

# PSYCHOSOCIAL ADAPTATION OF CHILDREN AND ADOLESCENTS WITH LIMB DEFICIENCIES: A REVIEW

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**ABSTRACT.** *Children and adolescents with congenital or acquired limb loss must contend with a number of medical and psychosocial stressors that might be expected to increase their risk of maladjustment. Yet several studies suggest remarkably good psychosocial adjustment in this population. This paper reviews the available data on the psychosocial status of the pediatric patient with a limb deficiency. Possible explanations related to disability characteristics, such as degree of disease visibility, are offered for the reported positive outcomes. Psychosocial factors that may influence the adaptation process are also reviewed. Finally, methodological limitations of prior studies are delineated and suggestions for future research are offered. Clearly, prospective longitudinal studies with appropriate control groups are necessary for an understanding of the adaptive process in specific pediatric groups with limb deficiencies.*

Most studies of the psychosocial adjustment in patients with **limb deficiencies** have involved American war veteran amputees or older adults with amputations secondary to vascular disease (Frank, Kashani, Kashani, Wonderlich, Vorlamf, & Ashkanazi, 1984; Jensen, Krebs, Nielsen, & Rasmussen, 1985; Sherman & Sherman, 1985). Collectively, these studies report a high frequency of problems after amputation, including unemployment, financial difficulties, and psychological symptoms (Caine, 1973; Frank et al. 1984). As many as half of all adult amputees require some type of psychiatric intervention (Caine, 1973). In contrast, the available literature suggests that **pediatric amputees** report minimal psychosocial distress, achieve good functional outcomes, and adapt well to their disability. The consistency of these positive findings across studies and age-groups is striking, particularly in view of the normal developmental demands of late childhood or adolescence, which would seem dependent upon physical abilities. During a developmental period when body image, peer relationships, independence, autonomy, and physical appearance are of primary importance (Tebbi & Mallon, 1987), one might expect that a limb deficiency would pose a particular risk for psychosocial problems.

Why, then, is the child or adolescent amputee, with a highly visible cosmetic and functional impairment, apparently so resistant to maladjustment? To address this ques-

tion, research on the psychosocial status of children and adolescents with limb deficiencies was reviewed with special attention to the disability characteristics and psychosocial variables that may affect adaptation and influence the functional outcome of juvenile amputees. Identification of factors that reduce the amputee's risk of maladjustment or facilitate the adjustment process may also have significant implications for promoting healthy adjustment in other chronically ill or physically disabled pediatric groups.

### AMPUTEE LITERATURE OVERVIEW

Three-fifths of all childhood limb deficiencies are congenital in origin (Lambert, 1972b). Among children with acquired limb deficiencies, amputations secondary to trauma are approximately twice as frequent as limb loss due to disease. Accidents with power tools and machinery, and vehicular accidents are common causes of limb loss in children and young adults (Tooms, 1986). Malignant and benign tumors account for the majority of amputations for disease processes, particularly within the 10- to 19-year age-group (Reinstein, 1980). The remainder of amputations are due to vascular malformation, neurogenic disorders, and miscellaneous disorders (Tooms, 1986). Adolescents with an acquired amputation secondary to osteosarcoma, the most common pediatric bone malignancy (Bode & Levine, 1982), are the group most frequently studied. With improved treatment, the survival of patients with osteosarcoma has increased so that greater attention can be devoted to minimizing psychosocial distress and facilitating adjustment.

#### *Psychosocial Adjustment*

Most of the earlier attempts to assess adjustment in adolescents with acquired limb loss focused on functional outcome, i.e., social, vocational, and educational achievement as described in Table 1. For example, Boyle, Tebbi, Mindell, and Mettlin (1982) studied 27 patients who had a limb amputated because of cancer during adolescence and compared them to 8 patients of similar ages with amputations necessitated by trauma. The time elapsed between surgery and patient interview varied widely, from 3 months to 17 years (mean = 7.2 years). Ratings based on self-reported marital and child-bearing patterns, educational and vocational attainments, perceived social support, functional independence, and adaptation to prosthesis identified 85% of the cancer amputees as adequately adjusted. Five of the 8 traumatic amputees also were rated as having made a good adjustment. However, as a group, they were generally less successful educationally and vocationally than the cancer amputees, despite the fact that their amputations tended to be less extreme. As noted by the authors, differences between these groups may be due to the lower socioeconomic status of the traumatic amputees rather than the circumstances of the amputation. The traumatic amputees were also described preoperatively as "unruly and physically oriented, and were less likely to use their prostheses." Thus, the preoperative differences between these two groups limit conclusions from this study.

A study of 33 Brazilian adolescents (ages 10-20 years) who had undergone amputation because of cancer also reported generally good adjustment (Tebbi, Petrilli, & Richards, 1989). Three-fourths of the amputees felt that they were functioning independently in and out of the home. Although school-aged patients reported academic and social problems and less than half of the subjects who had been employed before surgery had returned to their jobs, many reported improvement in several aspects of their lives as the length of time since surgery increased. A separate group of 20 cancer patients who were adolescents and young adults at the time of amputation, who were disease-free at the time of interview, and who survived for at least 5 years postdiagnosis, also reported leading functional and full lives (Tebbi & Mallon, 1987). Nearly 50% had achieved some

college education, 85 % worked at least part-time, and 85 % were either married or dating someone regularly. However, many patients had major concerns about their ability to have a satisfying sexual relationship and to have children.

Although global adjustment appears to be favorable in most adolescent amputees, some specific difficulties are consistently identified in the literature. Patients with acquired amputations are not precluded from obtaining employment or achieving academic goals, but they do encounter difficulties upon re-entering the work force or returning to the classroom. Some report having to quit their jobs, change career plans in the direction of less physically demanding jobs, or take part-time jobs (Boyle et al., 1982; Tebbi et al., 1989). Some feel they are discriminated against in hiring or promotion because of their disability (Boyle et al., 1982). Short-term concerns include practical issues, such as getting around facilities (Boyle et al., 1982; Tebbi et al., 1989), keeping up with school work, getting along with classmates (Boyle et al., 1982; Tebbi & Mallon, 1987; Tebbi et al., 1989), and gaining independence from parents (Tebbi & Mallon, 1987). Homemakers report problems with household chores, caring for children, getting around the house, shopping, and becoming isolated (Tebbi et al., 1989).

### ***Phantom Limb Pain***

A common postoperative complaint reported among adolescents with acquired amputations is phantom pain, defined as painful sensations that appear to emanate from a portion of a limb removed through amputation (Sherman, Arena, Sherman, & Ernst, 1989). Phantom limb sensations do not occur in children with congenital limb deficiencies (Lambert, 1972a). Boyle et al. (1982) reported that all adolescent cancer amputees surveyed ( $n = 27$ ) experienced chronic phantom pain immediately after surgery; 70 % of cancer amputees still experienced pain at the time of interview, as did 75 % of traumatic amputees. The mean time elapsed between time of surgery and time of interview was 7.2 years for cancer patients and 3.4 years for traumatic amputees. Two of the traumatic amputees reported that it took 3 to 4 years before the pain stopped. Similarly, a study of 33 Brazilian adolescent cancer patients reported that all experienced phantom pain after amputation, and two-thirds continued to have pain at the time of interview. Mean interview time was 17 months after surgery (Tebbi et al., 1989). These studies, however, failed to distinguish phantom pain from stump pain in the residual limb (Sherman et al., 1989), which indicates pathology and also influences phantom limb pain. Other reported postsurgical problems included physical limitations and decreased mobility. Yet the majority of amputees rated postsurgical problems as less severe than they had expected prior to surgery (Tebbi et al., 1989).

### ***Perceived Attractiveness***

Adolescent amputees often report self-consciousness regarding their impaired body image (Tebbi & Mallon, 1987) and may be bothered when people stare at them or ask questions about their surgery (Tebbi, Stern, Boyle, Mettlin, & Mindell, 1985). Perceived physical attractiveness was strongly predictive of positive self-esteem among 41 children with congenital and acquired limb deficiencies (Varni, Rubenfeld, Talbot, & Setoguchi, 1989a). This relationship between self-esteem and perceived physical attractiveness has also been documented across the developmental spectrum for youngsters with normal appearance (Dushenko, Perry, Schilling, & Smolarski, 1978) and for children with physical anomalies, such as cleft lip/palate and dental-facial malocclusion (Starr, 1980; Lucker, Graber, & Pietromanoca, 1981). These findings support the need for cosmetically appealing as well as functional prosthetic devices for the amputee. Interestingly, although the

TABLE 1. Summary of Amputee Studies

| Study  | Sample N  | Age Range<br>(Mean age) of<br>Subjects at Time<br>of Interview | Outcome Measures  | Domains Assessed  | General Conclusions  |
|--|---|--|---|---|--|
| Tebbi, Petrilli, & Richards<br>(1989)            | 33 cancer amputees  | 10-20 years<br>(14.4 years)                                    | Questionnaire in interview format   | Social, educational, vocational   | Adequate short-term adjustment;<br>some specific problems identified   |
| Varni, Rubenfeld, Talbot,<br>& Setoguchi (1989a) | 34 congenital limb loss<br>7 acquired limb loss<br>(n = 3 due to trauma;<br>n = 4 due to disease) | 8-13 years<br>(10.5 years)                                     | Children's Depression Inventory<br>(Kovacs, 1983)<br>Self-Perception Profile for Children<br>(Harter, 1985a)<br>Social Support Scale for Children<br>(Harter, 1985b)<br>Family Environment Scale<br>(Moss & Moos, 1981)<br>Children's Hassles Scale<br>(Kanner et al., 1985)<br>Degree of Limb Loss Scale | Depressive symptomatology<br>Self-esteem<br>Social support<br>Family functioning<br>Microstressors<br>Degree of limb loss | Social support, family functioning,<br>and microstressors significantly<br>associated with general self-esteem;<br>self-esteem significantly predicts<br>depressive symptomatology |
| Varni, Rubenfeld, Talbot,<br>& Setoguchi (1989b) | 36 congenital limb loss<br>6 acquired limb loss   | 6-13 years<br>(8.4 years)                                      | Child Behavior Checklist<br>(Achenbach & Edelbrock, 1983)<br>Family Environment Scale<br>(Moss & Moos, 1981)<br>EAS Temperament Survey  | Behavior problems/social<br>competence<br>Family functioning<br>Child temperament   | Child temperament and family<br>environment significantly<br>predicted psychosocial adaptation   |
| Varni, Rubenfeld, Talbot,<br>& Setoguchi (1989c) | 24 congenital limb loss<br>3 acquired limb loss   | 8-13 years<br>(10.2 years)                                     | Children's Hassles Scale<br>(Kanner et al., 1985)<br>Social Support Scale for Children<br>(Harter, 1985b)<br>Children's Depression Inventory<br>(Kovacs, 1983)<br>Degree of Limb Loss Scale   | Microstressors<br>Social support<br>Depressive symptomatology<br>Degree of limb loss                                      | Microstressors and social support<br>significantly predicted depressive<br>symptomatology; as a group,<br>children not clinically depressed  |
| Tebbi & Mallon (1987)                            | 20 cancer amputees; 5<br>years disease-free   | 10-23 years<br>(15.75 years)                                   | Questionnaire in interview format   | Social, educational, vocational<br>achievements; interpersonal<br>problems  | Good functional outcomes in<br>educational, occupational, and<br>social adjustment; some specific<br>problems identified   |

|   |  |   |   |   |   |
|---|--|---|---|---|---|
| Tebbi, Siern, Boyle,<br>Mettlin, & Mindell (1985)       | 27 cancer amputees   | 14-37 years<br>(23.3 years)   | Questionnaire in interview format   | Perceived social support,<br>scholastic/school<br>achievement, vocational<br>achievements, interpersonal<br>problems  | Confirmed role of social support,<br>particularly family support, in<br>adjustment process  |
| Weddington, Segraves,<br>& Simon (1985)                 | Extremity sarcoma<br>survivors:<br>15 amputees<br>20-limb salvage patients | 15-71 years<br>(37.9 years)   | Cognitive Capacity Screening<br>Examination<br>The Hopkins Symptoms Checklist<br>(Derogatis et al., 1974)<br>Beck Depression Inventory<br>(Beck, 1967)<br>Profile of Mood States<br>(McNair et al., 1971)<br>Karnofsky Performance Scale<br>(Karnofsky & Burchenal, 1949)<br>Global Adjustment to Illness Scale<br>(Derogatis, 1976)<br>Schedule for Affective Disorders &<br>Schizophrenia - Lifetime<br>Version (Endicott & Spitzer,<br>1978) | Cognitive capacity<br>Psychological distress<br>Depression<br>Affective states<br>Current physical performance<br>and activity states<br>Psychosocial adjustment to<br>illness<br>Past/present psychiatric<br>disorders | No significant differences between<br>amputees and limb-salvage<br>patients on psychological outcome<br>measures; 55 % of patients<br>adjusted well to disease/surgery;<br>most subjects had mild<br>psychological symptoms |
| Boyle, Tebbi, Mindell,<br>& Mettlin (1982)              | 27 cancer amputees<br>8 traumatic amputees                                 | 14-37 years<br>(23.3 years)<br>16-22 years<br>(19.0 years)                    | Questionnaire conducted in<br>interview format  | Social, educational, vocational/<br>occupational  | 85 % of cancer amputees had<br>adequate overall adjustment;<br>traumatic amputees experienced<br>less successful adjustment   |
| Sugarbaker, Barofsky,<br>Rosenberg, & Gianola<br>(1982) | Soft-tissue sarcoma<br>patients:<br>9 amputees<br>12 limb-salvage patients | All subjects<br>< 21 years<br>Sociodemographic<br>variables not<br>identified | Sickness Impact Profile<br>(Bergner et al., 1976)<br>Katz's Activities of Daily Living<br>Scale (Katz & Apkom, 1976)<br>The Barthel Index<br>(Mahoney & Bartel, 1965)<br>Psychosocial Adjustment to Illness<br>Scale (Derogatis, 1975)<br>Change in earning potential   | Quality of life; behavioral,<br>psychosocial, economic  | No significant differences in quality<br>of life measures between<br>limb-salvage procedures and<br>amputation  |

majority of patients state that they are satisfied with the appearance of their prosthesis, only a few will wear a prosthesis strictly for cosmetic reasons (Boyle et al., 1982; Tebbi et al., 1989).

More recent studies of adjustment have focused on newer treatment regimens incorporating intensive chemotherapy and improved surgical methods for extremity sarcomas, generating questions regarding the potential psychological advantages of "limb salvage" techniques. Although the physical rehabilitation following limb-sparing is more difficult, it is assumed that limb sparing will lessen loss of function and cosmetic defects, maintain the patient's physical appearance, and therefore facilitate psychological functioning when compared to amputation (Sugarbaker, Barofsky, Rosenberg, & Gianola, 1982). Weddington, Segraves, and Simon (1985) compared cancer patients who had undergone amputation with those whose affected limb was preserved. Interviews conducted 1 to 5 years after surgery showed no significant differences on measures of cognitive capacity, anxious or depressive symptomatology, global physical and psychological functioning, and adjustment to illness and surgery. Specific assessment of body image and satisfaction with physical appearance was not included. Although there were a few adolescents included in this study, most patients were older (mean age at surgery, 33.6 years for amputees and 36.2 years for limb salvage patients). Regardless of surgical approach, patients showed good to excellent adjustment on a scale assessing psychosocial adjustment to cancer and revealed only mild psychological symptoms on standardized psychological measures. Similar findings were observed in young adult patients treated for soft-tissue sarcoma. Limb-sparing procedures plus irradiation and chemotherapy did not result in substantially better quality of life compared to amputation plus chemotherapy when assessed 1 to 3 years following surgery. Therefore, despite the improvement in cosmesis, no psychological advantage of limb-salvage surgery over amputation has yet been demonstrated (Sugarbaker et al., 1982; Weddington, et al., 1985).

### Summary

Overall, young patients with acquired limb loss have reported positive psychosocial outcomes despite negative expectations prior to surgery regarding physical functioning and disease-related problems. Phantom limb pain and self-consciousness about body image were commonly cited concerns of adolescent patients. Although amputees initially encountered many of their anticipated problems, transition to independence did not appear to be significantly deterred. The difficulties reported highlight the need for increased attention to facilitating mobility in the school and work environment and provision of functional prostheses. Education of the patient's support networks, peers, and classmates about limb deficiencies may serve to minimize social problems for these patients. Attention to the student's educational needs during hospitalization to maintain school progress is also necessary to reduce academic obstacles (Tebbi & Mallon, 1987; Tebbi et al., 1989). Pain management and patient education regarding interpersonal concerns are also significant areas for future intervention.

### CHRONIC ILLNESS AND PSYCHOLOGICAL ADJUSTMENT

Studies of children and adolescents with diseases such as chronic juvenile arthritis (McAnarney, Pless, Satterwhite, & Friedman, 1974), cerebral palsy, or juvenile diabetes (Wallender, Varni, Babani, Banas, & Wilcox, 1988) have reported an increased risk for psychological problems. In general, the literature indicates that children with chronic physical disorders are twice as likely to show maladjustment than healthy children (Eiser, 1990; Pless & Nolan, 1991; Pless & Roghman, 1971). Results from the Ontario Child

Health Study, a survey of 3,294 randomly sampled children, confirmed that children with chronic illness and disability were at increased risk for psychiatric disorders and social adjustment difficulties when compared to healthy peers (Cadman, Boyle, Szatmari, & Offord, 1987). It is unclear from collective studies, however, whether the child's psychological adjustment alters the degree of physical impairment, whether physical impairment affects psychological adjustment, and whether both are related in a reciprocal fashion or related to other unknown factors. The cross-sectional nature of most studies precludes delineation of the direction of cause and effect (Stein & Jessop, 1984).

The risk for psychiatric impairment seems particularly greatest for pediatric patients with chronic disease with central nervous system (CNS) involvement. For example, Breslau (1985) found that children with congenital physical conditions involving the brain had more psychopathology than physically disabled children without cerebral involvement. These findings are consistent with Rutter, Tizard, and Whitmore's (1970) Isle of Wight report of a greater prevalence of emotional problems in brain-affected chronically ill children than in children without CNS disorders. Similarly, Seidel, Chadwick, and Rutter (1975) reported that among crippled children comparable in terms of visibility of disorder, psychiatric problems were twice as common when the physical condition involved brain abnormality. These findings also suggest that the visibility of the handicap does not necessarily account for the association between brain involvement and psychopathology.

### **RISK FACTORS**

In light of the association between chronic illness and maladjustment, researchers have attempted to determine what variables mediate the perhaps unique adjustment process of children and adolescents with limb deficiencies who, as a group, appear to have few psychological problems. Demographic, medical, and psychosocial risk factors have been examined for their implications for psychosocial adjustment.

#### **DEMOGRAPHIC FACTORS**

In those studies in which demographic variables have been examined, age, sex, and socioeconomic status have not been found to significantly predict adjustment in children and adolescents with limb loss, primarily those with congenital deficiencies (Varni et al., 1989a, 1989b, 1989c). One study that did report poorer adjustment in amputees from lower socioeconomic groups, identified other premorbid differences that could account for later adjustment difficulties (Boyle et al., 1982). Compared to American adolescents, Brazilian adolescent amputees had greater difficulty in obtaining a prosthesis, which may have contributed to functional difficulties (Tebbi et al., 1989). Although socioeconomic data were not obtained in this study, the differences in prosthetic ownership rates may reflect socioeconomic factors.

#### **MEDICAL FACTORS**

##### ***Degree of Limb Loss***

Specifically, in adolescents with congenital limb loss, degree of limb loss has not been found to be predictive of maladjustment (Varni et al., 1989a, 1989b, 1989c). Degree of limb loss was assessed by a scale that assigns a number to the level of limb loss for upper and lower limbs and summing the limb loss ratings. These findings of a lack of a direct relationship between degree of impairment and adjustment are consistent with those

observed in other pediatric groups with physical disability (McAnarney et al., 1974; O'Malley, Foster, Koocher & Slavin, 1980). O'Malley and associates (1980) found that psychosocial adjustment ratings in 115 long-term survivors of childhood cancer were not significantly related to the degree of functional, physical, and cosmetic impairment. Wallender, Feldman, and Varni (1989) found no significant differences in psychosocial adjustment in children with spina bifida with differing degrees of disability parameters. In a study of 42 children with chronic arthritis, those with no significant associated disability actually had more psychological problems than the more disabled patients (McAnarney et al., 1974).

Any explanations for these findings must be viewed as speculative given the limitations of published research in this area. It may be that children with more severe disabilities must confront their impairments sooner and then begin to develop successful compensatory coping mechanisms. Support for this explanation is provided by a study comparing adolescent patients with osteosarcoma who underwent amputation with those who had limb-salvage procedures (Kagan, 1976). Amputees tended to use denial for shorter periods of time, were more mobile and able to return home sooner, and adapted better to subsequent treatments. Amputees also have a greater degree of disease visibility due to their limb loss than limb-salvaged patients, which may force them to view themselves as more disabled and paradoxically facilitate better adjustment.

An alternative explanation is that patients who are visibly disabled tend to be perceived as more handicapped, and others may therefore make allowances for their behavioral, emotional, or social problems. Tebbi et al. (1985) found that adolescent cancer patients perceived others to feel sorry for them, although the actual perception of the patients by others was not assessed. The youngster who appears less disabled, on the other hand, is more likely to face expectations of behavior and performance that are inconsistent with his or her capabilities. The inability to meet these expectations may adversely affect self-image and overall adjustment. From this perspective, the reactions of others to disability and the manner in which the patient perceives and incorporates these social responses play a significant role in the amputee's adaptive process.

### **Disease Course**

Pinkerton (1974) reported that a fluctuating course of illness had a negative impact on psychosocial functioning in children with chronic illness. The need for prolonged maintenance chemotherapy in some cancers also carries potentially important psychological implications. One might therefore expect those children who require prolonged treatment for cancer to be less well-adjusted than those who undergo amputations with a shorter subsequent course of chemotherapy. The removal of the diseased limb in an amputation may also be viewed as symbolic of cure, which could contribute to better adjustment. Controlled studies comparing disease-free cancer amputees to cancer patients with progressive or recurrent disease, as well as those in remission and medically stable, would examine the effect of disease course on adjustment.

### **Prosthetic Functioning**

Access to a functional prosthesis is another factor that affects adjustment by facilitating independence and reducing postsurgical complaints. Goldberg (1984) reported that vocational adjustment in a group of lower-extremity adult amputees was more favorable for patients who previously had realistic vocational plans and stable work history and who used their prosthesis properly. Previous vocational development was not assessed in the present studies of late adolescent and young adult amputees. In addition, the relationship



between adjustment outcome measures and the use and satisfaction with prostheses has not been measured specifically. However, one could speculate that amputees with fully functional and comfortable prostheses would be more mobile, less physically restricted, and more independent.

For example, Tebbi et al. (1989) found that 66% of Brazilian adolescent amputees had a prosthesis but only 58% of these used the prosthesis daily, largely because it was uncomfortable. Many patients reported problems with re-entry to work or school that might have been lessened with regular use of a comfortable prosthesis. In a study in which all but 2 of 27 adolescent cancer amputees wore their prostheses daily and were satisfied with them, adequate global adjustment was reported (Boyle et al., 1982). By contrast, 3 of 8 traumatic amputees in this study did not use their prosthesis regularly and 6 complained of the need for frequent repair of their prostheses. This group had less adequate adjustment than the cancer amputees but was also from a lower socioeconomic status and exhibited premorbid behavioral differences (Boyle et al., 1982). These findings underscore the need to evaluate each patient's prosthetic use as a potential predictor of later adjustment problems (Tebbi et al., 1989).

### ***Etiology of Limb Loss***

In the amputee literature, etiology of limb loss (congenital vs. acquired, and acquired limb loss secondary to disease or trauma) has not been consistently considered in the analysis of adjustment. Boyle and associates (1982) examined the psychosocial adjustment of both cancer and traumatic amputees, although only a small number of traumatic amputees were included in this study. Varni and colleagues (1989a, 1989b, 1989c) primarily examined children with congenital limb deficiency. Yet, etiology of limb loss may differentially affect adjustment and family functioning.

For example, children with congenital limb loss typically have longer periods to prepare for their limitations. The opportunity for preparation may be less disruptive for families, thus facilitating the patient's adjustment. In contrast, children with an acquired limb loss must adjust immediately to their disability, altering their individual and family life-style to meet the demands of their new functional capacities and limitations. The patient with an acquired amputation secondary to trauma may be predisposed to psychopathology that significantly impacts the patient's subsequent adaptation to limb loss. On the other hand, the patient with an acquired amputation secondary to disease must often contend with longer hospitalization, ongoing disease therapy, and threat of recurrence. Which of these factors has the greatest impact on adjustment to limb loss is a question that warrants further examination. A current research protocol at our institution attempts to assess psychosocial adjustment in adolescent cancer and traumatic amputees using well-developed psychometric instruments, with consideration to etiology of limb loss as a variable in the adaptation process.

## **PSYCHOSOCIAL FACTORS**

### ***Stress Level***

Psychosocial adaptation to stress can be conceptualized in relation to both risk and resistance factors (Daniels, Moos, Billings, & Miller, 1987). Consistent with the stress-psychological distress relationship generally noted in children and adolescents (Compas, 1987; Mullins, Siegel & Hodgkes, 1985; Varni et al., 1989c), greater stress levels, represented by "daily hassle" microstressors, are positively associated with maladjustment in children with limb deficiencies. In a study of 27 children aged 8 to 13 years, 24 with

congenital and 3 with acquired limb deficiencies (Varni et al., 1989c), the sum of negative ratings of events on the Children's Hassles Scale (CHS: Kanner, Harrison, & Wertlieb, 1985) was significantly correlated with depressive symptomatology. However, the mean number of negative events reported and the negative intensity ratings of this group were no different than ratings reported by physically healthy children, suggesting that these limb-deficient children were not experiencing an increased number of microstressors. In addition, the limb-deficient group did not manifest clinical levels of depression on the Children's Depression Inventory (CDI: Kovacs, 1983). Average severity of symptomatology was similar to norms of physically healthy children, although there was great variability. Microstressors were also found to have a significantly negative impact on general self-esteem.

It is likely that daily stressors are quantitatively similar for physically healthy and limb-deficient children. However, the effects of chronic strain resulting from functional limitations imposed by amputation and from being physically different from one's peers are largely unknown. A prolonged period of stress may deplete available resources for coping with future stressful events and may have a qualitatively different impact on adjustment. This could be addressed through a prospective assessment of coping styles throughout the course of a child's disease, rehabilitation, and long-term adjustment.

### ***Child and Family Characteristics***

Temperament has been proposed as a risk factor for emotional problems. Using an interactional model of risk research, Varni et al. (1989c) found that in children with congenital or acquired limb deficiencies, temperament was a statistically significant predictor of psychosocial adaptation, as determined by the Child Behavior Checklist (CBCL: Achenbach & Edelbrock, 1983). Specifically, increased emotionality predicted greater internalizing and externalizing of behavior problems and lower social competence. However, there was also a significant interaction between a child's emotional status and family cohesion; the relationship between emotionality and behavior problems held only when family cohesion was low. Clinically, these results suggest that temperament must be considered within the context of family environment when assessing the adjustment of physically handicapped children (Varni et al., 1989b). They also suggest that premorbid adjustment may have significant impact on a patient's adjustment to limb loss.

In addition to family cohesion, a moral-religious emphasis, less family conflict, and higher family organization also predicted better psychosocial adaptation (Varni et al., 1989b). Organization is defined as clarity and structure in planning family activities and responsibilities. Low family conflict and higher family organization were also associated with higher self-esteem. Family variables, such as parental depression and medical symptomatology, increased family stressors, and less family cohesion have also been associated with psychological and physical problems in other pediatric groups (Daniels et al., 1987). Likewise, both static and transient family characteristics have been assumed to play a significant role in childhood trauma and accidental injuries (Matheny, 1988) that can result in amputation.

### ***Social Support***

Like family environment components, which can be viewed as risk or protective factors in the psychological adaptation process, the child's social support may mitigate or potentiate the adverse effects of potential risk factors such as stress. Varni and associates (1989c) reported that social support had a direct effect on the limb-deficient child's adjustment, although it did not buffer the effect of daily stressors. Overall, their model of Stress  $\times$

Social Support predicted 73% of the variance in depressive symptomatology by a hierarchical multiple-regression analysis. A positive association between perceived social support and psychological adjustment and self-esteem has been documented by these authors in other studies of children aged 8 to 13 years with congenital and acquired limb deficiencies (Varni et al., 1989a, 1989b). Assessments of the differential effects of support from classmates, parents, teachers, and friends in this same age-group indicated that perceived classmate social support appears to be the most significant predictor of self-esteem and severity of depression (Varni et al., 1989a, 1989b).

Older adolescent amputees were reported to perceive family, especially mothers, as the best and most readily available source of emotional support (Tebbi et al., 1985). Other amputees and peers were described as providing less support, tending to avoid or pity the amputee. Interestingly, however, there was no statistically significant correlation between the amount of support at the time of surgery and postsurgical adjustment (Tebbi et al., 1985). This finding may be due to low patient variability, as most patients were identified as well-adjusted and receiving "adequate" social support. The reported age-related differences in perceived emotional support may reflect developmental differences in preferences for support. They may also reflect methodologic differences, in that the adolescent amputees were asked retrospectively and specifically about support at the time of surgery, when parents are the most readily available source of support.

These findings not only emphasize the significance of peer behavior and attitudes toward children with cosmetic and physical handicaps but suggest the need to assess independent sources of social support in relation to adjustment, instead of relying on global indices. From a preventative perspective, the available findings suggest that children and adolescents with limb deficiencies might benefit from social-skills training in which they are taught how to avail themselves more fully of social resources and to access classmate and peer support better (Cohen, Sherrod, & Clark, 1986). Training of parents and teachers as well as family therapy should also be a focus of future intervention efforts to optimize social support for the patient with a physical handicap.

## METHODOLOGICAL ISSUES

Not only are empirical studies of pediatric amputees limited in number, but there are notable problems with the existing research. Before one can conclude that children and adolescents with limb deficiencies are exceptionally resilient to the psychosocial and other stressors they face, methodologic limitations of the available research must be considered.

### *Design and Sample Selection*

Most of the amputee research is **descriptive and exploratory** rather than empirical and hypothesis-driven. Thus, many studies assess adjustment by using nonstandardized and semi-structured interviews rather than well-developed psychometric instruments with demonstrated reliability and validity. Consequently, direct comparisons across studies are difficult. In addition, **most studies are cross-sectional, with few prospective studies of adjustment.**

**Adequate control groups are notably absent in the available studies.** This review did not identify any comparisons of adolescents with limb deficiencies to physically healthy adolescents, adolescents with cancer not requiring amputation, or other pediatric patients with chronic physical disorders. Appropriate comparison groups are necessary to control for the nonspecific effects of chronic disease and cancer. Most of the research has also focused on acquired amputations secondary to disease or trauma. Some studies have included both acquired and congenital limb deficiencies (Varni et al., 1989a), but not

compared these two groups on adjustment measures. Typically, studies of acquired amputations include patients who differed in age at the time of surgery, without assessment of age-related developmental changes associated with coping and adaptation. This is particularly important in light of evidence of developmental differences in coping with stressful events (Altshuler & Ruble, 1989). For example, one study included amputees and limb-salvage patients ranging in age from 17 to 71 years (Weddington et al., 1985), with no separate analyses of potential age effects.

### **Outcome Measures**

The frequent absence of a theoretical framework in the studies reviewed leads to a lack of appropriate outcome measures and to widely varying adjustment criteria. For example, in one study the “well-adjusted” patient was defined as one who attended school before surgery, returned to school, had friends, and was socially active at the time of interview, so the majority of the sample met these criteria (Tebbi et al., 1985). In another, adjustment was defined by “satisfactory” achievement in educational and occupational areas and adequate social contacts, which were more or less determined by general clinical impressions (Boyle et al., 1982). The lack of standardized adjustment measures also limits comparison of the degree of adjustment of pediatric amputees to population norms.

Furthermore, conclusions are often based solely on retrospective self-reports of child and adolescent patients, with few or no objective data to validate these reports. Therefore, it is possible that at least some of the reported positive psychological outcomes may reflect adolescent denial. Failure to endorse responses indicative of maladjustment has been reported in other studies of both healthy and chronically ill adolescents (Kellerman, Zelter, Ellenberg, Dash, & Rigler, 1980). Most studies do not include empirically based research interviews of psychopathology in children and adolescents. **Adequate amputee functioning may therefore be an artifact of insensitive diagnostic instruments that do not assess a wide range of behaviors to allow for psychiatric diagnostic formulation.**

**Patients are also frequently interviewed at various times following surgery,** sometimes several years later. Often, the interval following surgery for acquired amputations is not specified (Varni et al., 1989b). The length of time elapsed between surgery and interview should be considered in assessment of adjustment, as problems may change over time. Physical complaints, such as phantom pain, may gradually improve with time (Sherman et al., 1989). Although not directly assessed in the studies reviewed, disease occurrence may be less of a threat for those assessed at longer intervals following surgery. It should be noted that the amputee studies cited here included few if any patients with metastatic disease, which may also have contributed to their overall positive outlook (Tebbi et al., 1989). In those studies that included a preponderance of congenital amputees, patients were enrolled in an ongoing rehabilitation project and the stage of clinical management was not specified (Varni et al., 1989a, 1989b, 1989c). Lastly, little information is conveyed about the patient's premorbid status, which can ultimately affect the ability to adapt.

### **CONCLUSIONS AND RECOMMENDATIONS**

A review of the available literature suggests that **young patients with limb deficiencies, as a group, appear to be relatively resilient to maladjustment.** However, the methodological flaws of some of these studies limit definitive conclusions about the psychosocial status of these patients. Until these methodological limitations are addressed in future studies, young amputees and limb-salvaged patients should not be excluded from being considered vulnerable to adjustment problems.

The findings also suggest that many of the same variables that predict maladjustment in children with chronic diseases are also important in the process of adjustment to limb deficiencies. The child's temperament, level of stress, and family variables have been proposed as potential risk and protective factors. However, these variables predict only a portion of the variance in psychological symptoms, and many other interacting variables, such as coping ability, attributional processes, cognitive capacity, and CNS involvement, may predispose the child or adolescent to increased psychosocial problems. Clearly, multivariate models that examine an interactional weighting of risk and protective factors are necessary to define the most potent predictors of functioning in children with physical limitations (Lewis, Dlugokinski, Caputo, & Griffin, 1988).

Although there are similarities in the variables that affect psychosocial adjustment in different pediatric populations with chronic disease, there may be quantitative or qualitative differences in these factors that account for the consistent reports of positive psychosocial outcome in children and adolescents with limb deficiencies. Quantitatively, it may be that the child or adolescent with a limb deficiency encounters more social support, attention from others, or greater family cohesion than those with other diseases or disabilities. They may also experience similar stressors but at different points during the course of their illness, which could facilitate or impede adjustment, particularly if there is a critical phase in the adaptation process. Relative to other chronic disease groups, the amputee also receives more time-limited, intensive treatment, typically has no acute exacerbations of disease, and has undergone a surgical procedure that could be viewed as signifying termination of disease. Successful coping with repeated disease-related stressors before and following surgery may actually strengthen the cancer amputee's tolerance for subsequent stressors. From a stress-tolerance hypothesis, the amputee may not perceive ordinary stressors to be as disruptive as other chronically ill or healthy peers do, so that he or she appears to be resilient on adjustment measures.

To date, no studies have used well-developed psychometric instruments to examine the psychosocial adaptation of patients with acquired amputations in relation to other physically disabled or chronically ill or healthy children or adolescents. Wallender, Varni, Babani, Banas, and Wilcox (1988) compared 270 children with six different chronic physical disorders: juvenile diabetes, spina bifida, hemophilia, chronic obesity, juvenile rheumatoid arthritis, and cerebral palsy. Amputees were not included in this study. They found few differences between these groups and no distinct patterns of disease-associated behavioral problems on the Child Behavior Checklist (CBCL: Achenbach & Edelbrock, 1983); they were indistinguishable in their psychosocial adjustment. According to maternal report, these children as a group did experience more behavioral and social competence problems than would be expected from standardized norms (Achenbach & Edelbrock, 1983). These findings were interpreted as suggesting that it is the experience of a chronic physical disorder, rather than the unique demands of any particular disease, that best predicts adjustment.

Other studies suggest that certain features characteristic of chronic disorders are related to the patient's adjustment. For example, in a study of 304 children with congenital physical disabilities and 360 physically unimpaired children, Breslau (1985) found that the risk of severe psychiatric impairment was increased in disorders with central nervous system involvement. In long-term survivors of cancer, presence of functional but not cosmetic impairment was associated with increased risk for academic and adjustment problems (Mulhern, Wasserman, Friedman, & Fairclough, 1989). Hurtig, Coepke, and Park (1989) found that pain frequency in children and adolescents with sickle cell disease was inversely related to academic performance (one measure of adjustment). Frequency of hospitalization and emergency room visits, and severity of pain did not significantly

affect adjustment in that study. These last findings also suggest that phantom-pain frequency should be examined more closely in amputees when assessing vocational and academic adjustment.

The child or adolescent with a limb deficiency also experiences a unique combination of pain sensations, visible disfigurement, and physical or functional limitations. One approach to delineating the relationship between these specific potential stressors and psychosocial adaptation would involve a comparison with chronic pediatric disorders along these three dimensions. An initial analysis might involve two groups of children with the same degree of physical disability or pain but different degrees of cosmetic disfigurement. For example, a child with chronic arthritis may experience pain and functional limitations, but may not have the visible cosmetic impairment characteristic of the amputee. Patients with cancer may experience one or more of these stressors as a result of prolonged treatment. Children with cutaneous hemangiomas are cosmetically impaired, but typically have no pain or functional impairment. At the other end of the spectrum, physically healthy children would not experience any of these symptoms.

This approach has been used to evaluate the adjustment of children with visible versus invisible handicaps. Goldberg (1974) found that children with facial disfigurement were less well adjusted than children with congenital heart disease. These findings suggest that the degree of physical disfigurement had a more significant impact on adjustment than the severity of physical limitations. Similarly, Potter and Roberts (1982) evaluated peer acceptance of chronically ill children as a function of disease chronicity, incidence, and severity of observable symptoms. They found that the observable symptoms of children with epilepsy made them significantly less attractive to peers than children with juvenile diabetes, a less observable illness with a lower degree of perceived severity. In young adult survivors of end-stage renal disease, those with more visible handicaps appeared to be at risk for maladjustment as indexed by lower scores on measures of social maturity and self-concept (Beck, Nethercut, Crittenden, & Hewins, 1986).

Lastly, amputee research to date has assessed psychological symptomatology and adjustment based on single measures at a single point in time rather than examining quality of life. These measures are usually retrospective and given months to years following surgery. Serial evaluations of quality of life, encompassing physical functioning, occupational and school performance, social adjustment, and psychological state (Mulhern, Horowitz, Ochs, Friedman, Armstrong, Copeland, & Kun, 1989), would allow us to evaluate the patient's pattern of functioning over time. It is essential to consider the pattern of dysfunction, as well as cumulative dysfunction, as equivalent total dysfunction over time may be manifested in different ways (Schipper & Levitt, 1985). Prospective longitudinal assessment of large samples at various points following surgery, using well-developed psychometric instruments (Weddington et al., 1985), is necessary to reliably assess the psychological and functional status of these patients with acquired limb deficiencies.

Within this context, controlled studies comparing the adjustment of cancer amputees with that of patients treated with limb-sparing surgery are particularly important. Thus far, **limb salvage has not been shown to offer patients any quality-of-life advantage or significant improvements in psychological outcome in comparison to amputation** (Sugarbaker et al., 1982; Weddington et al., 1985). Therefore, the choice of limb-sparing surgical procedures on the basis of psychological reasons is not substantiated (Sugarbaker et al.), particularly given the healthy psychological outcomes documented for pediatric amputees. Further research should focus on developing reliable quality-of-life measures that are sufficiently sensitive to detect differences between limb-salvage patients and amputees, given the potential impact of these data on medical choices. Knowledge of

the adjustment process in patients with acquired limb deficiencies will be important in developing preventative and intervention programs that facilitate adjustment to a multitude of chronic disorders.

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