

Meeting the Psychological and Physiological Needs of the Students with Cancer in the United States. Policy and Practice in the Schools

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Abstract: This paper focused on the meeting the needs of students with cancer in the schools in the context of the United States. The social environment surrounding the child cancer has changed. The remission rate for children with cancer is relatively high, so we must consider whether the students is anticipating treatment, actively in treatment, or post-treatment when one thinks about the potential mental stressors and cognitive impacts of cancer on the child's education. In this paper, the articles and guidelines related to the care and accommodation in schools are reviewed on the viewpoints of the general framework, policy, students' psychological and physiological needs, and the roles and professional development for the teachers and practitioners working for schools. In the section of the general framework, the guideline by American Academy of Pediatrics, which suggests the Multidisciplinary team members should have pediatric expertise within their specialty area. As for the policies, the sun-protection policy are highly noticed. In the United States, skin cancer has the largest population of the patients, and WHO and other countries has implementing the policy. In the section of students' difficulties, the psychological needs such as trauma, depression, and anxiety disorders. With respect to the teachers and staffs' professional development, three cases are showed. The first is about teaching strategy, the second is the medical staffs' activities for the improvement of patients' education, the third is the collaborative strategy for making the multidisciplinary team and meeting needs of students in the daily lives in the schools. Two recent policies and act has grown around 2010, but there are fewer attention to the child cancer than adults. Much attention has been paid to the improvement in the quality of care and teaching for the students with cancer during the past two decades. It includes the new ways to define and measure quality, recognition that doing so can identify strategies to enhance care, and systematic efforts by both government and private insurers to apply these principles. Further research are required along with the curriculum development and systematical educational plans, and teachers professional development in the viewpoint of treatment and caring for the students' invisible illness and disabilities.

Key words: *child cancer, school, educational needs, the United States*

INTRODUCTION

In recent years, the theme of treatment and education for the children with the child cancer has changed in special and inclusive education. For example, Root et al. [1] suggests that the practitioners working with children diagnosed with cancer in the school environment must consider several facets in order to effectively work

with the child and family. The social environment surrounding the child cancer has changed. The remission rate for children with cancer is relatively high, so we must consider whether the students is anticipating treatment, actively in treatment, or post-treatment when one thinks about the potential mental stressors and cognitive impacts of cancer on the child's education. They also shows the facts associated with childhood cancer that are relevant to school-based

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practitioners, common stressors for children and adolescents with a personal cancer diagnosis in their lives, research-based interventions, and accommodations and modifications to consider. This increase interest in the treatment and education for the students with cancer results not least from the belief that generating, developing, and implementing the program or the course of study in the special educational schools/classes for the health impaired students, and processes will be pivotal to quality improvement for the reasonable accommodation in the regular schools with the principle for the Convention on the Rights of Persons with Disabilities prepared by the United Nations.

In the field of the education and accommodation for the students with cancer in schools, recent studies have furthered our understanding of the concepts and practices for the children with cancer that inform particular cases of the individual students. These study have primarily focused on specific topics, such as effect of psycho-educational training program for parents [2], the role and function of the school counselors for the children with cancer [3], and the practice for enhancing the quality of life through professional intervention [4], among others. Similarly, prior research has suggested that the care and accommodation for the schooling for the students with cancer. Understanding this evolution is essential since it has suggestively informed not only the principles at different stake holders, but also the overall educational landscape regulating the care and practical accommodation in the schools, validating certain types of care and treatment in schooling.

OBJECTIVES

To this end, this paper explore the recent progress and standards of care and treatment in the schooling for the students with cancer as articulated in successive practices, teachers professional development, and related activities by investigating how the schooling actors (especially the practitioners and the special educational needs coordinators) enhancing their practice for teaching and caring. This is considerable academic and practical interest given that professionals' understanding of the care and education for the students with cancer determines the form and level of the schools' support receives. Moreover understanding the types and tendency of the care and special treatment in education are given priority over others might help practical features in the classrooms for the students with cancer prepared teachers and other related practitioners.

The remainder of this paper is organized as follows. In the next section, the materials and methods are described as to implement the inductive content analysis and qualitative research methodology. The next after this section the findings are presented, arguing that the features of practice and accommodation in schools along with the some documents and the guidelines for the treatment and care for the children with cancer. The comprehensive content analysis would illustrates the core principles and practical sides associated with each phase, as well as the features of the practice and curriculum development on the landscape of schooling. In the last section, the main implications of this study for the theory and practice for the care and education for the students with cancer and sketch possible directions for future research.

MATERIALS AND METHODS

3.1. Research Design

This study focused on the discourse analysis in the document and the guidelines related to the educational treatment care, teaching method and curriculum development, and other support and accommodation focusing the issues about the students' psychological and pathological problems.

Since the American Academy of Pediatrics published guidelines for pediatric cancer centers in 1986 and 1997, it is said to be a significant changes in the delivery of health care having prompted a review of the role of tertiary medical centers in the care of pediatric patients [5]. The potential effect of these changes on the treatment and survival rates of children with cancer led to this revision. According to the American Academy of Pediatrics, the intent of the academy to revise the statement is to delineate personnel and facilities that are essential to provide state-of-the-art care for children and adolescents with cancer and this statement emphasizes the importance of board-certified pediatric hematologists/oncologists, pediatric subspecialty consultants, and appropriately qualified pediatric medical subspecialists and pediatric surgical specialists overseeing the care of all pediatric and adolescent cancer patients and the need for facilities available only at a tertiary center as essential for the initial management and much of the follow-up for pediatric and adolescent cancer patients [5].

Basically, this survey has conducted in the content analysis, but for confirming the reality of the research questions and the insights, the systematic review has been implemented for the theoretical reinforcement.

3.2. Data Collection

In this research, data has been collected by

compiling a preliminary list of the articles and guidelines related to the educational care and treatment, teaching, and accommodation in the United States. To identify the related articles and guidelines, a comprehensive literature search in the ERIC database of published papers in English using the keywords “child cancer” and “pediatric cancer” and related phrases. The criteria for selection has been set for maximizing the inclusion of all relevant articles.

RESULTS AND FINDINGS

4.1. General Framework for the Treatment of Children with Cancer

In the United States, the oncologic care of the child or adolescent with cancer should be coordinated by a pediatric hematologist/oncologist who is board certified in the subspecialty of pediatric hematology and oncology by the American Board of Pediatrics [5]. Other subspecialists should be similarly board certified when applicable.

According to the guideline for the pediatric cancer prepared by the American Academy of Pediatrics, three major points are showed. The first is that children and adolescents with newly suspected and/or recurrent malignancy should be referred to a pediatric cancer center for prompt and accurate diagnosis and management. The second is that children and adolescents with newly diagnosed and/or recurrent malignancies should have their treatment coordinated by a board-certified pediatric hematologist/oncologist; treatment should be prescribed and initiated at a pediatric cancer center but may be continued at a center not specialized in the care of the pediatric oncology patient under the continuing oversight of the center's multidisciplinary team. The third is that multidisciplinary team members should have pediatric expertise within their specialty area. These three factors, especially the final one are important for this research. As mentioned above, the focus is on the students in the schools, so the treatment and care in their daily life in schools are more inquired. For constructing the multidisciplinary care for the children with cancer, the network overlapping the professional area of each field for human service area.

4.2. Sun-Protection Policy related to Child Cancer

In 2002, the U.S Centers for Disease Control and Prevention recommended that schools adopt policies that reduce exposure of children to ultraviolet radiation to prevent skin cancer. Within the United States, cancers of the skin are the most frequent type of cancer, with more than 1 million new cases occurring annually [6]. Then, the

protection is critical issues related to the child cancer.

The World Health Organization (WHO) estimates that between two and three million non-melanoma skin cancers and 132,000 melanoma skin cancers occur globally each year [6]. Fulmore et al. [6] also suggests the event of further depletion of the ozone, these cases will increase dramatically and it is a misperception that skin cancer is not a threat to youth, as exposure accumulates over a lifetime. They indicates that the primary prevention should begin during early childhood to reduce excessive exposure to UV radiation, which is a contributing factor to malignant melanoma and cumulative exposure also is a risk factor for non-melanoma skin cancers. Fulmore and his colleagues explore the long-term risks of exposure to ultraviolet radiation and provide invaluable information and resources for teachers and communities for educating children about skin cancer and sun protection, including (1) school and community programs; (2) national standards and guidelines; (3) a content review of selected textbooks; (4) student learning activities by grade level; and (5) links to classroom resources.

Reynolds et al. [7] reports the development of a school sun-safety policy measure and baseline descriptive statistics from the assessment of written policies collected in 2005-2007 from public school districts that enrolled in a randomized trial evaluating a policy promotion program. They collected the written policies from 103 of 112 school districts in Colorado state and Southern California state prior to randomization, and developed methods for selecting policy headings/sections topics likely to contain sun-safety policies for students and for assessing the presence, strength, and intent of policies. Their findings that 31% of districts had a policy addressing sun safety, most commonly, protective clothing, hats, sunscreen, and education at baseline. More California districts (51.9%) had these policies than Colorado districts (7.8%, p greater than 0.001). Policy scores were highest in districts with fewer Caucasian students ($b = -0.02$, $p = 0.022$) in Colorado ($b = -0.02$, $p = 0.007$) but not California ($b = 0.01$, $p = 0.299$).

They concludes that the protocol for assessing sun-safety policy in board-approved written policy documents had several advantages over surveys of school officials. The sun-protection policies, Reynolds et al. [7] suggests, were uncommon and limited, and they insists that California has been more active at legislating school policy than Colorado School district policies remain a largely untapped method for promoting the sun protection of children. But the cases of sun-protection policies are to be found outside the United States.

Ettridge et al. [8] shows the relationship

between sun- protection policy and associated practices in the early childhood services in Australia. Limiting exposure to sunlight during childhood can significantly reduce the risk of skin cancer. Ettridge and colleagues conducted the first national study to assess the sun protection policies and practices of early childhood services across Australia, and it also examined the key predictors of services' sun protection practices in 2007. According their article, at the time of 2007, 1017 respondents completed a self-administered survey about the sun protection policies and practices in their early childhood service (response rate of 59%). Their summary math is as follows. Most (95%) had a written sun protection policy, and the most common policy inclusions were hat wearing (91%), sunscreen use (87%) and enforcement of policy (97%). Less frequently reported inclusions were protective clothing (69%), information for parents/caregivers (58%) and regular reviews/updates of policies (65%). Ettridge et al. [8] indicates that the popularly basic sun protection practices (e.g. required any type of hat and sunscreen use) were more commonly reported than extensive practices (required protective clothing or regularly applied sunscreen), and then higher sun protection policy scores, being a formal childcare service as opposed to a kindergarten/pre-school and having Sun Smart status as opposed to not, were associated with higher sun protection practice scores ($P < 0.001$). They concludes that sun-protection policies may be improved through encouraging services to have more specific policy inclusions and to model their policies on the Sun Smart Early Childhood Program.

4.3. Students with Child Cancer from Psychological and Physiological Perspectives

As showed in the previous section, the care and treatment and the reformation of the system for the students with cancer are strongly required not only the family and community but also in the schools. And we can find some discussion about it in the debates since 1970s.

Peckham [9] considers educational implications of a child with cancer, including incidence, telling the child about his/her disease, school re-entry, what classmates want to know, counseling the child with cancer, handling the issue of death, and staff issues, including with a lesson plan on childhood cancer for elementary students.

Harris [10] suggests as a result of advancements in medical expertise and technology, children and adolescents diagnosed with cancer now have opportunities to participate in many typical activities, including school. This is said to be a common understandings focusing on the children's

lives in the school age and the public schooling. But he also shows, school reintegration reflects positive adjustment to their illness, to some extent. Nevertheless, children and adolescents with cancer may experience consequences that result in problems with school functioning and performance, along with other psychosocial difficulties. Accordingly, Harris insists on the necessity for noticing the role of the school-psychologists and school counsellors. Harris explains that school teachers and other practitioners may not be equipped to appropriately intervene with this unique population of students. One means of offsetting such consequences, and thus facilitating successful school reintegration, is consultation between children or adolescents, parents and/or caregivers, school personnel, and health professionals. The "eco-triadic model of educational consultation" may be useful as a means of providing indirect and direct services to children and adolescents with cancer. This article provides a description of the model, describes the model's application to school psychologists' work with this unique population of children, provides checklists to help guide school psychologists' intervention throughout the school reintegration process, and highlights implications for school psychological practice.

Little and Akin-Little [11] also stresses the importance of school psychology for responding the educational needs of the students with pediatric cancer. They suggests it is not uncommon for children or adolescents to be exposed to traumatic events, and students' experiences such as sexual or physical abuse, severe accidents, cancer or other life threatening illness, natural or man-made disasters, or the sudden death of a relative or peer can all result in maladaptive responses. As all children are in attendance at schools, this location seems the most logical place to meet the needs of children who have experienced these types of events. They also show that it is imperative that psychologists working in schools have training in meeting the needs of this segment of the population. Their manuscript summarizes the incidence of trauma in children, discusses the schools as a prime location for the provision of mental health services, and argues for the need to include training in trauma and trauma interventions in school psychology training programs.

Gothelf et al. [12] conducted a pilot study for fluvoxamine treatment for depression and anxiety disorders in children and adolescents with cancer,

to evaluate the safety, tolerability, and benefit of fluvoxamine for the treatment of major depressive disorder or anxiety disorders in children and adolescents. Their study was conducted from 2001 to 2004 at a pediatric hematology-oncology center. Fifteen children and adolescents with cancer were treated with fluvoxamine 100 mg/day in an open prospective 8-week trial. Safety and tolerability were evaluated at baseline and at weeks 4 and 8 by blood tests and the Side Effects Checklist and clinical benefit was assessed with the Clinical Global Impressions-Improvement, the Children's Depression Rating Scale-Revised, and the Pediatric Anxiety Rating Scale. Results: Fluvoxamine was well tolerated by all subjects. Psychiatric symptoms improved significantly. They concluded that fluvoxamine appeared to be well tolerated and was associated with a promising reduction in the depression and anxiety symptoms of pediatric patients with cancer.

Planning and practicing the support and care for children with cancer, physiological aspects as well as psychological one have to be highly noticed. Gorin and McAuliffe [13] describes the implications of childhood cancer survivors in the classroom and the school. Reviewing the long-term or late effects of cancer diagnosis and treatment on children, they examine the implications of these effects on the educational needs of the child or youth and explore the implications of childhood cancer survivorship on the school, particularly for female students. According to Gorin and McAuliffe, over the last 25 years, treatments for childhood cancers have increased survival rates by 45 per cent, to nearly 77 per cent. It is estimated that one in 900 people aged 15-44 years in the USA is a childhood cancer survivor; 80 per cent of children diagnosed with cancer in 1990 will survive into adulthood. So they implemented comprehensive literature review of studies relevant to female childhood cancer survivorship and education over the past ten years was conducted, having been collected through searches of databases. Long-term and late effects of cancer have been observed in neurocognition, cardiopulmonary symptoms, second cancers, reproductive organs, and hearing loss. Other health effects, such as impaired growth, osteopenia, hepatitis C infection, oral and dental malformations, and behavioral risk factors such as fatigue, obesity, and smoking have also been reported among childhood cancer survivors. These longer-term treatment sequelae, particularly on neurological systems, have implications for

changed student educational needs, including the provision of specialized instruction, classroom adaptations, as well as ancillary health services. One of their research implications has been shown as implementing the ecologic model and a research agenda is proposed for better integrating the increasing numbers of childhood cancer survivors into the educational environment. Another implication is that the practical interventions for survivors who are experiencing difficulties in school are listed.

4.4. Professional Development for the Practitioners in Schools

The schools are also the stage for supporting and caring the students with pediatric cancer, but there are some problems to be solved. In 2010, it has been estimated that one in 900 adults is to be survivors of some form of pediatric cancer [14]. The numbers are told to be somewhat lower for survivors of brain tumors, though their numbers are increasing. Schools mistakenly believe that these children easily fit pre-existing categories of disability. Though these students share some of the characteristics of other types of disabilities, they present a unique constellation of challenges that require flexibility and adjustment on the part of schools and teachers [14].

Survivors demonstrate a constellation of late effects which may change and increase in intensity over time; they are not static. The changes appear to be greater than those delineated for students with learning disabilities, in that they appear to be more than a response to new environmental expectations. Most of these children were not identified as eligible for special education prior to their diagnosis with brain tumors. Bakon [14] suggests, for many survivors, following the acute phase of illness and a period of home instruction, the expectation of the educational environment is that the students will be able to perform in the same way that the student did before diagnosis. In actuality the diagnosis and treatment of brain tumors in children typically result in a significant number of new challenges for the child. Sometimes these changes do not occur immediately and there may be a disconnection between the time that the student receives treatment and the time that the problems are noted. This article provides information about the range of late effects evidenced by survivors. It describes a retrospective study of evaluation data from the Survivor Education and Reintegration Support Program at Carlow University. The program is

designed to support schools, families and survivors as they adjust to the issues of survivorship. Information gathered on late effects and some suggestions for how schools may successfully address the myriad needs of survivors will be provided.

For the support, care and accommodation in the schools, it is inevitable for the practitioners and staffs to develop and understand for the students needs. Donovan [15] presents a practices for improving teaching technique that aims to demonstrate pedagogy consistent with the characteristics of effective health education curricula that is student-centered, builds personal and social competence, and embeds assessment throughout the learning process for the students with cancer. This teaching technique is appropriate for middle and high school students grades 7 through 12. The initial impetus for this teaching technique come from the serious case of the middle school student, was diagnosed with a rare form of cancer known as Ewing's sarcoma. Like many other children and adolescents who are diagnosed, Tim is a cancer survivor. In fact, childhood cancer today is more correctly characterized as a life-threatening chronic illness than a fatal disease. Upon reflection of his illness experiences and path to recovery, Tim believed that some of his fears, uncertainties, misconceptions, and anxieties could have been ameliorated if, in the course of his school health instruction, prior to becoming ill, students had opportunities to learn about these issues. The purpose of this teaching technique is to make Tim's unique request possible, and to guide such a learning opportunity in a way that is beneficial for all learners. This type of approach involves teaching and learning to enhance interpersonal communication and social support (healthy relationships) around cancer issues in a general health education context.

Brown et al. [16] illustrates the collaborative development of a teacher training program for teachers who have a child with cancer in their classroom. Five hundred twenty-eight kindergarten through 12th grade public school teachers were surveyed to identify their training needs. Based on these needs a computer-based training program was developed in collaboration with a review panel including 2 physicians and 1 child life specialist. Following construction of the program, 28 participants were recruited to pilot test the self-paced training program. Teachers' perceived knowledge and perceived preparedness

increased significantly after completion of the training program as did their objective knowledge of childhood cancer. Overall, participants rated the training program as effective and easy to use. The majority of participants indicated an interest in using computer-based training programs in the future to meet their continuing education needs. The results of this study suggest that school practitioners can work collaboratively with medical practitioners to develop training programs for teachers of children with cancer.

CONCLUSION AND DISCUSSION

Much attention has been paid to the improvement in the quality of care and teaching for the students with cancer during the past two decades. It includes the new ways to define and measure quality, recognition that doing so can identify strategies to enhance care, and systematic efforts by both government and private insurers to apply these principles [17]. Perrin [17] reviews these gains as is these quality measurement efforts have focused mainly on adult health care inspite of the students' benefit. Two recent federal programs has made to expand quality measurement of child health care. Enacted in 2009, the Children's Health Insurance Program Reauthorization Act provides systematic support for efforts to develop and implement a set of child health quality measures. This federal support represents the first major public investment in improving child health care quality. The Affordable Care Act, which became law in 2010, extends those activities by focusing attention on improving care for people with chronic conditions, including new ways to organize care using teams of doctors, nurses, and others focused on improving chronic care outcomes. For children especially, this multidisciplinary team care should also focus on prevention of chronic conditions and their consequences. Despite these significant efforts to expand quality measurement among children and youth, Perrin [17] finds that most measures and improvement activities focus on children without chronic conditions, and few measures of chronic conditions go beyond examining what kinds of monitoring children with specific conditions receive. Only limited attention is paid to how well the children are functioning in the schools. A number of networks working with children with specific chronic health conditions including cancer, cystic fibrosis, and sickle cell disease have developed effective measures of functioning for children with those conditions and active programs to improve

such outcomes. These networks may offer the best examples of how to improve care and outcomes for young people with cancer. Broadening their impact to larger numbers of children will require developing measures of functioning and quality of life and targeting interventions and efforts to improve those outcomes.

Further research are required along with the curriculum development and systematical educational plans, and teachers professional development in the viewpoint of treatment and caring for the students' invisible illness and disabilities.

REFERENCES

- [1] Root, Melissa M.; Bray, Melissa A.; Maykel, Cheryl; Cross, Karen; Shankar, 16. Nilani L.; Theodore, Lea A. Students with Cancer: Presenting Issues and Effective Solutions. *International Journal of School & Educational Psychology*. 2016; 4(1): 25-33.
- [2] Mahmoud S, Elaziz NAA. Effect of Psycho-Educational Training Program for Parent's Having Child with Leukemia on Their Experience and Psychological Wellbeing. *Journal of Education and Practice*. 2015;6(12): 13-29.
- [3] Bauman, SSM. School Counselors and Survivors of Childhood Cancer: Reconceptualizing and Advancing the Cure. *Professional School Counseling*. 2010;14(2): 156-164.
- [4] Ventegodt S, Omar HA, Merrick, J. Quality of Life as Medicine: Interventions that Induce Salutogenesis. A Review of the Literature. *Social Indicators Research*. 2011;100(3):415-433.
- [5] American Academy of Pediatrics, Section on Hematology/Oncology. Guidelines for Pediatric Cancer Centers. *Pediatrics*. 2004; 113(6): 1833-1835.
- [6] Fulmore JS, Geiger BF, Werner KA, Talbott LL, Jones DC. Sun Protection Education for Healthy Children. *Childhood Education*, 2009;85(5);293.
- [7] Reynolds KD, Buller DB, French SA, Buller MK., Ashley JL. School Sun-Protection Policies: Measure Development and Assessments in 2 Regions of the United States. *Journal of School Health*. 2012;82(11);499-507.
- [8] Ettridge KA, Bowden JA, Rayner JM, Wilson CJ. The Relationship between Sun Protection Policy and Associated Practices in a National Sample of Early Childhood Services in Australia. *Health Education Research*, 2011;26(1);53-62.
- [9] Peckham VC. Children with Cancer in the Classroom. *Teaching Exceptional Children*, 1993;26(1);26-32.
- [10] Harris MS. School Reintegration for Children and Adolescents with Cancer: The Role of School Psychologists. *Psychology in the Schools*, 2009; 46(7);579-592.
- [11] Little SG, Akin-Little A. Trauma in Children: A Call to Action in School Psychology. *Journal of Applied School Psychology*, 2013;29(4);375-388.
- [12] Gothelf D, Rubinstein M, Shemesh E, Miller O, Farbstein I, Klein A, Weizman A, Apter A, Yaniv I. Pilot Study: Fluvoxamine Treatment for Depression and Anxiety Disorders in Children and Adolescents with Cancer. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2005;44(12);1258.
- [13] Gorin SS, McAuliffe P. Implications of Childhood Cancer Survivors in the Classroom and the School. *Health Education*. 2009;109(1);25-48.
- [14] Barkon B. Learning Profiles of Survivors of Pediatric Brain Tumors. *Physical Disabilities: Education and Related Services*. 2009;28(1);34-69.
- [15] Donovan O. Building Personal and Social Competence through Cancer-Related Issues. *Journal of School Health*. 2009; 79(3); 138-143.
- [16] Brown MB, Bolen LM, Brinkman TM, Carreira K, Cole S. A Collaborative Strategy with Medical Providers to Improve Training for Teachers of Children with Cancer. *Journal of Educational & Psychological Consultation*, 2011;21(2);149-165.
- [17] Perrin JM. How Can Quality Improvement Enhance the Lives of Children with Disabilities? *Future of Children*. 2012;22(1). 149-168.