# Serving the Student-Survivor:
## Exploring the Transitional and Psychosocial Needs of School-Aged Children with Cancer and Chronic Illness

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# Signature Sheet

This thesis, written under the direction of the candidate's thesis advisor and approved by the chair of the master's program, has been presented to and accepted by the Faculty of Education in partial fulfillment of the requirements for the degree of Master of Science. The content and research methodologies presented in this work represent the work of the candidate alone.

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# Abstract

The advances in medicine today have created an emerging population of student-survivors, school-aged children living with and/or recovering from serious health conditions (Bauman, 2010). Each school day in the United States, 46 young people, or the equivalent of two classrooms of students, learn they have cancer (Cure Search National Childhood Cancer Foundation, 2010). These statistics reflect the fact that cancer is one of the most chronic illnesses in childhood**.** Most serious childhood medical issues will have life-long ramifications. This qualitative research study is comprised of an in-depth review of the research literature and the responses and information gathered from two professionals. The purpose of the study is to identify common issues faced by student-survivors and to examine the relationship between psychosocial support and school performance. The results indicate that there is a commonality of psychosocial issues that affect this population. Chronically ill children are experiencing school-related problems and the information being exchanged between the trinity of professionals, which includes-educators, medical professionals, and mental health professionals- to families is inconsistent and confusing thwarting access to resources. It can be concluded that the needs of this population are not being met in the traditional context of the public school system and that teachers are feeling ill prepared to serve them, but that positive school experiences, in one form or another, amidst childhood illness can provide the social structure necessary to alleviate the feelings of isolation and psychological distress commonly experienced.

Childhood is perhaps the hardest time of all. As a child he is a strange creature in a strange land. It was my own fate to be just strong enough to play about with the other boys, and attempt all their games and "stunts" without being strong enough actually to succeed in any of them. It never used to occur to me that my failures and lack of skill were due to circumstances beyond my control, but I would always impute them, in consequence of my rigid Calvinistic bringing-up, I suppose, to some moral weakness of my own. I suffered tortures in trying to learn to skate, to climb trees, to play ball, to conform in general to the ways of the world. I never resigned myself to the inevitable, but overexerted myself constantly in a grim determination to succeed…And this is the tragedy, I suppose, not only of the deformed, but of all the ill-favored and unattractive to a greater or less degree. The world of youth is a world of so many conventions, and the abnormal in any direction is so glaringly and hideously abnormal….

-Bourne, The Handicapped-By One of Them, 1911

# Chapter 1 Introduction

“Each school day in the United States, 46 young people, or the equivalent of two classrooms of students, learn they have cancer,” (Cure Search National Childhood Cancer Foundation, 2010). These statistics reflect the fact that cancer is one of the most chronic illnesses in childhood. Childhood is defined by its shared familial, school, and social experiences. These experiences, if positive, have historically and sociologically proven to be some of the most influential and essential building blocks to the overall well-being and success of any young person. A disease diagnosis like cancer and the treatment and hopeful recovery that follows in a child is unexpected and will affect all of the aforementioned aspects of the child’s life from diagnosis and beyond. Before a health crisis and generally speaking, a child’s biggest concern should be to pass that math test, finish that art project, or finish a family project at home. Once a serious health issue ensues, the child’s biggest responsibility is to get better, feel better, and survive.

Fortunately, many of these student-survivors (Bauman, 2010), school-aged children living with or surviving cancer and other serious and chronic illnesses, are getting better, but not without concern. Research has shown that “survivors of pediatric and young adult cancer face a substantial risk of late effects and early mortality. By 30 years from initial diagnosis, 73 percent of survivors will develop at least one chronic physical health condition; in 42 percent the condition will be severe, disabling, or life-threatening,” (Hobson, 2007). This is why it is imperative that this unique population receive ongoing psychosocial support along with their medical follow-ups as they transition through the milestones of life, which most definitely include the school experience.

It is natural that the child might struggle with this new identity around illness and survivorship. The mixed messages, expectations, and stigmas that come with it from parents, teachers, doctors, and so on, are especially confusing and hard to process for a child. This research addresses how the school experience, in particular, is affected by the child's cancer experience/health crisis and how that experience affects the child. Once the school-aged child experiences a serious illness their roles change and feelings of hopelessness and social isolation can arise amidst the reconceptualization of a new reality. Cancer patients and chronically ill individuals seem to feel like they have been removed from the typical flow of life, spending more time getting treatment and getting better than anything else. Their world now extends beyond the familiar home, classroom, and schoolyard and into hospitals, doctor's offices, and pharmacies. The adults they interact with on a daily basis now go beyond their immediate family and teachers to include physicians, therapists, and social workers.

## Statement of the Problem

Children missing school due to medical treatment is not a new concern. Over one million children 5 through 17 years of age are hospitalized in the U.S. each year. Illness severe enough to require hospitalization is often preceded by missed days of school; thus, it also entails additional days missed as children recover after discharge. Even a brief hospitalization can be disruptive to a child's education (Eaton, 2012). This qualitative research assesses the issues that are arresting developing efforts to properly serve this unique and emergent population of young people. It is apparent that the professionals working with the student-survivor population are increasingly finding themselves struggling to serve and transition them appropriately and cooperatively.

There are three core concerns that drive the assumptions of this research:

1. The needs of this population are not being appropriately identified and served within the context of the traditional public school system. Most regular classroom teachers have not been prepared for their unique educational needs nor trained to apply the necessary accommodations and modifications. Many of these students are experiencing school related problems, marginalization, and stigmatization.
2. The essential communication and collaboration between the child's family and the child's educational team and medical professional team is lacking and inconsistent which affects the child's positive growth, family dynamics, social development, and access to resources.
3. There is not enough emphasis and attention on the psychosocial well being of the child after a serious illness, which is affecting school performance and impacting developmental stages and quality of life.

## Purpose

The reason for wanting to explore this aspect of education and this unique population of students is a personal one for the researcher, being that she is an educator, currently a student, and also a person living with cancer. Being an educator, and therefore a part of the interdisciplinary team of professionals whom will work with this population, she felt a professional responsibility to improve the way that society is "packaging and serving" the school experience to these student-survivors so that they may have the same opportunities for educational success as their peers.

Being a survivor as a young adult and now an adult living with cancer and its chronic conditions, she felt a personal responsibility to explore and bring attention to the needs of the child with cancer. The researcher is specifically concerned with the psychosocial needs of children with cancer, which she believes that, when appropriately addressed and nurtured, will have positive affects on everything else in the child's life, school included.

## Research Questions

Who is involved in facilitating care to school-aged children with cancer or chronic illness? What are the commonalities of psychosocial issues affecting student-survivors? What are the perceptions of families and teachers in regards to the information they are getting from medical professionals about student-survivors and around mental/emotional health and school? What resources and policies have been developed to meet the needs and transitional needs of this population? How are resources and information being disseminated to the professionals and the families? How has the family dynamic been affected by the child's health crisis? What are the general attitudes that these student-survivors and have about their future and their educational future, in particular?

## Theoretical Rationale

> The younger person, in order to experience wholeness, must feel a progressive continuity between that which he has come to be during the long years of childhood and that which he promises to become in the anticipated future; between that which

> he conceives himself to be and that which he perceives others to see him and to expect of him, (Erikson, 1968, p.87, as cited in Waterman, 1982).

The sociological perspectives of social theorists, Erikson and Cooley (Waterman, 1982) support the research assumptions in regards to the needs of the student-survivor population. Erikson's Psychosocial Stage Theory of Development describes the impact of social experience across the whole lifespan and aligns well with the research. In it, he outlines eight distinct stages of development. The first five stages of his theory occur amidst infancy, childhood, and early adolescence, which is in context with the school-aged/student-survivor population of this study. Erikson's stage theory supports the research assumptions in regards to the unique personal challenges and psychosocial needs that these young people are facing as student-survivors. In Stage 4, Industry VS Inferiority, children in the early school years-ages 5-11- are encouraged by parents and teachers to develop a feeling of competence and belief in their skills. School seems to be a productive environment for this stage of development. Erikson theorizes that those school-aged children who receive little or no encouragement from parents, teachers, or peers will doubt their abilities to be successful. In Stage 5, Identity VS Confusion, during adolescence years- children explore their independence and develop a sense of self. Those who receive proper encouragement and reinforcement will emerge from this stage with a strong sense of self and a feeling of independence and control. Those who remain unsure of their beliefs and desires will feel insecure and confused about themselves and the future. Completing this stage successfully leads to fidelity, which Erikson described as an ability to live by society's standards and expectations. Erikson believed that the way a person processes and internalizes a conflict or crisis during each stage will serve as the turning point towards positive or negative development and growth. Erikson also believed that the degree to which crises in earlier stages are resolved affects a person's ability to better resolve crises in later stages. Hence, why psycho-social support should be especially recognized and emphasized with this young, impressionable population of student-survivors.

Another one of the main elements of Erikson's psychosocial stage theory is the development of the ego identity. Ego identity is the conscious sense of self that we develop through social interaction, which according to Erikson, is constantly changing due to new experiences and information we acquire in our daily interactions with others. C.H. Cooley defined this Symbolic Interaction Theory based phenomena as the "looking glass self"- where one's sense of self-concept, especially during youth, is heavily influenced and defined by how others relate to them (1902, as cited in Zastrow & Kirst-Ashman, 2010, p. 296). According to Erikson's theory formation of identity is something that begins in childhood, becomes particularly important during adolescence and continues throughout life. Though identity development is a lifelong process, it is exacerbated in childhood and adolescence, where major milestones are being sought, expected, and hopefully reached. When roles are not integrated and identity is not clear, an individual is said to be in a state of role confusion.

Couple these theories with the medical model of disability, a sociopolitical model that reaches to explore how illness (or disability) affect the individual and society, and it becomes clear that the physical condition is intrinsic to the individual and that illness and disability may reduce the individual's quality of life, and cause clear disadvantages. These are the very assumptions and concerns that drive this research.

## Background and Need

> With thoughtful effort, professionals can unite as catalysts to instigate the future direction of this field by collaborating on research endeavor. Results from these initiatives can subsequently guide policy and practice related to programmatic structures and teaching strategies for these children. Additionally, existing policies need to be expanded to ensure equal access to best practices for seriously ill children. Establishing clear guidelines will result in equitable allocation of resources and funding resulting in more appropriate educational programming for these children (Irwin, et al., 2010. p.77).

Nan Songer was a special educator and a progressive advocate for the educational rights of children with disabilities. She spearheaded the 2009 formation of the 501(c)(3) not-for- profit professional association called, The Association of Pediatric Hematology and Oncology Educational Specialists (APHOES). This group tasked itself with the duty of creating positive educational experiences for students suffering from blood disorders and cancer. Their mission spans multiple disciplines but the goal is collective. Their work and the work of others helped to ease the stress for children and their families as they re-enter school after hospitalization (Mixon-Martin, 2012). Songer strongly believed that the educational needs of students with cancer and blood disorders were being overlooked. Songer's vision was to create standards across the US for professionals working with these children to improve the quality of the education they receive.

## Assumptions

Health and one's physical condition is intrinsic to the individual, and therefore, illness and disability may reduce the individual's quality of life, and cause clear disadvantages. Psychosocial support is not emphasized or encouraged enough in our schools or our society. Psychosocial support, especially for school-aged children with illness, needs to fit individual needs and be age appropriate. The needs of this population are not being appropriately identified and served within the context of the traditional public school system.

## Summary

New mandates are necessary to address the unique needs and profiles of student-survivors in our schools and communities today. With more awareness and research into the social experiences of school-aged children with illness, professionals might be more empowered to come together and push for and participate in the reform necessary. More dedicated research into analyzing existing research and laws is necessary so that future research initiatives and solutions would thrive rather than stagnate and/or marginalize.

The recommendations and standards of practice for the adults working with student-survivors need to be better refined and reformed than they are now. Regular classroom teachers would feel better prepared to serve student-survivors in their classrooms. With reform and better communication, the stresses that already affect the child and that extend to the family would be alleviated. Families would feel more informed and confident if their relationships with the professionals were better established.

# Chapter 2 Review of the Literature

## Introduction

Chapter 2 includes an overview of the topic as understood through the framework of historical context and prior research. The theoretical background and historical context of the complexity of disabilities in the classroom have been discussed and will be followed by a critical review of supporting research.

## Historical Context

Historically, access to education has always been a major focus of the disability rights and the civil rights movement. Many of these student-survivors do not qualify for traditional special education programs, yet they have unmet learning needs. These unmet learning needs can be attributed to and associated with chronic absenteeism, disease symptoms, side effects of medications, and various secondary psychosocial effects, side effects, and late effects (side effects that present themselves later) of having or having had a serious medical condition (Thies & McAllister, 2001). Resources for this population are not being consistently or appropriately disseminated, which is thwarting accessibility. This could be seen as a violation to their civil rights. All of the people involved in the child's recovery and success need to know, understand, and implement all means necessary to ensure that these children receive the free and appropriate education that they all are entitled to (as outlined in Public Law 94-142-FAPE).

Some student-survivors qualify for an Individualized Education Plan (IEP), which is created using guidelines set out by the federal government in the Individuals within the Disabilities Education Act (IDEA), which is an education law. Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prohibits discrimination thus allowing public schools to provide accommodations so students with qualified disabilities can have equal access to school activities and the curriculum. Although children with cancer should be considered covered under the IDEA Act and/or 504 of the Rehabilitation Act under “other health impairment” a committee meets to determine eligibility that each student must meet in order to qualify for either accommodation. Student-survivors do not always fit the specific and rather inflexible criteria, which contribute to the concerns around the proper delivery of appropriate educational services and or around the long-term effects and quality of life issues for this population. Further more, as students with IEPs graduate (if they had qualified for them at all), they are no longer covered by IDEA because it only covers K-12 and they must know how to navigate solely through the system under the civil right schema under Section 504, Rehabilitation Act, the American with Disabilities Act (ADA) and its Amendments (ADAAA). In addition to IDEA, NCLB of 2001, (P.L. 107-110) seeks “to ensure that all children have fair, equal, and significant opportunity to high-quality education and to reach or exceed minimum proficiency on challenging state academic achievement standards and state academic assessments,” so while states increase their efforts to implement this standards-based curriculum for all students, there will be a need to increase collaborative teaching initiatives (amongst special education and general education) and solutions among the entire array of instructional services and resources available to targeted populations such as student-survivors.

## Supporting Research/Review of the Previous Literature

### *School Counselors and Survivors of Childhood Cancer*

This article is based on the literature review of what survivorship means to the survivor of childhood cancer and how school counselors factor into the amelioration of the academic, career, personal, and social concerns that can arise. This research was in response to the rising statistics that reflect the fact that cancer is one of the most prevalent chronic illnesses in childhood and that there are noteworthy differences that exist between the cancer experience of children and adults. With increasing survival rates, school counselors and school personnel will not only encounter childhood cancer survivors with greater frequency, but will also have opportunities to facilitate their adjustment.

Bauman (2010) outlines ways that school counselors could benefit the “student survivor” throughout 3 re-conceptualized phases of survivorship. These phases are defined by the research as the, “Cancer Survivorship Outcome Continuum.” The 3 phases defined and explored are, the acute survival phase, the re-entry survival phase, and the extended survival phase. Results conclude that counselors can recognize the critical issues faced by individuals and families who are affected by the cancer experience at different points in their life and help them with necessary adaptation tasks. During the first two phases, acute survival phase and re-entry survival phase, the school counselor can be especially vital to the transitions that occur by acting as advocates for the academic, social, and personal development of survivors.

### *Psychosocial Health: Surviving Cancer*

The researchers, Eilerstein, Rannestad, Indredavik and Vik (2011) explored the psychosocial health of children and adolescents that have survived cancer. The increasing survival rates for childhood cancer have illuminated quality of life concerns as the child and the family face many challenges and struggle to achieve normality after diagnosis and recovery. Prior research of psychosocial outcomes for cancer survivors has shown varying and conflicting results. The researchers also realized that prior studies had not involved or allowed for comprehensive assessment of the child-survivor, the parent(s), and the teacher.

The researchers carried out the population-based, case-control study on 50 children aged 6-20 who had been treated at the Pediatric Department of St. Olay's University Hospital. The participants had survived/been healthy for, at least, 3 years after diagnosis. Assessment also included the point of view of families and a teacher. The control group was an invited friend, without cancer, of each survivor that was of the same gender and age, by 1 year or less. Also included in the control group were the respective families and teachers of each child without cancer. The children and the parents collected data using a behavioral Strength and Difficulties Questionnaire (SDQ) that was assessed. There were 5 problem identified on the scales; an Emotional Symptoms Scale; Conduct Problems Scale; Hyperactivity/Inattention Scale; Peer Problems Scale; and a Pro-Social Scale. The answers to each scale together cumulated a *total difficulties* score.

The results reflected that children surviving cancer had significantly higher mean total difficulties score then compared to their control group, specifically, in regards to the Emotional Symptom Scale and Peer Problem Scale. The teachers were asked to assess the children's academic performance and adaptive functioning assessed by the Achenbach System of Empirically Based Assessment (ASEBA) questionnaire. Researchers concluded that there was poorer academic performance from the student-survivors compared to their peers. The observed differences found between children surviving cancer and the controls were highly significant.

Results indicated the need to develop adequate supportive interventions and programs for long-term follow-up care for children with cancer. The results also reflected an essential need for an interdisciplinary collaboration among the families, the health care professionals, and teachers. The results suggest that this collaboration and these relationships should be established at time of diagnosis to prevent maladjustments and to promote optimal psychosocial health throughout the rest of the survivor's life.

### *Returning to School*

Selwood (2013) conducted an audit of the information given by healthcare professionals to children, families, and teachers about the return to school of students with cancer. Knowing that cancer changes lives at diagnosis, during treatment and recovery, and beyond raised concerns for the researchers, nurse practitioners at Alder Hey Children's Hospital in Liverpool. Their concerns were that the physical, emotional, and cognitive changes might affect the child negatively in school. Also children returning to school as soon as possible helped them maintain a sense of normalcy, leading to better school performance and better psychosocial support.

It also became apparent to the researchers that the patients and the families were getting varied advice from medical professionals and that families were interpreting information in different ways. This miscommunication was affecting the child's school attendance and potential to lead a normal life.

The researchers devised two brief questionnaires to audit the staff and parents attending the Alder Hey Oncology unit during a 2-week period in 2007. Parents were asked open- ended questions about what kind of information they received and by whom and then responses were collected anonymously. Staff members were asked one comprehensive, open-ended question about what information they gave to families that related to children attending school.

A third parental survey was developed to explore the nature of information the school had received about the child in regards to his/her prognosis and capabilities. Results indicated that there was a sense that school personnel did not receive sufficient information about what the student-survivors were experiencing or about what they needed in place to facilitate the transition the classroom. The results also concluded that the families had received inconsistent advice from medical professionals especially about when to go to school. The research results implied that professionals from the medical and educational disciplines believe that the return to school should be encouraged to normalize the child's lifestyle. The results also conclude that the liaison between school and hospital systems needs improvement.

### *The Health and Education Leadership Project*

Thies and McAllister (2001) researched the educational and psychological needs of children with chronic illnesses. They realized that this population was growing and that children were experiencing school-related problems. Learning needs for this population were unmet. As a group these students did not qualify for traditional special education programs. The Health and Education Leadership Project (HELP) is a multiple phase program developed by 30 representatives from New Hampshire public schools to support efforts to meet the health and education needs of students with chronic health conditions.

Results confirmed the researcher's initial concerns, that the learning needs of this population are unmet and that children with chronic health conditions are experiencing more school-related problems than their peers for uniquely different reasons. The results indicated that the major contributing factor to these problems is the need for improved communication and collaboration between the families, schools, and health care providers so that specific needs can be clearly defined and the children better served. The immediate goal of this project was to improve the quality of life for students with chronic health conditions. By assessing these needs, the researchers collected and analyzed the data to establish guidelines for collaboration, and to develop and disseminate a curriculum and initiatives to support these students. The research and subsequent program development that followed are used to provide an example for future phases of the initiative in the New Hampshire public school system to and as a foundation for supporting children with chronic illnesses.

## Summary

After analyzing the prior research within the theoretical contexts of Erikson and Cooley and the historical context of civil rights and, more specifically, disability and education rights, the research assumptions seem even clearer and more concerning. The student-survivor's psychosocial development is more fragile than that of their "healthy" peers, because each stage of age-appropriate conflict (and, in effect, development) is being compounded with the unique and serious crisis of cancer and illness. Psychosocial health and transitional support needs to be better addressed. Erikson's emphasis on the idea that daily social interactions influence the evolution of the young ego identity and Cooley's "looking glass self" perspective both support the assumption that the school experience in some form is a normalizing and shaping force for the student-survivor and that continuing to have some sort of school experience will alleviate some of the role confusion that occurs amidst management or recovery of a serious illness. These theories also support the assumption that the messages and information that these student-survivors are getting from the other adults and the professionals working with them need to be more comprehensive, more sensitive, and more family-centered in order to benefit the child.

# Chapter 3 Method

## Introduction

This qualitative study uses two modes of research methodology to explore the transitional needs and psychosocial issues of school-aged children with cancer and chronic illness- a critical analysis of prior research and expert interviews. The phases of knowledge that emerged from the research literature formed the framework for the interview questions.

## Sample and Site

The target participants of each expert interview are non-patient volunteers with whom the researcher has a dual, personal relationship. They were selected on the basis of the professional experiences and the expert knowledge that they have had with the population being explored. The professional experts include: a Social Worker/MSW and a published Anthropologist/PhD. No direct sample and site in regards to the population being studied, student-survivors, were directly obtained or observed during this research.

## Access and Permission

Accessibility to the experts was available because of the dual, personal relationship that the researcher has with them. All necessary consent and permissions were obtained to solicit each participant for participation and information.

## Ethical Standards

This study adheres to the ethical guidelines for including human subjects in research according to the American Psychological Association (2010). Additionally the proposal was reviewed by the Dominican University of California Institutional Review Board for the Protection of Human Subjects, approved, and issued number #10184.

## Data Gathering Strategies

Past research was reviewed and analyzed prior to conducting two expert interviews. The inquiry tool for the data gathered from the interviews was an open-ended questionnaire. A blank outline of the interview questionnaire was presented to each expert in individual emails. Responses were to be typed by the expert and emailed back to the researcher. As it turned out, one set of expert responses was emailed back and one expert interview was conducted over the telephone. The responses of the semi-structured telephone interview were knowingly tape recorded and transcribed by the researcher.

## Data Analysis Approach

The basic tasks of reviewing and critically analyzing the previous research then making sense of the responses of the interviews were the bulk of the analysis. The first step in this preliminary analysis was to research prior data on school-aged children with cancer or other chronic illness. Multiple information seeking modes to find relevant journals and text to support the research were used to complete the literature review section of this research. The second step was the analysis of the expert interviews. The interview instrument asks open-ended questions that speak to the expert's general measures of past and present experiences and observations about the population. The questionnaire asked for the expert's professional understandings around the psychosocial health, education, interdisciplinary collaboration, policy, and the family dynamics of the student-survivors and their families that they had worked with. A chart with responses from both expert interviews were embedded into the next chapter (Chapter 4-Findings). Common threads were identified and organized according to relevance and "categorized" into themes. Basically, these were the themes that seemed to capture the ideas central to the experts interviewed, the literature reviewed, and the outcomes and assumptions anticipated. The findings of each method were combined and summarized into *working papers* for the transparency and purpose of the research. A working paper can be defined as a single subject (or theme) backed up by the quotes of subjects and their transcribed interviews (McIntyre, 1995).

# Chapter 4 Findings

## Interview Responses

The sampling of data collected was from the responses of each expert interview. The themes were comprised of a combination of emerging information from the initial research questions and assumptions, previous research and the review of the literature, and the responses of the expert interviews. As mentioned before, the first expert interview's responses were sent back to the researcher in an email then transcribed. The second interview was conducted over the phone and transcribed by the researcher. Both were embedded into chart form so that the findings for transparency and then were summarized and fleshed out into *working papers* to highlight the evidence that support the research assumptions and main themes best.

Expert Interview Responses- See Appendix for Chart of Full Transcribed Responses

## Major Findings/Themes

The assumptions were supported, some stronger than others, and crucial themes emerged, but the components of each one were not exclusive. For example, it was observed that the family dynamic as well as age and developmental and transitional issues were underlying components of each major theme. Like the experience of illness, the understanding and "themes" that emerged throughout the research could not be definitively categorized or contained to just one box.

*I. Psychosocial Support and Developmental Needs of the Student-Survivor*

Feelings of Depression and Isolation, Stigmas, Role Confusion, Family Dynamics, Side Effects, Transitional Issues, Developmental Theory/Impact-Age, Support

*II. Professional Power Dynamics and Policy*

Dissemination of Information, Allocation of Resources, Transitional Needs, Marginalization/Inequality, Policy, Power Struggles

*III. School and the Student-Survivor*

A Sense of Normalcy, Hope for the Future, Developmental Impact-Age, Family Dymanics, Teacher Preparedness, Transitional Issues, Inequality, Activism

## Summary of Overall Major Findings-*Working papers*

### *Working Paper I- Psychosocial Support and Developmental Needs of the Student-Survivor*

Accepting an illness or diagnosis is just the first step to the challenge of figuring out how it will fit into one's life, and working through feelings is important because how one feels can alter a view of self, life, and what decisions one makes about treatment and the continued maintenance of good, over all health. There is no way to predict how and why an individual will react and internalize a health crisis although the results of this research do indicate that there is a commonality of issues that almost everyone experiences, but that the age of the survivor seems to play a big role in the maintenance of these adjustments.

The concerns and the consequences of this issue extend into the family. Family dynamics as well as socio-economic status are influential as well. It is apparent that psychosocial support should be emphasized and encouraged but should fit the needs of the person in order for it to be beneficial to a sustained well-being. It is evident that, often times, these different aspects of support and the many resources available are not thoroughly explored with the student-survivor or their family.

Both experts emphasize the importance of having support and a support system for the student-survivor and the family. Each expert, when recounting their experiences, describe a sense of flexibility and openness that was necessary for them to have in order to reach each family and in order to understand each families experience with illness as unique and with its own set of needs. Each expert recounts how roles are being constantly stepped into and out of by everyone as needed. Both experts made reference to age and adolescence, in particular, as being an especially challenging time for this population. Each expert recounted the physical effects of illness not just as physical hardships but as emotional and stigmatizing as well.

*Some wanted us to be there, every where…and we just followed the lead of the family and what they wanted for the for the sick child and found that what each family wanted for every child was different." (CM)*

*I worked with the families almost as often as I worked with the youth. A cancer diagnosis impacts every aspect and component of a child's life. (JL)*

*I experienced a mix of extremes: from absolute hopefulness and optimism, to incredible hopelessness and resolve to die – both of these two cases were diagnosed with the exact same, rare cancer. One was on suicide watch almost every week. Though it's hard to say if his depression existed prior to his diagnosis, it was absolutely clear the impact this diagnosis had on him. The disabilities he received as a result of his diagnosis were almost more defeating to him than the cancer itself, and his resolve to die was so strong every week, almost everyday. Any bit of joy that I could bring he and his family, I would bring tenfold. He was so severely depressed, and that hopelessness permeated every cell of his already compromised body. He unfortunately succumbed to his cancer…" (JL)*

*One of the kids was in the hospital 4 days a week…and she made friends with the nurses and aides. I would say to add to another list of concerns is that another issue for parents is that the children just get to be kids and not just sick people. That's a big one. But there is a whole range of them out there. There are a whole lot of kids trying to take care of parents…around worries…and seeing their parents distressed even this little child that I wrote about a lot…her mother said that when I cried the little girl would pat her head and say Mommy its going to be alright…so I think that children can take on a huge amount of responsibility…worrying that their parents are worrying about them and a lot of the kids. (CM)*

*Their experience impacts them so significantly, in ways that general population providers cannot understand unless they spend a good deal of time understanding the psychosocial effects a cancer diagnosis has on an individual, understanding the specific, tiny details and areas of life that are compromised - especially the psychosocial (which is considered the most neglected but often the most vital area of cancer care). The older these kids are, the more impacted I believe they are, with more difficult life experiences and milestones compromised or put on hold as a result of their diagnosis. (JL)*

*Also children as they became adolescents they would want to act out and rebel against all of the things that they had to do all the time…act out in very dangerous ways…not take their meds…all the things that normal teenagers do but because of their health it is dangerous buy it was like an embarrassment thing…they just didn't want to be the weird kid. (CM)*

*What made one of these kid's experiences one way and the other so far the other way, I have no idea. Developmentally, there could have been some components of developmental theory and what stage each was at in their life that impacted their conceptualization of their situation… Language barriers and isolation could certainly have played another part, with the 23-year old client alone for much of his journey, with language barriers impacting his experience severely…I cant say much more as to what made their experience so different, except maybe that exactly: two kids with the exact same diagnosis, at the same hospital, living in the same house, from the same background and culture, around the same age, can have completely and totally different experiences traversing their cancer journey. No two experiences can ever be alike, despite how similar it might appear." (JL)*

*The one thing I already named which is really important is who is going to take care of that child if the child can't function as an adult….or even just the not knowing of what you are asking…the what ifs…another big concern of parents was certainly the issue of stigma…would their children and society as a whole…who might look more tolerantly on children that some sort of disabilities when they are young but as they get older it substantially increases…as they got older the stigma can really increase so parents would get tremendously worried about how children could survive emotionally as they got older with their conditions… about their visible or even physical disabilities…would people take advantage of them…would they get raped…would the boys get recruited into gang and not in a "good" way…because he isn't smart enough…people were very concerned about what would happen if something happened to them…what would happen to their kids…so they were worried about how to develop a network of care…how to create a support group. (CM)*

### *Working Paper II- Professional Power Dynamics and Policy*

Understanding each of the multi-disciplinary institutions involved in the child's future is very important. There needs to be more of a navigation system from treatment into survivorship and with every transition there after. With a better navigation system the direction of transition reform will be more centered and the support necessary to navigate the unfamiliar and complex landscape of cancer survivorship and chronic illness less challenging. It is apparent that information needs to be translated to the student-survivor and the family throughout the different stages of the health crisis and experience, but that mandates and policies moving forward should aim to provide the child and the family with tools and resources to address the psychosocial, developmental, and educational needs of the student-survivor at the time of diagnosis. The experts made I clear that the there are power struggles and alliances going on within the professional teams that are, inevitably, affecting the quality of care for the child. Each expert mentioned the biggest gap being between the medical team and, basically, everyone else. This top down approach to communication rarely works in any case and definitely does not work for these kids or the people trying to help them. This power conflict broaches a much bigger issue here that is inequality.

*I worked very closely with the oncology social work team at UCSF, in-patient and out-patient, who were the direct mental health providers for the family. Due to their schedules and overwhelming caseload, I had the great fortune to work so closely with the clients despite not working directly for UCSF, providing much of the mental health services they were unable to provide at length. They were so grateful for my presence in the treatment that they regarded me as one of their own, providing incredible support and collaboration in our treatment. The medical team was largely unavailable to me, despite attempts to collaborate with them, so the UCSF social worker became my main liaison for any medical information/needs… The medical teams were largely unavailable to me, despite attempts to collaborate with them, so the UCSF social worker became my main liaison for medical information/needs. (JL)*

*We could have gotten teachers but we didn't because of the human subject issue and having to negotiate with schools being such a human subjects nightmare…every institution is a big thing. What we did do was sit in on team meetings…the clinical hours which would include the families and we would go with the family to each clinical meeting- the speech therapist, the OT, the psychologist and then the whole team would have a meeting and you could see the power in the room… We would see a lot of judgment and where constructing collective stories whether it was right or wrong…there was definitely a fragmentation of services and a critique that had direct affect on the delivery of services to the children. Often the parents are the ones trying to take the information back and forth themselves…I thought of them as "culture brokers"…or they would even physically/literally bring x-rays from one professional specialist to another to try to make this connection happen. I really began to see how parents were the ones trying to solve the problem of this fragmentation. (CM)*

*The kids that I worked with came from very low income homes, mostly monolingual Spanish speaking, with limited resources and limited assistance due to language barriers. Helping the families better understand their child's diagnosis and resources available to them were nearly as important as working with the children themselves, as the stress and emotional impact the diagnosis had on the entire family was debilitating, emotionally and financially. (JL)*

*I would say that another big pattern is that there was also there was a big issue of trust…about the professionals…could they be trusted to be willing to give as much to their kids as a white middle class kids cause I was working with black/poor families…like would they be willing to trust the clinicians advice like your child is too ill for a bone marrow transplant…the parents would wonder is my child really too ill or is my child born black and so…there is a lot of contractually a lot of allocation of resources issues…allocation of resources is a real problem…so a lot of stigma about resources and a lot of parents have really become politically active. (CM)*

*In ending, for educational, mental health, and medical professionals, I think it is absolutely paramount to take developmental theory into account in all holistic care of children returning to the classroom, to fully understand just what stage they are in and how that diagnosis might have affected their transition from one developmental stage onto the next. (JL)*

*Then the children themselves play another piece of this transitional thing…big price to pay for adolescents reaching adulthood, because pediatric services get terminated after a certain age-18- what I found the doctors were still during a group meeting that they were still seeing people up until their 30s but the lower specialists like OTs etc. were like how can you do that? The sickle cell girl died at 19…it all fell apart when she lost her services… This one girl after 18 was trying to manage her illness on her own and she died…partly because she was trying to navigate herself amongst all these professionals and institutions and systems and she died. She died at 19. And she was this remarkable woman. At 18, if a medical team had been there for her…its not like the wouldn't have but some will and some wont and the whole thing just fell apart…a lot of doctors try to work around it…but it is a huge problem. I can guarantee you from every side that this transition issue, the age transition is huge. The clinicians and the families are all talking about it and it is a very underfunded research problem and not just research problem but practical problem. (CM)*

*Parents really thought that professionals-clinical and teachers did not take advantage of their own expertise and knowledge…they really thought that they knew a lot but that they were not heard…which flipped that whole idea that the parents always come with the problem and the professionals come with the expertise…the parents have expertise too…even the kids have expertise too…they know things about their bodies and minds too…the whole thing is that how do make the best of the expertise in the room not just the professionals but the parents and the kids. (CM)*

### *Working Paper III- School and the Student-Survivor*

Throughout the literature as well as in the expert interviews there was a serious call to action to better develop and define the role and skills of the teachers working with this population. The results gathered from the literature review concluded that even the teachers, themselves, felt ill prepared and at a loss on how to teach this unique population. Schools face challenges incorporating children with different illnesses into the classroom and most educators have had little training about the needs of children with medical conditions in the classroom (Irwin and Elam, 2011, p.68).

Whether it is the regular classroom teacher or the teacher charged with providing home instruction under IEP/504 modifications, few education programs include training for childhood chronic illness. Opportunities for training are minimal, at best, despite this need (Irwin, M.K et al., 2011, p.75). Regular classroom teachers who are lacking the preparedness to deal with a student-survivor are either lowering expectations or holding them back, neither of which are fair or appropriate options to serve the child or his or her future. Parents are often finding themselves looking for alternative education for their student-survivors as a way of avoiding the rigidity of school policy or becoming political activists, themselves, which can be financially and emotionally stressful to an already stressful situation. Parents should feel confident that student-survivors are getting the education that they deserve. One expert concluded that most parents did not feel this way and were concerned and taking action. The age of the student-survivor was an issue again that was mentioned by both experts. The younger the student-survivor is the more hopeful he or she seemed to be about school and education. The older they get the harder the transitions. While not quite as emphasized as the research initially assumed, the expert data did include some instances of school being a normalizing force for their student-survivor's experiences as well as a place that provided hope for the future and for healthy social interaction.

*I was not directly involved with the educational component but I was aware of the resources the hospital provided to give the kids some semblance of a normal education while receiving treatment…UCSF did have a tutor that worked on-site (Family House) to provide the kids some bit of their grade appropriate curriculum, but I was never directly involved with them. (JL)*

*The parents talked about school a lot…huge issue…in some ways it became the bigger thing…like especially if the clinical/medical stuff was even sort of under control…if the medical stuff is overwhelming than that's what it is…but if not school is their biggest concern…they are very aware that their children getting an education is crucial to their children's lives or often their school is being interrupted…they feel like if they are in Special Ed that they aren't getting very good education or are worried about how far they can or will go after that and after being in special education…all of that is really huge…I would say that all of the activism that I see with the parents is all about school…is about changing that…they are very concerned that their children will somehow be written off…written off as un-teachable…treated as un-teachable…I think that you know that it is a message to school professionals but also a message to society…how seriously are we willing to fund programs that will be willing to educate our children even if they have disabilities even if they require something different comparatively…you know I think that most parents want more inclusion…with other kids…they also wanted more flexibility…more flexible forms of teaching…I think those are the big things. More modifications and accommodations. More options for the kids that have to spend a lot of time in hospitals. The kids that could go to school every day idea that even if the child is still cognitively impaired that he or she could still learn and that he or she wants to be a part of the world and that school is supposed to facilitate that even if it means having to be more creativity. (CM)*

*He took this experience as one to completely change his life around for the better – he became self-taught in raw and vegan nutrition, completely shifted his diet to fill his body with only that which he read could be some natural savior for him. He was his biggest advocate, researching the latest updates in natural treatment of cancer. He wanted to become a doctor, he said, so he could provide the kids what he was not receiving from his own medical team. His resolve was not only to not die, but to live a more full, vibrant, and future-focused life than he ever had before. After being told he was in remission, he relapsed a few months later and eventually succumbed to his same cancer, never losing his optimism and faith even in his final week… (JL)*

*I think that kids…some of the children were kind of encouraged by the parents to get into health positions…because they had spent so much time in the hospital…that idea that they could*

> *become a nurse or even a doctor or that they could help other kids like them…or help them in a way…probably were to interview them now they might be a little more pessimistic about their future but in their adolescents they were really into that idea…you could still see where they still felt optimistic when they were younger but the health crisis seemed to really affect the school experience. (CM)*

# Chapter 5 Discussion

## Comparison of Findings to Previous Research

Although findings of this literature review “indicate that transition research is in early stages of development” (Betz, 2004) when juxtaposed with the findings fleshed out of the expert interviews it still does provide some circumstantial evidence for the research assumptions being made. For the most part, the results of the literature review were consistent with the initial research assumptions and theories.

With the growing number of young people projected to contract cancer and with the prevalence of side effects and reoccurrences later in life, it is critical for all adults working with them to be aware of how to thoroughly and appropriately care for them, especially when trying to transition back into “normal” life. Communication and collaboration among professionals is lacking. Student-survivor’s psychosocial development is fragile and oftentimes compounded by other issues associated with age and circumstance. Psychosocial health and transitional support need to be better addressed and encouraged. School can be normalizing force to some-especially the younger student-survivors-and can be a place for healthy age-appropriate interaction.

The viewpoints and perceptions that the experts arrived upon in their responses to the research questions varied according to their positions and purposes. While both experts were working with young people with cancer and other chronic and terminal illnesses, their roles were very different. Their relationships with the children and their families were very similar while their relationships and experiences with other professionals quite different.

## Limitations of the Study

The limited access to the student-survivor population in real time and real observable learning environments (such as a classroom, home, or hospital setting) limited the scope of this study and any participant-observational nature. Data were limited to only two sectors of the professional disciplines that the research mentioned and the age range of the children that the two professionals had experience with were mostly adolescents.

Data from the expert interviews did not speak to the educational aspect or support the assumptions in regards to the impact of school on the student-survivor's experience as much as the researcher had hoped. A larger pool of participants, in general, would have enriched the data and its implications immensely.

## Implications for Future Research

Future research is vital for this population of young people. It became apparent that the inequality issues are bigger than first presumed and go beyond what made sense to discuss at this stage in this research. Socio-economic issues are compounding the stresses and marginalizing the lives and opportunities of student-survivors and their families. These societal and cultural disparities need to be further examined.

Also worth mentioning and exploring further, are the effects of the ACA (American Health care Act 2014) on the needs of student-survivors-which came into existence in the midst of this research. The absence of the “pre-existing condition clause” on the lives of these young people should be a fortunate thing. Lastly, I think that a longitudinal study on how student-survivors are doing in adulthood and how their opportunities, endeavors, and quality of life have compared to their peers without illness would be very interesting and thoughtful research to pursue. There are many meaningful branches to climb in regards to this research.

## About the Author

Devon Malia Lanin is a former elementary school teacher. She holds a sociology degree from Sonoma State University and a multiple education credential from Dominican University of California and is looking forward to obtaining a Masters degree from DU of C in May of 2014 as well. She intends to further her work and research with the student-survivor population and also plans on starting a comprehensive learning center that will combine mental and emotional counseling with educational counseling in an effort to target and supplement the unique needs of every learner.

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# Appendix

## Chart of Transcribed Expert Interview Responses

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|---|
| **1. Please describe how you are involved in facilitating care/to and or observing children/adolescents with cancer or chronic illness.** |
| **JL -** I received my Master's in Social Work in 2013 and spent a year of my master's practicum working for Circulo de Vida, a non-profit serving Latinos with cancer. The bulk of my caseload was with adolescents, specifically high-school aged youth, who were currently receiving treatment at UCSF while residing at a care home next to the hospital with their families. I provided counseling, psycho-education, and case management for both the youth and their families. I was not directly involved with the educational component, but I was aware of the resources the hospital provided to give the kids some semblance of a normal education while receiving treatment. I also worked indirectly with an organization called First Descents, a non-profit providing adventure therapy for young cancer survivors. |
| **CM-** It was so clear to me that I had to go besides the clinical side of things. I needed to understand the family and shift my intention to what is it like and how are people dealing with this? Collaborating with a researcher-trained as an OT/PHd OT and a Masters in Developmental Psychology- which was not clinical like my usual focus at all. This all started in 1990 in Illinois…an over 25 years grant from NIH…which switched my focus to an ethnographic study and the "family perspective" of things. 15 year study of African-American study of families with children with disabilities. We got close to a total of 7 million dollars for the study. An in-depth longitudinal study with videotapes and transcriptions which gave us a long term perspective. Video taking and clinical interactions, following family in their homes, at church, in their communities. We started at very early child hood and now they are in their late teens and early 20s. 50 families at first …20 of them stayed and participated for 10 years or more. |
| **2.Please describe and what capacity you are involved and/or communicate with the children's family. How did you communicate with the children's family?** |
| **JL -** I worked with the families almost as often as I worked with the youth. A cancer diagnosis impacts every aspect and component of a child's life, and the families were often times more impacted than the kids were. The kids I worked with came from very low-income homes, mostly monolingual Spanish speaking, with limited resources and limited assistance due to language barriers. Helping the families better understand their child's diagnosis and resources available to them were nearly as important as working with the children themselves, as the stress and emotional impact the diagnosis had on the entire family was debilitating, emotionally and financially. Normalcy in every sense of the word was gone. Their lives were completely uprooted as they all traveled hundreds (some thousands of miles, from Mexico) to be with their loved ones while they battled their respective diagnoses. |
| **CM** - We each took our own families and observe them in different situations. Because of their health conditions there were a lot of clinical environments. Lots of layers. Some clinicians agreed. Some didn't. Then I would interview the parent. Like after a clinical apt I would take the parent to lunch or to the park or something and I would say…I know I was there, but can you tell me how that was for you? How was that appointment for you? To try to get their point of view and to get these narratives. Then I would talk to the clinicians and therapists that would agree to be a part of it and ask them for their experience. We actually ended up going to and videoing a whole bunch of funerals. One family- the mother of the child that was sick had this onslaught of deaths- her mother, her father and then her own daughter. I became a kind of a… part of the family…they would recruit us as the film makers for these events…I think that we played an unexpected role especially for some of the families that had stories to tell…there was something about having witnesses that turned out to be very important…even though we were really supposed to be interventionists, we kind of ended up being that at times…or they would just find roles for us that we ourselves would fit. It was really interesting. In some ways it was more intense then I thought. Even though our study has finished we have "family reunions" with some of them. We turned out to be a good, stable person in their lives that they needed. We have seen them over the years. Some wanted us to be there every where and we just followed the lead of the family and what they wanted for the sick child and found that what each family wanted for every family was very different. We were sometimes even pulled in by other parts and people of the family besides the one with medical problems. There were so many things going on with the primary care giver or care givers- other illnesses, incarcerations, etc.… and then there were some more what we call "normal or nuclear" families. You just follow the lead of the people who tell you and show you about what is important in their life. I think this would have been hard for clinical people.<br>We found clinician first then got access to the family. Contacted therapists who were interested in being involved. Thought we would play more of a background role. Once we got clinicians involved, then OTs who described us as liaisons, families would have to agree and fill out all of the proper paper work. They could withdraw whenever they wanted to. |
| **3. Please describe and at what capacity you collaborate and communicate with other professional disciplines involved in each child's transitional journey?** |
| **JL -** I worked very closely with the oncology social work team at UCSF, in-patient and out-patient, who were the direct mental health providers for the family. Due to their schedules and overwhelming caseload, I had the great fortune to work so closely with the clients despite not working directly for UCSF, providing much of the mental health services they were unable to provide at length. They |

were so grateful for my presence in the treatment that they regarded me as one of their own, providing incredible support and collaboration in our treatment. The medical team was largely unavailable to me, despite attempts to collaborate with them, so the UCSF social worker became my main liaison for any medical information/needs. I was also very involved with the head of the house that all of the kids lived at, Family House, which was a free home for kids and their families to stay at while their children were actively receiving treatment at UCSF, however long that might be. They were an incredible resource and organization, caring for these families as if they were a part of their own family and doing everything in their power to make the house feel nothing like a hospital, giving the family some bit of refuge and respite away from their very sterile life across the street at the hospital. UCSF did have a tutor that worked on-site to provide the kids some bit of their grade-appropriate curriculum, but I was never involved directly with them.

**CM -**Once we got the families in the study, then the families would help recruit the clinicians. They would ask…Can these researchers sit with my child and me during our appointments? Physical Therapy aids were important. We could have gotten teachers but we didn't because of the Human Subject issue and having to negotiate with schools being such a human subjects nightmare…every institution is a big thing. What we did do was sit in on team meetings…the clinical hours which would include the families and we would go with the family to each clinical meeting- the speech therapist, the OT, the psychologist and then the whole team would have a meeting and you could see the power in the room…like the main doctors would always come in late and interrupt…the lowest on the totem pole was the social worker…everyone was always annoyed with them… because the family thinks they are a cop…the PTs had a good amount of power…the OTs not so much…you could all hear their points but they would all have to agree on things like…does the kid or even the mom needed a wheel chair they would all have to agree to allow it to her and would critically decide…We would see a lot of judgment and where constructing collective stories whether it was right or wrong…there was definitely a fragmentation of services and a critique that had direct affect on the delivery of services to the children. Often the parents are the ones trying to take the information back and forth themselves…I thought of them as "culture brokers"…or they would even physically/literally bring x-rays from one professional specialist to another to try to make this connection happen. I really began to see how parents were the ones trying to solve the problem of this fragmentation.

Then the children themselves play another piece of this transitional thing…big price to pay for adolescents reaching adulthood, because pediatric services get terminated after a certain age-18- what I found the doctors were still during a group meeting that they were still seeing people up until their 30s but the lower specialists like OTs etc. were like how can you do that? The sickle cell girl died at 19…it all fell apart when she lost her services.

They were trying so hard to follow the rules. This one girl after 18 was trying to manage her illness on her own and she died…partly because she was trying to navigate herself amongst all these professionals and institutions and systems and she died. She died at 19. And she was this remarkable woman. At 18, if a medical team had been there for her…its not like the wouldn't have but some will and some wont and the whole thing just fell apart…a lot of doctors try to work around it…but it is a huge problem. I can guarantee you from every side that this transition issue, the age transition is huge. The clinicians and the families are all talking about it and it is a very underfunded research problem and not just research problem but practical problem.

**4. Please discuss any patterns of psychosocial issues/concerns that you identified during your time with this population.**

**JL** -I experienced a mix of extremes: from absolute hopefulness and optimism, to incredible hopelessness and resolve to die – both of these two cases were diagnosed with the exact same, rare cancer. One was on suicide watch almost every week. Though it's hard to say if his depression existed prior to his diagnosis, it was absolutely clear the impact this diagnosis had on him. He had a rare type of cancer called Rhabdomyosarcoma that began in the joints, with his so close to his hip that he lost all sexual functioning and ability to use the bathroom naturally ever again for the rest of his life. He was 23 years old, a young man supposed to be at the prime of his life, being told he would never be able to sit on a toilet normally or have an intimate relationship with a woman ever again. The disabilities he received as a result of his diagnosis were almost more defeating to him than the cancer itself, and his resolve to die was so strong every week, almost everyday. Any bit of joy that I could bring he and his family, I would bring tenfold. He was so severely depressed, and that hopelessness permeated every cell of his already compromised body. He unfortunately succumbed to his cancer, but all of us on his case were somehow able to manage to track down an organization that flew his wife and two year old daughter to San Francisco from Mexico, so he was able to spend his final months with his wife and baby. A reminder that though life was so far from what he ever knew, he was able to have a bit of normalcy when they arrived. On the flip side, I had another young boy, 18 and a senior in high school, who had almost an entirely different experience. Prior to his diagnosis, he was a member of a gang, he was involved in a number of shootings, he cared nothing for school or his future, and stated he probably would have died by gun fire had he not been diagnosed. He took this experience as one to completely change his life around for the better – he became self-taught in raw and vegan nutrition, completely shifted his diet to fill his body with only that which he read could be some natural savior for him. He was his biggest advocate, researching the latest updates in natural treatment of cancer. He wanted to become a doctor, he said, so he could provide the kids what he was not receiving from his own medical team. His resolve was not only to *not* die, but to live a more full, vibrant, and future-focused life than he ever had before. After being told he was in remission, he relapsed a few months later and eventually succumbed to his same cancer, never losing his optimism and faith even in his final week, still reaching out to me asking me to tell him jokes. What made one of these kids experiences one way and the other so far the other way, I have no idea. Developmentally, there could have been some components of developmental theory and what stage each was at in their life that impacted their conceptualization of their situation. Language barriers and isolation could certainly have played another part, with the 23-year old client alone for much of his journey, with language barriers impacting his experience severely. The other resided in Fresno, with family and friends close-by and no language barriers impacting his experience. I cant say much more as to what made their experience so different, except maybe that exactly: two kids with the exact same diagnosis, at the same hospital, living in the same house, from the same background and culture, around the same age, can have completely and totally different experiences traversing their cancer journey. No two experiences can ever be alike, despite how similar it might appear.

**CM -**The one thing I already named which is really important is who is going to take care of that child if the child can't function as an adult….or even just the not knowing of what you are asking…the what ifs…another big concern of parents was certainly the issue of stigma…would their children and society as a whole…who might look more tolerantly on children that some sort of disabilities when they are young but as they get older it substantially increases…as they got older the stigma can really increase so parents would get tremendously worried about how children could survive emotionally as they got older with their conditions… about their visible or even physical disabilities…would people take advantage of them…would they get raped…would the boys get recruited into gang and not in a "good" way…because he isn't smart enough…people were very concerned about what would happen if something happened to them…what would happen to their kids…so they were worried about how to develop a network of care…how to create a support group…I would say that another big pattern is that there was also there was a big issue of trust…about the professionals…could they be trusted to be willing to give as much to their kids as a white middle class kids cause I was working with black/poor families…like would they be willing to trust the clinicians advice like your child is too ill for a bone marrow transplant…the parents would wonder is my child really too ill or is my child born black and so…there is a lot of contractually a lot of allocation of resources issues…allocation of resources is a real problem…so a lot of stigma about resources and a lot of parents have really become politically active…around disability issues and especially around school issues…that's really big…like this idea of warehousing kids in special ed and they get really angry about it and some of them really fight and fight like go to Sacramento…and some people wonder how do they even have the time or energy to really fight with everything that they are already going through with their child…their concern has become that big and it means that for some reason that if they don't fight that they might give up. The only other thing is that they just might despair and just give up…a lot of struggle with depression and even morally that they cant give up.

**5. What were the children's general attitudes about their future and about their educational futures in particular? How had their health experience affected their school experience?**

**JL-** See above ☺

**CM -** So, um…I think that kids…some of the children were kind of encouraged by the parents to get into health positions…because they had spent so much time in the hospital…that idea that they could become a nurse or even a doctor or that they could help other kids like them…or help them in a way…probably were to interview them now they might be a little more pessimistic about their future but in their adolescents they were really into that idea…you could still see where they still felt optimistic when they were younger but the health crisis seemed to really affect the school experience… a lot of them that were out of school a lot…when they were missing school a lot parents really juggle what they should do…how to manage everything…ask for accommodations…etc.…It is a big issue for the parents…not sure about the kids as much… one of the kids was in the hospital 4 days a week…and she made friends with the nurses and aids. I would say to add to another list of concerns is that another issue for parents is that the children just get to be kids and not just sick people. That's a big one. But there is a whole range of them out there.
There are a whole lot of kids trying to take care of parents…around worries…and seeing their parents distressed even this little child that I wrote about a lot…her mother said that when I cried the little girl would pat her head and say Mommy its going to be alright…so I think that children can take on a huge amount of responsibility…worrying that their parents are worrying about them and a lot of the kids…also children as they became adolescents they would want to act out and rebel against all of the things that they had to do all the time…act out in very dangerous ways…not take their meds…all the things that normal teenagers do but because of their health it is dangerous buy it was like an embarrassment thing…they just didn't want to be the weird kid…

**6. Please add any other information that you think/feel is important for professionals in the fields of education to know about the needs of school age children, survivors of cancer and other chronic illnesses, in returning to the classroom.**

**JL -** Their experience impacts them so significantly, in ways that general population providers cannot understand unless they spend a good deal of time understanding the psychosocial effects a cancer diagnosis has on an individual, understanding the specific, tiny details and areas of life that are compromised - *especially* the psychosocial (which is considered the most neglected but often the most vital area of cancer care). The older these kids are, the more impacted I believe they are, with more difficult life experiences and milestones compromised or put on hold as a result of their diagnosis. Proms, football championships, graduations, first dates – things that are so typical and defining of the adolescent journey for identity – may now be non-existent, and are often times irreplaceable. Simple things that we take for granted, forgetting how important and defining they are, are lost during treatment for some of these kids. Remembering that in their journey, and taking those little things into account that are incredibly defining and monumental to an adolescent figuring out who he or she is, is vital for anyone involved with these children when they return back to the classroom, back to the field, back to their community. Also, remembering how important small things that we can do as professionals in the field are – visits from pieces of their old life, bringing events *to them*, video notes from classmates, anything to bring a bit of normalcy back to a severely disrupted life, is critical in their successful transition through developmental experiences and stages. Most importantly, talking to them about their experience, and not being afraid to talk to them about it. And if you are, because most of us are so afraid, owning up to that fear and providing them that support regardless of our own discomfort of what is now their reality. In ending, for educational, mental health, and medical professionals, I think it is absolutely paramount to take developmental theory into account in all holistic care of children returning to the classroom, to fully understand just what stage they are in and how that diagnosis might have affected their transition from one developmental stage onto the next.

**CM -** The parents talked about school a lot…huge issue…in some ways it became the bigger thing…like especially if the clinical/medical stuff was even sort of under control…if the medical stuff is overwhelming than that's what it is…but if not school is their biggest concern…they are very aware that their children getting an education is crucial to their children's lives or often their school is being interrupted…they feel like if they are in Special Ed that they aren't getting very good education or are worried about how far they can or will go after that and after being in special education…all of that is really huge…I would say that all of the activism that I see with the parents is all about school…is about changing that…they are very concerned that their children will somehow be written off…written off as un-teachable…treated as un-teachable…I think that you know that it is a message to school professionals but also a message to society…how seriously are we willing to fund programs that will be willing to educate our children even if they have disabilities even if they require something different comparatively…you know I think that most parents want more inclusion…with other kids…they also wanted more flexibility…more flexible forms of teaching…I think those are the big things. More modifications and accommodations. More options for the kids that have to spend a lot of time in hospitals. The kids that could go to school every day idea that even if the child is still cognitively impaired that he or she could still learn and that he or she wants to be a part of the world and that school is supposed to facilitate that even if it means having to be more creativity…parents really thought that professionals-clinical and teachers did not take advantage of their own expertise and knowledge…they really thought that they knew a lot but that they were not heard…which flipped that whole idea that the parents always come with the problem and the professionals come with the expertise…the parents have expertise too…even the kids have expertise too…they know things about their bodies and minds too…the whole thing is that how do make the best of the expertise in the room not just the professionals but the parents and the kids…