



CYSTIC FIBROSIS AND ART THERAPY

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Introduction

Cystic Fibrosis (CF) is a common genetic disease affecting many children and young adults. This article will describe the physical and psychosocial impact of the illness through a description of three children seen in private practice. The author will provide a rationale for using art therapy with youngsters with CF to enhance their coping skills and to work through many of the physical and emotional issues they encounter in everyday life.

Overview of CF

Cystic fibrosis is the most common genetic disease in the United States today, claiming more lives than any other genetic disorder. Accounts go back hundreds of years in Northern Europe, about the “salty skin” of some sick children as noted by physicians and parents. “Not a new disease . . . but a newly recognized disease,” CF had its earliest description as a single entity when Dr. Dorothy Anderson wrote the first clinical and pathological study and gave the disease its name in 1938 (Orenstein, 1997, p. XII).

It is now known that children with CF have excessively salty perspiration (Di Sant’Agnese, Darling, Perera, & Shea, 1953). A “sweat test”—a laboratory method for the collection and analysis of CF sweat—was an important development in identifying patients (Gibson & Cooke, 1959).

A giant step forward occurred in the care and prognosis of those with CF when the gene was identified,

bringing wide-ranging effects on understanding the basic defect, developing new ideas for therapy and the ability to diagnose the carrier state (Rommens, et al., 1989).

This is a noncontagious, inherited disease in which both parents must carry the abnormal CF gene. CF affects 1 in every 2,500 babies; 1 in 25 Caucasians carry the CF gene. It is common to both males and females. Once considered a fatal disease of childhood, the life expectancy has increased, due to early diagnosis and improved treatment. There is as yet no treatment that successfully remediates the basic defect. There is still no cure for CF.

Physical Impact of CF

CF has an extensive impact on the body as it involves multiple systems. To further complicate matters, not every case entails the same level of physical involvement. Most patients manifest the disease in the respiratory system while others struggle with debilitating gastrointestinal problems that can involve one or more the following: the liver, pancreas, bile ducts, gallbladder and/or intestines. There is a small percentage of infants who are born with a blocked intestine, referred to as meconium ileus, which can require surgery in the first days of life. Meconium ileus is an obstruction of the intestine (ileus) due to overly thick meconium, the dark sticky material normally present in the intestine at birth (Orenstein, 1997, p. 83). As some patients age, diabetes can also enter the picture

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In loving memory of Meredith and Tony.

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since there is some limitation of the pancreas to produce insulin. Other systems, such as the sweat glands and reproductive systems are also effected. The thicker mucous in the body of the individual with CF, instead of serving a protective purpose, blocks tubes and ducts in some or all of the systems.

Fortunately, growing awareness and knowledge of CF means earlier detection of physical symptoms and complications. Great strides have been made in the past few years with respect to early diagnosis and improved treatment. There now exists optimism as new antibiotics gene therapy, digestive enzymes and postural drainage (a form of respiratory therapy) are part of the medical regime available. Transplantation of damaged organs (lungs, lung/heart or liver) has become part of the improved picture for those requiring organ replacement. Until a cure is found, transplant presents hope for renewed life to some individuals with CF.

Psychosocial Impact—Family

CF also imposes significant stress on the entire family. According to Leonhart, Rothberg and Seiden, "The parents often are greatly disturbed and this feeling influences the child's outlook and the ability of the family to comply with the preventive medical program" (Leonhart, Rothberg, & Seiden, 1984, p. 71). At the time of diagnosis, the parents are given extensive information that is sometimes difficult to comprehend. Husbands and wives may have varying reactions to the new situation, making discussion difficult. As each copes differently to the CF diagnosis, their desire for intimacy may change. Financial strains due to inadequate or nonexistent insurance coverage can add to the psychological turmoil. Children with and without cystic fibrosis pick up tension that can pervade a household.

Because CF manifests itself so differently in each child, predictions of outcomes may be quite unclear. Uncertainty becomes frightening. Living with the unknown day-to-day can easily unbalance the equilibrium of the family. However, it should be noted, most families do adjust to the initial shock of diagnosis and do go on to enjoy a functional family life.

Siblings in a family have some degree of rivalry, though bonds may be strong. Understandably, some children without CF could resent the extra care a brother/sister may receive, or feel guilty that they do not have the disease. Conversely, the child with CF might wonder why the others without CF are so lucky

and he/she got stuck with CF, or be concerned for the worry caused parents or siblings. Art therapy can be beneficial in working through these issues both for the child with CF and for the siblings. Parents can be helped to find support in groups with other parents dealing with the complexities of cystic fibrosis.

School

A child with CF who does well can attend school regularly and carry a full load of classes and activities when the disease is stabilized. Only a few special considerations need to be noted: The child with cystic fibrosis may cough more than other children and may require more frequent bathroom privileges. CF is not contagious and not a threat to anyone but the child affected. Taking medications for respiratory infections and enzymes for digestive problems can be handled by the homeroom teacher or school nurse. Some children are very matter-of-fact about their routine and their illness while others may want to keep some semblance of privacy.

Occasionally adults can say things regarding CF and mortality that are repeated at school in disastrous ways. For instance, a youngster might be told or overhears that "Johnnie has cystic fibrosis and it is a life-threatening disease." Next day, the youngster blurts out to Johnnie, "My mommy says you're going to die!" So being honest, yet optimistic, becomes the only coping course for the CF-involved parent and child. Most parents and children with CF are able to adopt a positive outlook, which in turn creates a beneficial influence on their health. Thoughts of illness and mortality can be approached and expressed in the art therapy session where the art becomes a buffer or safety zone. Dangerous unnerving topics can be effectively and safely approached through the creative process.

Body Image

Almost all teenagers have concerns and doubts about their body and their appearance. Adolescence is a crucial turning point, a time of increased vulnerability and upheaval, a shifting of allegiance from parent to peer group and self. According to Emunah (1990),

Physical growth and sexual maturation necessitate the development of a new concept of body image. Furthermore, a form of expression is

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