

To Achieve (E)Quality Health Care for Childhood Cancer Survivors

Brad J. Zebrack, Ph.D., M.S.W., M.P.H.¹

Mark A. Chesler, Ph.D.^{2,3}

¹ School of Social Work, University of Southern California, Los Angeles, California.

² Department of Sociology, University of Michigan, Ann Arbor, Michigan.

³ International Confederation of Childhood Cancer Parent Organisations, Nieuwegein, The Netherlands.

An expressed goal of psychosocial oncology research and intervention is to facilitate the adjustment of patients and their family members to both the short-term and long-term consequences of treatment, recovery, and survivorship.¹ One of the driving forces in this field is the need to identify factors that predict variability in psychosocial outcomes. This research approach is predicated on the assumption that, given accurate knowledge of a client's needs, risks, and lifestyle, clinicians will be better able to provide cost-effective quality care. It also assumes that if such knowledge were available and acted on, patients, survivors, and their families would be able to gain access to appropriate medical and psychosocial care. These concerns are critical both during the diagnostic/treatment phase and after treatment ends, when screening and surveillance for long-term survivorship and late effects of treatment and second malignancies have priority.²

Understanding patient and family needs, risks, lifestyles, and potentials for growth, particularly for survivors of pediatric disorders and their families, necessitates an awareness of the strong, often covert, influences of culture, race/ethnicity, and socioeconomic status in shaping family reactions and responses to health problems.³ Cancer literature suggests that culturally different views of the meanings of illness and treatment exert a strong influence on both patients' and care providers' behaviors.⁴⁻⁶ As McCubbin et al.³ stated, effective interaction with families of different cultural backgrounds may depend on the awareness and sensitivity of pediatricians and other health care professionals to the affect of culture and ethnicity on a child's psychosocial development as well as on the family's response to the long-term care of a child with a chronic condition or disability. Unintentional and often institutionalized forms of discrimination in the provision of care (e.g., unconscious bias; poverty; and racial inequalities in education, financial resources, transportation facilities, and insurance) often determine the level of care available to entire groups of patients and families. As a result, neither equitable nor adequate access to follow-up and long-term care is assured for everyone in the current health care environment.

Recent observations and studies of accumulative stress and tem-

Address for reprints: Brad J. Zebrack, Ph.D., M.S.W., M.P.H., School of Social Work, University of Southern California, 669 West 34th Street, Los Angeles, CA 90089-0411; Fax: (213) 821-2088; E-mail: zebrack@usc.edu

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poral clustering of stressful life events among minority populations suggest a higher prevalence of psychological and physical health morbidity in low socioeconomic status and racial/ethnic minority populations.⁷⁻⁹ These are the undeniable effects of the everyday realities of racism, sexism, and other forms of interpersonal and institutionalized discrimination. Their existence reinforces the need for clinicians to be cognizant of stressful, nonmedical events (e.g., inadequate funds for transportation to clinics, or loss of a job for a parent who missed work to be with an ill child), as well as the context of the cultural and socioeconomic inequality and discrimination in which these events take place and the culturally derived meanings persons of diverse backgrounds attribute to these events.

Unfortunately, and despite the growing attention to inequalities in health care, we know little about how socioeconomic, racial, and sociocultural status may affect the long-term adjustment and functioning of ill children and their family members.^{3,4} Despite advances in our knowledge of psychosocial outcomes for the population of childhood cancer patients and survivors, the impact of poverty and restricted access to long-term health care and psychosocial outcomes to our knowledge has not yet been determined empirically for children with cancer and their families. The ways in which cultural, racial/ethnic, and economic differences contribute to variations in stresses, coping processes, and psychosocial outcomes for childhood cancer patients and their families remain undocumented in detail. Furthermore, although the majority of childhood cancer patients in North America are treated at centers within cooperative trials groups and on protocols in centers with specific expertise, the difference between “the majority” and “all” children being treated at such centers and with such protocols most likely falls on families of poor or middle-class children of color or rural and poor whites. Lacking data, we suspect that this is even more clearly the case when we discuss long-term aftercare for survivors than it is for the diagnostic and treatment phases of care. Everything we know about the cultural and social demographics of health access and care would predict disparate outcomes. Even the Childhood Cancer Survivor Study (CCSS), which is to our knowledge the largest National Institutes of Health (NIH)-funded study of childhood cancer survivors performed to date, has relatively low minority representation when compared with U.S. demographic figures, therefore limiting the applicability of CCSS findings to the entire U.S. population of childhood cancer survivors.

Access to necessary medical and psychosocial support services is a function of having health insur-

ance, is mediated by socioeconomic status, is influenced by individual and family attitudes and beliefs toward the need and efficacy of such care, and is affected by the personal and institutional attitudes and practices of care providers and facilities. Differential access to societal resources and institutionalized bias/discrimination lead to inequalities and variations among these factors, resulting in an “unequal burden of cancer” in the U.S.¹⁰ And, if we believe that such inequalities have a dramatic impact in the U.S., the situation in other nations of the world should give us pause. Although cure rates for children with cancer approach 75% in the U.S. and other wealthy nations, in the less wealthy nations of the world cure rates still hover around 25%. In addition to the impact of culture itself, poverty, inadequate health resources for life-saving chemotherapy and radiation therapy, inadequate numbers of and poorly trained physicians, and a lack of sanitation and health infrastructures take a deadly toll. This is an international as well as national concern!

Recommendations

A systematic and coherent program to diminish or eradicate inequalities in the provision of care to children with cancer and their families would involve:

- A national health care plan for all citizens.
- Follow-up treatment and surveillance programs located in accessible community locales.
- The implementation of evidenced-based guidelines for quality medical and psychosocial care (such as those developed by the Children’s Oncology Group for survivors of childhood, adolescent, and young adult cancers [see URL: <http://www.survivorship-guidelines.org>; accessed October 31, 2005]).
- Protection for family economic and employment losses in the care of ill children.
- Guaranteed access to appropriate educational services for children both during and after treatment.
- The provision of opportunities for health care providers to interact with those who are culturally different from themselves and/or the predominant culture in the medical center as a way to enhance the providers’ abilities to interact with diverse populations and provide culturally sensitive and competent care (e.g., classes to promote new language acquisition).
- Public education and advocacy for expanded and more equal services by groups of patients and families.
- Research that documents and explores inequalities in care provision and suggests remediation efforts.
- Internationalization (globalization) of care in ways that extend the treatment gains of the wealthy nations to children and their families around the world.

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