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ABSTRACT

There are at least three aspects to the psychological impact of acquired immune deficiency syndrome (AIDS) on children. First is the psychological response of the child with AIDS; second, the response of the child in a group at high risk for AIDS; and third, the psychological response of children in general to the perceived threat from AIDS. Pointing out that the majority of pediatric patients with AIDS are preschool children, this paper describes the child and adolescent ill with AIDS, characterizes the child's understanding of his/her condition, anticipates developmental problems associated with AIDS, and considers the effects of stigmatization on those having AIDS or in association with those having the disease. Implications for clinicians are discussed. It is concluded that the type of care system established for many of the survivors of disasters must be put in place to adequately address the needs of children and adolescents at risk for AIDS. (RH)

Psychological Impact of Aids on Children

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The focus of this presentation is the psychological impact of AIDS on children. It is not possible to separate out the social and cultural issues related to AIDS from the psychological. There are at least three components to the psychological impact of AIDS. First is the psychological response of the child with AIDS; second, the response of the child in a group at "high risk" for AIDS; and third, the psychological response of children in general to the perceived threat from AIDS.

There is very little in the scientific/psychological literature that directly pertains to the psychological impact of AIDS in children, but there is abundant data to suggest the potential psychological consequences of AIDS on children and adolescents. At this time, one has to assume that the child and his or her peer group will view AIDS as a communicable, stigmatizing illness.

AIDS in children is a problem small in numbers, but great in impact. Of the cases reported to the Communicable Disease Center as of January 1, 1986, 240 cases were in children and adolescents 13 years of age or younger. The number of cases of AIDS in the pediatric population has been steadily increasing since the earliest diagnosed case reported to the Communicable Disease Center in 1979. The numbers are likely to continue to increase. 75% of the AIDS cases in young children were from documented IV drug abusing parents.

The majority of pediatric patients with AIDS were preschool-aged children. Of the 107 children and adolescents with AIDS as

of 1985, 84 (79%) were younger than six years of age at the time of diagnosis of AIDS. All of these children whose case investigations have been completed (90%) acquired AIDS either from a blood transfusion, or because they were born to a mother who had AIDS who was a member of a high risk group or was a sexual partner of someone in a high risk group. It must be remembered that infected mothers are often asymptomatic before and during preganancy and at the time of birth, making any direct intervention such as avoidance of pregnancy or abortion impossible. Cases in hemophiliacs and children receiving transfusions account for 20% of cases in children reported to the Communicable Disease Center.

Almost all very young children with AIDS have hepatosplenomegaly, interstitial pneumonitis and poor growth. They appear chronically ill and may have frequent bouts of diarrhea, otitis media, and rashes. The average age of presentation has been five months with a range from 1-21 months. In 30%, the clinical onset was before three months of age. Of the children aged 18 years or younger with outcome reported to the Communicable Disease Center, 65% have died. Children get a highly virulent form of the disease and die faster and die from overwhelming infection.

The child who has become an AIDS victim is the victim of an illness that befell him or her through no direct action, no conscious act, no misbehavior. Yet, depending on the developmental stage of the child or adolescent the child may assume blame or guilt as if the illness were in response to some wrong action or thought. The exception of course, is the sexually active, or IV drug abusing, adolescent whose activities may have placed him or her at risk.

The child with hemophilia, or similar disorder, already coping with a chronic illness that has heightened his sense of vulnerability, will be stigmatized as a result of this very vulnerability--a true double jeopardy. With better screening of blood products, the future morbidity of this group may be reduced, but there is a whole group of youngsters who remain at risk for AIDS. These youngsters also now face a new and complex relationship with medical caregivers around the safety of treatment that goes beyond AIDS.

The preschool child, in particular, has little ability to comprehend the causality and nature of an illness and tends to interpret pain and other symptoms as a result of mistreatment, punishment or "being bad". In a child's mind nothing happens by chance, and he looks for reasons for an event. Children up to the ages of 8 to 10 often attribute illness and injury to recent family interactions; for example, they get sick because of their disobedience or because the parents failed to protect them. They might then blame themselves or other family members for causing the disease. These distorted interpretations of their bodily ills often become perpetuated by their reluctance to ask questions and vent their irrational fears about why they became ill. Siblings will share in these distortions or inhibitions and need careful therapeutic attention.

Young patients afflicted with a transmitted illness will usually learn of the transmission before or during adolescence, if they live long enough. In the case of a stigmatizing illness, outside contacts may inform the child through hostile, taunting comments about the presumed mode of transmission at a very early age. Such

a revelation is traumatic to the parent/child relationship as well as the child and because of appropriate, but immature cognition the true etiologic understanding may not be comprehended by the child and incapable of integration. Many afflicted children voice hostile accusations against their parents as they try to master the anger, sadness, and anxiety around by their recognition of the nature of their disability. Their parents already feel guilty. Further, they express a strong anger toward gay people as the group responsible for thei illness regardless of the actual direct mode of transmission.

In the absence of precise studies on children's reactions to AIDS, it is necessary to look for an applicable paradigm from the past. Rather quickly one is struck by the difficulty of finding a truly applicable model and confronted with the unique stigmatizing aspect of the threat of AIDS. It would be logical to look to the responses of children to polio, a potentially devastating illness, transmitted in a manner at first mysterious, until the viral etiology was discovered. Polio led to changes in the pattern of social contact, parents restricted the contact of children with each other, activites were limited, et cetera. But there was little of the stigmatization of the individual by others. However, the children, in many instances, felt that even non-stigmatizing illness was a type of retribution or manifestation of a failed competency. Think also of the child with leukemia and the reaction of others to the child. There is the fear on the part of others that somehow contact with the child might be infective, but the emotional response is more immediately one of sadness or empathy. However, in the case of an AIDS child,

at the present time, it appears that whatever the predisposing problem--hemophilia another causative agent requiring the child to need a transfusion, or the accident of birth to an infected individual--the child becomes a carrier of a "sexually transmitted disease." These children and adolescents are modern lepers. This is a new and horrifying psychological burden for the child. This child is virtually doomed to isolation by virtue of the theoretical possibility of transmission in the school, or in the daycare or foster care setting. In those AIDS children who are immune-compromised the danger is in exposure to others who may condemn the child to isolation and its attendant psychological problems.

There are unique and troubling psychological problems for uninfected children of AIDS parents. These children must contend with the uncertainty of the potential for being infected and/or developing the illness. Perhaps equally stressful is the transmission of the stigma associated with their parents' illness and the implications of their way of life. The child may become the object of homophobia or scorn rather than being an object of empathy. A sibling, as in the news article, may share the same fate.

This is not idle speculation. I surveyed a group of children and school guidance counselors. With relatively little effort I was able to secure from both groups a fairly accurate understanding of the etiology of AIDS and possible modes of transmission. However, with the children, after their rather factual descriptions, there was a primary association with sexual transmission and "the homos."

Sick jokes abounded. I expected to find a more direct sense of threat from this outside infectious agent, but it was telling and unfortunate that the specificity of the association with homosexuality was so overwhelming as to obscure outside threats.

Further, when we think of the impact of parental attitudes on child attitudes, we are again faced with the near paralysis and hysteria demonstrated when health care and education has been sought for AIDS children in public schools, day care settings and even hospitals. What child with any other illness is subject to the demonstrations associated with Ryan White's desire to return to school? Ryan White, a child with hemophilia, unfortunately got the wrong blood transfusion, and by all known data is not a threat to anyone but is treated as a pariah.

The hysteria associated with Ryan White is not a childhood psychological phenomena, but rather it is an adult psychological response reflected in the attitude of the children. The impact of such an adult response and its imposition on children may have long-lasting effects in determining attitudes. The most recent example of the potential role of parents in influencing child attitudes can be seen in the material written on nuclear threat.

What are the specific expectable responses of the child with AIDS? There is a small, but unfortunately growing group of children born with AIDS or born at risk for the development of AIDS. These children will grow up in an uncertain, isolated, stigmatizing world. The children are now so young and small in number that one cannot precisely define a response, but one can be constructed. There is

the fear of contamination by the child or death of the child, on the part of caretakers which will inevitably affect the bonding by either the natural parent, guardian, or caretaker. In most instances, there will be parental or caregiver withdrawal or psychological preparation for the loss of the child which will inhibit a normal object relations and develop a solid sense of self. There is a very high incidence of parental abandonment of these children in the IV drug abusing community. Further, there is often a parent who has died or is dying, which is traumatic for the affected or unaffected child. Some parents will, from the outset, manifest the symptoms associated with mourning the loss of the perfect child--a phenomena beautifully described by Solnit and Stark. The parents of premature children who had hopes raised for the salvation of their children are devastated a second time. The child will not be able to experience the normal socialization of unaffected children and thus will grow up in an isolated and skewed world. The asymptomatic child who does not know the source of his or her isolation will develop a sense of lowered self-esteem or may develop a host of ultimately maladaptive defenses to deal with the isolation. These defenses will include isolation of affect, pathological denial, depression and in some instances, more severe developmental disturbances. If and when the child becomes symptomatic, the response described before will become evident.

In a more formal manner, clinicians will have to become alert to the mental status manifestation of AIDS in children. This is an unexplored territory, but AIDS-related changes in mental status will have to become part of the differential diagnosis of behavioral

and neuropsychological disorders seen in children. In adults the psychological manifestations are decreased concentration, increased irritability, anxiety and depression. These are pervasive and non-specific symptoms in the child and adolescent population and more detailed evaluation will have to evolve. A progressive leukoencephalopathy has been noted. Very young children have died with the manifestations of a dementia and evidence of brain atrophy on autopsy.

In the older child with AIDS, who more than likely at this point has developed AIDS associated with some serious concomitant illness requiring blood or blood products, one can expect to see a major depressive episode and, worst of all, the isolation and stigmatization that have been discussed, superimposed on an already evident vulnerability. In these children the chronic dependency on care by parents and the medical community may block the expression of anger at becoming a victim. These children are most vehement in the expression of anger toward the gay community and ironically often have to fend off an implied homosexual identification.

There is yet another and growing group of young people, the adolescent boys and girls who are AIDS carriers, who through sexual contact or IV drug use are now "at risk" for the development of AIDS. These youngsters already caught up in a more turbulent developmental phase will be faced with coping with a potentially fatal illness that indelibly marks their conduct and sentences them. The depression that follows the chronic worry and the restriction on normal socialization will be massive. The risk for suicidal behavior will be great,

as will other forms of risk taking behavior.

The fears associated with AIDS also have a major impact on the psychological development of non-involved adolescents, who as a normal part of development, go through a phase of questioning their sexual identity and may manifest normal developmental concerns with homosexuality. Such fears stir up in heterosexual adolescents, not in identity crisis, an attitude of "watch out for the gays" which will have a strong and possible broader influence on the internalizaton of prejudicial attitudes toward not only the AIDS group, but also other alien groups.

In unaffected adolescents, it can be expected that there will be a marked change in the easy intimacy associated with normal adolescent development. The suspicion and constraint may well have a negative impact on the resolution of many interpersonal tasks of development and the consolidation of a healthy identity. The restraints and constriction of sexual habits and expression may at first be greeted with relief by many, but will inevitably have a major regressive impact, at a later time, on psychological development.

What can be done to help in the current climate of uncertainty and fear? One needs to acknowledge the present uncertainty and the fear. This is not as easy as it may seem because the press is increasingly focussed on the latest discovery of the latest virus or viral antibody. With this comes a tendency to hope and believe that all will be well. This only enhances a denial of the stress and does not support appropriate, specific education. It is specific and ongoing education that needs to be done. There is evidence from

the most recent concerns with nuclear threat, that overdramatization does not produce an effective education of the child; rather there is a shutting off of the psychological response and a diminished receptivity to education. What is needed is a sustained flow of factual data regarding transmission, the carrier state and prognosis. It must be remembered that while AIDS is now associated with homosexuality, that, as the illness evolves, it is more likely to be a heterosexual illness.

In the AIDS child population, there needs to be a concern for maintenance of the proper psychological supports in the face of uncertainty. Education of child caregivers will be difficult because of the social context of the usual care providers for young children. There is a very real resistance on the part of caregivers, medical and non-medical, to care of AIDS cases. Education alone and a series of precautionary steps have not diminished caretaker anxiety. In more instances than we would like to think, support services of welfare, the VNA and others have been silently withdrawn from AIDS families. This anxiety and withdrawal is conveyed to the children and generates certain types of behavior, as well as increasing the liklihood of abandonment.

Mental health providers, I am afraid, have shared in the anxieties associated with the care of AIDS patients and as a group increased effort at training to work with AIDS patients must take place. This will facilitate providing the very necessary psychological support system. In children and adolescents with the type of illness we are considering the reliance on peer support such as

in self-care homes is not feasible. Mental health professionals must be a part of health caregiver support teams and provide therapeutically-oriented group support for health workers. Further, many of the children are of "high risk" parents who may already have some compromise in their caregiving capacities. The need to deal with these inherent psychological vulnerabilities especially in "at risk" children must not be overlooked because of the presence of AIDS in a family member. As AIDS children grow older, they will need support groups and affiliative groups to deal with a disease they may or may not manifest. The adolescent might well benefit from group support and education such as is offered in DES support groups. Further, it could well be helpful to consider the development of hospice centers for the specialized care of the continuing number of children and adolescents who will die from AIDS-related diseases.

Though we are often most concerned with AIDS as an acute, fulminant illness with a high mortality from a psychological perspective, there needs to be a recognition of the type of continuing psychological support that must be provided to both victims, those "at risk" and their families. The type of care system established for many of the survivors of disasters must be put in place to adequately address the needs of children and adolescents "at risk" for AIDS. The problem is not going to be shortlived, nor cured by the first vaccine. Our techniques for understanding or intervening in the scenes portrayed by the newspaper articles are inadequate. We must prepare now to address attitude change, support development and gain knowledge of more specific mental health intervention.

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