

**ART THERAPY WITH
CHRONIC PHYSICALLY ILL
ADOLESCENTS**



ABOUT THE AUTHOR

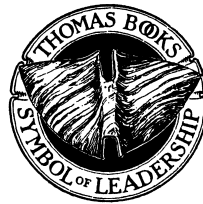
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ART THERAPY WITH CHRONIC PHYSICALLY ILL ADOLESCENTS

Exploring the Effectiveness of Medical Art Therapy
as a Complementary Treatment

By

RUTH R. LUGINBUEHL-OELHAFEN, M.D., DTATI



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*I wish to dedicate this book to all my patients,
who took me with them on their difficult journey and
who introduced me to the depth of their emotional struggle
in accepting and integrating their illness into their lives.*

PREFACE

Improved therapeutic interventions in medicine during the last 25 years have increased the chances of survivability for children with a wide range of conditions, including those in the newborn intensive care unit. In industrialized countries today over 85 percent of children born with chronic conditions will survive until at least the age of 20 years (Blum, 1992). As noticed by Golombek et al. (1989), adolescence becomes more complex as our social system becomes more technological and industrial. This is particularly true for physically impaired adolescents. Therefore, as professionals providing services in the medical health care system, we must expect to be increasingly confronted by the difficulties faced by these adolescents.

As a pediatrician I have learned that in early childhood, where the child is in a dependent position due on the one hand to his developmental immaturity, and on the other hand to physical illness, it is important to support the caregiving system. The better my understanding of family dynamics, the more I have the parents as allies and the more I can empathize and obtain cooperation and compliance. This will, in turn, facilitate the patient's course of treatment and his prognosis for a relatively smooth development.

But when the child is older, he should be encouraged to participate in decision-making and treatment. Communication with adolescents, however, poses a particular challenge for the doctor or other caregiving professional. At this transitional stage of their lives – no longer children, not yet adults – adolescents are experiencing many internal and external changes which, even in physically healthy teenagers, are accompanied by emotional turmoil over such issues as body image and social acceptance. For the teenager with a physical illness, these struggles are even more pronounced (Neinstein, 1991 & Hofmann, 1997). To reach independence while a chronic physical condition

forces the individual back into dependence is a very difficult endeavor. In this situation it appears almost hopeless to get in control of one's own life, being constantly pushed back into the overwhelmingly controlling environment of the health care system. It seems impossible to leave the family core, when a chronic physical illness keeps the patient from socializing with peers.

Since I became a doctor I have tried various ways of reaching out to my adolescent patients. Too often, however, they choose not to communicate much and overtures about a recommended treatment or procedure evoke defiant reactions, a response typical of an age group that is striving for independence and suspicious of the expectations of anyone in a position of authority.

A communication vehicle that is potentially appropriate for this particular group is art therapy, due to its non-verbal approach (Linesch, 1988 & Riley, 1999). Art can represent a safe place in which to express and explore feelings. It may allow a person to present one's own reality when that reality is too emotionally charged to be expressed in words. Art offers an opportunity to become aware of and to observe one's own peculiar truth with more distance; it is as if the artist's product talks back to the artist. This is a kind of dialogue that takes place parallel to, and somewhat independently of, the relationship with the art therapist (Edwards, 1987).

As a pediatrician I am increasingly confronted with chronic physical illness in adolescence and its impact on the adolescent's future life. With my background in art therapy I am wondering whether this therapeutic approach can be helpful to this population in expressing and exploring its issues. During my search I found a great deal of literature about so-called medical art therapy with children and adults, but only a few case reports about adolescents. So I decided to focus more on this specific age group. For this work I have chosen a "client-centered" therapy approach, offering the client a non-threatening and non-judgmental environment rarely using directives. This therapeutic process is paced by the client and his actual needs, and therefore, gives him as much freedom and control as possible (Wadeson, 1980).

As a theoretical foundation for the case studies I used Erik Erikson's theory of Psychosocial Ego Development, since according to him development and maturation are based on resolving life crisis (Berzoff, 1996). I further consulted Neinstein (1991) and Hofmann (1997) concerning the issues of chronic physical illness in adolescence. Fi-

nally I included Wadeson's approach (1980) to art therapy in general, Linesch's (1988) and Riley's (1999) approach to art therapy specifically with adolescents, and Malchiodi's approach (1999) to medical art therapy.

The purpose of this book is to explore the effectiveness of art therapy as a primary intervention with an adolescent population with chronic physical illness – in this particular case, with adolescents in chronic renal failure either on hemodialysis, peritoneal dialysis or after kidney transplantation. The hypothesis is that art therapy (1) facilitates expression of emotions through artwork, ideally including verbal expression; (2) enhances self-esteem and identity; (3) helps them cope with their chronic physical illness; and (4) finally, offers an opportunity to vent anger and frustration (catharsis). By obtaining a safe place to explore issues related not only to the developmental stage but also to the conditions of chronic physical illness, these teenagers may begin to discover their individual strengths through art therapy, rather than dwell primarily on their individual weaknesses. In other words, the book will explore whether art therapy can be a means by which this population could be helped to accept and integrate their chronic physical conditions into their lives and to find an appropriate place in our society. In addition, this book will investigate whether art therapy could become a sanctuary, one in which the patient is allowed to keep control, to make his own decisions and to explore and develop a sense of freedom in an overwhelming controlling environment.

This book consists of four chapters with Chapter 1 providing an in-depth perspective on literature review and adolescence as a developmental stage. The psychological impact of chronic physical illness in adolescence, creativity and art therapy, medical art therapy, and the creative process is discussed. Chapter 2 studies methodology, independent variables, settings, procedures, materials used, and the gathering of data. Chapter 3 addresses case histories, their artwork, the short-term treatment group, and the long-term treatment group. Seven clients and examples of their artwork are presented. Chapter 4 discusses results, conclusions, and ideas for further studies.

R.R.L-O.

CONTENTS

	<i>Page</i>
<i>Preface</i>	vii
Chapter 1: Literature Review	3
A. Adolescence as Developmental Stage	3
B. The Psychological Impact of a Chronic Physical Illness in Adolescence	11
C. Creativity, Creative Process and Art Therapy	22
D. Art Therapy with Adolescents and Medical Art Therapy	27
Chapter 2: Methodology	39
Chapter 3: Case Histories and Artwork	51
A. Short-Term Treatment Group	51
1. Emma, female, 13 years	51
2. Joan, female, 17 years	57
3. Martin, male, 15 years	66
B. Long-Term Treatment Group	73
4. Abdul, male, 16 years	73
5. Jayson, male, 13 years	98
6. Katja, female, 12 years	124
7. Nadja, female 13 years of age	148
Chapter 4: Discussion	177
<i>Bibliography</i>	201
<i>Index</i>	203

ILLUSTRATIONS

	<i>Page</i>
Figure 3.1. <i>Wild Animals</i> , collage by Emma, 13 years.	54
Figure 3.2. <i>Bud of a Flower</i> , clay sculpture by Emma, 13 years	56
Figure 3.3. <i>My Family</i> , drawing by Joan, 17 years	61
Figure 3.4. <i>Me and Andrew</i> , clay sculpture by Joan, 17 years	61
Figure 3.5. <i>My House and My Church</i> , drawing by Joan, 17 years	62
Figure 3.6. Untitled, mobile by Joan, 17 years	64
Figure 3.7. <i>My Tree</i> , drawing by Martin, 15 years	70
Figure 3.8. <i>A Bridge</i> , drawing by Martin, 15 years	71
Figure 3.9. Untitled, watercolor by Abdul, 16 years	77
Figure 3.10. Untitled, watercolor by Abdul, 16 years	81
Figure 3.11. Untitled, charcoal by Abdul, 16 years	82
Figure 3.12. Untitled, pencil drawing by Abdul, 16 years	84
Figure 3.13. Untitled, pencil drawing by Abdul, 16 years	85
Figure 3.14. <i>My Tree</i> , pencil drawing by Abdul, 16 years	88
Figure 3.15. <i>Bridge Drawing</i> , pencil drawing by Abdul, 16 years	90
Figure 3.16. <i>Da Vinci's Anatomical Wheel</i> , pencil drawing by Abdul, 16 years	91
Figure 3.17. <i>My Landscape</i> , pencil drawing by Abdul, 16 years	92
Figure 3.18. <i>My Landscape</i> , continuation of pencil drawing by Abdul, 16 years	93
Figure 3.19. <i>My Landscape</i> , continuation of pencil drawing by Abdul, 16 years	94
Figure 3.20. <i>My Totem Pole</i> , pencil drawing by Abdul, 16 years . . .	96

Figure 3.21.	<i>My Flags</i> , pencil crayon drawing by Jayson, 13 years.	103
Figure 3.22.	<i>The Rainbow</i> , watercolor by Jayson, 13 years	105
Figure 3.23.	<i>Fast Flying Balls</i> , watercolor by Jayson, 13 years.	107
Figure 3.24.	<i>Animals</i> , collage by Jayson, 13 years	108
Figure 3.25.	<i>Sports</i> , detail of the collage by Jayson, 13 years.	110
Figure 3.26.	<i>Sports II</i> , detail of the collage by Jayson, 13 years.	111
Figure 3.27.	<i>Cars</i> , collage by Jayson, 13 years	113
Figure 3.28.	<i>In Honor of Hockey</i> , clay sculpture by Jayson, 13 years.	114
Figure 3.29.	Untitled, watercolor by Jayson, 13 years.	115
Figure 3.30.	Untitled, clay sculpture by Jayson, 13 years	117
Figure 3.31.	<i>My Tree</i> , watercolor by Jayson, 13 years	118
Figure 3.32.	<i>Michael Jackson's Glove</i> , papier maché sculpture by Jayson, 13 years	120
Figure 3.33.	<i>Happy Pumpkins</i> , clay sculpture by Katja, 12 years.	128
Figure 3.34.	<i>Bee Family</i> , clay sculpture by Katja, 12 years	129
Figure 3.35.	<i>Bird</i> , pipe cleaner object by Katja, 12 years	131
Figure 3.36.	<i>Teddy Bear</i> , clay sculpture by Katja, 12 years	132
Figure 3.37.	<i>Bird's Cage</i> , popsicle sticks object by Katja, 12 years.	133
Figure 3.38.	<i>Christmas Tree</i> , collage by Katja, 12 years	135
Figure 3.39.	<i>Snowman</i> , clay sculpture by Katja, 12 years	136
Figure 3.40.	<i>A Sitting Girl</i> , oil pastels by Katja, 12 years	138
Figure 3.41.	<i>Lucky</i> , oil pastels by Katja, 12 years	140
Figure 3.42.	Untitled, collage by Katja, 12 years	142
Figure 3.43.	Bowl, papier maché object by Katja, 12 years	143
Figure 3.44.	<i>My Personal Dream Catcher</i> , by Katja, 12 years.	145
Figure 3.45.	<i>Running Dog with her Puppy</i> , pencil drawing by Katja, 12 years.	147
Figure 3.46.	Untitled, mixed media collage by Nadja, 13 years.	153
Figure 3.47.	<i>My Mug</i> , clay mug by Nadja, 13 years.	154
Figure 3.48.	Untitled, oil pastels by Nadja, 13 years.	156

Figure 3.49.	<i>Molly and Paul Holding Hands</i> , chalk pastels by Nadja, 13 years	157
Figure 3.50.	Untitled, watercolor by Nadja, 13 years	159
Figure 3.51.	<i>Styles of Ways of Clothing, Styles of Hair</i> , chalk pastels by Nadja, 13 years	160
Figure 3.52.	<i>Under Sea</i> , chalk pastels by Nadja, 13 years	161
Figure 3.53.	<i>Mr. Happy Potato Head</i> , papier maché container by Nadja, 13 years	167
Figure 3.54.	<i>Mermaid</i> , therapeutic puppet by Nadja, 13 years.	171
Figure 3.55.	<i>My Dream Catcher</i> , Nadja, 13 years	174

PLATES

Plate 1.	<i>A Landscape</i> , watercolor by Abdul, 16 years	45
Plate 2.	<i>A Day of Celebration</i> , watercolors by Abdul, 16 years	45
Plate 3.	<i>The Green Step Towards the Sun</i> , oil pastels by Abdul, 16 years	46
Plate 4.	Untitled, chalk pastels by Abdul, 16 years	46
Plate 5.	<i>Sports</i> , collage by Jayson, 13 years	47
Plate 6.	<i>Sports II</i> , collage by Jayson, 13 years	47
Plate 7.	<i>My White Rabbit</i> , oil pastels by Katja, 12 years	48
Plate 8.	<i>Spring Flowers</i> , watercolors by Katja, 12 years.	48
Plate 9.	Untitled, chalk pastels by Nadja, 13 years.	49
Plate 10.	<i>Family Portrait</i> , chalk pastels by Nadja, 13 years.	49
Plate 11.	<i>Mark's Story</i> , chalk pastels by Nadja, 13 years.	50
Plate 12.	<i>Our World, the Mermaids' World</i> , chalk pastels by Nadja, 13 years	50

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Chapter 1

LITERATURE REVIEW

A. ADOLESCENCE AS DEVELOPMENTAL STAGE

In talking about adolescence, the first thing to keep in mind is this: we are not talking about a homogeneous group, but rather a group that displays “wide variability in biological and emotional growth. Each adolescent responds to life’s demands and opportunities in a unique and personal way” (Neinstein, 1991, p. 39). According to Neinstein, adolescence has been described as “a period of extreme instability” or “normal psychosis” (Neinstein, 1991, p. 39).

According to Anna Freud, “struggles of the ego to master the tensions and pressures arising from the Id lead in the normal case to character formation” (Freud, 1958, p. 257). She described “this battle between ego and Id as terminated by a first truce at the beginning of the latency period and breaking out once more with the first approach to puberty” (Freud, 1958, p. 257). “The individual recapitulates and expands in the second decennium of life the development he passed through during the first five years” (Freud, 1958, p. 256).

To further understand the developmental tasks of adolescence, I will use the theoretical framework of Erik Erikson’s theory of Psycho-social Ego Development. I will have a look at his study of the developmental tasks starting from birth and leading to adolescence.

According to Erikson (1950/1963), the ego is shaped and transformed not only by biological and psychological forces, but by socio-cultural forces as well. Erikson identified the ego strengths as well as the vulnerabilities that a person has to face during each stage of development. He stated that at each stage of psychosocial development

there is the potential for the emergence of a unique kind of ego strength, as long as the individual faced and mastered the age-specific crisis with an age-specific concern at an age-specific time (Berzoff, 1996). It is important to understand that these stages are not sharply demarcated. They may overlap, regress, stagnate and catch up again, depending on an individual's life circumstances and his capability to cope. Childhood failures to master the age-appropriate developmental task limit the adolescent's ability to deal with the challenges of physical maturation, vocational search and self-definition. The result is a psychopathologic identity confusion in adolescence, which may even persist into adulthood (Jaffe, 1991).

According to Erikson, the first stage "Basic Trust vs. Basic Mistrust" (infancy, ages 0 to 18 months) – the oral stage according to Freud – is about establishing a basic trust between the child and the primary caregiver; therefore, the trust is to overcome "basic mistrust which is an inborn discomfort caused by the immaturity of homeostasis" (Erikson, 1950/1963, p. 247). The accomplishment of the "nuclear crisis leads to a general state of trust, which implies not only that one has learned to rely on the sameness and continuity of the outer provider, but also that one may trust oneself and the capability of one's own organs to cope with urges" (Erikson, 1950/1963, p. 248). "Consistency, continuity and sameness of experience provide a rudimentary sense of ego-identity" (Erikson, 1950/1963, p. 248) – of trustworthiness.

Erikson's second stage (early childhood, age 18 months to 3 years) – parallel to Freud's anal stage – is about "Autonomy vs. Shame and Doubt." Due to growing muscular maturation, this stage is one of ambivalence between "two sets of social modalities: holding on and letting go" (Erikson, 1950/1963, p. 251). Children at this stage need to achieve some sense of independence over their own body, including some sort of control over what is inside and outside of it. If a child comes to feel that his wish to have a choice and his urge for autonomy does not jeopardize his newly achieved "basic trust," he will gain some confidence and pride (Berzoff, 1996). At this stage the child's main struggles are control issues. He has to gain some sense of having the right to have control, but he also has to accept the fact that he will be controlled by outer forces as well. The child will have to confront first boundary issues. He will have to learn that within his social environment his freedom will end where his neighbor's (in this case his caregiver's) freedom begins. For the first time he will be confronted with differentiation between his and another's privacy (Erikson, 1968).

This stage, therefore, becomes decisive for the ratio of love and hate, cooperation and willfulness, freedom of self-expression and its suppression. From a sense of self-control without loss of self-esteem comes a lasting sense of good will and pride; from a sense of loss of self-control and of foreign overcontrol comes a lasting propensity of doubt and shame. (Erikson, 1950/1963, p. 254)

Erikson's third stage, "Initiative vs. Guilt" (play stage, ages 3 to 6 years), corresponds to Freud's Oedipal stage. The child enters a period rich in imagination and creativity, and begins to differentiate between concepts of the self and others. He faces the task of how to identify with his parents' and their society's values. The child now starts to develop an "'inner voice' of self-observation, self-guidance and self-punishment" (Erikson, 1968, p. 119) – the conscience as the cornerstone of morality (Erikson, 1968). "Initiative adds to autonomy the quality of undertaking, planning and attacking a task for the sake of being active and on the move, where before self-will more often than not, inspired acts of defiance or protested independence" (Erikson, 1950/1963, p. 255). Whereas in earlier stages the struggle for autonomy had concentrated on keeping rivals out, initiative in this stage leads to anticipation and challenge of rivalry in order to reach a superior position. Competition adds to creativity for initiative (Erikson, 1968). If the child encounters too little appreciation or even opposition to his endeavor, he will develop feelings of guilt, and will react with withdrawal and loss of self-confidence.

The fourth stage, which is termed "latency" according to Freud (school ages, age 6 to 11 years), Erikson has described as the stage of "Industry vs. Inferiority." The child now moves beyond the family nucleus and dives into social life, developing cognitive skills, play skills and social skills, including the ability to express and integrate his own feelings (Berzoff, 1996). It is the time to go to school, to learn, to develop competence, new physical and mental capabilities and to promote self-confidence. Children now are eager to make things together, to share responsibility and, therefore, to develop team skills, including the acceptance of rules. Through interaction with his peers, the child evolves ways to maintain self-esteem, developing increased ability to tolerate frustration. If for any reason the child is deprived of participating in social life and/or of developing a sense of achievement, he will grow feelings of inferiority.

Adolescence (ages 11 to 19 years), according to Erikson, is the stage with the psychosocial task of "Identity vs. Role Confusion." Adoles-

cence is “a psychosocial stage between childhood and adulthood, and between the morality learned by the child, and the ethics to be developed by the adult” (Erikson, 1950/1963, p. 263). It is the stage of inner turmoil and instability, of ambivalence and inconsistency. Like Anna Freud, Erikson postulated that “in their search for a new sense of continuity and sameness, adolescents have to refight many of the battles of earlier years . . . only now with a new addition of genital maturity” (Erikson, 1950/1963, p. 261). Adolescents now become “primarily concerned with what they appear to be in the eyes of others as compared with what they feel they are” (Erikson, 1950/1963, p. 261). Individuals at this stage are looking beyond their parents for a sense of self and are prone to follow idols, apparently losing temporarily their own ideals. They are in a stage of suspended morality, while they are formulating new personal ideologies based on values that differ from their parents (Berzoff, 1996).

Acknowledging Erikson’s statement about the sociocultural influence on human psychological development, I think we also have to consider sociocultural and economic changes in modern times while working with today’s adolescents. Therefore, I will explore a more recent study published by Golombek and colleagues (1989), a group of North American psychoanalysts. As our social system becomes more technological and industrial, the roles and tasks assigned to adults become more complex. These role expectations, in turn, require a longer education and training and intensified experimentation for adolescents in preparation for adulthood (Golombek et al., 1989).

While Blos was one of the first psychoanalysts to subdivide adolescence in five subphases (“Preadolescence, Early Adolescence, Adolescence Proper, Late Adolescence and Postadolescence” [Jaffe, 1991]), Golombek’s work is based on a model with three subphases – “Early, Middle and Late Adolescence” – each with specific developmental challenges (Golombek et al., 1989), including two transitional stages, before and after adolescence respectively. The first transitional stage before adolescence, so-called “Pubescence,” includes all changes associated with movement from childhood into adolescence, especially physical changes. “Youth,” the second transitional stage after adolescence, encompasses the changes associated with the progression from adolescence into adulthood (Golombek & Kutcher, 1990).

During “Early Adolescence” (ages 12 to 14 years), the child is dealing again with the early challenges that are rooted in Erikson’s stage of

“Trust vs. Mistrust.” The stress of new physical and psychosocial changes associated with altered adult reactions and expectations makes the child at this stage vulnerable. Preoccupied with rapid body changes, his former body image seems to be disrupted, which could be a source of anxiety (Hofmann, 1997). He narcissistically focuses attention on his body, and attempts to integrate rapidly increasing height, the changing shape, growing physical competence, rising sexual feelings and a new sense of power into his body image (Hofmann, 1997). His sexuality turns into a genital sexuality with increased interest in sexual anatomy and physiology, often provoking anxieties and questions regarding normalcy of functioning (Neinstein, 1991). The teenager begins to withdraw his interest in the parents as primary caregivers in order to explore his own environment. His feelings of mistrust for adults who seem ungiving and alien, change quickly with feelings of need, deprivation and hunger for attention and care. The result is difficulty in relatedness. He appears to be less self-confident and uncertain about his own beliefs, values and ideals. The internal self seems to fall apart. The child is anxious and depressed (Golombek et al., 1989). His cognition is still dominated by concrete thoughts; the teenager is not yet able to perceive long-range implications of current decisions and acts (Hofmann, 1997).

During “Middle Adolescence” (ages 14 to 16 years), the teenager seems to reactivate earlier issues of Erikson’s “Autonomy vs. Shame and Doubt” stage. He is involved in a “process of personality recrystallization,” taking in new identifications and self-representations while discarding old ones (Golombek et al., 1989, p. 501). Having experienced the majority of its pubertal changes, the body image as part of the personality starts to crystallize as well. Thus the middle adolescent still has to explore his sexual role. Therefore, great interest is invested in the ideal male or female appearance to determine what attracts the opposite sex. There is still little concern about reciprocity, commitment, and mutual caring, which will develop during later adolescence (Hofmann, 1997). With an increasing self-confidence and self-esteem, he develops a higher ability to assume and explore a variety of roles. Adolescents at this stage tend to present some sort of “omnipotent, grandiose and arrogant characteristics” (Golombek et al., 1989, p. 501). They rapidly gain competence in abstract thinking, but tend to revert to concrete thoughts under stress (Hofmann, 1997).

Finally, during “Late Adolescence” (ages 16 to 18 years) the adolescent has to face again the challenges associated with Erikson’s “Initia-

tive vs. Guilt” stage. With an increased ability of introspection, he appears also more willing to attempt to influence his environment. Demonstrating the highest level of curiosity in his outer world, the level of anxiety and depression seems to increase again. “Although identity structure seems to have been reestablished for most, the late adolescent is inexperienced regarding his reconstructed personality” (Golombek et al., 1989, p. 502). This inexperience causes discomfort, as the teenager struggles to integrate sexual, vocational, religious and political identities. By then the adolescent has established abstract thought processes, and is now capable of perceiving and acting on long-range options (Hofmann, 1997). Finally, with the relative consolidation of his identity, he is ready for more intimacy, the stage of young adulthood (“Intimacy vs. Isolation” in Erikson’s terms).

In his longitudinal study, Golombek found three routes of passage through adolescence: “Stable/Clear Route” (clear of personality disturbances at each subphase of adolescence, 35% of average population); “Fluctuating Route” (clear during one subphase but disturbed at another, 40% of average population); and “Stable/Disturbed Route” (personality disturbances at each subphase, 25% of average population) (Golombek et al., 1989, Golombek & Kutcher, 1990). The course taken by any particular individual is dependent on such factors as: his constitution and temperament; his environment, including the amount of stress with which he is confronted; his social support system, and so forth (Golombek & Kutcher, 1990). Whether or not the stress factors of chronic physical illness influences the route of passage through adolescence is still a debate in literature (Capelli et al., 1989, Silver et al., 1990, Suris et al., 1996).

While I used Erikson’s theory of Psychosocial Ego Development as a developmental framework helping to understand adolescence as a developmental stage, my therapeutic interventions as an art therapist are guided by an Object Relations psychodynamically oriented framework. The focus of Object Relations theory is on the complex relationship of self and others. It explores “the process whereby people come to experience themselves as separate and independent from others, while at the same time needing profound attachment to others” (Melano Flanagan, 1996, p. 127). Object Relations theories focus on the interaction individuals have with other people, and how he/she internalizes these interactions. Therefore, it includes “the whole internal world of relations between self and other, and the way in which

others have become part of the self” (Melano Flanagan, 1996, p. 128). The word “object” traditionally is used for person.

Winnicott (1956), a major Object Relations theorist, believed that for a healthy psychological development

important needs have to be met including the need to be seen and valued as a unique individual, to be accepted as a whole with both good and bad aspects, to be held tight and to be let go, and to be cared for, protected, and loved. (Melano Flanagan, 1996, p. 130)

Like the body takes in food in order to grow by metabolizing protein, fat and carbohydrates, the psyche takes in experiences with other people and processes them to become part of the psychological self.

Winnicott (1956) was especially interested in the capability of being together as a prerequisite for the ability to be alone and enjoy separateness. He stressed the importance of inner representations of others by internalization of good objects as a condition for this kind of healthy independence. The inner world has to be peopled with enough comforting figures, in order to develop the capability to be alone, or even enjoy solitude. According to Winnicott (1956) only a “good enough mother” (or caregiver) can create a “holding environment” necessary for the internalization of experiences with good objects (Melano Flanagan, 1996). A “good enough mother” is capable “for attunement to the baby’s changing developmental needs” (Melano Flanagan, 1996, p. 138), without being neither neglective nor over-protective. She is able to adapt and change according to the changing needs of her child, and the growing child’s decreased dependence (St. Claire, 2000). She offers her baby a “holding environment” subtle enough to be protective without being overly limiting.

Winnicott (1956) created the term the “transitional object.” He observed that children in their attempt to move towards a state of separateness often use well-defined objects or rituals to sooth themselves in absence of their “good enough mother.” “These ‘transitional objects’ offer ways for the child to hold onto the internal representations of others when she is not yet able to do so on her own” (Melano Flanagan, 1996, p. 138). The “transitional object” is a bridge to the possible existence of a beloved person even in absence.

Winnicott (1956) further stressed the importance of flexibility and genuineness of attachment to nurture the “true self,” the core of a personality. “The ‘true self’ is the repository of individuality, uniqueness, difference” (Melano Flanagan, 1996, p. 140).

The True Self cannot emerge if the child feels she must be exclusively attuned to the needs of others in the family system and if she needs to be a certain way in order to be recognized and acknowledged. Instead the child may develop a False Self, one that seeks to suppress individuality and molds itself to the needs of others. This False Self, trying so hard to be responsive and to take care of others, ultimately becomes overly compliant. (Melano Flanagan, 1996, p. 140)

In summary, Object Relations theorists focus on the individual's internal world, which comprises representations of self and others, representations formed by ideas, memories and experiences in interaction with the external world. As therapists we are objects of this external world. By trying to develop a working alliance with the client, we are building a new relationship with him/her.

An object relations-oriented approach to treatment is often particularly useful in understanding and treating an adolescent population. Although adolescents struggle with conflicts related to authority and dependence, they still have very strong need for control with a reliable object. The art therapist can provide the adolescent with a non-judgmental, non-critical and reliable adult who they can go to with their concerns and problems, which they may not be able to, or elect not to discuss with their parents. In this environment they can test out behavior, explore ideas, thoughts and feelings they may not be able to express elsewhere. Also they are provided with a holding environment, in which they can learn to understand aspects of themselves, their feelings and their relationships. They maybe provided with a new or different object experience.

For the chronic ill teens, such an experience is control. They often struggle with intense conflicts about their body, illness, self-esteem, and so forth, which they are not able to discuss or share with anyone else. The opportunity to connect with an adult in a new way is often very helpful. In art therapy these teens can use the relationship with the therapist, the artwork, and the experience to learn more about themselves, their illness, coping styles, and enhance their capacity for relatedness with others.

B. THE PSYCHOLOGICAL IMPACT OF A CHRONIC PHYSICAL ILLNESS IN ADOLESCENCE

Successful development occurs through a process of continuous focusing and engaging in relevant developmental tasks. For chronically ill adolescents, however, stressors and tasks occur simultaneously. These adolescents must strive to maintain a delicate balance between appropriate developmental progression and physical health (Seiffge-Krenke, 1998). In general, the existence of a major life crisis such as a chronic physical illness during adolescence is likely to exaggerate the challenges of this developmental stage (Eiser, 1993). This impact is not only dependent on the individual's variability in ego-strength, stability and developmental stage, but on such factors as age of onset, course, visibility and prognosis of the chronic illness. In addition one has to consider the individual's support system (family dynamics, school environment, sociocultural relationships, friends, etc.) (Neinstein, 1991).

One would expect a chronic physical illness to have the biggest psychological impact on the body image of an individual. However, research suggests that chronic physical disease per se does not seem to have a negative impact on body image (Neinstein, 1991; Hofmann, 1997). Rather, there seem to be many factors that determine the psychological impact of chronic physical illness:

1. *Age of onset of the disease:* In general, the younger the child when first affected, the less disruptive the disease will be in a developmental sense. Congenital conditions or those with early childhood onset usually are well-integrated into identity, achieving a satisfactory adaptation by the time the child reaches adolescence. But in later stages like adolescence, the problems increase significantly. "Adolescence, however, is a time of exceptionally active intrapsychic reorganization and the additional stress of chronic illness . . . can overwhelm integrative functions already working at maximum capacity" (Hofmann, 1997, p. 741). With the onset of a disease in early adolescence the teenager's biggest concerns often are about body image and sexual functioning. Delayed puberty and pubertal growth spurt, or bodily malformations can create increased anxieties over sexual functions and sexual relations. The lack of growing physical competence may cause segregation from peers, and therefore add to an inferior self-image. This can contribute to lowered self-esteem, increased absences from school and

other social activities. As a result, it causes the teenager in this stage to become angry and/or depressed. Therefore, the more visible the disease the bigger the psychological impact in this age group (Neinstein, 1991). For those who are struck by a physical illness in middle adolescence, all of the problems described above also hold true, but they can often be more extreme since middle adolescence is the most devastating time for a chronic illness to strike. An adolescent in this phase is involved with separation, peer interaction, and sexual attraction. The consequences of a chronic disease have a very disruptive effect on the adolescent's natural urges (Neinstein, 1991). "At the age when even the healthiest young person feels different from peers and feels 'no one understands me,' the teen with chronic physical illness often feels even more removed from the mainstream" (Blum, 1992, p. 365). In addition, his feelings of omnipotence and personal invulnerability – typical traits for middle adolescence – are hurt. That may cause the adolescent to be reluctant to accept the diagnosis of a life-long or potentially fatal disease. With this reluctance goes a denial of the consequences of the disease, and the refusal to comply with treatment (Eiser, 1993). For those who develop a chronic illness in late adolescence, they usually go through less turmoil. The teenager at this stage will have already gained some self-confidence and identity. Concerns are focused on vocational and educational plans, financial resources, prospects for living independently, sexual function and future sexual relations (Neinstein, 1991).

2. *Degree and type of impairment:* A seriously impairing condition seems to have the biggest impact in middle adolescence as this is the time of heavy investment in emancipation and independence (Hofmann, 1997).

3. *Degree of visibility of the disease:* Directly visible conditions may cause a sense of personal devaluation and diminished self-esteem, especially in early adolescence. As a result there is a tendency for self-protective withdrawal and social isolation, or provocative acting-out in defense against possible rejection (Hofmann, 1997).

4. *Prognosis of disease:* The stress of uncertainty has the bigger impact than that when the course of the disease is known, even when leading to death (Boice, 1998; Blum, 1992).

5. *Course of illness:* Diseases with a fluctuant course with remissions and relapses are a bigger burden compared with chronic persistent conditions (Boice, 1998; Blum, 1992).

6. *Family issues*: The response of the family is a significant factor in the adolescent's compliance and adaptation. The parents may have to cope with the following: (1) guilt at causing renal failure, (2) fatigue and burnout associated with constant care and appointments, (3) inadequacy at not being able to help or fix the problem, (4) frustration with the medical establishment for no cure, (5) overprotection versus being too lenient, (6) marital stress, (7) rivalry between the sick child and his siblings, and (8) behavioral issues of neglected siblings, and so forth. Frequent trips to the hospital, daily home dialysis (hemodialysis and peritoneal dialysis) interfere with family schedules, school and vacations (Taylor, 2000). The more parents are able to be supportive in a way that achieves an appropriate balance between the required management of the disease and the teen's developmental needs, the smoother the adolescent will adapt. Often it is difficult for parents to provide required support in management of disease, avoiding the risk of overprotectiveness. Financial concerns may make the situation more difficult (Hofmann, 1997).

One of the main developmental issues in adolescence is the individual's conflict around autonomy and dependence. According to Boice (1998), autonomy is part of psychological well-being. "Achievement of autonomy depends on many factors, including the willingness of family and friends to allow the individual to take chances and realize personal potential" (Boice, 1998, p. 933). Therefore, to fully understand the independence struggle of an adolescent with chronic physical illness, we have to distinguish between "disability" and "handicap." In Blum's (1992) words (p. 366), "A disability is a restriction in functional capability imposed by physiology; a handicap, on the other hand, is determined by the social context coupled with the functional capability." In other words, while the teenager has to accept, to learn to cope with, and to adapt to a disability, the environment can help the adolescent in dealing with a handicap. Therefore, autonomy is dependent on the affected teenager's adjustment to the disease on the one hand, and on his support system on the other hand.

It is important to differentiate between two categories of autonomous behavior in the context of chronic illness. The first concerns autonomous behavior in a general sense, relevant to all individuals and relating to everyday issues. The second concerns responsible behavior specific to the management of the disease (Eiser, 1993). With regard to the first category, the disabled teenager should not be treat-

ed differently than his healthy peers. However, we have to keep in mind that the chronic condition may have a negative impact on self-confidence as it relates to the achievement of life's daily tasks. The second category is a more complex issue and is very much dependant on the cognitive development of the patient, and the onset, kind, course and prognosis of the disease. The more the teenager is able to understand the disease and its consequences to their full extent, the more he may be ready to take over responsibility in the disease's management, and therefore, will show reliability in compliance. Both categories of autonomy have to be achieved in the developmental process of maturation, paced by the adolescent's individuality.

This quotation by Blum (1992, p. 367) is an appropriate summary of this paragraph:

We talk about development during the teenage years as a movement from dependence *to* independence. In truth, it is a movement from dependence *through* independence *to* interdependence." I think that independence is not synonymous to autonomy. Rather, to function within the frame of this interdependence means to be autonomous.

At this point I would like to focus on the process of achieving autonomy in the management of a disease that strikes during adolescence. The teenager goes through a process of adjustment after disclosure of the diagnosis of a chronic illness that is very similar to what Kuebler-Ross describes as the transitions people go through when dealing with death. Those stages are "denial – isolation," "anger," "bargaining," "depression" and finally "acceptance" (Gabriels, 1988; Kuebler-Ross, 1969; Weldt, 2003). Hofmann describes five phases of adaptation: Phase 1 extends from the first few days after disclosure of the diagnosis through the first week. Initial disbelief and shock is characteristic. The adolescent in his helplessness, with his anxiety over having lost control, and his unconscious fears of possible devaluation and loss of esteem, reacts with denial, depression, regression, anger and social withdrawal. Phase 2 extends from approximately the second week through the first month. The adolescent's biggest concerns are about physical integrity, body image, sexual identity, independence, peer acceptance and self-esteem; in other words, issues typical for this age but now in the context of a more complex situation of illness. Regression, resistance towards taking responsibility, reluctance to re-engage with peers, and anger and frustration are common reactions. Phase 3 extends over the second and third month after onset. The teenager is

mainly concerned about re-entering the mainstream of life, fearing devaluation and rejection. Behavior varies from avoidance of usual activities to testing the parameters of his altered lifestyle and compromised independence. Rebellion against the limitations of disease-management requirements and testing out through non-compliance and, therefore, through disease exacerbation are often observed reactions. Phase 4 extends through the first few years after onset. By this time the adolescent's perception of the disease should be relatively realistic. Still concerned about previously listed issues, now he begins to contemplate possible future effects of the disease, and to develop adaptive coping, including reintegration into normal activities. At this point the teenager is ready to take a more active part in the management of the disease. Phase 5 extends through late adolescence into young adulthood. The patient begins to focus on acquisition of an adult level of autonomy, career plans, interpersonal relationships, and so forth. In general, the better the earlier conflicts have been resolved, the better the patient will adapt to his disease.

However, it is very important to keep in mind that these phases rarely are linear and chronological phenomena. Patients tend to go back and forth, regress, move ahead or skip part of phases only to get back to them later. As therapist it is important to acknowledge caution in using these phase-oriented schemes in order to remain as flexibly attuned to the patient as possible, and to avoid misleading assumptions and expectations (Kuebler-Ross, 1969).

Lazarus and Folkman define coping as cognitive and behavioral abilities to respond to any kind of internal or external forces or stressors (Eiser, 1993). Two types of coping strategies are described: (1) "Problem-focused" or "Primary control" concerns the attempt to change or control some aspects of the stressor or the environment, (e.g., taking an active part during a painful treatment of a disease, and therefore, have more control), and (2) "Emotion-focused" or "Secondary control" concerns the attempt to manage or regulate the negative emotions associated with stressors (e.g., trying to control anxiety or fear through relaxation exercise done before the painful treatment) (Eiser, 1993). Both coping strategies are seen within the same individual, independently of the kind of stressor (disease-related or daily life-related stressors). Depending on factors like the individual's age and temperament, past experiences with coping styles and family traditions, one or the other style may be dominant. A change in children's

use of coping strategies during development has been noticed. With increasing age and maturation, the emotion-focused coping becomes more dominant. However, the adolescent has first to become aware that emotions can be brought under personal control to a certain extent (Eiser, 1993).

Adolescents cope with their chronic physical illness by using a wide range of adaptive and maladaptive defense mechanisms. These defense mechanisms may be employed unconsciously, but the result is that negative emotions are made more controllable by placing them into manageable proportions. In other words, they help the patient move back toward homeostasis (Hofmann, 1997). The following defense mechanisms have been described in adolescents who have to deal with chronic physical illness:

1. **Intellectualization:** This behavior separates the realities from the disease from the emotional impact. While suppressing the emotional part, the factual aspect is dealt with rational objectivity, as if it had nothing to do with the patient.
2. **Compensation:** Lost qualities are substituted by new constructive activities.
3. **Displacement:** Concerns about oneself are substituted by concerns about something or somebody else.
4. **Projection:** Self-blame and guilt over a situation are unconsciously shifted onto someone or something else.
5. **Regression:** In order to avoid unbearable responsibilities, the patient moves back to a more child-like dependence.
6. **Denial:** Threatening aspects of the disease are suppressed, as if they did not exist. (Hofmann, 1997; Neinstein, 1991)

Behaviors such as acting out or panic attacks are often seen when uncontrollable fears and anxieties overwhelm the patient.

The ultimate adaptive goal is insightful acceptance of the chronic conditions and its limitations, but this is rarely accomplished during the adolescent years and may take well on into adulthood to achieve, if ever. (Hofmann, 1997, p. 743)

To complete the list of psychological impacts of a physical illness I will explore the adolescent's behavior of secondary gain. Secondary gain describes the phenomenon that is often observed with chronic illness (physical and/or mental), where the patients receive benefits or

satisfactions as a result of their disabling conditions. An adolescent with chronic illness can use his illness to avoid issues that frighten him (e.g., dependence, separation, sexuality, etc.); he may enjoy the absence from school; he may also develop a feeling of entitlement or right for special treatment; within a family dynamics he may exploit the situation by being spared from duties and responsibilities; and so on. Secondary gain from illness can be a very powerful phenomenon and it can be a major obstacle to adaptive or positive life changes. While the adolescent may have limited conscious awareness of the gain of the illness, the process often is largely unconscious. It is very important that clinicians consider the impact of secondary gain in the assessment and treatment of any individual with a chronic illness (Mackinnon & Michels, 1987).

At this point I would like to focus more specifically on my population, adolescents with the condition of chronic renal failure. To understand the psychological impact of this condition to its full extent, we need some medical background information.

Chronic renal failure (CRF) describes a condition in which the kidneys do not work properly anymore – that is, they do not perform the function of the elimination of toxic waste; the regulation of total body fluid balance, electrolytes (Sodium, Potassium) and minerals (Calcium, Phosphate); the regulation of blood pressure; the production of Erythropoietin (a substance important for the production of hemoglobin); the metabolism of vitamin D; and, therefore, the regulation of the bone metabolism, etc. The causes that lead to CRF are multiple (congenital dysplasia, acquired glomerulonephritis, vasculitis, interstitial nephritis, pyelonephritis, hereditary cystic kidneys, tumors, etc.), as our population showed. General clinical manifestation of CRF are edema, anemia/fatigue, anorexia/nausea, renal osteodystrophy/growth retardation, hypertension/headache, neuropathy with gross/fine motor delay, delayed sexual and cognitive development, menstrual irregularities/impotence, and skin problems (with itchiness due to the build-up of toxic wastes in the skin), as well as well-known drug side effects.

When talking about end-stage renal failure (ESRF) we are describing a condition in which conservative (non-invasive) treatment (remarkable dietary restrictions with limitation in fluid/salt intake, diuretic and antihypertensive medication, managing anemia and growth retardation) of CRF is not sufficient anymore. Renal replacement thera-

py like hemodialysis, peritoneal dialysis or kidney transplantation is necessary in addition to all above listed restrictions.

Each of the more invasive treatments has its specific advantages and disadvantages:

- **Hemodialysis:** This is a procedure, in which the blood circulates out of the body through a machine with a filter system and back into the body for about 3–4 hours, 3–4 times a week. The advantage of this treatment is that it brings a fast correction of fluid, electrolyte and metabolic abnormalities. It requires anticoagulation to prevent the clotting of the blood in the machine, special nursing skills and high surveillance during the procedure due to high complication rate (hypotension, dysrhythmia, muscle cramps, seizures). A vascular access has to be established, which requires sterile handling due to high risk for infections. In children, a central venous line with its tip in the right heart is surgically inserted, and needs careful dressing after each use. With these tubes attached to the chest the child has to follow certain restrictions in physical activities: no swimming, and no team sports with potential body contacts (hockey, football, soccer, etc.). Although physical activity is recommended, it has to be on a more individual basis (bicycling, jogging, etc.). Other big disadvantages are frequent trips to the hospital, frequent absence from school, impediments with regard to participation in social activities, interference with outings and holidays, which involves the whole family (Taylor, 2000).
- **Peritoneal Dialysis:** This is a procedure, in which a sterile solution (dialysate) is instilled into the peritoneal space. Waste particles are removed from the blood across the peritoneal membrane by diffusion during the 3–4 hours of dwelling of the fluid in the abdomen. Four to six times a day these dialysate bags have to be changed; that means the patient has extra fluid in his abdomen for almost the entire day, often causing discomfort with stomach pain and feelings of fullness. Although this relatively safe procedure is very time-consuming, it offers a certain independence from the hospital since it is usually done at home. As with hemodialysis, access to the body has to be installed surgically, and then handled in an absolutely sterile manner to prevent infections (peritonitis being the most fatal complication) (Taylor, 2000).

- **Transplantation:** This is a procedure, in which the patient will have an organ implanted, either from a living-related donor or a compatible donor who suddenly died (cadaveric). With increased scientific knowledge about immunosuppression, this kind of renal replacement therapy seems to be most successful. A careful, often very annoying assessment (including blood typing, HLA [human leukocytes antigen] tissue typing, antibody cross-match compatibility testing, beside all the diagnostic imaging, etc.) of the patient and the donor is required previous to surgery. In the case of a living donation, hospitalization and transplantation are carefully planned. In the case of a cadaveric donation, all the patient's test results will be added to an international waiting list. The patient must always be ready to reach the hospital within two hours of time. And he may have to wait for weeks or years, which makes the situation very stressful. Renal transplant surgery is the least complicated of the transplantation interventions and requires about 4–8 weeks of recovery in hospital. Immediately after surgery the immunosuppressive treatment has to be started. Since the risk for rejection is higher at the beginning, medical controls with bloodwork and biopsies are more frequent at the beginning, and looser later on. Associated problems with immunosuppression are high risk for infections, nephrotoxicity, neurotoxicity and (in longer terms) lymphoproliferative neoplasias (leukemia, lymphomas, etc.), beside specific drug side-effects for the particular drug used. Nowadays a transplanted kidney survives for about 10–15 years on average, and then has to be replaced by any kind of renal replacement therapy. That means that the younger the patient, the higher the risk for multiple transplantation (Kosmach, et al. 2000).

It is very important to understand ESRF as a chronic, life-threatening condition without real cure, since none of the above listed treatments offer a permanent rescue – a fact that has to be kept in mind when considering psychological impact.

During my literature search I could not find any studies on the psychological impact of ESRF in childhood and adolescence. I did, though, discover a few for adulthood. Although a lot of the age-related issues are quite different, some of them appear to be common to both young and old.

In their work with adult hemodialysis patients Buchanan and Abram (1984) describe mainly two stages of adaptation to the disease and its treatment. The initial stage includes an acute psychological response that is characterized by “hope for future well-being and anticipated benefits from increased efficiency” (Buchanan & Abram, 1984, p. 274). The concept of hemodialysis as a chronic lifelong treatment has not been established at this point of time. Gradually, however, this hope changes to fear of an unknown future. Withdrawal and reclusion from social contacts are common reactions. At this stage it is important to encourage the patient to ventilate his feelings. The chronic stage of adaptation is characterized by the realization that dialysis has become a way of life. Often “despair and doubt replace an overly optimistic expectation of the treatment” (Buchanan & Abram, 1984, p. 275). Regression and/or depression are common reactions.

During these stages of adaptation Buchanan & Abram (1984) noticed three main areas of conflicts:

1. *Independence*: While the patient has to accept the dialysis regimen and remains fully dependent upon a machine for the rest of his life, he is expected to assume the responsibilities of a healthy person in his “spare-time.” “It is extremely difficult, however, to live a life with such duality of purpose. It is much more common to adopt one of the two extremes, either of which is considered by us maladaptive” (Buchanan & Abram, 1984, p. 277). On the one hand Buchanan and Abram are talking about an extreme dependent and submissive behavior, and on the other hand about an excessive independent and rebellious behavior.

2. *Identification with the illness*: Again, two extreme patterns of behavior are commonly seen. One extreme represents the “identifier” who becomes totally absorbed in hemodialysis and makes this treatment modality the purpose of his life; the other extreme is the “avoider” or “denier” who denies the severity or even the existence of his disease.

3. *Expectations*: Conflicts root in the difference between the patient’s expectation of his life and the expectations of the medical staff. During both stages of adaptation the patient may “perceive the staff as constantly being at cross purposes to him,” which can end up in mistrust (Buchanan & Abram, 1984, p. 278).

Stapleton (2000) categorized stressors connected with ESRF in physiological, psychological, role disturbance and life change. Physiolog-

ical stressors are due to the toxic effect of uremia and include disturbances in body chemistry (altered body fluid and electrolyte homeostasis) and organ system disturbances (hypertension, anemia, osteodystrophy, etc.). Psychological stressors include body image, frustration in basic drives, fear of death and dependence – and independence conflicts. While sitting at the hemodialysis machine and watching the blood circulating, the patient comes to perceive himself as part of the machine – or to incorporate the machine upon which he is dependent for life into his body image (Stapleton, 2000). Sitting there “on the leash” conducting the blood from the body to the machine and back the dependence becomes almost literal. A body, which is intoxicating itself, not being able to clean the blood anymore, changes in value, which contributes to a disturbance in body image. Frustrations in basic drives like satisfaction of hunger and thirst, sexual drive and so on add to this problem. Role disturbances include the fact of being forced to eliminate social, family and occupational roles, leading to feelings of isolation and disengagement. Often, time for treatment interferes with other desirable life activities, and makes the planning for outings and holidays impossible. These and other lifestyle changes are even more pronounced for patients who wait for a cadaveric transplant and live in constant uncertainty and ambivalence (Stapleton, 2000). These stressors together with the characteristic symptoms of CRF (chronic fatigue, low energy level, nausea, itchiness, etc.) and the restrictions in diet and physical activity contribute to the feelings of powerlessness and helplessness. The disease process of CRF leading to ESRF itself is a factor over which the individual has little control. Even in kidney transplantation, the inability to control or predict the outcome of the transplant is a real cause of feelings of powerlessness. This occurs not only postoperatively, but also for the rest of the life, since the risk for rejection, although decreasing in time, is always real.

Clearly, ESRF treated with whatever modality has a huge psychological impact on an individual’s personality and life. The way a patient is able to cope with these circumstances is very much dependent on his character, his social support system, his developmental stage and, last but not least, his own resources.