneself or one's environment in order to make a decision about an important life choice" (Grotevant, 1987, as cited in Schwartz, 2001, p. 11). Commitment is "the adherence to a specific set of goals, values and beliefs" (Marcia, 1988, as cited in Schwartz, p. 11). From these two dimensions, Marcia (1993) devised four identity statuses, each representing a high or low degree of exploration and commitment. For example, identity diffusion is the state that is characterized by an individual who is apathetic, and does not engage in either exploration or commitment; identity foreclosure symbolizes the individual who has made a commitment to a certain identity, but without first exploring various alternatives; and identity achievement is representative of the individual who has searched for an identity and has chosen facets that he or she commits to (Schwartz). Due to the limited opportunities for patients diagnosed with renal failure to engage in exploration, they are more likely to enter a state of identity diffusion or foreclosure (Garrison & McQuinston, 1989).

According to Travis (1975) "being different is the touchstone of identity problems in the chronically ill adolescent" (p. 61). A key aspect of Erickson's (1968) stages is that

healthy adjustment includes the integration of a person's self-concept and the demands of their environment. Chronic renal failure places a large number of demands on an adolescent both physically and emotionally. By considering relevant developmental issues, Erikson's theory offers a means of identifying the areas of psychosocial adjustment that potentially pose the most difficulties for adolescents living with chronic renal failure. Erikson's psychosocial stages of development focus on how the interaction with one's environment plays a large part in the formation of identity during adolescence. The cognitive development during adolescence is also relevant when attempting to understand the challenges faced by patients living with chronic renal failure. This is the focus of Piaget's (1967) stages of development.

Piaget

Piaget (1967) describes the age of adolescence as the formal operational stage. During this stage of development, starting at the age of eleven, children begin to acquire the ability to think abstractly and hypothetically (Piaget & Inhelder, 1969). Piaget and Inhelder identify this as the stage where adolescents develop the ability to adapt to their present reality, but more importantly, they develop the ability to see beyond the here-and-now. Eventually, adolescents are able to grasp the possibilities that his or her choices hold (Inhelder & Piaget, 1958). Until this developmental milestone is achieved, the adolescent's ability to foresee the consequences of his or her actions is limited. For children who have renal failure this may manifest in noncompliance with medical regimens (Garrison & McQuiston, 1989). Hemodialysis and other medical treatments come with immediate and undesirable side effects, making it difficult for adolescents to look beyond the side effects and foresee the long-term benefits.

As the adolescent acquires the skills for formal operational thought, he or she pays particular attention to existential issues (Inhelder & Piaget, 1958). These issues are especially difficult for adolescents living with a chronic illness because of the very real possibility of premature death (Garrison & McQuiston, 1989). This reality can make it difficult to experience hope for the future, another factor exhausting the adolescent's motivation to adhere to medical regimens (Maikranz et al., 2006).

During adolescence the development of a value system, by internalizing societal ideals and theories, serves as a foundation upon which a life plan is built (Inhelder & Piaget, 1958). A key feature of adolescent development is an inherent need to change society. The adolescent "feels he has to work out a conception of life which gives him an opportunity to assert himself and to create something new" (Inhelder & Piaget, p. 342). For adolescents diagnosed with chronic renal failure this need to be assertive and self-sufficient is compromised by the lack of control they experience in their lives due to illness (Garrison & McQuiston, 1989). By considering the developmental tasks that challenge adolescents, the ways in which chronic renal failure possibly impede psychosocial adjustment and development become more evident.

Psychosocial Issues Related to Renal Failure

General Psychological Adjustment

There is little debate that the effects of chronic renal failure can have a negative impact on the psychological adjustment of children and adolescents. Fielding and Brownbridge (1999), Fadrowski et al. (2006), Garralda et al. (1988), and Goldstein et al. (2006) have found that children and adolescents who have chronic renal failure are more prone to experience psychological problems than healthy control groups. Garralda and

colleagues conducted a study investigating the psychiatric adjustment of renal failure patients (non-dialysis and dialysis patients) and a non-patient group. The children involved were between the ages of 2 and 18 years. Data was gathered from multiple sources, such as the patients, parents, and the school environment. Standardized instruments were used to assess the children's psychiatric functioning, which included the Birleson Depression Inventory and the Lipsitt self-concept scale. Garralda et al. compiled their data and created a composite psychiatric rating scale. They found statistically significant differences between the groups' scores. There was a high prevalence of poor psychiatric adjustment in both groups of renal failure patients. Children in both the dialysis and non-dialysis groups reported significantly higher rates of anxiety and worrying than the controls. Definite global psychiatric disturbances were found in approximately one third of the dialysis group. Garralda et al. found that these were emotional and mixed conduct-emotional disorders. Magrab (1975) suggests that these issues should be viewed as already preexisting and are only exacerbated by the stress of hemodialysis treatment. Understandably, determining cause and effect is ethically impossible. Nevertheless, a correlation exists between psychological maladjustment and renal disease treatment.

The physical symptoms of renal failure are related to poor psychological adjustment, manifested in anxiety and depression amongst children and adolescents diagnosed with the disease (Fielding & Brownbridge, 1999; Garralda et al., 1988); however, the psychosocial effects extend beyond the presence of poor psychological adjustment. The omnipresent nature of chronic renal failure can reach the very core of how children and adolescents perceive and construct their sense of self.

Self-Concept

Eiser (1985) broadly defines self-concept as “any aspect of a sense of self, including an idea of personal likes and dislikes, successes and failures, or interactions with others” (p. 9). According to Eiser, the extent in which chronic illness influences a child’s self-concept is dependant on whether or not the illness challenges the central characteristics of his or her self-concept. Information that is inconsistent with the way that they define themselves will be difficult to integrate with their self-concept (Eiser). For example, if a child identifies herself or himself as an athlete and renal failure limits her or his involvement in sports, the child will have a conflicted sense of self. According to Erikson’s model of development, if the demands of chronic renal failure are not integrated into the adolescent’s concept of self, development is impeded. Garralda and colleagues (1988) found that children and adolescents diagnosed with ESRD had higher rates of poor self-concept, an overarching issue associated with patients’ lack of independence and poor body image.

Peer relations have a large impact on defining the adolescent’s self-concept (Erikson, 1968). Having to miss school and social events interrupts the adolescent’s social development. Primary peer relations tend to be limited to the family members and the hospital staff. These strong relationships serve as proxies for the peer relationships that these children and adolescents are isolated from (Travis, 1975). Therefore, the function and qualities of these relationships should be taken into consideration when addressing issues related to self-concept (Teyber & Littlehales, 1981).

Devins et al. (1997) note that a patient’s self-concept is often heavily influenced by the central roles they play. ESDR limits the roles that adolescents can play by

removing them from school and social environments. For some patients “the self is defined exclusively in terms of one’s disease, its treatment, and related experience” (Devins et al., p.530). Devins and colleagues investigated the relationship between self-concept, age, and the psychosocial impact on patients diagnosed with ESRD. By using a number of standardized tests and self-report measures, they assessed 49 adult patients maintained on dialysis and 52 adult renal transplant recipients for self-concept and illness intrusiveness in relation to their age. The mean amount of time participants had been diagnosed with ESRD was five years. The mean age of the entire sample was 43.5 years. Within their findings Devins et al. refer to participants entering their early adult years; however, no age range was given leaving the generalizability of their findings and their definition of early adult years questionable. Self-concept was assessed through a self-report measure that determined how closely patients identified themselves as being “the chronic kidney patient” (Devins et al., p. 530).

Devins et al. (1997) hypothesized that patients diagnosed with ESRD entering their early adult years who identified their illness as a central aspect of their self-concepts would show lower psychosocial adjustment. Contrary to their hypothesis, Devins and colleagues found that younger adult patients who saw their self-concepts as dissimilar to that of “the chronic kidney patient,” experienced poorer psychosocial well-being due to the intrusiveness of their illness. Younger patients who identified themselves as being similar to “the chronic kidney patient” showed increased well-being, despite the intrusiveness of their illness (Devins et al., 1997). The authors speculated that younger patients with ESRD who had effectively integrated their illness as part of their self-concept were more capable of adapting their aims to what they could realistically

achieve. Devins et al. believe that this adaptation to reality is indicative of more effective coping strategies, which result in better psychosocial adaptation. In contrast, young adults who maintain self-concepts that ignore the realities of renal failure may subscribe to goals that are out of reach. As symptoms and treatment for ESRD progressively disrupt and limit meaningful activities for patients, the more likely they are to show lower psychosocial well-being (Devins et al.). Devins et al. conclude that interventions to help patients adapt to living with ESRD should take into consideration the developmental stage of the patient (Devins et al.).

During adolescence, as part of the development of one's self-concept, physical appearance is often of high importance. Physical appearance becomes one of the most accessible ways for adolescents to express their identity. The physical differences caused by chronic renal disease can make body-image issues a concern for this population (Garrison & McQuiston, 1989).

Body image

“Body image is a term frequently used to describe how an individual mentally represents or perceives his or her body. It can also include an individual's attitudes and feelings about physical, emotional, and interpersonal views of oneself” (Malchiodi, 1999, p 20). For the adolescent with renal disease, the expected normal body changes during puberty coupled with stunted growth, swelling from retained body fluids, weakness, and scarring from multiple surgeries, often makes it very difficult to develop a positive self-image (Reynolds et al., 1986; Travis, 1975). Garralda et al. (1988) linked somatic symptoms to psychological issues, such as low self-concept, experienced by patients undergoing hemodialysis treatments.

Most children diagnosed with renal failure are significantly smaller for their age (Garalda et al., 1988). Through systematic interviews with adolescents diagnosed with chronic renal failure, Reynolds et al. (1986) found that the issues for patients related to growth and short stature were as equally anxiety provoking as the illness itself. Being of short stature made finding clothes that fit, and were age appropriate, a major concern for these teenagers. They were also often refused entry to age restricted events based on their physical appearance (Reynolds et al.). Reynolds et al. found that teenage boys were especially negatively affected by their short stature. They were often teased and bullied, and could not keep up with their peers while participating in physical activities. Reynolds and colleagues found that teenage girls most often had concerns relating to boyfriends and worried about whether or not they would ever get married. Concerns about scars and short stature led them to believe that they would not find a partner who would find them attractive (Reynolds et al.).

Although these issues may not seem as serious as other physical symptoms of chronic renal failure, in light of the developmental issues faced by adolescents, poor body image and stunted growth greatly restrict the opportunities these adolescents have to express their individuality and independence.

Dependence and Lack of Control

The teenage years are meant to be the time where independence is fought for (Erikson, 1968). For the patient with chronic renal failure there is little opportunity for independence. In fact, during the child's younger years, "the normal developmental surge for self-control... is largely defeated by the adults who drive him in the direction of submission, dependence, and passivity" (Travis, 1975, p. 214). This is especially a

concern for adolescents who are attempting to resolve developmental tasks related to their autonomy and identity (Rianthavom and Ettenger, 2005). Dialysis treatment basically immobilizes patients, requiring them to rely heavily on medical staff and family members. Since dialysis is a life maintaining treatment there is little flexibility in terms of treatment schedules. Patients generally see the time that is spent on hemodialysis as unproductive (Weldt, 2003). This lack of control is usually a very frustrating experience for an adolescent living with ESRD (Garralda et al., 1988; Garrison & McQuiston, 1989).

Children and adolescents with ESRD on hemodialysis often display regressed behaviour in two ways. One is in terms of neurological delays caused by the disease. Patients often exhibit cognitive impairments related to the illness, which result in developmental delays (Garalda et al., 1986; Rainthavorn & Ettenger, 2005; Travis, 1975). Children and adolescents also display psychological regression, which serves as a defense mechanism to cope with the infringement and lack of independence imposed by the treatments they undergo (Garrison & McQuiston, 1989; Travis; Weldt, 2003).

This lack of independence has been shown to carry over into patients' later stages of life. Rosenkranz et al. (1992) conducted a survey to assess the psychosocial adaptation and educational statuses of 479 children and adolescents living with chronic renal failure who were receiving treatment in Western Germany nephrology centers. The mean age of the patients at the time of assessment was 13.6 years of age, with 64% of the patients falling between the ages of 7 and 18 years. Patients who were under 6 years old made up 16 % of the sample and those who were over 19 years made up 20% (no age range was given). Patients were either (a) receiving conservative treatment, (b) on hemodialysis, (c) another form of dialysis, or (e) had received a transplant. Rosenkranz and colleagues

found a lack of vocational training opportunities amongst the adolescents (13 to 18 years old) receiving hemodialysis treatments. In addition, 86% of patients over the age of 17 did not display levels of independence that would be appropriate for their age group (Rosenkranz et al., 1992). They attributed these findings to the delayed psychological development and poor psychological adjustment related to the disease itself, as well as the disruption and limitations that treatment for chronic renal failure placed on vocational training opportunities.

During adolescence, patients with chronic renal failure often feel a lack of control over their lives based on the dependency that they have on medical staff and treatment. In order to feel that they retain control over their lives, adolescent patients can challenge the dependency they experience by choosing not to adhere to treatment regimens (Garralda et al., 1988).

Treatment Adherence

Research has shown that there is a relationship between psychosocial adjustment and treatment adherence amongst pediatric patients diagnosed with chronic renal failure. Garralda et al. (1988) found that amongst the group of children and adolescents on hemodialysis, marked psychological disturbances negatively correlated with treatment adherence. Therefore, children and adolescents who showed poor psychological adjustment were less likely to adhere to treatment.

Brownbridge & Fielding (1994) completed a study that explored the relationship between patients' psychosocial adjustment and their adherence to diet restrictions and medical regimens. The study included 60 children and adolescents already undergoing or starting hemodialysis treatments over a period of two years, living in the United

Kingdom. The mean age of the patients was 13.5 years, ranging from 2 to 21 years old. The mean duration of hemodialysis treatment for the patients was 19 months, ranging from one month to six years. Standardized questionnaires were used to assess patients' anxiety, depression and behavioral disturbance. They found a positive correlation between low treatment adherence and poor adjustment to diagnosis and dialysis. Higher rates of anxiety and depression were also positively correlated with lower rates of treatment adherence. Interestingly, patients who had a greater desire for a kidney transplant showed lower treatment adherence. Age negatively correlated with treatment adherence meaning that older patients tended to show less treatment adherence (Brownbridge & Fielding). These findings suggest that the specific developmental issues experienced by adolescents are relevant to treatment adherence issues amongst ESRD patients.

Erikson's (1968) theory of development is useful in understanding the issues that may lead to nonadherence among adolescents living with ESRD. For adolescents who have renal failure, teenage rebellion, can take the form of refusing to take medication or not adhering to dietary restrictions (Brownbridge & Fielding, 1994; Travis, 1975).

Treatment adherence among adolescents is a serious issue having severe consequences. In Canada, between 1990 and 1999, the leading cause of death amongst pediatric renal failure patients (under 18 years old) was attributed to social causes, such as drug abuse, suicide, and refusing to continue treatment (Canadian Institute for Health Information, 2001).

Treatment adherence is especially important for renal transplant recipients.

Current statistics regarding the outcome of transplants for adolescents are concerning.

Adolescents (11 to 17 years old) show the second lowest transplant survival rate after five years (77.3%) compared to all other age groups (The Scientific Registry for Transplant Recipients, 2005). Non-adherence is believed to be a major factor in transplant failure among adolescents (Maikranz et al., 2006; Rianthavorn & Ettenger, 2005). Over 12% of all renal transplant failures in adolescents were found to be a result of not adhering to medication regimens, which is four times the occurrence found in adults (Rianthavorn & Ettenger). Rianthavorn and Ettenger acknowledge that the actual incidence of non-adherence among adolescents diagnosed with ESRD is largely unknown. Self-reporting represents the most common method of determining treatment adherence; however, its reliability often is questionable. Patients who either do not realize the consequences of not adhering to their treatment regimen, or those adolescents who actively make a choice to not adhere to treatment regimens tend to not admit to these behaviours (Rianthavorn & Ettenger).

According to Piaget's (1967) theory of development, without the transition into formal operational thought, adolescents are unable to think outside of their present circumstances. Rianthavorn and Ettenger believe that the tendency for adolescents diagnosed with ESRD to not comply with treatment regimens is related to an undeveloped ability to foresee the long-term consequences of their immediate actions. Even though this is a difficult developmental task for "healthy" adolescents, it is vital to understand that for adolescents with ESRD it is compounded by developmental delays caused by the illness itself (Rianthavorn and Ettenger). Rianthavorn and Ettenger stress that when assessing patients with ESRD, developmental principles should be used to

determine the stage at which they are functioning, as biological age is not a reliable indicator.

Maikranz et al. (2006) investigated the relationship between hope and illness-related uncertainty to the psychosocial functioning and treatment adherence among pediatric patients receiving renal and liver transplants. Maikranz et al. used Snyder, Irving and Anderson's (1991) definition of hope as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal directed energy) and (b) pathways (planning to meet goals)" (p. 287). Over a period of three months, 70 pediatric patients, aged 7 to 8 years, and their caregivers were given questionnaires to assess perceptions of hope and illness uncertainty, while treatment adherence was assessed through self-report and monitoring through blood tests. They found that patients who did not exhibit depressive symptoms, but had high levels of hope and low levels of illness uncertainty were more likely to adhere to treatment (Maikranz et al.).

The literature involving children and adolescents diagnosed with chronic renal failure has indicated that the unique experience of the illness and its treatment affects multiple facets of their lives. Research has focused on the areas that pose psychosocial challenges for this specific population. Children and adolescent patients living with chronic renal disease tend to show poorer psychological adjustment, self-concept, and body image (Devins et al., 1997; Fielding & Brownbridge, 1999; Fadrowski et al., 2006; Garralda et al., 1988; and Goldstein et al., 2006; Reynolds et al., 1986; Travis, 1975). These issues have been shown to be particularly difficult for adolescent patients. Over dependency and a lack of control is a concern for this population (Rianthavom & Ettenger, 2005). Recent research has focused on the serious issue of treatment adherence

amongst adolescent patients diagnosed with chronic renal disease. A link has been made between poor psychosocial functioning and low adherence to treatment regimens (Brownbridge & Fielding, 1994; Garralda et al.).

Living with chronic renal failure poses many challenges for the adolescent patient. Adolescent patients are not only dealing with the symptoms of the disease, but also the effects of treatment. The normal developmental challenges faced by this age group are compounded by the limitations and restrictions imposed by chronic renal failure. Although medical advances have vastly improved the survival rates for adolescents diagnosed with kidney disease, concerns over their psychological adjustment and development has led to a body of research that identifies a need for interventions that address these issues (Brownbridge & Fielding, 1994; Devins et al., 1997; Fielding & Brownbridge, 1999; Fadrowski et al., 2006; Garralda et al., 1988; and Goldstein et al., 2006; Reynolds et al., 1986).

Psychosocial Interventions

Common Approaches

Although there is a large body of research indicating a need to provide interventions that address the psychosocial issues faced by children and adolescents living with chronic renal failure, there exists little research exploring the use of interventions for this population. Because of their extended contact, the nursing staff often find themselves providing emotional support for patients with chronic renal failure (Teyber & Littlehales, 1981).

Although it has commonly been the pediatric psychologist's role to advocate for the emotional and psychological wellbeing of patients, Magrab (1975) and Fischbach, et

al. (2005) recommend that a multidisciplinary team be formed to address the encompassing psychosocial issues faced by children and adolescents being treated for chronic renal failure. Teams usually include the medical staff, dietitian, social worker, pediatric psychologist or psychiatrist, and child life specialist.

It is common practice today for hospitals to employ child life specialists who are trained to support children's adjustment to the hospital environment (Child Life Council, 2007). They provide age appropriate activities that help prepare patients and offer support to patients during medical procedures. Child life specialists often use therapeutic play methods, which include the use of dolls and medical play to demonstrate procedures. Their goal is to "minimize the negative impact of situational disruptions while maintaining individual growth and development and family relationships" (Child Life Council).

Supportive group therapy has been used to allow pediatric patients on hemodialysis to share their emotions, as well as to provide opportunities to interact with and feel connected to a peer group (Magrab, 1975). Magrab constructed a pilot project that used a token economy program to encourage treatment adherence amongst pediatric patients on hemodialysis. When the patients' blood levels showed they were adhering to their treatment regimens they were given points that could be exchanged for rewards. Patients were also awarded group points when all patients adhered to their treatment. Points could be exchanged for toys for the unit, special time with the staff members, and outings. Magrab reported that there was an immediate improvement in the children's treatment adherence.

Although these interventions provide much needed support to children and adolescents diagnosed with chronic renal failure, the research suggests that a variety of interventions should be introduced to address the psychosocial effects these patients are dealing with. Art therapy is a viable and appropriate therapeutic intervention that provides patients with opportunities to express and deal with the issues they face.

Medical Art Therapy

Medical art therapy is a growing field that involves using art therapy within healthcare settings to help individuals cope with the psychosocial issues of being ill. “Medical art therapy is a term which has been applied to ‘the use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body, or who are undergoing aggressive medical treatment such as surgery or chemotherapy” (Malchiodi, 1993, p. 2).

Cathy Malchiodi is the leading art therapist in this field. She states the following about the utility of medical art therapy:

Because it encompasses both the creative process and self-expression, art is recognized for its therapeutic role in helping children cope with stresses and short and long-term sequelae associated with physical illness, impairment, or injury, medical procedures such as surgery or pharmacological interventions, and hospitalization. (Malchiodi, 1999, p. 13).

Malchiodi (1999) also notes that despite the inherent benefits of using art in these situations there is little research available in this area of art therapy. Comparatively, there is very little literature available regarding the use of art therapy with pediatric patients diagnosed with chronic renal failure. However, literature available that describes how art

therapy has been used with other pediatric populations, such as patients diagnosed with cancer, offers suggestions of how art therapy interventions can be used to deal with the psychosocial issues these populations often share.

Assessment

Malchiodi (1999) states that art-based assessments provide therapists, as well as the medical team, information relevant to the patient's psychosocial functioning. Art therapy assessments can also be useful to determine the developmental stage or cognitive functioning of the child (Malchiodi). This would be especially valuable with patients experiencing renal failure to assess their use of regression as a coping skill and how patients are affected by the cognitive symptoms of the disease.

Wallace, et al. (2004) asked kidney transplant recipients visiting a renal clinic during a period of six months to participate in the study. They tested 64 patients between the ages of 6 and 21 years old. They measured the prevalence of depression and posttraumatic stress by using the Formal Elements Art Therapy Scale (FEATS) and two self-report assessments. Out of the 14 FEATS scales, they used 7 (prominence of color, color fit, implied energy, space, realism, details of object and environment, and person), elements that have all been linked to severe depression. Since FEATS was not originally standardized for use with children, normative scores for the age group were taken from 332 school-aged children. Wallace et al. found that unlike the self-report assessments, all participants were able to complete the FEATS assessment, regardless of age. They found that 36% of the pediatric renal transplant recipients had symptoms of depression and post-traumatic stress disorder. Although FEATS was shown to be helpful in identifying depression in pediatric and young adult patients who had undergone a renal transplant,

the arts based assessment lacked sensitivity in identifying depression in the pediatric sample compared to the self-report assessment. Wallace et al. admit that the validity of their study could be limited due to the fact that the FEATS assessment was originally standardized for an adult population diagnosed with severe depression, and was never intended to be used with a pediatric population. Wallace and colleagues state that the elements the FEATS scales focus on overlook the image as a whole, which could be a more sensitive means of assessing for depression in this population. Wallace et al. concluded that the study of more appropriate arts based assessments used with children within a medical setting is warranted.

Developing Self-Concept

During adolescence, patients usually have the capacity to understand the concept of death and the reality of their illness (Malchiodi, 1999; Travis, 1975). By engaging in art making, patients can express feelings about themselves and their situation, which they may not feel comfortable talking about. The artwork functions as a form of communication, but also as a tangible expression of the patient's sense of self (Malchiodi, 1999).

Art therapy can be used to help children redefine or protect their self-concept. Rollins (1990 as cited in Council, 1993, p. 78) notes the "humanizing influence" that art therapy has on children in a hospital environment where the majority of their interactions are with machines rather than with humans. Art therapy has been used to address self-concept issues with patients diagnosed with chronic illnesses such as cancer. Council (1993) describes a case example of a 5-year-old boy diagnosed with cancer who, after being subjected to distressing treatments and tests he immediately sat down to draw an

image of himself and requested that it be hung up in the clinic. Councilll suggests that this was a way in which the boy could state and protect his self-concept while it was being compromised by invasive medical procedures. Another case presented by Rode (1995) describes how a child diagnosed with cancer used videotapes of herself performing dance routines and plays as way to preserve her self-concept, despite her physical deterioration. When her health worsened and she was no longer able to walk, she was able to watch the videos of herself and present them to her visitors so as to keep her self-concept intact.

In one of the few studies conducted involving art therapy and dialysis patients, Weldt (2003) investigated adult patients' responses to the drawing experiences as well as emergent psychosocial issues. All patients in this study were over the age of 30. The patients were asked to draw three drawings. One drawing was meant to represent the patient's body-concept and self-image. Participants were instructed to "draw a person from memory. Include the whole figure. For this drawing use grey pencils" (Weldt, p. 94). Interpretive protocols set forth by Bach (1990) and inductive reasoning were used to analyze and interpret the data collected. One of the emergent themes noted was the patient's sense of self. While all patients gave positive verbal descriptions of themselves, their self-portraits gave inconsistent information suggesting difficulty in integrating their illness into their self-concept. For example, one patient, whose wish was to be independent, completed a self-portrait that depicted a woman with very small proportioned light blue feet. Bach (1990) identifies light blue to possibly represent a loss of vitality. Also, the proportion of her feet may have symbolically represented her lack of mobility (Weldt). These findings suggest that art therapy is useful by providing additional information about a patient that would otherwise not be verbalized. In addition to the

usefulness of art therapy to assess patients, Weldt found that there were therapeutic benefits. All participants in Weldt's study gave positive feedback about their art therapy experiences. Patients reported that they felt their treatment time went by quickly and they were able to better express their emotions through their drawings than verbally.

Control and Empowerment

The very nature of the creative process allows children complete freedom in an environment where it is lacking. Rode (1995) states that art therapy creates a transitional space where children can create structure and order with art materials. Bach (1990) notes the necessity of choice when it comes to art therapy interventions. To truly give control over to the child, the art therapist must give them the choice of whether or not to make art at all (Bach). This sense of total control facilitates autonomy in the patient (Nishida & Strobino, 2005). By engaging in the creative process children can gain a sense of mastery, which helps them deal with feelings of helplessness (Malchiodi). Children can depict medical procedures to gain better understanding and familiarize themselves with what is being done to their bodies. According to Malchiodi (1999), while children are often forced to remain passive during medical procedures, art therapy interventions give them the opportunity to become active and regain a sense of control.

Body Image

The art images made by children with chronic illnesses can provide healthcare providers a glimpse of how these children comprehend and view their body image, while also helping to identify and understand their physical symptoms (Malchiodi, 1999). Art therapy has been used with other adolescent populations who suffer from poor body image such as those diagnosed with anorexia (Malchiodi). As Malchiodi suggests, a

simple body outline can be drawn where patients can visually represent the physical symptoms of their illness and how they see themselves. Van der Vlist, Wolff, Nanta, and Van deVen (1989) present a case example of a 15- year-old boy diagnosed with chronic renal failure, who had been on hemodialysis, and undergone three kidney transplants, the third of which was successful. Van der Vlist et al. found that being physically different was an emergent theme within the boy's drawings. While on hemodialysis he drew pictures of himself as being overweight and described himself as "a fatty," clearly referring to the physical symptom of fluid retention. He was also able to depict the painful side effects of the treatment by drawing self-portraits. Van der Vlist and colleagues advocate the use of art to facilitate adjustment and the expression of emotions related to the physical changes that occur in adolescents diagnosed with chronic renal failure.

The fact that art therapy can be offered during dialysis treatment offers both positives and negatives. While Weldt (2003), and Nishida and Strobino (2005) found their patients enjoyed having meaningful activities during treatment, the hemodialysis units were noisy and offered little privacy. There were many interruptions by medical staff, which may have limited the patients' disclosures about their images. Although these environmental factors were disruptive, Nishida & Strobino found that they gained more insight into how their clients experienced their treatment environment. Nishida & Strobino also found that art therapy encouraged positive interactions between patients and hospital staff.

Conclusion

Chronic renal failure is a disease that becomes embedded in every aspect of life for a child or adolescent. The physical symptoms and treatments have a profound effect on the patient's everyday life. Adjustment and adaptation to the limitations of having a chronic illness becomes an important part of development for these patients. This is particularly true for adolescents. The developmental tasks that this age group is striving for, such as gaining independence and a sense of identity, are often counter to the demands of chronic renal failure such as dependence and limited social interactions. Serious issues such as psychosocial adjustment and treatment adherence are in need of intervention.

Art therapy literature in related populations suggests that art therapy could help these patients cope with the psychosocial effects of chronic renal failure (Councill, 1993; Malchiodi, 1999). According to Nishida and Strobino's (2005) findings, an art therapist would be a valuable addition to the multidisciplinary renal team. The lack of literature on the use of art therapy with pediatric renal patients compared to the disease's prevalence emphasizes the need for further research in this area.

Present Research – Rational

The primary aim of this case study research is to explore how art therapy can be used within the unique context of hemodialysis treatment with a female adolescent patient diagnosed with ESRD. The literature points to a number of psychosocial issues for this particular population and demonstrates a need for therapeutic interventions. Because art therapy has been used with other medical populations and recognizing the particular issues and experiences faced by pediatric patients on hemodialysis, the present

study questions how art therapy interventions can benefit this population. This case study serves as a preliminary study in which questions and suggestions will be made to encourage further research.

The population has been delimited to a female adolescent undergoing hemodialysis treatment three times a week at a children's hospital in a large urban centre. The case study does not attempt to make any causal links, and findings will be specific to the experiences of the participant involved.

Research Questions

Primary Research Question

How can art therapy be used to address the psychosocial issues experienced by an adolescent female diagnosed with chronic renal failure?

Subsidiary Research Questions

- 1) How can specific developmental theories provide further understanding of a patient's psychosocial issues?
- 2) How are arts-based interventions potentially useful when working with an adolescent patient?

Methodology

Setting and Context

When collecting data for a case study, researchers must consider the context from which they were taken (Stake, 1995). Data can be influenced by "temporal and spatial, historical, political, economic, cultural, social, and personal" factors (Stake, p. 43). A description of the case's context helps paint it as both a unique and typical situation. The hemodialysis unit is a unique setting that varies greatly from the context of the patient's

home or school environment, yet it gains a sense of ordinariness when compared to descriptions of other pediatric hemodialysis units. The hemodialysis unit was a single large room, approximately 400 square-feet, which offered dialysis treatment to a maximum of six pediatric patients. The patients' chairs were lined up side by side along the wall facing the door. The amount of space taken up by the dialysis machines, medical equipment, and storage left little room for the hospital staff and family members to move about. The room was brightened with murals and seasonal decorations put up by the child life specialist on the unit. There were windows in the room but the children's chairs were positioned facing away from them.

A description of the setting in which I was working is vital in understanding how the art therapy sessions were managed by the client and myself. Malchiodi (1993) notes that the context in which medical art therapy is offered differs from that conducted within psychiatric settings. Privacy is not always possible when art therapy is conducted on open units. On the hemodialysis unit there were curtains that could be pulled for minimal privacy, but these were rarely accessible because of the placement of the chairs and were seldom used because the nursing staff needed to continually monitor the patients' health and the hemodialysis machines. The room was often very noisy with staff members talking, patients crying, and machine alarms sounding. Interruptions during the art therapy sessions were commonplace due to the patient's need for medical attention, as well as the curiosity of staff members and other patients.

Recruitment

The site and participant were selected as part of my second year internship. The patient, who will be referred to as Violet, was referred for art therapy sessions by the

child life specialist working on the ward. I shared the role of researcher and art therapist, which was explained to Violet during the initial session. Parental consent and Violet's assent were obtained for this study. A Preliminary Consent Form (See Appendix A) was signed by Violet and one of her parents during the initial therapy sessions. Once the proposal for the present study was reviewed and approved of by the university, Violet and her parents were provided with a Letter of Information (See Appendix B) and an Informed Consent Form (See Appendix C), which they both read and signed.

Participant

Personal & Demographic Description

Violet was a 14-year-old female patient, undergoing tri-weekly hemodialysis treatments for ESRD at a children's hospital, located in a large urban centre. One of the first things I observed about Violet's physical appearance was her small stature. Her medical records showed her height and weight fell below the third percentile for her age group. Violet's appearance was often unkempt; her hair was not brushed, and she usually had make-up smudges under her eyes, which was often a result of having to wake-up early to be transported to the hospital for treatment. Although Violet's affect was often playful and she was able to joke around with the staff members and other patients, she could be quite standoffish and distant, acting indifferent towards any provisions made for her. She was often observed complaining to the nursing staff about the hospital food or being bored.

Violet lived with her parents and eight-year-old brother. Her father worked long hours. Violet stated that he left very early in the morning and was usually very tired when he came home. Her mother worked fulltime at a restaurant and had a university degree in

psychology. Due to her parent's busy schedule, Violet came on her own for treatment by transportation arranged and provided by the hospital. Her hemodialysis treatments lasted for approximately 5 hours a day, starting early in the morning. On the days Violet was not on dialysis she attended public school and while at the hospital she had a tutor work with her on homework assignments.

Beginning Diagnosis/Clinical Impressions

Violet was diagnosed with cystinosis at an early age. It is a recessive hereditary disorder, meaning that both her parents were carriers of the recessive trait (Broyer, Tete, & Gubler, 1987). Cystinosis is a disease where amino acids build up and crystallize within the body causing damage to cells. Damage especially occurs to the kidneys and eyes (Broyer et al.). Violet was also diagnosed with metabolic bone disease (caused by ESRD) and had moderately severe asthma. Violet displayed high anxiety before having medical procedures and often refused them. Nursing staff had, in certain cases, administered sedatives to help calm Violet before these procedures.

Medical History

As was predicted by the prognosis of cystinosis, Violet was diagnosed with ESRD at the age of 10. A year after beginning hemodialysis treatment, Violet received a renal transplant from her mother. The following year she developed an acute cellular rejection of the transplant, which was never resolved despite multiple attempts to suppress it with immunosuppressant steroids. After two years, Violet was in the advanced stages of renal failure and needed to begin hemodialysis treatments again. She was reluctant at first, but said that she had been feeling "bad lately" and agreed with her physician that she needed to begin treatments. In the following months, Violet's fluid retention and blood pressure

reached dangerously high levels. Due to concerns over the long-term impact on Violet's central nervous system, plans to remove her transplant were discussed. Violet accepted the need for the operation.

Just prior to the beginning of the art therapy sessions, team members reported in rounds that Violet had been experiencing nausea and significant weight loss. She had refused a trial of nutritional supplements, and was currently not adhering to any diet restrictions (a low potassium and low sodium diet, and 1.5L of fluid per day). Despite medical requirement, her blood pressure was not being measured regularly at home.

Goals and Initial Treatment Plan

The initial therapeutic goals of the art therapy sessions were to develop an alliance with Violet and a time and space in which she could express her emotions, needs and desires. Art therapy sessions were planned to help promote Violet's independence and autonomy. Violet stated that she was often bored during her dialysis treatment and said she needed more meaningful activities to fill her time.

Case Study Methodology

Due to the exploratory nature of this research, a qualitative case study methodology was both appropriate and feasible. The questions being investigated could not be answered with a yes/no or true/false statement, and require a more elaborate inquiry. As Yin (1994) states, "how" and "why" questions, which do not lend themselves to quantitative study, are better explored through qualitative methods. A case study method allowed me to explore my research questions in a context where multiple variables could not be manipulated nor controlled. Berg (2004) comments that case

studies are “able to pick up nuances, patterns, and more latent elements other research methods overlook” (p. 251).

The criterion for evaluating qualitative case studies is based on the study’s trustworthiness (Lincoln and Guba, 1985). Case studies allow for the collection of detailed data in the interest of providing the best understanding of the participant’s experiences (Yin, 1994). Stake (1995) fittingly uses the term “experiential understanding” to describe this attribute of qualitative case studies (p. 37). Lincoln and Guba state that a study’s credibility can be increased through “prolonged engagement” with the phenomenon (p. 301). Over a period of seven months I remained present on the hemodialysis unit for extended periods of time and was able to observe Violet in and outside of therapy sessions. I was witness to the entire treatment process and the routine medical procedures that Violet experienced on a weekly basis. I also observed her interactions with other patients, family members, and the nursing staff.

Data used in case studies are characterized as being rich, detailed, and in-depth (Berg, 2004). By collecting data from a variety of sources, case studies hope to present a well-rounded depiction of the identified phenomenon (Berg). This increases the study’s transferability and dependability (or in quantitative terms, validity and reliability). Data can include life histories, documents, oral histories, in-depth interviews, and participant observation (Berg). By triangulating multiple data sources the researcher can compare and contrast her findings relating to the same phenomenon in question (Yin, 1994). This addresses the credibility and dependability of a study by ensuring that one depiction of the phenomenon correlates with another. In the present case study, verbal data, observed behaviours, and the client’s artwork served as multiple data sources used to explore the

same phenomenon. Direct quotes and participant artwork have been included in the present study to increase the study's transferability, and dependability. This "thick description" allows the audience to view the data without having to look through the subjective filter of the researcher (Stake, 1995).

To address dependability and confirmability the researcher's methods need to be explicitly stated so that any other researcher could conduct a similar study (Yin, 1994). Ideally the entire process of the study should be clearly laid out and linked to each part of the study (Yin). By defining and clearly outlining my research procedure, others are able and invited to critically analyze my research methods to determine its strengths and weaknesses.

Member checking is a research tool used to address the credibility of qualitative research (Stake, 1995). It involves the researcher presenting his or her conclusions to the participants, asking if they accurately reflect their experiences. At the conclusion of the therapy sessions I reviewed Violet's artwork with her. I took this opportunity to present my preliminary findings and ask her if they were representative of her experiences. Violet agreed with the themes I have presented in this study and identified them as being important to understanding her experiences.

Qualitative Data Collection

After each art therapy session I recorded detailed process notes in a private room. My process notes included Violet's presentation that day, a description of the artwork, the art making process, my own associations to the images, as well as a reflexive portion. The artwork created during the art therapy sessions were documented by taking digital photographs. Multiple sources of data were collected for the purposes of triangulating my

findings. These included Violet's medical charts, information provided by staff on the health care team, and observations of the interactions between Violet and her parents.

Data Analysis

The process of data collection and data analysis in case study research usually occurs in a simultaneous manner (Stake, 1995). This allowed the research questions, literature, and theory to guide my research, while remaining flexible to the issues that emerged in the art therapy sessions. I followed Marshall's (2006) analytic procedures for qualitative research to organize, and categorize my data, and form interpretations. I spent time rereading my process notes and the information I had gathered from the nursing staff and family members. After immersing myself in the data, I coded my notes by highlighting key words and phrases. These key words and phrases were then categorized. I was able to pull out the most prevalent categories and themes from the data using this analytic procedure.

Reflexivity and the Researcher's Role

Stake (1995) describes the researcher's subjectivity as one of the main issues that need to be considered when conducting case study research. This is directly related to the trustworthiness and credibility of the study. Instead of acting as the expert on the phenomenon being studied as in quantitative research, qualitative case study researchers view their participants as the experts and try to come to understand the phenomenon through their participants' experiences (Yin, 1994). This being true, the subjectivity of the researcher is not denied in qualitative research. My own experiences and assumptions act as a lens through which I view Violet and her experiences. By keeping a reflexive

portion of my process notes I was able to consistently reflect on my thought processes and gain insight into how my subjectivity has possibly influenced my research.

By realizing and outlining my assumptions prior to conducting the present case study, I have tried to minimize the amount that they bias how I collect my data and what conclusions I draw. Based on the presented literature and my own similar experiences with chronic illness, I made the assumption that having to be treated for renal failure and being maintained on dialysis is a distressing experience for children, which negatively affects their psychosocial adjustment. By suspending this assumption, I was able to note the strengths Violet displayed. I was amazed by Violet's resilience. I also assumed Violet to represent a typical case within the larger population of adolescents on hemodialysis treatment. A detailed understanding of a typical case "increases the confidence that readers have in their (or researcher's) generalization" (Stake, 1995, p. 9). Stake comments that case study research emphasizes understanding a single case, and although it is unable to provide grand generalizations, a single case study can lead to the modification of generalizations.

Lincoln and Guba (1985) advocate for "peer debriefing" as a means of gaining the unbiased perspectives of peers" (p. 308). For the present study I had both academic and on-site supervision, with which I discussed the issues and questions that arose during my research process. I also met with a peer group once a month to discuss our research processes and were able to offer each other suggestions and bring up any potential issues.

Early on in the research process, I had hesitations in choosing to write a case study due to the challenging setting where the sessions were to be held. I had assumed that a traditional therapeutic frame would need to be adapted to suit the needs and

situations of my client. For example, I assumed that the session needed to be held behind closed doors with the assurance that there would be no interruptions. My advisor was able to point out that I was making an assumption based on what my training was based on. This setting was the antithesis of the above; privacy was thinly veiled by a curtain and interruptions were a guarantee. Because the setting was not consistent with a traditional therapeutic frame I was questioning the value and benefits of conducting therapy there. Following my advisor's advice, I allowed myself to challenge this assumption, and was able to come to my own conclusions informed by my observations and experiences of the present case.

I entered the site being aware of possible emotional triggers for myself. There were a lot of convergent points where my own life events paralleled those that I saw Violet experiencing. As a child I spent a lot of time in the hospital due to chronic illness and had major surgery in my early teens. I've experienced similar medical procedures to those that Violet has had. Being able to anticipate and prepare for these reactions has been very helpful in separating my own experiences from those of Violet. I was able to discuss some of these parallel experiences with my peers and supervisors, which allowed me to gain an unbiased perspective and limited how these experiences affected my research.

Taking on both a researcher and therapist's role was challenging. I was forced to continually compare my aims as a researcher to my therapeutic goals for Violet, making sure that my need to gather data did not compromise the therapy I was offering Violet. I was tempted to self-disclose to Violet my own experiences, but I made a choice to keep my personal experiences separate and remained focused on Violet's experiences.

Undoubtedly, my past experiences affected my responses to Violet; however, I kept a reflexive journal and discussed these potentially countertransferential issues in supervision.

Reflexivity was essential in negotiating the dual role of both researcher and therapist. The paramount goal of the art therapy sessions was to provide Violet with therapeutic benefits in her best interest. This process has not only provided me with a deep understanding of Violet's experiences, but also has helped me as a clinician, by putting my client's interests as first priority.

Case Study

Selection of Sessions

Sessions were held on average twice a week for an hour, depending on Violet's treatment schedule. We met for a total of 26 sessions during a 7-month period. I have chosen to include synopses of the sessions that were the most representative of the themes and issues that emerged relevant to the research questions. Understandably, my primary role was as therapist; therefore, there were many sessions that were therapeutically important, but were not relevant to the current research questions.

Therapeutic Approach

Within the art therapy sessions I took a non-directive approach. According to McNeilly (1983), themes within a non-directive art therapy approach may not be overt in their development, but tend to be more relevant since they have not been forced upon the client. A directive approach can elicit resistance from individuals who view the therapist as an authority figure (McNeilly). This is especially pertinent to consider when working with adolescents who are making efforts to gain their own autonomy and independence.

A non-directive approach can avoid these issues, while encouraging the client to become an active participant in their therapy (McNeilly). Bach (1990) emphasizes the importance of choice and not forcing any matter when working with chronically ill children. By taking a non-directive approach I hoped to emphasize Violet's autonomy and to empower her within the hospital setting.

*Session 1 (#1) **

Violet had shown no hesitation in accepting art therapy when it was offered to her, but was very aloof and guarded during our initial sessions. During our first session, she was wearing a t-shirt she had bought at a concert. "My Chemical Romance" was the band's name and the t-shirt was black with red and white gothic print. It had been the first concert she had ever attended. Violet said that her friend's stepfather went with them which meant they were able to do whatever they wanted. The enthusiasm with which she described the feeling of freedom and independence indicated that she was in the process of trying to distance herself from the parental restrictions that were normally placed on her; a common occurrence during adolescence (Inhelder & Piaget, 1958). She said that she had a good time but wasn't able to go in the mosh pit because of her dialysis line. Adolescents on dialysis treatment must be careful while engaging in physical activity so as to not damage or pull out their line, which could result in bleeding to death (Reynolds, et al., 1986).

I learned from the child life therapist on the unit that an art therapist had seen Violet when she first entered dialysis five years ago, and I asked if Violet could tell me about her experiences. She nodded and said quite plainly that her previous art therapist

* The first number represents the number of the session as discussed in the case study, while the second number denotes the actual therapeutic session.

was “weird and crazy. She always was trying to pull the curtains and wanted me to talk about my drawings. She wouldn’t let me take them home either.” I realized that this was a possible role that Violet’s transference would have me play in the future: “The crazy art therapist.” I would have preferred to pull the curtains for some privacy during our sessions, but for the reasons mentioned earlier this was not always possible. More importantly, Violet asked that they stay open. The only time the curtains were pulled was when Violet was having an invasive medical procedure done. The action of pulling the curtain had such a visceral effect that I chose to sacrifice privacy to allow Violet to feel safe during our sessions.

As I was aware of the difficulty I was going to have keeping a therapeutic frame in the hospital environment, it was important to maintain the boundaries which I was able to set in place. I explained to Violet that any artwork she made during our time together was solely hers, and that for its protection it would be kept at the hospital in a locked drawer until we finished working together. She shrugged her shoulders and asked me, “Now what?”

As a way to get to know Violet I suggested she do a drawing of the things that she liked, such as activities and interests. I offered her the art materials I had brought with me. She chose markers, a small sheet of paper, and began to draw with little hesitation. Violet’s drawing included elements she seemed comfortable drawing, such as flowers, a tree, and a sun (see Figure 2).

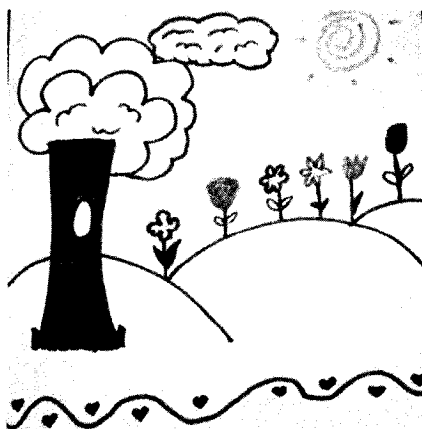


Figure 2 Violet's first image

She completed a pattern with a squiggly line and hearts near the bottom of the page. She then wrote her name in multiple directions overtop of one another creating a graffiti type image. This has been omitted from the drawing to maintain confidentiality. She completed two additional drawings during the session, one of which she didn't like and said she was going to rip it up. She looked at me hesitantly, as if she was expecting me to object, while she held the paper. I said that she could do whatever she liked with it. She shrugged and promptly ripped-up the image and threw it in the garbage.

It was apparent during our very first meeting that Violet was concerned with the amount of control she had, not only during our session, but also in every aspect of her environment. It seemed as though she was waging a battle to keep some form of autonomy in an otherwise highly controlled environment. In order to gain Violet's trust and begin to form a therapeutic alliance, it was imperative that I emphasized her control and creative freedom, while ensuring that she felt contained and supported during our sessions.

Session 2 (#2)

During our second session, Violet appeared to be relaxed. She held out her hands and showed me her new stick-on nails, which she had done herself. She asked what she

could do that day and I asked her to draw a family portrait so that I could better get to know her (see Figure 3).

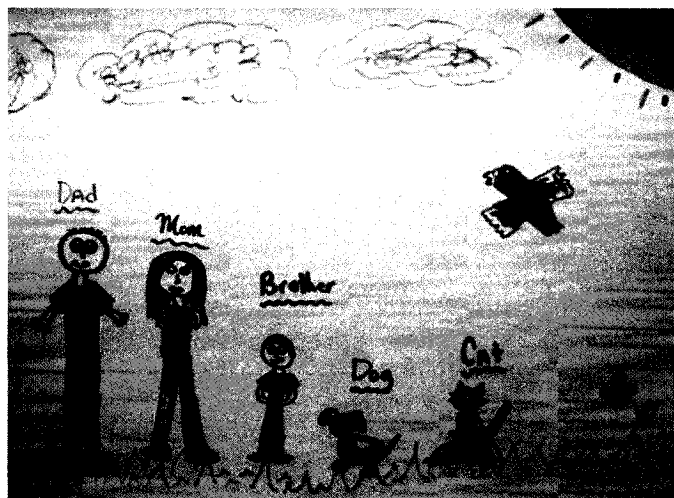


Figure 3 Violet's family portrait

She looked at me with a furrowed brow, and after a minute or two, began by drawing a sun and grass on the page. She then hesitated and said she wasn't very good at drawing people. I reassured her that I was not looking for "good" pictures. She began with her father at the far left side of the page. When she finished she commented that she didn't draw his hands correctly. She then drew her mother and her younger brother, with their hands behind their backs. At this point, she looked up at me and quietly asked if she had to draw herself in the picture. I reiterated what I had told her at the beginning of the session; that it was a family portrait to help me get to know her better. She proceeded to draw the family dog and cat. She said that she had discovered how to draw a bird the other day, and drew a blue bird in the sky. Lastly, she drew a purple flower on the far right side of the page and said it was finished. I asked her if she was in the picture. At first she shook her head no and then she pointed to the flower and said that it was her. I asked how it felt to be a flower, and she said that she didn't know. She just liked flowers.

The fact that she chose not to include herself as a figure in the family portrait may represent feelings of separateness from the family. Violet spent the majority of her time apart from her family, whether her parents were working or she was at the hospital for treatment. When Violet identified herself as the purple flower, I thought of a flower marking a grave. She also included a bird in the image, which Bach (1990) identifies as a symbol of the soul. Both images could reflect possible thoughts about her uncertain future and possible death. I was also struck by Violet's depiction of her mother. She looked more like an adolescent than a mother figure, with flowers on her jeans and a bright pink shirt. In many cases, due to the limitations of peer interactions for children on hemodialysis, parents often find themselves taking on the role of friend (Travis, 1976).

During the same session Violet asked to make what she called a "Cootie Catcher" and began to fold a piece of paper (see Figure 4).

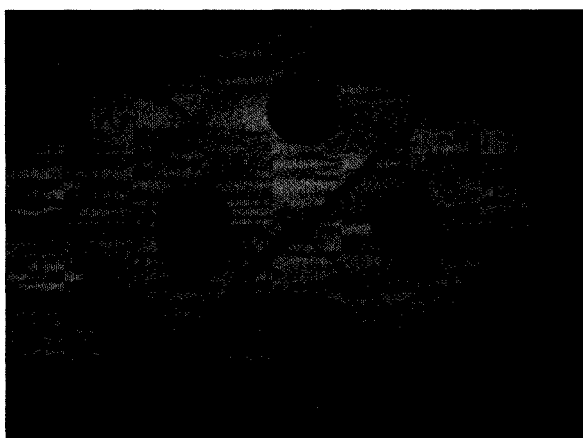


Figure 4 Cootie Catcher

As she folded, one of her fake nails broke off and she made a shocked face, followed by a pouted lower lip and pretended to cry. Another patient receiving hemodialysis treatments, who was much younger than Violet, made fun of her as she pouted and called her a baby. I was taken back by this sudden regressed behavior. This was an indication of how Violet

may have coped with anxiety, as was found to be common in adolescents diagnosed with chronic renal failure (Garalda et al., 1986; Rainthavorn & Ettenger, 2005; Travis, 1975).

Violet stopped pretend crying and began to label the folded paper with colours and numbers, and wrote fortunes on the underside of the flaps. The fortunes were as follows: “You will be rich;” “you will be ugly;” “you will have 15 kids;” “you will be poor;” “you will marry a frog;” “you will have 25 dogs;” “you will never be happy;” and “I hate you.” Out of all the outcomes only one reflected a positive fortune.

After writing the final fortune she folded it up, held it towards me, grinned, and said, “Pick a colour.” I ended up picking “You will be poor.” She laughed and then asked me to hold it so she could have a turn. The fortune she ended up with was “You will never be happy,” which she read aloud in a rather disappointed tone of voice. I asked her what she thought of the fortune she had picked. “I made this,” she said shrugging, “I should know which one to pick.” Despite knowing which fortunes were under which numbers, Violet had picked one of the most negative ones. Her comment indicated that she had done so unconsciously and demonstrated her perceived lack of control over the outcome of the event.

As viewed by Inhelder & Piaget (1958), adolescence should be the age at which the individual thinks of future possibilities. I felt that the use of the fortunes also expressed Violet’s ambivalence towards her future and a limited view of possibility. Even though she knew what she had written on the paper, she could not control the outcome. I drew a parallel between her perceived lack of control and her experiences living with her illness. Her health and the progression of her illness had always been outside of her control, yet the illness itself controlled nearly everything she did. Lack of

control and uncertainty seemed to be a relevant issue since her kidney transplant had failed.

During the second and first session, I observed Violet grab an alcohol swab that a nurse had used to clean her line before taking a blood sample. She held it up to her nose and inhaled deeply. I asked her what it smelled like. She held it out so that I could smell it. I said that it smelled like rubbing alcohol and she nodded her head in agreement. I asked how it made her feel. She said that she just liked the smell. I had concerns about this behaviour since adolescents diagnosed with chronic renal failure are at risk of developing substance abuse problems (Canadian Institute for Health Information, 2005), and brought it up with the child life specialist. She informed me that some medications affect the patient's sense of smell; making overpowering smells like rubbing alcohol quite pleasant.

Session 3 (#4)

During our fourth session I brought in a range of collage images I had cut out in the hopes that Violet would be able to use them to articulate her thoughts and emotions without having to verbalize them. The images that I had offered ranged from flowers and trees to barbed wire. The words that Violet chose to include in the collage show a representation of the range of words provided. I told her that if there was an image or word that she wanted that was not available I would try to find it for her. Violet was excited to look through the images and make a collage. She mentioned that she had boxes full of magazines that she had collected over the years in her bedroom. I asked if she looked through them often. She said that she didn't look at the old ones and wasn't sure why she kept them.

She took out the images and words one by one and sorted them into two piles; ones she would use and ones she would not use. She began by pasting the heart in the centre of the page, followed by the word “Dark” (see Figure 5).

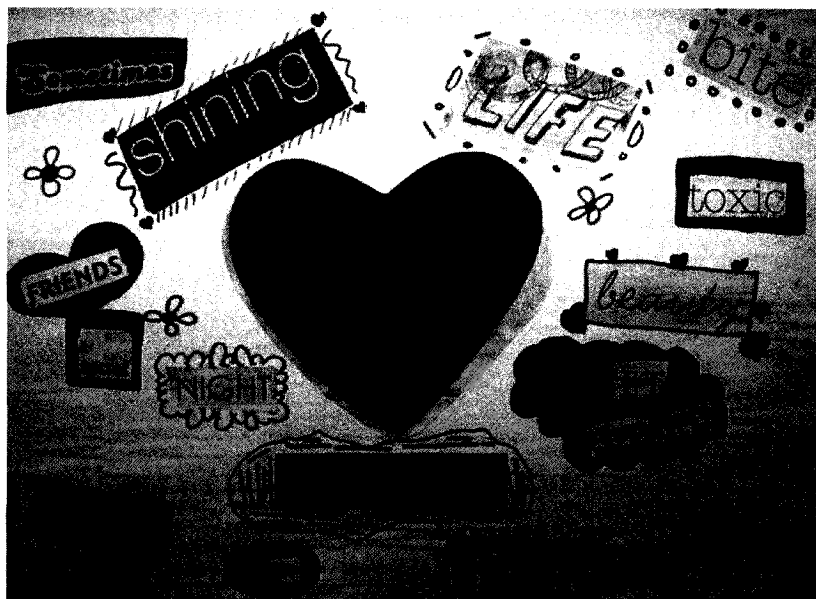


Figure 5 Violet's first collage

It was at this point that our session was interrupted by the need to have a medical procedure performed. Violet required some stitches to secure her catheter line in place. Without the stitches Violet ran the risk of her catheter coming loose, which could cause Violet to bleed to death. As soon as Violet saw the surgical staff enter the room she yelled out “No!” in objection and became very anxious. I moved the art materials and said that we could continue the collage after her stitches were done if she felt like it. She nodded and began to whimper as the surgical staff pulled the curtain around her. I heard Violet refusing to have the stitches done and the surgical staff tried to reason with her by explaining the risks. It took about 15 minutes until Violet agreed to let them proceed. When I returned I found Violet puffy eyed, looking exhausted and expressionless. I asked if she felt like continuing. She nodded but first wanted to review all of the images she had

made during our four sessions. She chose a graffiti image she had made during a previous session and the collage she had just started as her favourites. She continued to work on the collage by gluing the images onto the paper and then embellished them with markers.

When she had finished I encouraged her to tell me about her image. Violet was very reluctant to do so. She said, "It's just a picture. There's nothing to say." She eventually made some associations to the words she had included. She associated the word "bite" to the phrase "bite me." The word "Toxic" reminded her of a Britney Spears song. The lyrics of which were "With a taste of your lips/ I'm on a ride/ You're toxic/ I'm slipping under/ With a taste of poison paradise/ I'm addicted to you/ Don't you know that you're toxic." She noted within the heart the word "poison" and pointed at the skull in the center, but was not able to verbally articulate what she thought of the image when I asked her about it. She vaguely commented that the word "Dark" was related to the heart. Within her collage, Violet included imagery closely related to the physical characteristics of her illness. I inferred that the heart with poison and the skull symbolized her illness; Violet's blood was in reality becoming *toxic* and *poisoning* her.

Violet said that she chose the word "talk" because she felt she talked a lot. I found this to be inconsistent with my observations of her. Similar to what Nishida and Strobino (2005) experienced while conducting art therapy on a hemodialysis unit, I found that Violet was reluctant to talk openly with me. I believed that this was also due to the lack of privacy and the fact that our therapeutic alliance had not been fully established. I also observed that she kept conversations with staff and the other patients on a superficial level. It seemed that within this collage Violet was representing characteristics that were discrepant with the way in which she behaved. I asked her about the words "friends" and

“secret”. She said that she didn’t get to see many of her friends. This was especially true since one of her closest friends had moved to another city.

She also included the words “sweet dream” in her collage, which I thought might represent her hopes for the future. There also appeared to be words that could be related to Violet’s struggle to establish and define her self-concept and identity, such as “fake,” “beauty,” “problem,” and “life.” However, these words all seemed to be overshadowed by the large heart in the centre of the image. Despite Violet’s lack of verbal expression, I found that she was using the artwork to communicate volumes of what she felt she could not express otherwise.

Session 4 (#5)

The following session, Violet asked to make another collage only this time she wanted to look through magazines and choose the images and words herself. Initially, I thought that she was attempting to avoid expressing herself, because of her past reluctance to verbally communicate her emotions. By taking the time during our session to look through a magazine she could avoid expressing any difficult thoughts or emotions. At the same time I recognized her need to have control and make her own choices, leading me to choose to let her look through the magazines. To my surprise, she quickly flipped through the pages of one and quickly ripped the page out. She said that she was choosing things that she liked and were in her favourite color, pink. She specifically identified herself with a particularly bright hue.

Once she had chosen all of the images, she cut them out. She looked at the images and said that in order to fit them all she would need a larger piece of paper than last time.

Similar to her first collage, she began by placing a broken heart in the centre of the page (see Figure 6).



Figure 6 Violet's second collage

She continued to paste the other words and images on the page. While she did that she appeared to regress. She did not like using the glue and would cry out and make disgusted faces when it touched her fingers. She was otherwise quiet during the session. She asked a volunteer to bring her some alcohol pads. The volunteer brought her a handful and Violet would periodically open one and smell it as she worked.

I asked her what she thought of the word “Sloth.” She shrugged and said that she just thought it looked interesting. I asked if she knew the meaning of the word and she shook her head no. I gave her a short definition, after which she said that she often felt very tired and nauseous during and after her dialysis treatments. She said that she often felt frustrated as a result of missing social events with her friends because she wasn’t feeling well or she had to come in for dialysis treatments. I asked her if she had difficulty keeping up with her schoolwork, and she shrugged. Earlier that week the child life

specialist had mentioned concerns that Violet had not been attending school and was not willing to work with her tutor at the hospital.

Near the end of the session Violet was brought her lunch: a salad, a few pieces of cheese, a bagel, and some grapes. The hospital allows the patients to choose from a menu what they would like to eat during the day according to their diet restrictions. I had observed her on many occasions going through the menu, checking off food items and writing specific instructions for the food services staff about the preparation of her food. Despite having chosen her lunch herself, Violet looked at the food in disgust and stuck out her tongue. She told the nurses that she refused to eat her lunch. A nurse scolded her for ordering so much food and then not eating it. She seemed to take pleasure in being so demanding.

Session 5 (#6)

Violet's appearance was very different from previous sessions. She had straightened her hair and was wearing jeans instead of her usual sweatpants. She had not been hooked up to her dialysis machine yet and was walking around the room making faces at the two younger male patients in the room. The nurses called her over to her chair and began to prepare her to be attached to the dialysis machine. I had to wait until they were finished to begin the session with Violet. After she was hooked up she was eager to begin. She asked to make another collage on a large piece of paper.

I brought her some magazines and she went through the same process of gathering her images as in the previous session. She chose to use the liquid glue as opposed to a glue stick that I offered her, and did not make any comments about it being

“yucky” as she normally did. Similar to her previous collage, Violet included images of some of her favorite things, like the color pink and make-up (see Figure 7).

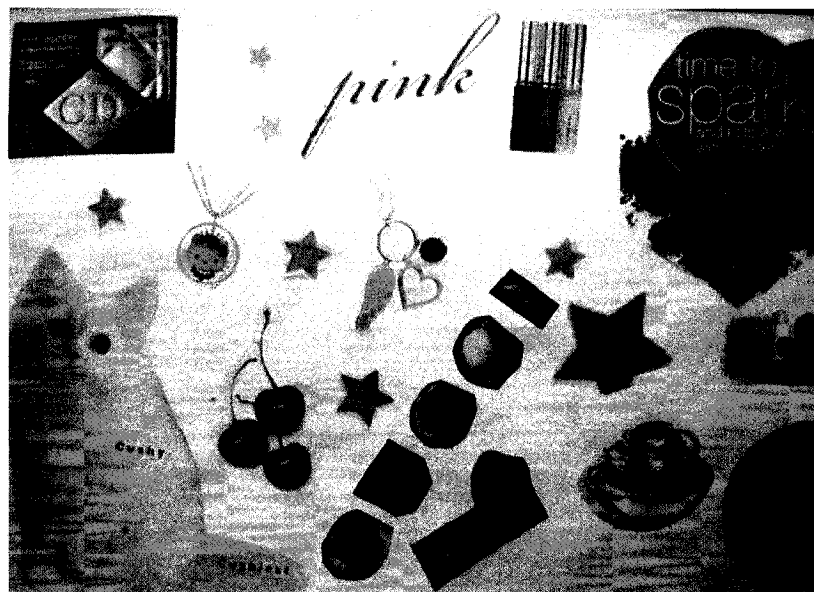


Figure 7 Violet's third collage

As she was working a nurse walked by peeling a grapefruit. Violet could smell it and suddenly looked at me and asked if I would go and buy her a grapefruit from the cafeteria. She told me that she used to eat them every morning when she was younger, but that she hadn't had one for five years because they reacted with some of her medications. She went on to explain that she couldn't consume anything containing grapefruit, like marmalade, which she had also recently discovered she liked. The fact that Violet asked me to go and buy her a grapefruit and then explained that she wasn't allowed to have them, demonstrated her struggle to adhere to diet restrictions and her reliance upon others to enforce them. By making me aware that she wasn't allowed to eat grapefruit, she was eliciting a rejection of her request. I said that it must be hard for her to give up some of the foods that she liked. She mentioned that she was not supposed to eat anything with lots of salt but that she did anyways; she ate what she wanted. Violet

obviously understood the medical implications these foods had on her health; however, she knowingly disobeyed them.

During this session the alarm on her dialysis machine was sounding almost every two minutes, indicating her blood pressure was out of its normal range. Violet became more and more frustrated. The nurses looked over and asked her to push the buttons on her machine for them. They called out Violet's name and ask what she was doing to cause the machine to alarm. That frustrated Violet even more. At one point she looked at me and said it was not her fault it was going off. I reflected that there were a lot of things that she did not have control over. A nurse came over and took Violet's blood pressure and gave her a wide-eyed expression. Violet saw this and rolled her eyes and said she knew her blood pressure was high. From then on, when her machine beeped she would pound her fist on the table to press down the image she was gluing and then reset her machine. She looked at me and whispered for my help to throw her machine out the window.

Violet told me that she was going to have her catheter replaced soon, which required an operation. She had a catheter access located near her right collarbone. As the catheter is a foreign body, it often produces an inflammatory reaction within the vein wall, causing scarring and eventually causes the vein to become blocked. When this happens the catheter must be placed in an alternate vein site. Patient's run the risk of running out of access sites, making hemodialysis impossible. During the previous three months, Violet's catheter site had been changed four times. She was aware of the seriousness of this issue and said if her access site wasn't working, she wouldn't be able to receive hemodialysis treatments anymore. "I'd be screwed," she said. I asked what her

choice would be in terms of treatment. She said that they'd have to keep trying.

Hemodialysis was her only option.

Session 6 (#8)

Two weeks passed and Violet had finally been scheduled to have her catheter replaced on the day we were to have our eighth session together. Violet was in a good mood and appeared not to be nervous about her operation later that afternoon. Being aware that Violet would be having the operation that day I had brought in some pink coloured paper for collage material. Since she had indicated that pink was her favourite colour, I hoped that the pink paper would encourage her to represent her self-concept within her collage, especially if she was going to have an invasive procedure that day. She was eager to begin working on her collage (see Figure 8).



Figure 8 Violet's fourth collage

Violet's mother was at the hospital that day but not in the unit and I asked where she was. Violet made a crying sound and said that her mom had left and was never coming back. A few minutes later her mother entered the room. She said that "they" (the

doctors) wanted Violet to go for dialysis every day that week because of her fluid weight. Violet rolled her eyes and said “That’s stupid.” Her mother agreed with her. I was reminded of the way she had been depicted in Violet’s family portrait. Their interactions were characteristic of two adolescent girls rather than mother and daughter. Consistent with the Travis (1975), I observed that the hospital staff and Violet’s mother often acted as peer surrogates. Violet’s mother said that she had been talking to the doctor about getting Violet on the transplant waiting list. The way in which Violet’s mother presented this information suggested she was trying to elicit a hopeful response from Violet. Given that Violet’s mother had donated a kidney graft, which subsequently failed, Violet’s next kidney would come from a cadaveric donor. Violet seemed excited about the news and smiled, but remained quiet. A few minutes later her mother had to leave and run some errands.

For the remainder of the session Violet appeared to be very distracted by the noise and people in the room which I assumed to be a sign of her getting more anxious about her surgery. She included some images of food in the collage, such as juice, chips and crackers. I noticed that the food she had chosen to put in her collage were foods that were not consistent with her diet restrictions because of their high sodium content. Violet mentioned that she had been fasting since the night before and that she was very hungry. She said that her mother always fasted with her before an operation.

The other images again reflected her interests in make-up and fashion, things that teenage girls are often invested in. It seemed as though Violet was attempting to define herself as a “normal” teenage girl through her collages, but also using them to express the issues she was facing.

Session 7 (#16)

Violet's catheter had been successfully replaced. During the eight sessions leading up to our 16th session her blood pressure had been under better control during hemodialysis treatments and her machine did not alarm as often as it had in the past. This improvement was short lived as Violet's new catheter required stitches to hold it securely in place. Violet was scheduled to receive stitches during the week leading up to our 16th session. She was very anxious and had refused to have them done. Violet cried loudly and would not let the surgical staff near her. Due to concerns for her safety her mother told Violet that she would be admitted to the hospital overnight if she did not agree to have the stitches. After hearing this Violet allowed the procedure.

As soon as I entered the room Violet asked to make another collage. I brought her a magazine and she quickly flipped through it, tearing out the images that she liked. She mentioned that she had to come in for dialysis an additional day that week because her fluid weight was too high. Unless it was removed through dialysis treatments, the presence of excess fluid in the cardiovascular system could result in high blood pressure (Travis, 1975). Violet tended to be hypertensive, which made it very important to monitor her fluid weight. Violet asked if I would be in again during the week and as I usually came in to see another client I told her I would be available for an additional session with her if she would like it. She seemed to be reassured by this. It had become very clear by that point in our therapeutic relationship that Violet had been able to trust me and was able to relate to me as a peer. As Travis (1973) points out, because of their prolonged interactions, the hospital staff often becomes the patient's primary form of social interaction. The developmental theories of Erikson (1950/1963, 1968) and Piaget (1967)

As she glued the other stickers and images, she asked if she would be able to take her artwork home with her when our sessions were over. I told her that she could do whatever she chose with them. She began to speak in a whiny voice and said that I was going to be leaving her alone at the hospital. She stated that she wasn't able to leave the hospital without having to come back for dialysis treatment; she was stuck there. She smiled afterwards in a way that made it seem as though she was joking. I reflected to her that it must be frustrating for her to have no choice but to continue to come in for treatments. I brought up the fact that she may have felt as though I was abandoning her. She nodded, became quiet, and then said that she might not be coming in for treatment after I had gone anyway. I asked her why she would not be coming for treatments. Violet said that she might have a transplant by then and smiled.

Session 8 (#21)

When I entered the unit that day, Violet was not in the room. She had been sent for an ultrasound to look at her catheter line. The nurses said that Violet had gone missing and did not finish her ultrasound. Moments later Violet entered the room and the nurses immediately asked her why she had left her ultrasound appointment before she was supposed to. Violet said that the ultrasound technicians had just left her lying on the bed so she left. The nurses told her she had to go up so they could finish and that they were waiting for her. Violet had a friend visiting her at the hospital that day and they were supposed to go shopping after her treatment. Violet wanted to begin her treatment because they were going to be late for the plans they had made that evening. The nurses said that she had to go back up to finish her ultrasound before they would hook her up for dialysis. Both Violet and the nurses were becoming increasingly frustrated. Violet

refused to go up and said that it was very painful to have it done. The head nurse said she would have to call Violet's mother if she did not go up that moment. Violet's choice to leave the ultrasound room was made without consideration of the consequences that it would result in. She was acting based on her desire to go shopping with her friend.

Violet's friend, who was getting equally frustrated, finally convinced her to return for the ultrasound. A few moments later Violet returned to the unit and appeared to be very angry. She did not get to finish her ultrasound because they had moved another patient to take her place. Violet yelled at the head nurse for making her do so much running around for nothing. She went and sat down in her chair. She yelled at the nurse saying that she just wanted to get started on her treatment. The head nurse agreed and in an annoyed voice said that Violet would just have to have her ultrasound done another day. By this time Violet was crying and very frustrated.

During my session with Violet it was clear that she was still angry. She was slouched in her chair and speaking in a loud, whiney sounding voice. Because of the limited social interactions that Violet had with her peers I decided to work with Violet and her friend to try and resolve the issue. I used Winnicott's (1989) squiggle game as an intervention, since it involved a sense of play, but would still provide insight into what Violet wished to communicate. The three of us alternated drawing squiggles and then had someone else make the squiggle into an image. Out of one squiggle Violet made a picture of an "ugly pig lady." She held it up and asked me who I thought it looked like. It was obviously meant to be an expression of anger towards the head nurse. She took another piece of paper and drew a large heart. In the centre of the heart she wrote her name,

which has been removed from the image to maintain confidentiality. Violet then wrote, “I hate you” next to the heart (see Figure 10).

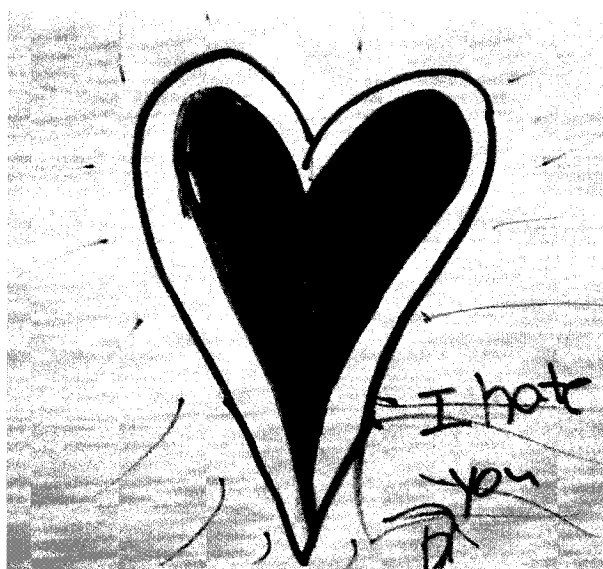


Figure 10 "I hate you"

She turned to me and asked me to deliver the paper to the head nurse. I told Violet that she could feel comfortable expressing anything to me but I did not feel that giving the head nurse the drawing would improve the situation she was in. She repeated a number of times that the head nurse hated her and was making her stay longer on purpose.

I reflected her feelings of frustration, anger and lack of control over what had occurred that day. While that was happening Violet's blood pressure was rising outside of her range limits. This caused the alarm on her dialysis machine to go off. The nurse told Violet to adjust her sitting position to help control her blood pressure or her treatment would be compromised and more time would be added. Violet refused at first, and said that she did not care and she would sit the way she wanted to.

The fact that Violet had left before her ultrasound was finished demonstrated that she was reacting to her current situation and not able to foresee the future consequences of her actions. This suggests that Violet had not yet made the full transition into the

formal operations stage of development (Piaget & Inhelder, 1969). Writing her name in the centre of the heart could be seen as an attempt to protect her sense of self during the chaos that had erupted that day, similar to the boy diagnosed with cancer described by Councill (1993). She was reacting in a way that suggested she felt she had no control over her situation. Violet refused to move her body position as a means of retaining some control over her situation. As Garrison and McQuiston (1989) note, it is normal for adolescents to challenge adult authority, but in the case of the adolescent living with a chronic illness, this behaviour can endanger his or her health.

After a few minutes of her alarm sounding Violet adjusted the position of her body and turned off the alarm. She seemed to have calmed down, but when I said that it was time for the session to end, she became very upset and told me that I could not leave her. Our therapeutic alliance had developed to a point where Violet was no longer indifferent to our sessions. I had become a source of structure and containment for Violet by accepting and acknowledging her frustration and anger; emotions that often made the nursing staff, and in this case her friend, feel uncomfortable. I told Violet that I would be looking forward to our next session and reassured her I would see her the following week.

Session 9 (#24)

I came into the unit and saw that Violet was playing dominos with some of the nursing staff. I was struck by the maturity she displayed. She was adding up the scores as each person had their turn. We began our session after they had finished their game. Violet had seen me working with another patient who had made a three-dimensional house out of foam sheets and she wanted to do the same (see Figure 11).

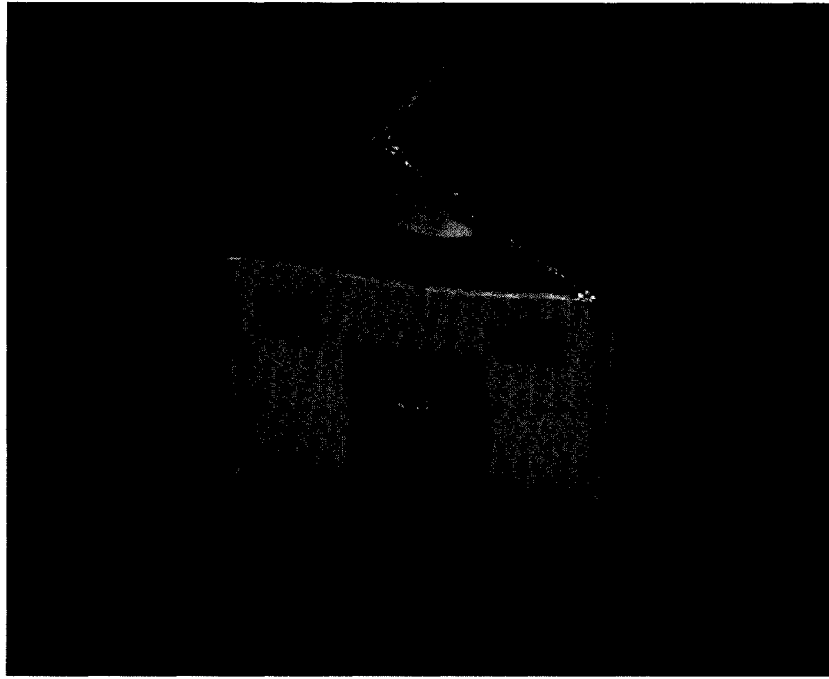


Figure 11 Foam house

I pulled out the various colours from which she could choose. She chose yellow for the walls and purple for the roof. Violet was hesitant to start and said that she needed my help. With a little bit of encouragement she began cutting out the pieces and gluing them together. She found that an easier way to make windows and a door was to cut them out and glue them to the walls of the house. She said she would actually never want to live in a yellow house; it wasn't practical. She put sparkle glue all along the edges of it and said that it was a very decorative house. She saw the roof begin to collapse and said that she needed to put something under it to support it until the glue dried. Her eyes scanned the room and then asked for a small paper cup to support the roof with. Violet was able to solve that problem without asking for my assistance or showing any signs of regression, which she had in the past. She had gained confidence in her own actions and was demonstrating a sense of independence during our sessions. She had also become a role

model for one of the younger patients on the unit who would often show Violet her artwork for approval and on occasion asked to sit beside her.

As she placed the cup under the roof, she mentioned that our sessions were almost over. We had only two more sessions together. She said that she wanted to go for dinner at one of her favourite restaurants after we had terminated. Violet had developed a strong alliance with me and was having to deal with the upcoming loss of the relationship. I explained to her that even though I was going to be sad that our sessions were ending, I was unable to go for dinner because of my ethical obligations of not meeting outside the hospital setting. She nodded her head and said that she was going to miss me. I felt that over the course of our therapy sessions Violet had come to trust me and became comfortable expressing her most deeply felt emotions, which ranged from fear to anger. Violet was able to work through some of her identity issues within this therapeutic relationship.

At that point, Violet leaned over the table and whispered to me that she had just been put on the transplant list that day. She appeared to be happy, but I wondered aloud if she had some conflicting emotions about going through it a second time. Violet shrugged and said that she had been through it all before. She was nervous the first time, but she had so many operations since then, that she was not afraid anymore. Violet reached across the table and took my hand. As she spoke she took a ring off of her hand and tried it on one of my fingers. It was too small, but it managed to fit my pinky finger. She removed the ring but continued to hold onto my fingers. She said that she would be happy to receive a kidney transplant, but that this time it would mean that someone had

died, which she felt uneasy about. She said that she might get a new kidney in a matter of months or even weeks.

This news was welcomed, especially since Violet continued to experience difficulties with her catheter line. I read in Violet's medical chart that she was going to be having another operation to replace her line and I would be seeing her the following day. She had undergone the same surgery just 16 weeks earlier, but the problems resurfaced soon thereafter. Since she would still be recovering when I saw her, I asked her if there were any art materials in particular she would like me to bring that day. Violet had seen me cast one of the other patient's hands and asked me to bring in the plaster cast materials. She also made a comment that I always wore my hair down and requested that I wear my hair in a ponytail the next time I saw her. Violet often wore her hair in a ponytail and I associated her request as an attempt to identify with me as a role model.

Violet's treatment was ending at the same time of our session. The nurse came and notified us that she would be getting Violet prepared to come off hemodialysis. Violet looked at me and asked if I would stay with her while she was taken off the machine. We all wore masks to prevent spreading infection while Violet's line was exposed. Violet was intently watching me and explained to me what the nurse was doing. It was an intensely intimate moment that Violet had chosen to share with me. I felt that she did not need me to stay with her for support, but instead she wanted me to bear witness to what she had experienced every single day she was in the hospital. This was a gesture that demonstrated and reaffirmed the strong alliance Violet and I had formed, and the amount of trust she had developed in me over the course of our sessions. I felt very privileged to have been invited to stay with her that day.

I had two more sessions with Violet following that powerful experience. During our second last session she was recovering from her surgery and was very sleepy. I made a plaster cast of her foot while she rested. We spent the remainder of the session reviewing her artwork and she decided which ones she wanted to take home with her. As she looked at the images I summarized the challenges that I thought she faced and also the strengths that I saw in her. She agreed that it had been very difficult for her to express herself during the start of our sessions, but that she didn't have those reservations in the later stages of therapy. She chose to take home all of the collages that she had made and stated that they were her favourites. During our last session, Violet made several attempts to continue our relationship, and asked if I could come and visit her. I reiterated the limits of our relationship and expressed my sadness that our time together had come to an end. I also emphasized the progress she had made during our sessions. As we were saying our goodbyes, Violet said that she was glad she had taught me how to be a "cool" art therapist, as opposed to a "crazy" one.

Discussion

This research paper sought to explore how art therapy could be used to address the psychosocial issues experienced by an adolescent female diagnosed with chronic renal failure. My inquiry was also guided by exploring how the developmental challenges faced during adolescence can provide a better understanding of how Violet experienced living with chronic renal failure. The initial therapeutic goals in the art therapy sessions with Violet were to allow her a time and space in which she could feel safe and free to express her emotions related to the psychosocial issues she was experiencing; also to develop Violet's sense of autonomy and independence as she tackled the developmental

tasks of adolescence. The art therapy sessions utilized the time that Violet usually spent waiting, to engage in the creative process of self-expression.

Violet's experiences of her illness cannot be fully understood without considering the developmental issues and tasks she was simultaneously facing. The significant limitation of social interaction and lack of control experienced by adolescent patients on hemodialysis has been shown in prior research to negatively affect their psychosocial adjustment and impede their development (Garralda et al., 1988; Rianthavorn & Ettenger, 2005; Wallace et al., 2004). Through my analysis of the data I have collected, three issues emerged as being central to Violet's experiences of living with end stage renal failure: First, Violet was being challenged by the lack of control experienced; second, Violet appeared to be having difficulty integrating her illness into her self-concept; and thirdly, her difficulties adhering to treatment.

Lack of Control

Research shows that ESRD patients often feel that they have no control over their lives due to their illness (Rianthavorn and Ettenger, 2005; Travis, 1975). This was another theme that pervaded Violet's art therapy sessions. As a way of coping with her lack of control, Violet showed a tendency to regress and become very demanding while on dialysis. I observed that the regressed behaviour continued outside of the art therapy sessions at the hospital, and that Violet often used that behavior to gain the attention of the nursing staff. There were many situations where Violet's frustration over her lack of control caused conflict between her and the staff members. Often adolescent patients react by acting out against the restrictions placed on them (Garrison & McQuiston, 1989; Rianthavorn and Ettenger, 2005; Rosenkranz et al., 1992; Travis, 1975).

Literature available relating to medical art therapy stresses the importance of choice and control as a therapeutic consideration for the patient (Bach, 1990; Malchiodi, 1999; Nishida & Strobino, 2005; Weldt, 2003). To ensure that I gained Violet's trust, it was vital that I provided Violet with as much freedom and control during the art therapy sessions as was possible. The non-directive structure of the sessions was also a way of increasing Violet's independence and autonomy. However, the structure that I did offer, served to encourage her to express herself through her artwork.

Self-Concept

Identity formation is central to development during adolescence according to Erikson (1968). As Eiser (1985) found, children had poorer self-concepts when their central self-defining characteristics were affected by their chronic illness. To facilitate the development of an individual's self-concept the core aspects that are in conflict with the lived experience of being ill must be lowered in value and replaced by other attributes (Eiser). As Rode (1995) comments, art forms can act as a transitional space for individuals to explore their self-concept. Within Violet's collages she represented images that were linked to the interests of typical teenage girls such as make-up, shoes, and jewellery. She clearly defined herself by these things, even though the realities of her illness made it very difficult to actually include these interests in her daily life resulting in a possible conflicted sense of self. Despite the relative value she placed on fashion and make-up, she was rarely able to dress the way she wanted or spend time doing her make-up because of the limitations imposed by her treatment regimen. For instance, many of the clothes she wore had to be comfortable due to the long periods of time on hemodialysis, and loose fitting clothes to allow the nurses access to her catheter. Violet

would often get iodine stains on her clothes while being hooked up to the dialysis machines, which prevented her from wearing her favourite clothes.

As Eiser (1985) states, the integration of being chronically ill into an individual's self concept is dependent on his or her acceptance of the illness. In Devins et al.'s (1997) study, adolescents demonstrated better psychosocial adjustment the more they identified with being a renal failure patient than those whose self-concepts were not defined by their illness, suggesting that adolescents benefit by integrating the realities of their illness as part of their self-concept. Through her artwork and our conversations, Violet showed increasing acknowledgment of the difficult challenges she faced. By also allowing Violet to express her frustrations and by bearing witness to her struggles, she could integrate aspects of her illness into her self-concept. Violet showed a shift in the value she placed on physical appearance to strengths and attributes that were relatively unaffected by her illness, such as her creativity and her ability to act as a role model for some of the younger patients on the unit. Her last collage that included a get-well card as the central image suggests that she had integrated aspects of her illness into her self-concept.

After children have experienced an invasive procedure they often experience the need to reaffirm their self-concept (Councill, 1993). When Violet had gone through a painful medical procedure she would often ask to review the artwork she had made. Bach (1999) states that all spontaneous pictures created by severely ill children should be seen as a reflection of themselves. When she felt her self-concept was threatened, Violet was comforted by the images she had created. Violet included her name in large letters on a number of art works as a way of maintaining and emphasizing her sense of self when she was unable to express it through independence.

At an age when being able to identify with peers plays an important part in identity formation, the differences in appearance and abilities resulting from a chronic illness are amplified (Garrison & McQuinston, 1989). I felt that Violet was overtly aware that she was living a life drastically different from the average teenage girl and was trying to overcompensate for these differences through the images she chose in her collages. She attempted to hide these differences from others and herself in order to ignore her identity issues. According to Eiser (1985), adolescents who have difficulty accepting their illnesses expect that others will react negatively towards them as well. The session during which Violet had brought a friend to the hospital demonstrated Violet's struggle with accepting her illness. It appeared that Violet wanted her friend to witness and accept her illness so that she herself could gain acceptance for herself. However, allowing herself to be witnessed also made her vulnerable. The events during that session showed Violet's friend just how dependant she was on the medical staff and treatments. Violet's fear of being rejected by her friend could have encouraged her angry outburst and resistance to the requests of the nursing staff.

Inhelder and Piaget (1958) acknowledge the fact that in addition to neurological growth, the social environment directly influences the attainment of developmental potential. To further facilitate Violet's acceptance of her illness and its integration into her self-concept, I created a space during our sessions where Violet felt free and able to express herself without reservations. Over the course of our 26 sessions Violet was able to gain trust in me and express the issues she experienced without the fear of being rejected. By inviting me to witness her being taken off of the hemodialysis machine, Violet was presenting her illness as a part of her self-concept.

Treatment Adherence

Current research identifies treatment adherence amongst adolescent renal failure patients as a major concern (Brownbridge & Fielding, 1994; Garralda et al., 1988; Maikranz et al., 2006; Rianthavorn & Ettenger, 2005). Findings suggest that treatment adherence is mediated by psychosocial adjustment and developmental factors (Brownbridge & Fielding; Rianthavorn & Ettenger, 2005).

Through information I had collected from the hospital staff, Violet's medical chart, and through direct admission by Violet, it became apparent that she was having difficulty adhering to her diet restrictions. This often led to her having to come in for additional dialysis treatments during the week. As described by Inhelder and Piaget (1958), an important crossroads between childhood and adulthood is gaining the ability to step outside of the immediate present and think about future possibilities. Before reaching the formal operations stage of development, adolescents lack the ability to consider the consequences before they act. By eating food that were not part of her diet, Violet gained immediate gratification, but this was short-term as her treatments became more aggressive causing her to feel ill. Violet expressed her difficulties adhering to her diet restrictions within her collages by including images of the foods she craved, such as chips and crackers.

Uncertainty is implicit in the experience of a chronic illness such as ESRD, which can lead to poor treatment adherence (Maikranz et al., 2006; Rianthavorn & Ettenger, 2005). Even when individuals receive transplants there remains a relatively large chance that their bodies will reject the new organ (Scientific Registry for Transplant Recipients [SRTR], 2005). Garrison and McQuinston (1989) suggest that for adolescents, the

uncertain nature of chronic illness can take away the motivation needed to adhere to strict and complicated treatment regimens. Violet's artwork often expressed uncertainty towards her future. For example, within her family portrait (see Figure 3) she represented herself as a flower, possibly marking a grave. While playing with the "cootie catcher" (see Figure 4) she indicated that she had no control over her fortune, which could parallel the uncertainty experienced by her in regards to her illness and environment. The image of the skull and the words poison and toxic in her initial collage (see Figure 5) indicated that she was aware of the seriousness of her illness and the possibility of her own death.

As Maikranz et al.'s (2006) study suggests, the increased feeling of hope correlates to better treatment adherence. It appeared that early in our sessions Violet lacked a sense of hope and did not feel motivated to adhere to her diet restrictions. The collages allowed her a creative outlet for her frustrations relating to her treatment adherence. The reduction of anxiety allowed Violet to regain a sense of hope. As described in Session 7, before she was on the transplant waiting list, Violet made a statement in which she envisioned herself with a transplant and not having to be at the hospital for hemodialysis treatments. In the same session, the collage that Violet completed (see Figure 9) showed evidence of hope, such as the phrase "Step up," and "Get well soon Girl" found in the card. This was a distinct shift from the uncertainty and anxiety apparent in her family portrait and initial collage. Although my sessions with Violet concluded before I was able to observe any change in her treatment adherence, during our second last session she acknowledged the importance of staying healthy and adhering to her diet if she was to receive a transplant.

My work with Violet over seven months identified several psychosocial issues that she was facing related to being diagnosed with chronic renal failure. The most prevalent issues for Violet such as lack of control, poor self-concept, and poor treatment adherence were consistent with the findings of available research in the area of study. Framing these issues within the developmental stage of adolescence, as theorized by Erikson (1950/1963, 1968) and Piaget (1967), offered a deeper understanding of how living with chronic renal failure impeded Violet's achievement of relevant developmental tasks. Through our therapeutic relationship Violet was able to identify and interact with me as a peer, which also appeared to foster the development of her self-concept. The art therapy interventions allowed Violet to express her fears and frustrations, as well as redefine aspects of her self-concept. By taking a non-directive approach while working with Violet, she was able to experience control and gain a sense of independence.

Limitations

Certain limitations to this case study need to be presented and discussed. The setting in which the therapy sessions were conducted posed many challenges. There were many interruptions and health related factors that made it difficult to maintain consistency in regards to the time and length of the sessions. Sessions could be as short as 20 minutes or be broken into two meetings because of medical procedures. Privacy and confidentiality was also limited due to the setting. Hospital staff members often looked and commented on Violet's artwork. These factors, no doubt, influenced what Violet felt comfortable divulging within the art therapy sessions.

The inherent nature of a case study is limited by the fact that findings are based solely on the observations and information gathered from one participant. Although

Violet's experiences may be representative of a typical case based on the literature available for this population, the findings cannot be generalized beyond her case.

Future Recommendations

Despite the growing amount of research identifying the negative impact that renal failure and its treatment has on the psychosocial adjustment of adolescents, there is little research devoted to finding therapeutic interventions to address these issues. Art therapy with patients diagnosed with chronic renal failure is not only feasible but also appropriate. Art therapy offers a viable form of therapy that can be used during dialysis treatment that allows patients to feel empowered in an environment where they rarely do.

This case study serves as a preliminary exploration of the use of art therapy with adolescent patients on hemodialysis. Further research is needed to determine the effectiveness of art therapy interventions with this particular population. A study investigating the use of art therapy and its effects on treatment adherence within this population would be very beneficial to this area of study, considering the concerns raised in previous research and the findings in this present case study.

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Appendix A: Preliminary Consent Form

Preliminary Consent Form

Authorization for case material, art work, photography, video recordings, and audio recordings related to art therapy.

I, the undersigned _____

Authorize _____

to take any:

	YES	NO
case material	_____	_____
art work	_____	_____
photographs	_____	_____
video recordings	_____	_____
audio recordings	_____	_____

that the therapist deems appropriate, and to utilize and publish them for educational purposes, provided that reasonable precautions be taken to conserve confidentiality and anonymity.

I would be interested in participating in an art therapy Master's degree research project which may include art products, verbatim quotes, case notes, and assessment results from these sessions. I acknowledge that the information from these sessions will remain confidential.

YES _____ NO _____

If yes, I understand that I will receive information explaining the project in detail and an Informed Consent Form upon favorable review by the Ethics Review Committee in the Department of Creative Arts Therapies at Concordia University.

However, I make the following restriction(s):

Signature of Participant

Date

Signature of Guarantor

Date

Witness to Signature

Date

Appendix B: Consent Information Letter

Consent Information Letter

Art Therapy Student: Heather Hawkins
Concordia University, Department of Creative Arts Therapies
1455 de Maisonneuve Blvd. W.
Montreal, QC H3G 1M8 Canada

Practicum Supervisors: Louise Lacroix, Concordia University
Bonnie Harnden, On-Site Supervisor

A. BACKGROUND INFORMATION

One of the ways art therapy students learn how to be art therapists is to write a research paper that includes case material and the artwork by clients they have worked with during their practicum. The purpose of doing this is to help them, as well as other student art therapists who read the research paper, to increase their knowledge and skill in giving art therapy services to a variety of persons with different types of problems. The long-term goal is to be able to better help the individuals who enter into therapy with an art therapist in the future.

B. PURPOSE

There has been a lot of research done on the issues that children on hemodialysis face, but there remains a need to better understand their experiences and what can help them deal with these issues. This research project hopes to provide opportunities for these patients to express themselves through making art. The artwork created by participants will be used to identify and relate their experiences to what existing research tells us.

C. PROCEDURES

Participants will take part in weekly, one hour, art therapy sessions while they are on hemodialysis, with the art therapy student. Within these sessions, participants will be encouraged to express themselves by making art and talking about their experiences and artwork. The sessions will occur until the beginning of April 2007. The student art therapist will keep the artwork for the duration of the sessions, after which it will be returned to the participants. The final research paper will include descriptions of the sessions, including aspects of the participants' experiences. Bound copies of the research paper will be kept by the Department and in the Concordia University Library.

D. RISKS

To the researcher's knowledge, your child's involvement in this research project holds no risks. However, certain individuals may find that have reactions or feelings that are uncomfortable because of the personal nature of the exploration. The researcher will address these feelings within the art therapy sessions.

E. CONFIDENTIALITY

Due to the personal nature of this information, it is understood that your child's confidentiality will be respected in every way possible. Neither your child's name, the name of the setting where the art therapy took place, nor any other identifying information will appear in the research paper on the artwork.

Whether or not you give your consent will have no effect on your involvement in art therapy. You may consent to all or just some of the requests on the accompanying consent form. As well, you may withdraw your consent at anytime before the research paper is completed with no consequences, and with out giving any explanation.

Appendix C: Informed Consent Form

Informed Consent Form

Authorization for photography, video recordings, audio recordings, and the use of case material related to the arts therapies.

I, the undersigned _____

Authorize Heather Hawkins, Art Therapy Student

to take any:	YES	NO
photographs	_____	_____
video recordings	_____	_____
audio recordings	_____	_____
case material	_____	_____

that the student art therapist deems appropriate, and to utilize and publish them for educational purposes, provided that reasonable precautions be taken to conserve confidentiality.

However, I make the following restriction(s):

Signature of Participant

Date

Signature of Parent

Date

Witness to Signature

Date

If at anytime you have questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.